

# **Psychological Functioning and Bereavement Care Needs of Bereaved Chinese Immigrants in Canada**

by

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# Approval

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**Date Defended/Approved:** December 12, 2017

## Ethics Statement



The author, whose name appears on the title page of this work, has obtained, for the research described in this work, either:

- a. human research ethics approval from the Simon Fraser University Office of Research Ethics

or

- b. advance approval of the animal care protocol from the University Animal Care Committee of Simon Fraser University

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## Abstract

The death of a loved one can be associated with significant physical and psychological morbidity for bereaved individuals. Bereavement care services aim to foster healthy adjustment to loss. Research and clinical observations, however, suggest that such services are under-utilized by ethnic minorities and immigrants. Using a mixed methods design, the current research examined the psychological functioning of bereaved Chinese-Canadian immigrants, and factors related to their access and utilization of bereavement care. Twenty-five first-generation Chinese-Canadian immigrants from Hong Kong, Taiwan, or Mainland China, who had been bereaved for 6 months to 3 years, completed Chinese-translated questionnaires on depression, anxiety, somatic symptoms, coping, and acculturation. Semi-structured interviews focused on their grief experiences, knowledge and experiences with bereavement care, and perception on barriers to access and ways to improve services. Quantitative results revealed that over half of the participants scored above clinical cut-offs on depression (56%), state anxiety (60%) and trait anxiety (64%). Eight themes emerged from the qualitative data. *Chinese cultural grammar, being an immigrant in a foreign land, and navigating uncharted territories in a foreign health care system* represented contextual forces that interacted to form barriers to accessing bereavement care. *Bereavement as a lonely journey* represented the core concern of the participants, with *coping strategies, religion and spirituality, post-loss changes and growth, and ideal services* emerging as outcome categories. Combined analyses on quantitative and qualitative data found that those displaying intense grief during interview also scored higher on depression and state anxiety. Emotion-oriented coping was associated with poorer psychological functioning, while taking solace in “good death”, cognitive reframing and discussing the loss with family predicted better adjustment. Those whose family members passed away in Canada or had received palliative care prior to death were more likely to receive pre-bereavement and/or bereavement follow-up care. Psychological morbidity and lack of discussion of grief with family were associated with increased initiative to seek professional help. Initiative to seek help, together with psychological morbidity, predicted subsequent access to bereavement interventions.

**Keywords:** Death; Bereavement Care; Chinese Immigrants; Barriers; Culture; Health Care Delivery

## **Dedication**

To my grandmother, Yu Fei, for your undying love and support. I miss you and wish that you were here to share this moment with me.

To my parents, Stephen Ho and May Lai, for all the sacrifices you have made as immigrants to a foreign land in order for me to pursue a better education.

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# **Chapter 1. Introduction**

## **The Varieties of Grief Experience**

The loss of a loved one through death is a universal human experience. Grief, as a reaction to loss, is said to be “the cost we pay for being able to love in the way we do” (Stroebe, Hansson, Schut, & Stroebe, 2008, p. 5), and “the form love takes when someone we love dies” (Zisook et al., 2014, p. 482). Grief is multifaceted in nature, with affective, cognitive, physiological and functional dimensions. It tends to take an oscillating course as mourning progresses (Zisook & Shear, 2009). Distressing emotions ranging from sadness, fear, guilt, anger, irritability, shock, yearning, to feelings of loneliness and helplessness are commonly reported (Bonanno & Kaltman, 2001). Cognitive difficulties include memory and concentration difficulties, a sense of disorganization and depersonalization, intrusive thoughts, preoccupation with memories of the deceased, and difficulty accepting the reality of one’s loss. Other more enduring cognitive changes include changes in one’s identity and a search for meaning and explanation of the loss.

In terms of physical health, bereaved individuals tend to have more somatic complaints, decreased sleep quality, negative health behaviour changes (e.g., poor nutrition, increased tobacco and alcohol use, reduced physical activity), increased physician visits, and poorer health status compared with same-age peers (Stahl & Schulz, 2014; Stroebe, Schut, & Stroebe, 2007). Increased mortality, particularly due to sudden, violent causes (e.g., traffic accidents) and suicide, is robust in the initial months post-loss and among younger bereaved individuals (Buckley et al., 2012). On a physiological level, grief is linked with impaired immune functions and hyperactivity of the hypothalamic-pituitary-adrenal (HPA) axis, the neuroendocrine system that controls stress responses (Assareh, Sharpley, McFarlane, & Sachdev, 2015). Elevated heart rate, blood pressure, and level of platelet activation and coagulation factors have also been observed in the early months of bereavement, which may increase cardiovascular risk among older adults



or those with pre-existing risk factors (Buckley et al., 2012; Williams, 2005). Finally, grief is associated with disruptions in social and occupational functioning. Bereaved individuals may withdraw from their social circles, become isolated, and have trouble developing new relationships (Laakso & Paunonen-Ilmonen, 2001). They also tend to report feeling less effective and confident in fulfilling their roles at home and at work (Bonanno & Kaltman, 2001). Absence from school or work and changes in employment status can be common grief reactions (Dyregrov, Dyregrov, & Kristensen, 2015).

Even though everyone will experience the death of a loved one at some point in his / her life, the experience of grief is highly heterogeneous across bereaved individuals. Decades of research in death, dying, and bereavement have confirmed the marked individual differences in the nature, intensity, and duration of grief, as well as subsequent adjustment. Each loss is unique, and no one grief reaction is considered necessary or sufficient to define grief (Agnew, Manktelow, Taylor, & Jones, 2010; Weiss, 2008).

Longitudinal research has revealed that the majority of bereaved individuals are able to cope with the loss by mobilizing inner resources and relying on informal support systems (Agnew et al., 2010). While they may report a high level of acute grief, intense suffering and impaired functioning during the initial months after a loss, their grief is more time-limited in nature; these individuals are usually able to return to normal, baseline level of functioning within 1 year (Bonanno & Kaltman, 2001). They are able to accept the finality of the loss, integrate this reality into their lives, and look forward to a future with joy, possibilities, and loving companionship of others (Shear, 2012). For them, grief is never cured but is greatly attenuated. While future episodes of yearning or sadness can be triggered by anniversary dates, significant life events, family holidays or subsequent losses, these individuals can nevertheless rebound and recover within a short period of time (Zisook et al., 2014).

For some individuals, the death of a loved one results in minimal grief, characterized by low self-reported level of distress, psychological morbidity or disrupted functioning from pre-loss to post-loss (Bonanno & Kaltman, 2001). The phenomenon of minimal grief has received considerably less research attention. Bereavement theorists have yet to agree on how to interpret minimal grief – whether a lack of overt distress is a

sign of denial or inhibited grief (Middleton, Moylan, Raphael, Burnett, & Martinek, 1993), or an indicator of personal strength and resilience (Bonanno, Papa, & O'Neill, 2001).

Unfortunately, for a substantial minority of bereaved individuals, grief runs a protracted, debilitating course. Approximately 7 to 20% of bereaved individuals continue to experience intense grief and persistent disruptions to physical and psychological functioning for years after the loss (e.g., Kersting, Braehler, Glaesmer, & Wagner, 2011; Schulz, Boerner, Shear, Zhang, & Gitlin, 2006). These individuals are at a higher risk for increased mortality, poorer physical health, impaired quality of life, greater social and work impairment, and negative mental health outcomes such as major depressive disorder, panic disorder, post-traumatic stress disorder (PTSD), suicidality, and substance abuse, compared with their non-bereaved counterparts or with those who manage to come to terms with their loss (Bonanno & Kaltman, 1999; Keyes et al., 2014; Lannen, Wolfe, Prigerson, Onelov, & Kreicbergs, 2008; Li, Precht, Mortensen, & Olsen, 2003; Prigerson et al., 1997; Silverman et al., 2000; Simon et al., 2007; Shear & Skritskaya, 2012; Stroebe et al., 2007; Stroebe, Stroebe, & Abakoumkin, 2005)

In Prigerson and colleagues' (1997) prospective cohort study, the authors examined patterns and impact of grief associated with conjugal bereavement. They tracked a group of 150 future widows and widowers who first completed an intake interview when their spouses were admitted to two hospitals with life-threatening illnesses. The participants completed subsequent face-to-face follow-up interviews at 6 weeks, 6 months, 13 months and 25 months after study entry. Mental and physical health outcomes measured included grief, depression, anxiety, suicidality, self-report of health status and physician diagnosis, and changes in health behaviours such as the use of alcohol and tobacco. By the 6-week follow-up, 96 participants were bereaved. Results showed that while 57% of these participants displayed high levels of grief at the 6-week follow-up, only 6% continued to report intense grief at the 13-month follow-up. The percentage increased slightly to 7% at the 25-month follow-up interview. The mean grief score declined quadratically throughout the study period, with a steeper decline between the 6-week and 6-month mark, and then gradually levelled off afterwards. Higher level of grief measured at the 6-month follow-up was associated with higher systolic blood pressure, higher level depression and suicidal ideation, increased smoking, poorer eating habits and impaired

sleep at 13 months, even after controlling for age, gender, and pre-bereavement level of depression and anxiety. Level of grief at 6 months also predicted cardiovascular problems, incidence of cancer, anxiety, suicidality, and alcohol use at the 25-month follow-up.

Barrera and colleagues (2007) examined grief patterns in 20 parents who had been bereaved for 19 months. They found that patterns of parental bereavement were mixed: 65% of their sample exhibited what the authors termed “integrated grief”, meaning that the parents managed to find a balance between expressing their grief and adjusting to a life without the deceased child. They were able to control when and where to express their grief, focused on bring life back to normal, managed to reframe the bereavement experience into positive terms, and rediscovered joy in life. They were able to maintain relationships with their surviving children as well with as friends and family. When asked to describe their pre-death relationship with the deceased child, these parents reported a balanced relationship of care, mutual admiration and respect. Their mean score on depressive symptoms, as measured by the Beck Depression Inventory (BDI), was more than 1 standard deviation below the clinical range. However, another 25% of the parents in the sample remained overwhelmed by their grief and unable to function well in life. Their grief reactions were uncontrollable and severe, and they failed to reframe the bereavement experience positively or foresee any future without their child. A number of these parents were devoid of social support. Their pre-death relationship with their deceased child was intense and enmeshed. Their mean score on the BDI was within the clinical range, and data from interviews suggested that they manifested symptoms consistent with the DSM-IV-TR criteria for depression.

In a seminal prospective cohort study by Bonanno and colleagues (2002), baseline interviews were conducted with 1,532 married individuals in the Detroit area, 205 of whom subsequently lost their spouses and participated in follow-up interviews at 6 and 18 months after the spouses’ death. Five divergent trajectories of grief from pre-loss to 18-month post-loss were identified. Most participants (46%) exhibited a “resilient” pattern, with low pre-loss depression score that remained unchanged at both 6 and 18 months of bereavement. Approximately 11% of participants exhibited the “common grief” pattern, characterized by a low pre-loss depression score that significantly increased at the 6-month post-loss follow-up, but returned to baseline, pre-loss level by 18 months. The

“chronic grief” pattern, in which an initially low pre-loss depression score significantly increased after the death of the spouse and remained elevated at 18 months, was found in 16% of the sample. Eight percent of participants displayed the “chronic depression” pattern; they were found to have high pre-loss depression that remained unchanged at 6- and 18-month post-loss. Finally, 10% of participants displayed the “depressed-improved” pattern. They displayed high level of pre-loss depression that became alleviated immediately after the death of the spouse. Improved emotional functioning was observed at 18 months of bereavement for these individuals.

Different grief trajectories were also found to be associated with different pre-loss predictors of functioning (Bonanno et al., 2002). Participants with the “common grief” pattern were more likely to have had a spouse who was seriously ill, but for whom they did not provide care. Those displaying the “resilient” pattern were more independent socially and in marriage, were more accepting of death, more strongly endorsed the belief in a just world, and had received more instrumental support from their social network after the loss. Those with the “chronic grief” pattern were more dependent interpersonally and on their spouse. Their deceased spouses were more likely to be healthy prior to death, and they were less likely to have been caregivers under high strain conditions prior to the spouse’s death. They also tended to have received less instrumental support from others during bereavement. Those with “chronic depression” and “depressed-improved” patterns shared many predictors. They were relatively negative and ambivalent about their marriage, scored high in neuroticism but low in extraversion, were more likely to hold negative worldviews such as the uncontrollability of negative events and belief of personal injustice, and had received low instrumental support from others. Those with “chronic depression”, however, had lower confidence in their own coping ability. Those with the “depressed-improved” pattern were less dependent on their deceased spouse. Their deceased spouses were also more likely to have been seriously ill prior to death.

More recently, Galatzer-Levy and Bonanno (2012) reanalyzed the dataset used in Bonanno et al. (2002) and extended the follow-up to 48 months post-loss. They also refined the method of defining grief trajectories using latent growth modeling. This time four distinctive patterns of grief were identified. The majority of participants (66%) demonstrated the “resilient” pattern, with stable, low depression scores throughout their

grief trajectory. For the 9% of participants who exhibited the “chronic grief” pattern, results from this recent study augmented what was originally observed in Bonanno et al. (2002). In the 2002 study, those with chronic grief experienced a sharp increase in depression scores which remained elevated at the 18-month follow-up. In the 2012 study, the authors found that at the 48-month follow-up, the depression scores for these participants gradually dropped back to the baseline, pre-loss level. Conversely, for those with the “chronic depression” pattern (15%), their depression scores were consistently high starting from pre-loss period, with no improvement even at the 48-month follow-up. Finally, another 10% of participants demonstrated the “depressed-improved” pattern, with an elevated pre-loss level of depression that greatly improved by 6 months post-loss and remained low at the 48-month follow-up. The “common grief” pattern, previously identified by Bonanno et al. (2002), was not supported in this study as its inclusion did not improve model fit over and above the 4-grief-pattern model. With regards to predictors of bereavement outcomes, financial strain was found to predict level of depression in all four patterns of grief. Poor self-report health status at 6-month post-loss predicted high level of depression only in the “resilient” and “depressed-improved” groups. Finally, low emotional stability was associated with the “chronic depression” and “depressed-improved” groups.

Collectively, results from these studies demonstrate that grief trajectories are highly variable and individualized, with each trajectory associated with different risk and protective factors that may influence bereavement outcomes.

## **Factors Associated with Bereavement Outcomes**

Past research has identified a number of risk and protective factors that contribute to bereavement outcomes. These factors can be classified in terms of situational factors, interpersonal factors, and intrapersonal factors (Stroebe, Folkman, Hansson, & Schut, 2006; Stroebe et al., 2007). Risk and protective factors often interact with each other, and individual differences in adjustment to loss likely reflect the unique, complex combinations of these factors which vary across bereaved individuals (Bonanno & Kaltman, 1999).

## **Situational Factors**

One of the situational risk factors with the strongest empirical support is the nature or cause of the death event. Sudden, unexpected or violent death (such as accidents, homicide or suicide) is more likely to be associated with prolonged grief and symptoms of depression and PTSD (e.g., Dyregrov et al., 2015; Kristensen, Weisaeth, & Weir, 2012; Shah et al., 2013). For example, in Keyes et al. (2014) population-based study on the relationship between unexpected death and the onset of anxiety, mood and substance use disorders, unexpected death was found to increase the odds of later onset of major depression, PTSD and panic disorder in bereaved individuals, regardless of at what point in their lives the unexpected death occurred. In addition, unexpected losses that occurred later in life (after age 40) were also associated with higher odds of developing mania, alcohol use disorders, specific and social phobia, and generalized anxiety disorder post-loss. More recently, Dyregrov and colleagues (2015) studied the impact of sudden and violent death on 37 bereaved parents and 36 bereaved siblings of those killed during the 2011 Norway Otoy Island massacre, when a lone gunman opened fire on 600 young people attending a youth camp. One and a half years after the killings, the majority of bereaved parents and siblings continued to score above clinical cut-offs on measures of posttraumatic stress symptoms (63% and 72% respectively), general psychological distress (88% and 75%), and prolonged complicated grief (82% and 75%). Psychological distress and hyperarousal further predicted the degree of functional impairment. Over half of the parents were on sick leave or receiving disability benefits due to their inability to return to work. Bereaved siblings reported absenteeism and poorer school performance as a result of their loss.

Past research on the circumstances surrounding death has found that access to palliative care, better medical care received by the deceased, a “good death” with less pain and suffering as well as respect for the patient’s and surviving family members’ dignity, and open communication with the medical team are associated with better emotional wellbeing of bereaved individuals (Fasse et al., 2014). Caregiving experiences have been found to both facilitate and hinder adjustment to loss. Caregivers, through interacting with their dying loved ones, often have advanced preparations for the loss, which in turn is associated with better bereavement outcomes. The eventual passing of

the patient can be seen as a relief, as demonstrated by the “depressed-improved” pattern of grief in the previously reviewed Bonanno et al. (2002) and Galatzer-Levy and Bonanno (2012) studies. Conversely, caregiving strain, witnessing the suffering of terminally ill patients, and the neglect of one’s personal needs predict post-loss level of depression and grief (Lobb et al., 2010; Stroebe et al., 2007). Bereaved caregivers who struggle with multiple, concurrent stressors such as financial strain and competing responsibilities at work and at home also experience poorer bereavement outcomes (Schulz, Hebert, & Boerner, 2008).

## **Interpersonal Factors**

Another risk factor that has received considerable research attention is kinship (i.e., the type of familial relationship between the bereaved and the deceased). In general, the loss of a spouse and the loss of a child are associated with more negative psychosocial outcomes.

The death of a spouse is consistently rated as the most stressful of all major life events in life event scales (e.g., Holmes & Rahe, 1967), with younger bereaved spouses being more likely to experience negative impact than older persons (Carr, 2008). From an attachment theory standpoint, the loss of a life partner represents the loss of an important attachment figure. Such a loss leads to a sense of emotional void or loneliness that cannot be alleviated by one’s social support network (Stroebe, Zech, Stroebe, & Abakoumkin, 2005). Conjugal bereavement often triggers a number of secondary losses, such as financial strain, the loss of meaningful social roles and identities, the loss of a helpmate, confidante and caretaker, and the loss of daily routines that used to provide structure and meaning to one’s life (Carr, 2008; Carr & Jeffreys, 2011; Hansson & Stroebe, 2007)

The death of a child has been considered the “ultimate loss” for parents (D’Agostino, Berlin-Romalis, Jovcevska, & Barrera, 2008, p. 33). This kind of loss is particularly difficult for parents due to the centrality and intimacy of the parent-child bond. The death of a child represents an existential crisis for parents as they confront a shattering of their identity, their meaning in life, as well as their hopes and dreams for the future (Polatinsky & Esprey, 2000; Woodgate, 2006). The death of a child also violates

parents' assumption about the order of the world, given the general belief that children should outlive their parents (Dijkstra & Stroebe, 1998). Grieving parents may feel a tremendous sense of failure at their role as protector and guardian. Blame and withdrawal from others due to negative reactions and stigma associated with child death can make social support particularly scarce for parents (Bucaro, Asher, & Curry, 2005). The grief associated with the loss of a child therefore tends to be the most severe, long-lasting, and debilitating among the different types of loss (Littlewood, Cramer, Hoekstra, & Humphrey, 1991; Oliver, 1999). In a large-scale population-based study examining the long-term consequences of parental bereavement, bereaved parents were more likely to report anxiety, depression, poorer psychological wellbeing, and decreased quality of life, compared to non-bereaved parents 4 to 6 years post-death (Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steinbeck, 2004). Twenty-six percent of the sample reported not being able to come to terms with the loss 4 to 9 years after their children's death, putting them close to three times as likely to suffer from anxiety and depression than those who had worked through their grief more completely.

With regards to other relationship variables, insecure attachment such as an anxious or avoidant attachment style predicts more intense grief and depressive symptoms post-loss. This relationship is especially strong among those who have lost their spouse (Itzhar-Nabarro & Smoski, 2012, van der Houwen, Stroebe, Stroebe et al., 2010). Research on the role of social support in buffering against the negative impact of bereavement has been inconclusive (Stroebe et al., 2006). Social isolation exacerbates psychosocial impairment after sudden losses (e.g., Dyregrov, Nordanger, & Dyregrov, 2003), but social support is more likely a general rather than a bereavement-specific "buffering" protective factor, since increased social support mitigates depressive symptoms in both bereaved and non-bereaved individuals (e.g., Stroebe et al., 2005).

### **Intrapersonal Factors**

Pre-loss level of psychological functioning is a strong predictor of bereavement outcomes. Past histories of anxiety, mood disorders, trauma and multiple losses are associated with the development of prolonged grief and subsequent psychiatric disorders after the death of a loved one (Lobb et al., 2010; Shear, Ghesquiere, & Glickman, 2013;



Zisook et al., 2014). On the other hand, religious involvement and spirituality are associated with more positive outcomes such as increased positive mood (van der Houwen, Stroebe, Stroebe et al., 2010)

Gender as a risk factor tends to interact with kinship. In the case of conjugal bereavement, mortality risk, disability and functional impairments are usually higher for widowers than widows (Lee & DeMaris, 2007; Stroebe et al., 2007). In the case of parental bereavement, however, bereaved mothers tend to have a higher risk of mortality, depression, anxiety, and hospitalization for psychiatric symptoms than bereaved fathers and non-bereaved parents (Kreicbergs et al., 2004; Li, Laursen, Precht, Olsen, & Mortensen, 2005; Li, Precht, Mortensen, & Olsen, 2003).

Recent research has begun to explore personality and cognitive variables such as appraisal, coping and meaning reconstruction associated with adjustment to loss. Neuroticism, a personality trait characterized by emotional lability, hostility, self-consciousness and impulsivity, is found to predict level of grief and depression in bereaved parents (Wijngaards-de Meij et al., 2007). Those with “well-adjusted personalities” such as an internal locus of control, optimistic outlook, and higher self-esteem are likely to be more resilient (Stroebe et al., 2006, p. 2446). Negative cognitions such as negative beliefs about the self, life, and one’s future, threatening appraisals of grief (i.e., the belief that one is unable to handle painful emotions), rumination over the loss, cognitive avoidance such as suppression of memories, and counterfactual thoughts about death are associated with greater distress (Boelen, van den Bout, & van den Bout, 2006; Shear et al., 2013; van der Houwen, Stroebe, Schut, Stroebe, & van den Bout, 2010). More active and forward-focused coping, defined as the ability to think optimistically, attend to the needs of others, maintain goals and plans for the future, regulate one’s emotion, and maintain a sense of humour, can facilitate adjustment to the loss of a loved one (Burton et al., 2012).

On a positive note, bereavement can also spark a journey of self-exploration, search for meaning, personal change, and enhanced coping. More recent research has begun to examine how bereavement can motivate meaning making and posttraumatic growth as ways of coping and adjusting to a loss. The death of a loved one, often perceived as an uncontrollable and unjust life event, may contradict one’s worldview on

oneself and the world (e.g., viewing oneself as worthy, and the world as “benevolent, predictable, and just”; Hibberd, 2013). This can trigger an existential crisis of meaning among bereaved individuals (Currier, Holland, & Neimeyer, 2009). In an attempt to reconcile the conflicts between one’s pre-existing positive worldview and negative appraisals towards death, bereaved individuals are compelled to undergo an active process of meaning reconstruction, where they need to 1) make sense of the loss, 2) identify benefits or “silver linings” to having lost a loved one, and 3) change their identities and developing a new view of themselves (Gillies & Neimeyer, 2006). Through meaning reconstruction, bereaved individuals integrate the loss into their identities, experience self-transformation and develop a new, different way of viewing the world.

Higher level of meaning reconstruction has been shown to predict better bereavement outcomes (Neimeyer, Baldwin, & Gilles, 2006). Meaning reconstruction is also associated with posttraumatic growth, where bereaved individuals report positive self-transformation such as being “sadder but wiser”, and more compassionate, mature, tolerant and empathic (Hibberd, 2013; Michael & Cooper, 2013). The discovery of new and increased personal strengths, increased courage to try new things, an attitude of “seizing the day” and “living life more fully”, increased religiosity and spirituality, improved interpersonal relationships, and a greater appreciation of life are common outcomes of posttraumatic growth among the bereaved (Gillies & Neimeyer, 2006; Michael & Cooper, 2013).

## **Bereavement Care Services**

The intense grief during the initial months after a loss has occurred, as well as the increased risk for severe psychosocial and physiological morbidity and mortality for a significant portion of bereaved individuals, suggest that care for the surviving family members should not terminate at the moment of someone’s death. Surveys on bereaved family members often reveal a high level of need for continued contact with health care professionals (Milberg, Olsson, Jakobsson, Olsson, & Friedrichsen, 2008; Wilkinson, Croy, King, & Barnes, 2007). Yet to many surviving family members, the death of a loved one represents abandonment by the hospital staff and the community support system (deCinque et al., 2006; Kusano, Kenworthy-Heinige, & Thomas, 2012). Many perceive this

as a major loss as they often feel isolated, alone, and unable to receive adequate and appropriate support from family and friends who may not understand the depth of nor compensate for the bereaved's loss (Gudmundsdottir & Chesla, 2006; Stroebe, Stroebe, Abakoumkin, & Schut, 1996).

Bereavement care is an integral part to palliative care, a comprehensive, multidisciplinary model of care that focuses on improving quality of life, relieving suffering, and providing physical, psychological, social, and spiritual support for patients with life-threatening conditions and their families (World Health Organization, 2016). The goals of bereavement care are twofold. First, bereavement care aims to be *preventive*, with the hope of fostering healthy adjustment and preventing the detrimental physical and psychological consequences of bereavement in surviving family members. Second, bereavement care can be *therapeutic* as it involves providing treatment to those presenting with complications (Lang & Carr, 2013; Morris & Block, 2015).

Health care professionals and research literature have been using the same terms – “bereavement care” or “bereavement support” – to mean three different types of support programs that vary in nature, practices and timing of delivery. The first type of “bereavement support” is *pre-bereavement or anticipatory grief support*. For many individuals whose family members are struggling with life-threatening illnesses, their grief often began at the time of diagnosis, when they were told that their loved one's condition is incurable. The impending death, coupled with increased life demands such as caregiving burden, financial difficulties and disruption of daily routines, can easily overwhelm one's coping resources (Ivoncavich & Wong, 2008). Bereavement support for family members of a dying patient therefore needs to be delivered before the actual death occurs, by preparing family members for the death (e.g., educating them on what will happen at the time of death), facilitating conversations between the patient and the rest of the family regarding end-of-life wishes and preferences, planning ahead for the feelings of grief, providing information on available support services post-death, and preparing for changes in roles and daily life activities after the loss (e.g., single parenthood, handling financial matters, or even taking care of household chores; Tabler et al., 2015). Staff members, through regular interaction with the family members on site, can observe and

assess their functioning in order to plan for transition of care and effective follow-up (Institute of Medicine, 1984).

The second type is *bereavement follow-up care*, in which health care professionals initiate and/or maintain contact with bereaved family members after the death of a patient. Such follow-up contact can involve attendance at funeral, phone calls from staff at regular intervals, sympathy and anniversary cards, mailing of condolence letters, information packages on local resources and educational material on bereavement, invitation for in-person meeting with staff, annual memorial services, or even home visits (e.g., Agnew, Manktelow, Haynes, & Jones, 2011; Barry et al., 2012). Bereavement follow-up care has both a compassionate and an informational focus. It allows health care professionals to convey empathy and care, as well as educating bereaved family members on grief, bereavement, and support services available. Such contact also allows for an assessment of need for further services and referral to formal support (Agnew et al., 2011; Donovan, Wakefield, Russell, & Cohn, 2015; Milberg et al., 2008).

The third form of bereavement care consists of therapeutically focused *bereavement interventions*. These include support groups, individual and/or group psychotherapy, and psychiatric / pharmacological interventions for those struggling with prolonged grief and significant emotional, social, occupational and family difficulties (e.g., Breen, Aoun, O'Connor, & Rumbold, 2014; Donovan et al., 2015; Lichtenthal et al., 2015).

Given the person- and family-centred care philosophy of palliative care, bereavement care must be tailored to meet individual and family needs (Canadian Hospice Palliative Care Association, 2013). In fact, previous research has shown that bereavement services with a therapeutic focus, such as grief therapy, have different levels of efficacy depending on clients' needs (Breen et al., 2014). Providing grief therapy *universally* to *all* bereaved individuals, regardless of need and level of risk, fails to demonstrate positive treatment effect (Currier, Neimeyer, & Berman, 2008). Indiscriminate provision of therapeutic services may even cause iatrogenic harm, resulting in greater distress among bereaved individuals due to the pathologizing of normal grief and interference with the natural grieving process (Jordan & Neimeyer, 2003; Schut & Stroebe, 2005). Research however supports the efficacy of *targeted* grief interventions for those

who are at risk of developing bereavement-related difficulties, or are already symptomatic before treatment commences (e.g., Boelen, de Keijser, van den Hout, & van den Hout, 2007; Currier et al., 2008; Shear, Kissane, Lichtenthal, & Zaider, 2007; Frank, Houck, & Reynolds, 2005;).

Previous research evaluating the effectiveness of bereavement care services has yielded mixed results, likely because the practice of bereavement care is highly diverse across different programs and organizations (Endo, Yonemoto, & Yamada, 2015; Forte, Hill, Pazder, & Feudtner, 2004; Holtzlander, 2008; Wilson et al., 2016;). Nevertheless, results from program evaluation of individual bereavement programs and satisfaction surveys suggest that the majority of bereaved family members who received bereavement care services have found them beneficial. Recipients of bereavement care services report that such services allow them to share their feelings and experiences with professionals or others who have suffered similar losses, as many in their social networks avoid bringing up the death (Berrett-Abebe, Leven-Russman, Gioiella, & Adams, 2017; Donovan et al., 2015). Most surviving family members appreciate continued connection with the staff previously involved in the care of the deceased, as it helps alleviate feelings of abandonment and isolation when the bereaved families transition from the hospital back to the community (Donovan et al., 2015; Lichtenthal et al., 2015). Many welcome phone calls, sympathy cards and notes, and staff's attendance of the funeral (Billings & Kolton, 1999; Kaunonen, Tarkka, Laippala, & Paunonen-Ilmonen, 2000; Macdonald et al., 2005). Continuity of care into the bereavement period helps bereaved individuals feel acknowledged, as they know that someone cares and remembered them (Donovan et al., 2015; Milberg et al., 2008). Follow-up contact is also considered an important source of informational support, particularly in terms of educating bereaved individuals on the grieving process and resources available in their communities. In an evaluation of a pediatric bereavement follow-up program at the Stollery Children's Hospital in Edmonton, for example, 62% of bereaved parents found the informational pamphlets on grief and resources helpful. Half of the sample reported that they even shared the pamphlets with other family members and friends who had suffered similar losses (deJong-Berg & Kane, 2006).

## The Changing Dynamics of Canada's Demographics

Sensitivity to a family's cultural background has always been the cornerstone of optimal palliative care, and this has become increasingly important given the changing demographic composition of Canada. The last three decades have witnessed a dramatic increase in the diversity of the Canadian population. Since the early 1990s, an annual average of 235,000 new immigrants have moved to Canada from foreign countries (Statistics Canada, 2016a). Data from the 2011 Census reveal that over 6.7 million people out of the total Canadian population of 33 million are immigrants (Statistics Canada, 2016b). Over 6.2 million people residing in Canada are visible minorities (Statistics Canada, 2016d). Close to 6.6 million Canadians do not speak English or French as their first language; 595,920 individuals do not know how to speak either official language (Statistics Canada, 2016e). Ethnic diversity is even more prominent in large metropolitan areas. In Metro Vancouver, for example, 42.7% of its population are immigrants (Statistics Canada, 2016b). Forty percent of the residents in Metro Vancouver do not speak either official language as their first language. Close to 130,000 individuals do not speak either English or French (Statistics Canada, 2016e). Our increasingly multicultural population implies that clinical encounters between patients and health care professionals from different cultural backgrounds are commonplace. Changing demographics make it necessary for health care professionals in palliative care to examine the role of ethnicity and culture on service delivery, and be sensitive to attitudes, beliefs, and preferred care for those who came to Canada from another culture (Carstairs, 2010; Kwak & Haley, 2005; Mjelde-Mossey & Chan, 2007). Almost all practice standards for palliative care include the need to assess and meet the culture-specific needs of the patients and families, to tailor services to the families' cultural values, and to promote equitable access to palliative care regardless of ethnicity and cultural background (e.g., National Consensus Project for Quality Palliative Care, 2013; Palliative Care Australia, 2005). The palliative care norms of practice put forth by the Canadian Hospice Palliative Care Association (2013), for example, emphasize the need to respect and take into account a family's cultural values, beliefs and practices in all aspects of palliative care provision.

## Cultural Issues in Death, Palliative Care and Bereavement Care

Culture is a unified set of values, norms, ideas, beliefs, practices and standards of behaviour of a particular group that are learned, shared, and guide thinking, decisions, and actions; it is the way a person accepts, orders, interprets, and understands experiences in life (Blevins & Papadatou, 2006; Hall, Stone, & Fiset, 1998; Thomas, 2001). It is dynamic and not a trait-like characteristic, and will interact with other factors to determine behaviours (Hall et al., 1998; Kagawa-Singer & Kassim-Lakha, 2003; Koenig & Davies, 2003). Kagawa-Singer and Kassim-Lakha (2003) have proposed two functions of culture: the *integrative* function of culture provides individuals with a sense of meaning and identity, while its *prescriptive* function provides rules to guide behaviours.

Culture serves as a context within which people interpret the world and decide on their behaviours. It shapes how people explain and find meaning in illness, death, and suffering. What constitutes health, what causes disorders and distress, and how to maintain, regain or attain health are culturally defined (Kagawa-Singer & Kassim-Lakha, 2003). It also determines how one should utilize health care services, what needs to be treated, what treatment is considered appropriate, how to communicate with the health care team, as well as what roles health care professionals, patients, and family members should play (Kagawa-Singer & Blackhall, 2001; Koenig & Davies, 2003; Kongnetiman, Lai, & Berg, 2008). Culture shapes the clinical counter where potentially conflicting interpretations, expectations, beliefs, values, and understanding between professionals, patients, and families may occur (Kagawa-Singer & Kassim-Lakha, 2003). It helps individuals understand and gain a sense of control, by way of beliefs, values and rituals, over unpredictable and uncontrollable events such as illness and death. It specifies the appropriate way to communicate care, ensure safety, and provide support for the members within the same culture (Ashing-Giwa & Kagawa-Singer, 2006; Kagawa-Singer & Kassim-Lakha, 2003).

When individuals face uncontrollable events, the basic core beliefs and value systems from their heritage culture are often the only things they can hold onto (Thomas, 2001). Immigrants from non-Western cultures and ethnic minorities are more likely to draw

from their heritage cultural norms, values and practices in the face of death, as they help provide meaning and guide decision-making (Kagawa-Singer, 1998; Kwak & Haley, 2005). While the extent to which individuals adhere to ethnic standards of health behaviours depends on their level of acculturation, even those who are highly acculturated may resort to values and assumptions in their heritage culture when facing highly emotionally distressing events in their lives (Noggle, 1995). Grief can make acculturated immigrants or ethnic minorities shift back to their ethnic roots, and resume long abandoned traditional cultural values and practices in order to adapt to the stressor and make sense of the world (Doran & Downing Hansen, 2006; Eisenbruch, 1984).

Sormanti and August (1997) described three core issues surrounding the beliefs in death in a culture: the relationship between the dead and the living, the nature of life after death, and the reconstruction of the relationships disrupted by death. While death and bereavement are universal phenomena, how strongly one reacts, how much distress one experiences, and how grief is expressed are affected by cultural values surrounding these three core issues (Bahl, 1996; Clements et al., 2003; Doran & Downing Hansen, 2006). All cultures have prescriptive rules and methods for adaptive coping, grief, and mourning. A behaviour or a belief, if taken out of its cultural context, may appear pathological, especially if it is evaluated against a standard from another culture (Kagawa-Singer & Kassim-Lakha, 2003). For example, traditional Western theories of grief have assumed that resolution of grief requires “working through” the emotions of grief, directly expressing feelings, and severing the emotional bond with the deceased (Lalande & Bonanno, 2006; Shapiro, 1996). Many of the treatments offered to the bereaved have previously deemed continuing bond as a form of pathological grief (Sormanti & August, 1997). In many other cultures, however, retaining the connection with the deceased is expected and considered normal and adaptive (Stevenson et al., 2016). In a cross-cultural study on the relationship between continuing bonds and self-reported distress, higher level of continuing bond at 4 months post-loss was found to predict lower level of distress at 18 months of bereavement for bereaved Chinese individuals (Lalande & Bonanno, 2006). Yet the reverse was true for bereaved individuals from the US: higher level of continuing bond was associated with higher distress. Lack of sensitivity to grieving practices seen as normative and adaptive in other cultures may interfere with the bereaved’s adjustment (Clements et al., 2003).



## **Unmet Needs and Disparities in Access and Experiences of Care for Immigrants and Ethnic Minorities in Palliative Care**

Previous research on health care utilization has found that ethnic minorities and immigrants tend to underutilize many important social and health services despite evidence of significant need (Mok, Lai, Lin, Wong, & Ganesan, 2003). The philosophy of palliative care involves the provision of sensitive and compassionate care to all members of the community (McGrath, Vun, & McLeod, 2001). Ethnic disparities in access to palliative and bereavement care, however, have been well documented.

Population health research has shown that ethnic minorities and immigrants of non-English-speaking background (NESB; i.e., people who do not speak English as their first language, came from a non-English speaking country or have at least one parent from a non-English speaking country; McKinley & Blackford, 2001) are grossly underrepresented in palliative care (Cohen, 2008; Hall et al., 1998; Kongnetiman et al., 2008; McGrath et al., 2001). For example, in their survey of the eight pediatric palliative care programs in Canada, Widger and colleagues (2007) found that most clients these programs served were Canadian-born English-speaking individuals. Fountain (1999) reported that while 9.7% of the population residing in the catchment area of the Southern Derbyshire Health Authority in the United Kingdom were ethnic minorities, they comprised only 1.5% of the patients receiving palliative care. In the US, where approximately half of the deaths occurred under hospice care, 76% of hospice patients were of Caucasian descent; African and Hispanic Americans were underrepresented in hospice use (National Hospice and Palliative Care Organization, 2012, 2015).

It is often assumed that individuals from non-Western cultural and linguistic backgrounds do not access palliative care services due to preference – that they prefer to keep their problems within the family system, or to rely on informal support network such as friends and extended family members (Bergman, Haley, & Small, 2011). Yet research has shown that informal support is not always as available to them as many have assumed (Scharlach et al., 2006). Even for those who are accessing services, their needs may still not be adequately met. Individuals from ethnic minorities or those not fluent in English tend to receive worse quality of care compared to their Caucasian, English-speaking

counterparts. Ethnic minority status is associated with less satisfaction with informational support, education, patient care, and emotional and spiritual support received from the hospice staff among bereaved family members (Holland, Keene, Kirkendall, & Luna, 2015).

Unmet needs among ethnic minority or NESB families and a lack of sensitivity to cultural issues among staff members working in palliative care services have been reported in previous literature. McKinley and Blackford (2001) interviewed nurses working in a pediatric intensive care unit on their experience working with NESB families. Results revealed stunningly insensitive practices of palliative care for those from non-Western backgrounds. Nurses often adopted what the authors termed “controlling practices” to enforce boundaries and limit their interactions with NESB families. For example, they limited communications to only the parents despite the parents’ expressed preference for the involvement of extended family members. Some put up instructions that were only in English when knowing that the families did not understand the language. Request for interpreter services could not be initiated by families themselves. The staff utilized interpreter services only because they had issues to relay to the families, but not because they wanted to give the families a chance to discuss their particular concerns. The staff also assumed that all families, regardless of their background, wanted to provide active care for their child and be responsible for decision-making, without realizing that such practices might not be endorsed by all families. When NESB families displayed reluctance to follow their recommendations, staff members tended to blame the families for being “different” and “difficult”. Some used coercion to make the families follow their recommendations in the guise of “doing them good”, and took NESB families’ silence as acquiescence and agreement. The staff was oblivious to the impact and the meaning of their actions, never questioning the underlying values and assumptions that informed their nursing practices. The authors noted that the nursing staff put NESB families in a position of submission as they imposed their “standard practice” on NESB families without examining whether it was right or appropriate for those from other cultural backgrounds.

McGrath and colleagues (2001) recruited 33 non-English-speaking, ethnic minority participants (Indian, Filipino, Chinese, and Italian) who were bereaved family members of terminally ill patients to participate in focus groups on their experiences of palliative care

services. Nearly all participants reported that they were not given choices on how they would like to care for their loved ones. Most reported difficulties associated with language barriers. Not being able to speak and understand English undermined these families' power in asserting choices and expressing needs in mainstream health care systems. They were also less likely to learn about or utilize mainstream services offered. Families reported feeling lost, helpless, discouraged and scared when navigating through the health care system. Communication with professionals was severely compromised.

Field, Maher, and Webb (2002) undertook a chart review of all NESB inpatients in an Australian hospice. They then interviewed health professionals and representatives from community organizations serving NESB individuals regarding the palliative care needs of those from diverse cultural and linguistic backgrounds and gaps in service provision. The authors found a high level of inaccuracies recorded on the admission forms for NESB patients (e.g., making up the religious background of patients based on their ethnicity), probably due to stereotyping and a lack of culturally sensitive intake process. Only 12.14% of all NESB inpatients accessed interpreter services. Most relied on family members, members from the same ethnic background, ministers and other hospice employees for communicating with health care professionals, a practice that was against Australian government's policy. Those who were unable to speak, understand and write English were more likely to be excluded from services that were routinely offered to English-speaking families. Interview findings showed that NESB individuals often retained values about death and dying from their heritage culture. In contrast to Western values that promote open discussion of life-threatening illnesses, many NESB communities, particularly Chinese and Jewish communities, maintained a veil of silence surrounding illness and death, and open discussion led to uncomfortable feelings and resistance.

Randhawa, Owens, Fitches, and Khan's (2003) interviews of South Asian cancer patients and family members who received palliative care revealed that participants were frustrated by the fact that communication with palliative care professionals only took place in English. Participants felt that there was not enough staff from other cultures that could speak other languages and understand diverse cultural and religious beliefs. Most were only partially aware of services available to them, and learned very little about their conditions.

Finally, Abbe, Simon, Angiolillo, Ruccione, and Kodish (2006) interviewed 17 NESB immigrant parents of children with cancer. Parents reported feeling fearful and worried that they would not be able to understand communication from the health care teams. No one informed them that interpreter services were available. Comprehension difficulties due to the use of jargon were frequent. Even when interpreters were used, the parents still could not fully understand due to the complexity of the information.

## **Barriers to Access and Receipt of Optimal Palliative and Bereavement Care**

The barriers to receiving optimal palliative and bereavement care services by ethnic minorities and NESB immigrants are multidimensional, reflecting interactions between personal and system factors. Lack of information about available services, language or communication barriers, and issues surrounding cultural competence and culturally sensitive services in palliative care are some of the most frequently identified barriers to access and optimal care (e.g., Arriaza, Martin, & Csikai, 2011; Davies et al., 2008). Barriers to accessing palliative and bereavement care put bereaved ethnic minority members and NESB immigrants in an extremely vulnerable position when they are trying to cope with the life-threatening conditions of their loved ones, which may exacerbate the negative impact of bereavement on their wellbeing (Chaplin, 2003).

## **Lack of Knowledge in Palliative Care and Availability of Services**

Past research highlights the lack of knowledge in available palliative and bereavement care services among individuals from culturally and linguistically diverse backgrounds (Ludke & Smucker, 2007; McGrath et al., 2001; Scharlach et al., 2006). Many of them do not know that palliative care exists or understand what it is (Calanzani, Koffman, & Higginson, 2013). They may have little awareness of available services in their community, which consequently limit their ability to decide on where they should seek help or how to meet their needs (Li, 2004). When trying to access health care, immigrants often encounter a foreign and unfamiliar health care system. Many may not be aware of their right to services, the roles of providers, or expectations for treatments (Oxman-Martinez & Hanley, 2004). Many NESB immigrants and ethnic minorities are particularly susceptible

to low health literacy, defined as the ability to obtain, understand and use health information and services needed to make wise health choices (Kidd et al., 2014; Kimbrough, 2007). Low health literacy has been shown to contribute to difficulties navigating the health care system and accessing palliative care services.

Kreling and colleagues (2010), for example, interviewed Latino and Caucasian bereaved family caregivers who had previously accessed hospice services. Results revealed that most Caucasian participants knew about hospice care before their family members got sick. Many had prior experience of having another relative receiving hospice care. They also had good knowledge of what hospice care entailed. In contrast, few Latino participants had previous experience with hospice care. Most had no knowledge or even misconceptions about hospice care, such as thinking that hospice was a place for poor elderly or people with disabilities.

Frey and colleagues (2013) interviewed cancer patients of Maori, Pacific Islander, and Asian descent living in New Zealand, their family members and health professionals to examine challenges to the use of hospice services. Patients and families reported a lack of familiarity with the role of hospice or the services available. There was a lack of awareness of what hospice services entailed and how they could be utilized. For instance, many did not realize that they could use hospice care as a form of short-term respite care. They also reported that hospice information was often provided by health care professionals without clear, thorough explanations, which further contributed to misinformation and misunderstanding of palliative care services. Patients and family members thought that a hospice was a cold, dark place where people went to die. Palliative care was a free service to all New Zealanders, yet participants equated free health care services with an inability to pay. They thought that palliative care was only offered to those who were poor, unemployed, and incapable of taking care of their families financially. This led to stigma, feelings of shame, and reluctance to access services among service users.

Enguidanos, Yonashiro-Cho, and Cote (2013) interviewed a community-based sample of 34 older Chinese Americans regarding their knowledge and perception of hospice care. Results showed a general lack of knowledge among the participants: only

11.8% of the sample reported knowing someone who had received hospice care. English-speaking participants tended to be more familiar with hospice services than Cantonese- and Mandarin-speaking participants. Misconceptions over the nature of life-threatening illnesses and hospice care were evident. Cantonese- and Mandarin-speaking participants greatly preferred quickly ending their life upon the diagnosis of a terminal illness. A number of participants viewed hospice care as “mercy killing” and were disappointed to learn that hospice care was not a form of assisted suicide. Participants also viewed hospice care primarily from a financial perspective. For instance, the motivation behind their preference for hastened death was to reduce financial burden, not only on family caregivers, but also on government funding and resources. Some perceived home death as the government’s way to shift health care costs and financial burden onto family caregivers.

## **Language and Communication Barriers**

It is often said that communication is the foundation of palliative care (Kang et al., 2005). Clear communication facilitates collaboration between family and health care professionals, better understanding of the family’s needs, and better services and support from professionals. The need for fluency in communication is even greater in palliative care as it requires a more meaningful and deeper level of discussion on pain, death, and suffering (Kemp, 2005). Medical jargon frequently used in palliative care, such as “do not resuscitate” or “withhold, withdraw, and discontinue treatment”, can be prone to misinterpretation by lay people (Long, 2011).

Language barriers have a profound impact on every aspect of one’s health care experiences. Ethnic minorities and NESB immigrants face significant problems around communication, often due to low English proficiency (Randhawa et al., 2003). Most palliative care services are only available in English. Information about relevant services is seldom available in different languages to accommodate those with poorer command of English (Evans, Menaca, Andrew, et al., 2012). Language barriers hinder one’s ability to gain information and knowledge about health and available services (Frey et al., 2013). Palliative care is about offering patients and family choices, but those with limited English proficiency are more likely to misunderstand information given, thus severely limiting their understanding of available choices and decision-making abilities (Munet-Vilaro, 2004;

Noggle, 1995). Communication barriers affect the care recipients' ability to understand and describe their experiences, as well as health care professionals' ability to assess symptoms and explain treatment options (Calanzani et al., 2013; De Trill & Kovalcik, 1997). Poor communication between health care professionals and patients / family members can lead to a lack of sensitivity to patients' cultural and religious needs, misdiagnoses, inappropriate treatment, misunderstanding of medical instructions, poorer quality of the therapeutic alliance, stress among professionals, and patient and family dissatisfaction with care (Abbe et al., 2006; Calanzani et al., 2013; Zanchetta & Poureslami, 2006). Communication difficulties exacerbate the power difference between patients/families and health care professionals, leading to feelings of helplessness, vulnerability, mistrust, or even discrimination (Evans et al., 2012).

Despite recommendations that professional translation services must be provided at all times, they are still not universally and consistently available (Contro, Larson, Scofield, Sourkes, & Cohen, 2012). Many health care teams still rely on family members (often children who speak fluent English) as translators, which creates problems due to power differences and family members' desire to protect their loved ones from distressing information (Calanzani et al., 2013; Randhawa et al., 2003). Even if professional interpreters are available, it is difficult to find someone who will work with the same family regularly and build a relationship strong enough to allow them to convey more sensitive information. Accuracy in communication may be compromised as information may be distorted through the process of understanding, converting and transmitting across different languages. Some medical terms or names of services have no equivalent in other languages, making translation more difficult (Calanzani et al., 2013). Many interpreters lack experiences working with patients with terminal illnesses, and have limited knowledge in the technology and terminology of palliative care (Evans et al., 2012; Randhawa et al., 2003). A literal translation can lead to misunderstanding and misinformation. Some ethnic minority groups, such as Chinese and Latino, are uncomfortable with the presence of an unknown third person (such as an interpreter) in the clinical encounter, and may feel less free to express concerns and ask questions (Barnes, Davis, Moran, Portillo, & Koenig, 1998; Frey et al., 2013)

## **Culturally Sensitive Care: Issues Surrounding Diversity of Health Care Professionals and Cultural Competence**

When one wants to communicate with someone about his or her health care needs, it is natural to prefer someone who shares the same culture, heritage, language, and history in order to build trust (Thomas, 2001). Many ethnic minority and NESB recipients of palliative care express a strong preference for professionals that can speak their native language, as they believe that the emotional issues raised by death and dying are best expressed in one's mother tongue (McGrath et al., 2001). Yet there has been a shortage of palliative care professionals that can speak other languages or reflect the demographic characteristics of the community they serve (Arriaza et al, 2011; Yang & Kagawa-Singer, 2007). A 2014 survey of 207 hospices in the US, for instance, found that hospice staff and volunteers were overwhelmingly Caucasian: 94% for staff, and 96% for volunteers. Only 1% of staff and volunteers spoke Spanish; even fewer spoke languages other than English or Spanish (Reese & Beckwith, 2015).

Cultural disparities exist between clinicians who are predominantly English-speaking and Caucasian, and families from diverse cultural and linguistic backgrounds (Hardy-Bougere, 2008; McKinley & Blackford, 2001). Previous research has shown that having bilingual professionals on staff can improve referral of ethnic minority patients to palliative care services, facilitate communication between patients and other professionals involved in their care, and improve understanding of patient and family needs due to shared heritage and language (Ackroyd, 2003). Yet the so-called "ethnic match" between care provider and recipient of care does not always guarantee better quality of care. Seto Nielsen and colleagues (2005), in their ethnographic study of palliative home care for Chinese immigrants with terminal cancer, interviewed 11 health care professionals with experience working with Chinese families. A palliative care physician noted that language capability did not equate to clinical competence, as he expressed the worry that ethnic match might simply be trading quality of care for linguistic similarities: ".....so you might have a clinically more capable nurse in palliative care who can't speak Cantonese or Mandarin, or you get a Cantonese-assigned nurse who has no interest or experience in palliative care" (Seto Nielsen, Angus, Howell, Husain, & Gastaldo, 2015, p. 376). Moreover, a match based on ethnicity alone does not equate a match in the language used. A home care nurse of Chinese descent reported that she was assigned to a Chinese



family, only to discover that the family spoke Cantonese while she herself was Mandarin-speaking. This suggests that “ethnic match” may have been done based on shared racial rather than linguistic similarities, with little consideration given to within-group variations (such as the use of different dialects within the same ethnic group).

Despite the emphasis on cultural sensitivity and competence in the practice standards of palliative care, achieving such goals in clinical practice has been difficult for several reasons. First, there has been a paucity of research on cross-cultural differences in end-of-life experiences, bereavement outcomes, the specific needs of ethnic minority groups, and the ways ethnocultural differences affect patient-professional interaction (Kagawa-Singer & Blackhall, 2001; Stroebe et al., 2007). Participants in published research on grief, palliative care and bereavement care are predominantly Caucasian, Christian, English-speaking middle-class individuals (e.g., Barrera et al., 2007; Keesee, Currier, & Neimeyer, 2008; Kissane et al., 2007; Mack et al., 2005; Shah & Meeks, 2012; Stahl & Schultz, 2014; Williams & Mccorkle, 2011). “Not speaking English as the primary language” is often one of the exclusion criteria in research (e.g., Billings & Kolton, 1999; van der Houwen, Stroebe, Schut, et al., 2010). Immigrants and ethnic minority groups had been excluded from research due to language barriers, a lack of strong relationships with the health care staff (e.g., Barrera et al., 2007), and unavailability of validated, translated measures (e.g., Sormanti & August, 1997). As a result, our current understanding of grief is largely based on the experiences of bereaved Europeans and Euro-Americans in Western cultures (Li & Prigerson, 2016). What constitutes “culturally sensitive care” is not clearly defined (Calanzani et al., 2013). A lack of cross-cultural research translates into a lack of empirically based evidence to guide culturally sensitive health care practices. There remains a limited understanding of health care needs, beliefs on health, and help-seeking behaviours unique to immigrants and ethnic minorities. Health care professionals working in palliative and bereavement care struggle with a lack of evidence-based practice guidelines, culturally and linguistically appropriate diagnostic tools, treatment protocols and educational resources when working with patients and families with diverse cultural backgrounds (Yang & Kagawa-Singer, 2007).

Second, there have been concerns about whether the core principles and values of palliative care, initially developed in Western countries, are equally generalizable to

other cultures (Calanzani et al., 2013; Liben, Papadatou, & Wolfe, 2008). The North American health care system is based on Western Judeo-Christian values that: 1) life is sacred and must be preserved at all costs, 2) autonomous decision-making must be maintained, and 3) no one should suffer (Kagawa-Singer, 1998). The belief in the centrality of individuality is fundamental in Western cultures and health care systems (Kagawa-Singer & Kassim-Lakha, 2003). In the dominant, middle-class, Christian, Euro-American belief system, the individual is the basic, central unit of society and is considered to be “autonomous, egalitarian, rational, self-assertive and self-aware” (Kagawa-Singer & Kassim-Lakha, 2003, p.580; Hsu, Kahn, Yee, & Lee, 2004). These form the core principles of palliative care in Western countries: openness in disclosure and communication, patient autonomy and participation in decision making, an egalitarian relationship between health care professionals and patients, overt expression of emotions, concerns, and needs in both the dying and the bereaved, and a promotion of self- and death awareness (Blevins & Papadatou, 2006; Liben et al., 2008). Such values underlie the standards of care and practice guidelines for palliative care practitioners (e.g., Canadian Hospice Palliative Care Association, 2013; National Consensus Project for Quality Palliative Care, 2013).

Health care professionals, trained under this model and working under these guiding principles, may assume that their care recipients also respond to the same set of values without questioning whether such values are equally endorsed by other cultures (Kagawa-Singer & Blackhall, 2001; Kagawa-Singer & Kassim-Lakha, 2003). For instance, while individuality, right to self-determination and autonomy are highly valued in Western cultures, collective consciousness may take precedence in other cultures (Beaty, 2015). In many non-Western cultures, decisions are made by consensus of the group. Independent decision-making without prior consultation with the group may be seen as rude, immature, and disrespectful. Some cultures see suffering as an inevitable and normal part of life (Prong, 1995). Maturity and responsibility are defined by one’s ability to carry out their presumed roles to the best of their efforts, despite life’s constant adversities (Kagawa-Singer & Kassim-Lakha, 2003). Cross-cultural knowledge requires taking a critical look at implicit beliefs that are valued in one’s culture (Shapiro, 1996). It can be challenging for professionals, with their own set of cultural lenses, to recognize that Western medicine is a social construction that reflects culture-bound values, beliefs, and practices, and that such values may not be universally accepted or appropriate for other

cultures (Calanzani et al., 2013; Kagawa-Singer & Blackhall, 2001; Kongnetiman et al., 2008). Mo and colleagues (2012), for example, examined whether patient autonomy improved wellbeing in a group of patients with terminal cancer in Korea. Contrary to results from previous research in Western cultures, Korean patients who were aware of the status of their illness and took active and full responsibility over treatment decision-making did not score higher on quality of life than those who were less autonomous. In fact, they scored lower in measures of physical and psychological comfort, environmental comfort, and emotional functioning. The predominantly Western values that guide palliative care may therefore clash with the cultural concepts of health endorsed by ethnic minorities and NESB immigrants, creating health care experiences that discourage them from seeking care (Yang & Kagawa-Singer, 2007). The lack of evidence-based information on the needs of individuals from diverse cultures, and the indiscriminate cross-cultural generalization of Western care principles, may result in culturally insensitive practices and policies in palliative and bereavement care. A mismatch between services offered and what patients perceive as “right for them” can lead to feelings of mistrust, prejudice, and discrimination (Frey et al., 2013). Clients’ prior unsatisfactory experiences with the health care system and resources will prevent them from subsequent use of those services (Calanzani et al., 2013; Li, 2004).

Third, despite the call for increased cultural competence training for health care professionals working in palliative and bereavement care, such recommendation is not consistently implemented. There is considerable variation in terminology, conceptual models, and content in cultural competence training programs (Evans, Menaca, Koffman, 2012). Little research exists on whether cultural competence training can improve quality of care. A number of barriers to incorporate cultural competence training in palliative care practice have been identified, including a lack of funding, lack of manpower to develop cultural competence programs, lack of knowledge on available training programs, staff members’ lack of time and interest in pursuing additional training, discomfort in working with diverse groups, lack of awareness of cultural diversity in the community they serve, and lack of knowledge in other cultures and implication of cultural differences for health care experiences (Calanzani et al., 2013; Evans, Menaca, Andrew, et al., 2012; Reese & Beckwith, 2015). There is also the concern that much of the current cultural competence training consists of “fact-files” or “cookbook approaches” – handing out lists of general,

purportedly “cultural-specific characteristics” of different ethnic groups, which may run the risk of perpetuating myths and stereotypes and ignoring within-group differences (Calanzani et al., 2013; Evans, Menaca, Andrew, et al., 2012; Seto Nielsen et al., 2015).

## **Chapter 2. An Example of How Culture and Palliative and Bereavement Care Intersect: Bereavement in Chinese Immigrants**

### **Utilization of Bereavement Services in Bereaved Chinese Immigrants in Canada**

Chinese is the second largest visible minority group in Canada, with a population exceeding 1.5 million according to the 2011 Census (Statistics Canada, 2016c). Close to 20% of the 2.3 million Metro Vancouver residents are of Chinese descent. The vast majority of ethnic Chinese in Canada are first-generation immigrants (Tong & Spicer, 1994). Despite the high proportion of Chinese settling in North America, empirical evidence shows that Chinese families, particularly those who were foreign born, use palliative care services substantially less than their Caucasian counterparts (e.g., Ngo-Metzger, Phillips, & McCarthy, 2008). Clinical observations from professionals working in the field suggest that, similar to their counterparts residing in Asia, Chinese immigrants in Canada tend to underutilize bereavement services after the death of their loved ones. Many show a disinclination to discuss grief, seldom respond to follow-up contact, and often decline invitations to participate in bereavement support groups. It is also unknown whether these families, particularly those with limited English fluency, have actually been referred to bereavement care in the first place.

Failure to utilize bereavement services, however, does not equate to an absence of need for such services (Payne, Chapman, Holloway, Seymour, & Chau, 2005). In fact, the underrepresentation of Chinese service users in bereavement care may be related to the poor awareness and knowledge of such services in Chinese communities in general. Cross-cultural linguistic research has shown that cross-linguistic differences are associated with differences in one's selective attention, perception, memory, information processing and mental representation of certain aspects of the world, with more recent research suggesting that gaps in concepts may reflect gaps in one's lexicon i.e., the lack of a word in the language to represent a certain concept (Fausey & Boroditsky, 2010; Fuhrman et al., 2011; Wolff & Holmes, 2011). In the Chinese language, there is no word that signifies "bereavement". Most people use the Chinese term for "sorrow" and

“sadness” as a synonym (Chan et al., 2005). The absence of a word equivalent to the English word “bereavement” in the Chinese language results in the need to make up a new term or to go with a long and clumsy literal translation of “the experience of losing someone close” (Chan & Chow, 2006; Fielding & Chan, 2000). Bereavement is therefore not a concept that can be easily attended to and mentally accessed among Chinese. This in turn can hinder the development, acceptance, and utilization of bereavement care in this population.

Moreover, bereavement care services were only first developed in Hong Kong in the early 1990’s, and remain relatively unknown or even non-existent in other Chinese communities (Chan & Chow, 2006; Chow, Chan, & Ho, 2007). Even in regions with better developed bereavement services such as Hong Kong and Taiwan, these services remain underused. For instance, Liu and Lai (2006) reported that despite frequent invitations through telephone and mail, less than 10% of the bereaved families who had previously received palliative services attended the annual memorial services held by their hospice located in Taiwan. Similarly, Chan and Chow (2006) noted that they struggled with a high no-show rate when they invited bereaved individuals to attend in-person interviews for assessing their bereavement needs. Given the infancy of bereavement support in Chinese communities, many Chinese individuals have no knowledge of its existence, and are unfamiliar with its nature and benefits. In Ping, Chan, and Lee (2002), for example, 72% of the participants who were suddenly bereaved for 50 days to 10 months in Hong Kong never heard of bereavement services. Among those who were aware of bereavement care, only 33% utilized such services. Reasons for non-participation included self- and family-reliance, lack of knowledge regarding bereavement services, and perception that bereavement services were “useless”. In Chan, Lee, and Chan’s (2013) qualitative study on bereavement care experiences of oncology nurses’ and bereaved family members of cancer patients in Hong Kong, both groups of participants defined bereavement care more in terms of end-of-life care for the dying patients, rather than support for surviving family members after a loved one’s death. The only need reported that truly pertained to bereavement care was bereaved families’ information need around funeral arrangements, which reflected an inclination to practicality often emphasized in the Chinese culture. Given the prevalent lack of awareness and knowledge on bereavement care in their native countries, it is reasonable to believe that Chinese bereaved immigrants, often facing

language barriers and low health literacy, may be equally oblivious to the availability of bereavement care services in Canada.

Another possible reason for the underutilization of bereavement care services by bereaved Chinese immigrants in Canada may have to do with whether current services are addressing their needs in a manner that is consistent with their cultural values.

## **Chinese Culture and Grief: A Primer**

### **Chinese as a Collectivist, Interdependent, and Tight Culture**

Unlike the prevalent North American culture which celebrates individualism, an independent view of self, autonomy, and expressivity of emotions, the Chinese culture is a collectivist and interdependent culture, meaning that one's individual identity is embedded, and defined in relation to, the collective identity of one's family and community (Markus & Kitayama, 1991). In-group goals and family interests tend to take precedence over individual needs and preferences (Ho & Brotherson, 2007). Individuals are bound by ascribed roles to fulfill group requirements. Personal self-identity is a collection of such ascribed societal roles (Blevins & Papadatou, 2006). Social harmony, interpersonal relatedness, and communal relationships are encouraged (Matsumoto, Yoo, Fontaine, et al., 2008). Cultural norms rather than personal attitudes and preferences are stronger determinants of behaviour. Gelfand and colleagues (2011) examined cross-cultural differences in the strength of social norms and tolerance of deviant behaviours, and distinguished between "tight" and "loose" cultures. Tight cultures, such as the Chinese culture, tend to have a higher demand for norm conformity and a more restricted range of socially permissible behaviours. Rules tend to be more prescriptive and rigidly enforced. A higher degree of social regulation of behaviours is evident. Deviation from norms is considered more threatening to social order and therefore seldom tolerated. Deviant behaviours come with harsh social consequences; quick and severe sanctions are imposed on those who deviate from norms (Gelfand, Nishii, & Raver, 2006).

## **Traditional Chinese Philosophies: How Taoism, Confucianism and Buddhism View Death and Grief**

The Chinese culture is strongly influenced by three major Eastern philosophies and religions: Taoism, Confucianism, and Buddhism (Ho & Brotherson, 2007). In Taoism, the word “*Tao*” means the way of life, which includes virtue, goodness, and moral excellence (Mok, Martinson, & Wong, 2004). Taoism has given rise to a more holistic worldview among Chinese, where objects, relationships, and ideas are perceived not in isolation but in relation to others. Mankind is seen as inseparable from the larger universe. Contradictory elements, expressed as the notion of “*yin*” and “*yang*”, are complementary forces that can coexist within the same entity. As a result, Chinese have been found to be more comfortable with internal inconsistencies in their thoughts, emotions, and behaviours, as their dialectical worldview implies that something can be simultaneously good and bad (Spencer-Rodgers et al., 2009). They also tend to embrace both sides of an argument in their reasoning and decision-making process since “there can be some truth to both of two opposing propositions and hence implies that no side should win in a debate” (Peng & Nisbett, 1999, p. 747).

The Taoist symbol of yin-yang is commonly used to represent the duality of life and death: opposite yet interdependent forces that form a complete whole (Ma-Kellams & Blascovich, 2012). Life and death are simply different sides of the same coin, and one cannot exist without the other. Death is therefore seen as a natural part of the life cycle and the universe (Ho & Brotherson, 2007). Changes are considered inevitable as the universe is in constant flux (Peng & Nisbett, 1999). Power and strength come from “going with the flow” when changes occur, and behaving in harmony with the nature of the universe (Mak, 2002). Taoist teachings suggest that people should not be fearful of death and should simply accept death as a part of nature (Chow et al., 2007; Mak, 2002). Fear towards death is a reflection of egocentricity and immaturity (Mak, 2002). Finally, Taoism emphasizes the belief of fate and destiny. As a result, many Chinese believe that the timing of death, the manner of death, and one’s life experiences are already predetermined.

Confucianism governs norms and social behaviours in Chinese culture. Family and social order are the essence of Confucianism. It defines the rules for engagement, action,



power differential, and responsibility in all human interactions. It sees relationships as hierarchical in nature, determined by seniority, age, position, and gender (Wang & Martinson, 1996). What social interaction patterns are appropriate for an individual depends on his or her position in the hierarchy (Chan et al., 2008). Those in the lower position (e.g., the young in a family) are expected to respect, obey, and be loyal to those in authority. Personhood is seen as a relational construct defined by roles and responsibilities for others (Payne et al., 2005). Traits such as loyalty, filial piety, conformity, social order, and self-restraint are highly valued (Ho & Brotherson, 2007; Hsu et al., 2004). Social cohesion is achieved through a suppression of open conflict and a submission to the collective wellbeing of families. The primary task in life is not to affirm one's individuality, but rather, to learn to accept one's rightful place in the social hierarchy, to observe the rules of the group, and to fulfill one's social roles. In individualistic cultures where autonomy is valued, people are encouraged to express their emotions, such as grief, when they are called for. However, in cultures that are more relational in nature, the expression of personal feelings and autonomy in a social setting is seen as a threat to interpersonal harmony and a sign of personal immaturity (Hsu et al., 2004).

Confucianism also contributes to the rituals of ancestor worship to express respect, to relate the living with the dead, and to keep the memory of the deceased alive through acts of remembrance. In the Chinese culture, grief and bereavement are not necessarily time-limited, nor are grieving family members expected to "let go" of the deceased (Li & Prigerson, 2016; Yick & Gupta, 2002). The Confucian emphasis on maintaining a sense of kinship through rituals underlies the Chinese cultural belief that the central element of bereavement is to have a continuing bond with the deceased person.

Filial piety, the expectation that children must totally submit to one's parents and elders, and are responsible to take care of their parents without question as a way to repay the parents' sacrifices and care, is one of the most important virtues in the Chinese culture (Chan & Chang, 2000; Kagawa-Singer & Blackhall, 2001). According to Confucian tradition, a child in a Chinese family serves the function of family continuity. The child is expected to bring honour to the family's ancestors, to take care of the parents when they are old, and to fulfill goals of the parents or the family. As a result, the parent-child bond is usually more enmeshed than that observed in Western cultures. Parents regard their

children as their possession (Chan & Chow, 2006). Given the interpersonal nature of individual identity in the Chinese culture and the centrality of a child's role in Chinese parents' identity, the greatest pain for Chinese people is to witness the death of their own children. Bereaved Chinese parents often quote the Chinese saying of "black hair should not precede white hair" i.e., the young should not die before the old, to describe the event (Chan et al., 2005). Parents may interpret child death as a punishment for their bad deeds from the present or past lives. If the death involves a son, the parents feel particularly guilty of losing the child that is responsible for carrying on the family name and lineage (Ho & Brotherson, 2007). They may feel like a failure as they cannot answer to their ancestors. The absence of a male child at the death of the parents is considered one of the greatest tragedies in the Chinese culture (Fielding & Chan, 2000).

Buddhism has contributed to the Chinese belief of reincarnation. It sees death as nothing to be afraid of, as it is only through death that one can be reborn and become human again in the next life. Buddhism teaches people to stop denying the inevitable nature of life and death. Acceptance of death can lead to a peaceful state of mind that paves the way for a better afterlife (Ho & Brotherson, 2007; Mjelde-Mossey & Chan, 2007). Buddhist teaching also emphasizes the concept of karma, which means that one's life experiences are determined by good deeds performed in one's current or past lives (Chan et al., 2005). The quality of one's afterlife depends on whether this person has lived a good life, defined as being moral and completing obligations to one's family. Events in life are not under the control of individuals, but are already predetermined to happen according to one's actions in present or past lives. Premature, sudden, or violent death reflects a punishment of sins one has committed, or punishment of one's family members due to their bad deeds in their present or past lives (Braun & Nichols, 1997).

Taoist, Confucian, and Buddhist values influence coping strategies used by bereaved Chinese. Reconnecting and maintaining a relationship with the deceased serves as a major coping strategy to help restore normal functioning. Such continuing bonds help instill a sense of harmony and wholeness (Ho & Brotherson, 2007; Hsu et al., 2004). The Buddhist belief of reincarnation and afterlife also helps keep the bereaved hopeful (Ho & Brotherson, 2007). The Taoist belief of letting nature take its course often empowers bereaved individuals by helping them accept the death through letting go of things they

cannot control (Mok et al., 2004). The belief of harmony with the universe helps Chinese people understand that although an event may appear undesirable, it is part of a larger, meaningful process in the universe (Mok et al., 2004).

Two of the most important Chinese cultural concepts that facilitate coping are the Taoist belief of fate and destiny, and the Buddhist belief of karma. Ho and Brotherson (2007), in their interview of bereaved Chinese parents in Macau, found that all the participants attributed the reason for their child's death to fate or destiny. The parents believed that everything that happened in life was predetermined. As a result, they felt that they had to accept the death of the child as the loss was destined to happen. They either saw it as part of their own fate, or as the child's fate. They also attributed the loss to the lack of "*yuan*", or predestined interpersonal affinity, between themselves and the deceased child. "*Yuan*" is the belief that supernatural forces in the universe govern interpersonal successes and failures. Insufficient "*yuan*" between parent and child is considered a possible cause for the premature termination of such relationship. The cultural belief of destiny and "*yuan*" was believed to relieve the participants from guilt and self-blame by attributing the death to supernatural forces that humans could not control or avoid. Moreover, as the parents cognitively adjusted themselves to belief that the death of their child was due to fate, they typically concluded that there was no need to talk about the death anymore. They expressed a pragmatic view of coping with the death – they believed that the only way to deal with the death was to accept the reality of the loss; talking about one's feelings was unnecessary and unhelpful as it would not change the fact that the child was forever gone.

In Chan et al. (2005), the taped counseling sessions of 52 bereaved persons living in Hong Kong were analyzed. Results were interesting in that even though the explicit cause of death was known to the bereaved, they still interpreted the cause of death in terms of traditional Chinese beliefs of fate and karma. Over half of the participants referred to the death as fate or the termination of "*yuan*", and 15 attributed the death to karma. Mjelde-Mossey and Chan (2007) interviewed 430 individuals in Hong Kong randomly selected from the city's telephone directory regarding their attitudes towards death and dying. Beliefs of "death is our fate" and "death is a part of the cycle of life" were considered

by the participants as the most useful in bringing comfort when someone faces a terminal illness, reflecting the fatalistic view of Taoism.

The use of fate and destiny as a coping mechanism is also evident among Chinese professionals who work patients with terminal illnesses. Papadatou and colleagues (2001) compared the experiences of 39 Greek nurses and 24 Chinese nurses in Hong Kong with providing services to terminally ill children. It was found that 35% of the Greek nurses, versus none of the Chinese nurses, expressed anger, frustration and sense of injustice over the children's death. While the Greek nurses remained distressed and failed to find a satisfactory explanation to account for the children's demise, Chinese nurses experienced significantly more relief of negative emotions as they perceived the death as a karmic consequence of the bad deeds one committed in the past lives. Such beliefs in the supernatural explanation of life's events may help defend one's ego and provide ready and convincing answers to experiences in life. It helps shield the person from blaming oneself or others for one's misfortune by attributing it to an external invisible force of nature (Mok et al., 2004).

## **Emotional Experience and Expression in the Chinese Culture**

Western interventions of grief and bereavement care often emphasize the identification, expression and interpretation of emotions as the goals for bereavement interventions (Christ, Bonanno, Malkinson, & Rubin, 2003; Whittam, 1993). Conscious and direct confrontation of negative emotions and the reality of the loss is seen as necessary for recovery to occur. There is also the assumption that families will do well only if there is open, honest, verbal communication among the members (Christ et al., 2003; Kagawa-Singer & Kassim-Lakha, 2003; Mahon & Page, 1995). Such explicit discussion of private thoughts and emotions is not limited within the family; it is encouraged in interventions such as support groups and one-on-one counselling for bereaved individuals (Packman, Horsley, Davies, & Kramer, 2006). Such values and assumptions behind the practice of bereavement care are consistent with Western cultural norms that emphasize individual emotional experience and emotional expressivity (Dere et al., 2013; Matsumoto, Yoo, Fontaine, et al., 2008).

Open, direct social sharing of bereavement experiences is not as highly encouraged by the Chinese as by the individuals from Western cultures (Bonanno, Papa, Lalande, Zhang, & Noll, 2005; Chow et al., 2007). Such sharing is inhibited in the Chinese culture due to 1) death being seen as a taboo topic, 2) the high context communication style, 3) the Chinese cultural values regarding emotional experiences and their expression, and 4) the hierarchy of social relationships.

### ***Death as a Taboo***

Death is a taboo topic as Chinese people believe that talking about death will bring upon bad luck (Li, Chan, & Lee, 2002; Liben et al., 2008; Mak, 2001). There is also the belief on the self-fulfilling power of words – once words are spoken out loud, they will become reality (Wiener, McConnell, Latella, & Ludi, 2013). Even for patients with terminal illnesses, discussion about death is frequently avoided for fear of robbing them of hope and hastening their death (Wang & Chan, 2015; Wiener et al., 2013). As a result, the bereaved are prohibited from talk about death openly despite their sadness (Ho & Brotherson, 2007; Li et al., 2002).

### ***Communication Styles***

Cultures differ in how much communication relies on explicit, verbal information as opposed to implicit nonverbal cues. East Asian cultures, including Chinese, are considered high context cultures, in which the emphasis on interdependence implies that ingroup members share highly similar experiences, expectations, and information about their collective world (Heine, 2012). Rules that guide behaviours are widely shared and implicitly understood. Given the prevalence of “common” knowledge and shared understanding within the culture, a lot of information can be left unsaid and does not need to be explicitly stated in communication. High context cultures give rise to high context communication – in high context communication, verbal messages are often indirect and ambiguous; one “talks around the point and embellishes it” (Hall, 1976). Meaning is implied rather than explicitly stated in words. High context communication is listener-oriented. It is not the speaker’s job to make the message explicit in order to facilitate understanding (Ting-Toomey, 1999). Instead, the onus is on the listener to “read between the lines” and infer the true meaning and intentions of the speaker hidden behind the words. A listener can decode the message by 1) attending to nonverbal cues, and 2) taking

into account background information such as past experiences with the speaker, the setting of that particular communication, and other contextual factors such as a shared cultural heritage (Hannover, 2009). It is the context, not the words, that conveys the meaning. The literal meaning of the words said is therefore less important than the way the words are said. This is in sharp contrast to low context communication, a style more prevalent in individualistic cultures such as the North American and other English-speaking cultures, in which messages are communicated directly, verbally, and explicitly (Gudykunst & Matsumoto, 1996). The speaker is the one responsible for constructing a clear, unambiguous verbal message that the listener can encode easily (Ting-Toomey, 1999).

Given the high context communication style in the Chinese culture, communication regarding emotions often takes a nonverbal, subtle, and indirect form (e.g., through the use of body language, eye contact and euphemism; Liben et al., 2008). The notion of “*zhih-yi*”, which means knowing what others think or feel without being directly told, is a vital means of interpersonal communication (Kagawa-Singer & Blackhall, 2001). The purpose of indirect, high context communication is to preserve social harmony and “face” i.e., not to embarrass or make others lose honour by directly posing potentially sensitive questions. Ambiguity helps prevent the violation of interpersonal boundaries and appropriateness. Open expression of intensely negative or disturbing emotions is seen as disrupting interpersonal harmony and violating social rules. One implication of high context communication style for grief and bereavement is that the bereaved are expected to express the emotional impact of their loss nonverbally and indirectly. In societies where direct emotional expression is taken for granted, bereaved immigrants who are culturally tuned to high context communication may be mistakenly perceived as 1) not experiencing intense grief, and/or 2) not needing bereavement care, since their emotional expressions of grief are not as obvious as it is expected in Western cultures.

### ***Chinese Cultural Values on Emotional Experiences and Their Expression***

Cultures differ in the value they place on personal feelings and emotional expression. In individualistic cultures, emotions have greater intrapersonal meaning; free expression of one’s personal feelings is a way to reaffirm individuality in relation to others (Matsumoto, Yoo, Fontaine, et al., 2008). Collectivistic cultures such as the Chinese

culture, however, place higher importance on groups, contexts, and relationships over individuality. There is a de-emphasis on intrapersonal experience such as personal feelings in favour of interpersonal relationships and group interest. Emotion is not necessarily a private experience; it is interdependent, involving the perspective of others and norms regarding social appropriateness (De Leersnyder, Boiger, & Mesquita, 2013). There is also an emphasis on a more externally focused thinking style i.e., a focus on external, concrete circumstances rather than internal emotional experiences (Dere et al., 2013). Cultural values on emotions may have implications for how aware and descriptive individuals are of their personal emotional experiences. Ryder and colleagues (2008), for example, examined differences in symptom reporting between Chinese and Euro-Canadian participants presenting to outpatient mood disorder clinics in Changsha, China and Toronto respectively. They found that Euro-Canadian participants had a higher level of psychological symptom reporting than Chinese participants. Chinese participants were less likely to report on their psychological experiences when asked to describe their symptoms. Chinese outpatients also scored higher on alexithymia, characterized by difficulty identifying and describing feelings, as well as an external-oriented way of thinking. External-oriented thinking was found to mediate the relationship between culture and report of somatic symptoms.

Cross-cultural research on emotional expression demonstrates that while the capacity to produce and identify facial expressions of emotion is likely universal, cultural differences in emotional expression are mostly accounted for by differences in cultural display rules (Ekman & Friesen, 1969). Display rules are cultural norms that regulate what, when, where, how, and to whom emotions can be displayed in the presence of others. Emotional expression is managed and modified according to social circumstances (Matsumoto, Yoo, Fontaine, et al., 2008). Collectivist cultures tend to be associated with more stringent display rules and less emotional expressivity in general. Masking of one's true feelings helps maintain the appearance of harmony and cooperation with others. Previous research has also demonstrated cross-cultural differences in the degree of coherence or consistency between one's outward emotional displays and inner emotional experiences. In Ekman's (1972) and Friesen's (1972) seminal studies on cross-cultural differences in display rules, American and Japanese participants were asked to watch a series of stressful videos, while their facial expressions were recorded without their

knowledge. In one condition, they watched the videos alone. In another condition, an older experimenter sat beside them when the videos were played. Results showed that in the first condition, both American and Japanese participants showed similar expressions of disgust when they were watching the videos by themselves. In the second condition, American participants continued to show facial expressions of disgust similar to those displayed when they were watching the videos alone. Japanese participants, however, tended to smile or attenuate their facial expression in the presence of others in the room. These findings have been consistently replicated in subsequent research (e.g., Matsumoto & Kupperbusch, 2001; Matsumoto, Yoo, Fontaine, et al., 2008) – for individuals from individualistic cultures, inner emotional experiences and outward emotional expression tend to be congruent i.e., there is a positive relationship between emotions felt and emotions shown, regardless of situations. For those from collectivist cultures, however, coherence between emotional experiences and emotional expression varies depending on the presence of others. When unobtrusively observed in private, these individuals tend to display emotions that are consistent with how they genuinely feel. When they are with others, however, incongruence between emotional experience and emotional display emerges. A decrease of happiness felt is associated with an *increase* in display of happiness, whereas an increase of negative emotions felt is associated with a *decrease* in display of negative emotions. Matsumoto and Kupperbusch (2001) argued that cross-cultural differences in the coherence of emotional experience versus emotional display could potentially lead to intercultural misunderstanding. Those from individualistic cultures may assume that emotional expression is always commensurate with one's genuine feelings, which may not necessarily be the case for those from collectivist cultures. Conversely, those from collectivist cultures, operating under the cultural display rule of emotional masking and concealment, may overestimate others' emotional intensity. Display rules and the mismatch between emotional experience and its expression can impede accurate assessment of the impact of grief and bereavement outcomes among Chinese.

More recent research on the relationship among cultural norms, values placed on emotions, and emotional regulation has found higher use of emotional suppression as a means to regulate emotion in collectivist cultures with 1) clear social hierarchy and power differentials, 2) an emphasis on the maintenance of social order and status pro,



behavioural propriety, and restraint of behaviours that may disrupt social harmony, and 3) an emphasis on the sacrifice of personal pleasure and immediate gratification for the sake of preserving long-term relationships with others (Matsumoto, Yoo, & Nakagawa, 2008). As opposed to Western theories of grief that see emotional expression as healthy and conducive to healing after bereavement, traditional Chinese medicine considers overt emotional expression a possible cause of illness. A healthy person in the Chinese culture is defined as someone who can always keep one's emotions under control and behave modestly (Chan, Ho, & Chow, 2001). The cultural norms of concealing and suppressing emotional expression may socialize Chinese individuals into believing that negative emotions are trivial matters not worthy of attention (Kung & Lu, 2008). Traditional Chinese medicine also suggests that emotions are linked to bodily functions. Psychological distress tends to be associated with a higher level of stigma among Chinese (Ryder et al., 2008). Channeling psychological distress into somatic symptoms is therefore thought to be the culturally safer and more sanctioned way of expressing emotional difficulties and personal problems (Kung & Lu, 2008).

### ***Hierarchy and Boundaries of Interpersonal Relationships***

Relationships in Chinese society are classified into three major categories: relationships with "*jiaren*" (family), "*shuren*" (acquaintances such as neighbours, friends, colleagues, or classmates), and "*shengren*" or "*wairen*" (strangers or outsiders) (Mok, Chan, Chan, & Yeung, 2003). Relationships with insiders and outsiders require distinct sets of social behaviours. Conversations with outsiders should typically be limited to superficial topics. Display of negative emotions or discussion of family issues in front of outsiders are strongly discouraged (Liben et al., 2008; Liu & Lai, 2006). Such social rules can discourage Chinese families from sharing their troubles with others (Li et al., 2002). Clinical observations have shown that while bereaved Chinese may have a great desire to talk about their experience with professionals, cultural restrictions prohibiting sharing family affairs and strong emotions with outsiders create ambivalence and reluctance in the bereaved towards seeking help from professionals and community resources (Chan & Chow, 2006; Mok, Chan, et al., 2003). Health care professionals therefore need to handle the clinical encounter skillfully and delicately in order to gain trust and elicit information. Yam, Rossiter and Cheung (2001), examining how nurses cared for dying infants in neonatal intensive care units in Hong Kong, noted the following:

Because the Chinese often avoid open display of emotions or discussion of their feelings, especially to people outside the family, nurses must be able to pick up the subtle and non-verbal ways of expressing emotion.....communication is a very delicate process that has to be individualized. Nurses need to have a wide repertoire of interpersonal communication skills to unravel the Chinese mind, in order to help the family to come to terms with their grief without risking the existing family dynamics (p. 656).

There is often an assumption that Chinese prefer to keep grief within the family (Braun & Nichols, 1997), and that they can rely on family members and their dense social network as a ready source of support and resources during bereavement (Chiu et al., 2011). Such an assumption may not be universally true for all bereaved Chinese individuals (Ng et al., 2016). First, the Confucian value of hierarchy of relationships in the structure of Chinese families implies that open and honest communication of issues around negative emotions, death and bereavement within a family cannot always happen. For example, those who stand lower in the family hierarchy are not encouraged to talk to those higher in the family hierarchy about concerns and emotions that may create discomfort and pain (Prong, 1995). Second, immigration often leads to a severance of ties with old friends and family. The geographical distance between immigrants and family members who may still be residing in their countries of origin suggest that the extended familial support network has shrunk for many Chinese immigrant families. Social support for Chinese immigrants is therefore not as readily available as many may assume (Chan & Chow, 2006).

Despite the Chinese cultural norm of reserving emotional expression for in-group members, cross-cultural research on in-group/out-group differences in emotional expressivity has found that individualistic cultures are associated with *higher* level of in-group emotional expression, while members from collectivistic cultures endorse *less* emotional expression within one's in-group (Matsumoto, Yoo, Fontaine, et al., 2008). Given the higher importance of interpersonal relationships with "insiders" than "outsiders", there is a higher need to maintain in-group social harmony and to avoid offending in-group members. Discussion of negative, socially forbidden emotions and experiences such as death and grief with in-group members (such as family and friends) carries a higher risk of negative social consequences. Even if bereaved individuals wish to speak to a family member or a friend about their grief, they may be disappointed to find that others are

reluctant to discuss such a taboo topic, as others are constrained by cultural display rules of masking their real affect and their fear of violating social norms. Past research has also found higher endorsement of self-reliance in Chinese compared with their Euro-American counterparts (Triandis, McKusker, & Hui, 1990). The motivation behind self-reliance in Chinese, however, is socially driven (Chiu & Hong, 2006) – individuals are motivated not to become a burden to others so as to ensure the wellbeing of the collective. All these factors make it more difficult for the bereaved to seek and receive adequate emotional support from their social network.

Taken altogether, the Chinese culture in general encourages passivity and suppression in the face of suffering and pain, and discourages open and verbal discussion on negative emotions and grief (Bahl, 1996; Prong, 1995). The commonly used expression of condolence in Chinese is “*jit oi shun bin*” in Cantonese or “*jie ai shun bian*” in Mandarin, which means “curb one’s sorrow and go along with the change”. This demonstrates the cultural expectation of coping with bereavement by inhibiting grief and accepting the loss silently (Chow et al., 2007). Many Chinese therefore prefer a more subtle, indirect, and gradual exploration of matters on death and bereavement that respect their cultural prohibitions and prescriptions in a clinical situation (Mak, 2001). Catharsis of emotions as the focus of therapy can be foreign to many Chinese given the cultural belief of keeping emotions under control as a sign of healthy, well-balanced and mature way of handling problems (Chan & Chow, 2006). Putting pressure on the bereaved to express emotions and to directly acknowledge the death often leads to early dropout from bereavement follow-up programs in Hong Kong. The process of engagement and trust building is crucial for Chinese clients to feel safe enough to express themselves (Chan & Chow, 2006).

Milberg and colleagues (2008) argued that if bereavement care were to be evidence-based, the format and the content of the program should be guided by surviving family members’ own report of needs and perspectives. In their review of the bereavement follow-up program at the Stollery Children’s Hospital in Edmonton, deJong-Berg and deVlaming (2005) expressed the concern that ethnocultural diversity might create differences in bereavement needs, and that research had to directly elicit bereaved ethnic minority families’ opinions on the best ways to support them. Yet research on bereavement outcomes and self-report needs for bereavement services in Chinese immigrant families

in Canada is virtually non-existent. Much of the current literature on the needs of bereaved Chinese immigrants consists of editorial pieces providing an anthropological overview of traditional Chinese values, rituals, and customs related to death. Even among ethnic Chinese residing in Asia, there has been a dearth of epidemiological research on the trajectories of grief or factors associated with bereavement outcomes (He et al., 2014; Li & Prigerson, 2016). Existing research from those Asian regions tends to be qualitative, descriptive accounts of bereavement experiences (e.g., Chan & Chan, 2011; Chan et al., 2005; Chow et al., 2007; Ho & Brotherson, 2007; Ng, Ho, Tsun, & Young, 2016). Compared with other aspects of palliative care, bereavement care tends to receive considerably less research attention in Asian countries. A recent systematic review of palliative care research undertaken in Hong Kong from 1991 to 2014 found that previous research in the area mostly focused on the symptoms and functioning of dying patients, attitudes towards death and dying, and issues related to end-of-life care such as decision-making, the concept of good death, and advance directives (Wang & Chan, 2015). Research on surviving family members tended to focus on their caregiving experience rather than bereavement outcomes, attitude towards and perception of bereavement care, and need for professional support. Whether findings from the limited empirical research undertaken on ethnic Chinese residing in Asia can be generalized to bereaved Chinese immigrants in a foreign country remains unknown.

## **Chapter 3. Design and Objectives of Current Research**

The current study was a mixed methods study with both quantitative and qualitative components. A mixed methods design is particularly appropriate for the current study as it allows for a more comprehensive assessment of the participants' needs for bereavement care services. Quantitative method helps quantify participants' clinical needs, as numerical data can be compared against a "yardstick" such as a clinical cut-off value to signify areas of clinical significance. Possible patterns of behaviours can also be more objectively and statistically tested. From a practical perspective, stakeholders such as practitioners, institutions and policy makers often want to see "hard numbers" that show evidence of gaps of services and justify the need for change in the health care system to better recognize the needs for bereaved individuals (Boykin, Schoenhofer, & Valentine, 2014). On the other hand, qualitative method preserves the voice of the participants. It directly reflects the perspectives of bereaved individuals, who are the targets and the end users of bereavement care services. It also helps preserve the richness and diversity of experiences in the participants' narratives. The highly heterogeneous ways grief is expressed, experienced and managed often cannot be reduced to a list of behaviours to be measured on a questionnaire. Employing both quantitative and qualitative research methods helps yield a richer and more complete understanding of the area of inquiry (Creswell & Plano Clark, 2011). The combination of two different but complementary sets of data also allows for triangulation of findings – to examine how well the quantitative and qualitative data converge and corroborate each other, thereby improving the validity of the results.

The current study employed a convergent parallel mixed methods design (Creswell & Plano Clark, 2011). Quantitative and qualitative data were collected in parallel, analyzed separately, and then integrated at the final stage of analysis, in which the qualitative data were quantified and transformed into categorical variables so that they could be subjected to statistical analyses together with the quantitative data. The quantitative data focused on the psychological functioning, level of somatic symptoms, coping strategies, and acculturation of bereaved Chinese immigrants. The qualitative data explored bereaved Chinese immigrants' descriptions of their grief experiences, needs for

and barriers to accessing bereavement services, and their suggestions for the best practices for working with Chinese immigrant families. The current study aimed to:

1. Describe the psychological functioning, the use of coping strategies, and grief experiences in bereaved Chinese immigrants;
2. Examine possible predictors of psychological functioning;
3. Understand their knowledge, attitude, perception and experiences with palliative care and bereavement care services in Canada;
4. Explore their perception on possible barriers to access, and ways to improve current services; and,
5. Examine possible predictors of bereavement service utilization.

The current study attempted to identify cultural-specific needs and barriers in accessing and utilizing bereavement services among bereaved Chinese immigrants living in Canada, in the hope of providing more empirical evidence to guide the practice of culturally sensitive care among health care professionals in palliative care, and improve the delivery of crucial health services to a vulnerable group of individuals in our increasingly diverse society. The results from the current study could potentially help ensure that people from diverse cultures have equal access to all services regardless of their ethnic background or ability to speak English.

## Chapter 4. Methods

### Recruitment

#### Initial Plan

The current study was originally intended to focus on the psychological functioning and bereavement service needs of bereaved immigrant Chinese *parents* whose children have died from life-threatening conditions, as well as the surviving children. To qualify for the study, the parents must be first-generation Chinese immigrants born in Hong Kong, Taiwan, or Mainland China, and must have had a child aged 0 to 17 who had been deceased for 6 months to 3 years. The siblings must be between the ages of 6 and 17 in order to be included in the study (i.e., for the parents to complete a parent-report measure on their psychological functioning). For surviving siblings who would like to complete self-report measures, they must be between 8 and 17 and be able to read English.

Ethics approval from Simon Fraser University, the University of British Columbia, BC Children's Hospital, and Canuck Place Children's Hospice was received 8 months after the date of submission of the initial application. The initial plan was to first recruit bereaved families of Chinese descent who were receiving services at BC Children's Hospital and Canuck Place Children's Hospice at the commencement of the study, as well as any other bereaved families that had received services during the past 3 years. Yet due to an organizational change at BC Children's Hospital at the time of the study (which led to the closure of the in-hospital bereavement care service), hospital policy forbade any access to the list of the children who had passed away at the hospital and the contact information of their families. As a result, only recruitment posters (written in English and Chinese) could be displayed on the hospital bulletin board.

With regards to recruitment efforts at Canuck Place Children's Hospice, staff at the hospice prepared a list of bereaved families they were serving or had served in the previous 3 years. Institutional policy forbade the practice of mail or phone contact that only targeted families of Chinese descent. As a result, letters of initial contact, issued by the medical director at Canuck Place, had to be mailed to *all* 74 families Canuck Place had

served from 2008 to 2010, regardless of their ethnic backgrounds. The letter included an invitation to participate in the study, and an information sheet with a brief explanation of the purposes and procedures of study participation. The documents sent to the families were written in both Chinese and English. Follow-up letters were mailed to the 74 families 3 months later.

In order to capture the bereaved families that did not receive services from BC Children's Hospital or Canuck Place Children's Hospice, recruitment posters were also displayed at SUCCESS, a social services organization providing assistance to Chinese immigrants in Vancouver, the Outpatient Psychiatry Clinic at Vancouver General Hospital, Family Services of Greater Vancouver, and mental health advocacy organizations working with Chinese immigrant families such as the Chinese Mental Health Promotion Program at the Vancouver and Richmond branches of the Canadian Mental Health Association.

Adopted from Hynson, Aroni, Bauld, and Sawyer (2006), a phone number with voicemail services was provided in the invitation letter and the recruitment posters. Potential participants were asked to call the number to obtain more information regarding the research. Individuals who received the invitation letter from Canuck Place but did not wish to participate could also leave a message on the voicemail.

These recruitment efforts, however, were unsuccessful. Only six voicemail messages at the contact number were ever received in 6 months. All of the individuals who called were excluded from the study when the author returned their calls to determine their eligibility. Five of the individuals saw the recruitment posters posted at the various community organizations. Three of them suffered the loss of other family members that were not a child. Two misunderstood the purpose of the study, thinking that it was a study on mental illness. The sixth individual was a manager calling on behalf of the Richmond School District after receiving an email from the Canadian Mental Health Association containing the recruitment poster, and asked if the study could be expanded to include other kinds of loss.



## Revised Plan

In light of the difficulties with recruitment, the scope of the current study was expanded with the supervisory committee's approval. In addition to bereaved parents who had lost young children, the expanded study would also recruit any bereaved Chinese immigrants who had lost a close family member. The new inclusion criteria of the study were as follows:

1. The participant must be born in Hong Kong, Taiwan, or Mainland China;
2. The participant must have lost a first-degree relative (i.e., parents, siblings, young or adult biological or adopted children), a spouse, or a close family member by marriage (i.e., parents-, siblings-, or children-in-law); and,
3. The death of the family member must have occurred between 6 months and 3 years prior to study participation.

An amendment to the research protocol was made and approved by the research ethics boards that granted the initial ethics approval within a week. New recruitment posters were disseminated to the community organizations and clinics that displayed the original poster. A website was also set up, providing information regarding the study written in both Chinese and English. In addition to the phone number, an email address was set up to facilitate contact with potential participants who visited the website. Through a referral by the program coordinator of the Chinese Mental Health Program at the Canadian Mental Health Association (Vancouver branch), the author was invited to Fairchild Radio, a major multicultural radio station in Canada with a large Chinese audience, and completed four live radio shows between February and May 2011 to speak about the impact of bereavement and the current research study. The shows were conducted in Cantonese. The author provided the contact phone number and the website address during the radio shows and invited any interested parties to call or email for further enquiry.

A total of 36 phone calls and 4 emails (with phone numbers for further contact included) were received in response to the radio shows. The author, who spoke fluent Cantonese and Mandarin in addition to English, was the one returning the calls to provide additional information about the study using the potential participants' preferred language.

When a potential participant expressed interest in participating, an initial phone screening questionnaire was completed to determine eligibility. Eligible individuals were then invited to an in-person meeting at BC Children’s Hospital, Simon Fraser University, or the participant’s home, wherever preferable and the most convenient for the participant. Among the 40 individuals who made contact with the author, 15 were deemed ineligible to participate in the study. Table 1 summarizes the reasons for exclusion from the study.

**Table 1. Reasons for Exclusion from the Current Study (N = 15)**

Reason	<i>n</i>	%
General enquiry on grief in the hope of helping their bereaved friends	8	53
The death of the family member occurred more than 3 years prior	3	20
Health care professionals seeking information regarding the study	2	13
Refusal to participate due to unwillingness to recall their losses	2	13

Note: Percentages do not necessarily add to 100 due to rounding error.

## Participants

A final sample of 25 bereaved Chinese immigrants met the inclusion criteria and were enrolled to participate in the study. Table 2 presents their sociodemographic characteristics. The participants’ ages at the time of participation ranged from 30 to 80 ( $M = 51.84$ ,  $SD = 11.44$ ). The sample was predominantly female ( $n = 21$ , 84%). On average they had been bereaved for 22 months at the time of participation ( $SD = 10.04$ , range = 6 - 36 months).

The majority of the participants were born in Hong Kong and spoke Cantonese as their first language ( $n = 22$ , 88%), while those who were born in Taiwan or Mainland China spoke Mandarin ( $n = 3$ , 12%). The mean length of residency in Canada for the participants was 21.28 years ( $SD = 8.41$ , range = 9 - 40 years). Fifteen participants (60%) rated their own English proficiency as “fluent” i.e., they were comfortable using English in both conversational and more formal settings, such as at school, at work or during physician office visits. Nine participants (36%) rated their English fluency as “conversational”, meaning that they felt they could handle basic, day-to-day conversation in English, but would either need to see a Chinese-speaking professional or have a translator present

during encounters with health care professionals. Only one participant spoke little to no English.

The majority of the participants ( $n = 18$ , 72%) had received post-secondary education. Most were working either full-time ( $n = 11$ , 44%) or part-time ( $n = 5$ , 20%). A total of 5 participants ( $n = 5$ , 20%) reported a change in their employment status due to grief after the death of their family member. Among those who were working part-time at the time of the study, 3 of them were working full-time before becoming bereaved. The participant who was on leave at the time of the study was working full-time before the death of the family member. One retired participant was working full-time before becoming bereaved.

**Table 2. Sample Demographics ( $N = 25$ )**

<b>Demographic Characteristics</b>	<b><i>n</i> (%)</b>	<b><i>M</i>(<i>SD</i>)</b>
Age (years)		51.84 (11.44)
Gender (male/female)	4/21 (16/84)	
Marital status		
Single	3 (12)	
Married / Common law	15 (60)	
Separated / Divorced	3 (12)	
Widowed	4 (16)	
Number of months of bereavement		22.08 (10.04)
Number of years residing in Canada		21.28 (8.41)
Country of origin		
Hong Kong	22 (88)	
Mainland China	2 (8)	
Taiwan	1 (4)	
Self-reported English fluency		
Little to no English	1 (4)	
Conversational English	9 (36)	
Fluent English	15 (60)	
Education (highest level)		
Elementary school	1 (4)	
High school	6 (24)	
Community college or trade school	6 (24)	
University	10 (40)	

Postgraduate education	2 (8)
Employment status	
Full-time	11 (44)
Part-time	5 (20)
Full-time homemakers	5 (20)
Retired	3 (12)
On leave	1 (4)
Household income	
< \$19,999	5 (20)
\$20,000 - \$49,999	9 (36)
\$50,000-\$79,999	7 (28)
> \$80,000	4 (16)

Table 3 presents information regarding the deceased family members. The majority of the participants ( $n = 12$ , 48%) suffered the loss of a parent. The mean age of the deceased family members at the time of death was 66.30 ( $SD = 23.30$ , range = 7 months to 90 years). The gender of the deceased family members was relatively equally distributed, with 12 males (48%) and 13 females (52%). The location of death varied. The majority of the deaths ( $n = 17$ , 68%) occurred within Canada, while eight (32%) occurred overseas in the participants' countries of origin. The majority of the deaths ( $n = 19$ , 76%) were considered "expected", usually the results of chronic, life-limiting illnesses such as cancer, heart failure, or chronic neurological diseases. The causes of the six sudden deaths were heart attack ( $n = 3$ , 12%), stroke ( $n = 2$ , 8%), and homicide ( $n = 1$ , 4%). The time interval between diagnosis and death highly varied across the deceased individuals, with a range of 0 months (for those that suffered from a sudden death) to 38 years.

**Table 3. Variables Related to the Deceased Family Members ( $N = 25$ )**

Variables	$n$ (%)	$M(SD)$
Relationship to the participant		
Parent	12 (48)	
Father	4 (16)	
Mother	8 (32)	
Spouse	4 (16)	
Husband	2 (8)	
Wife	2 (8)	
Parent-in-law	3 (12)	

Father-in-law	2 (8)	
Mother-in-law	1 (4)	
Siblings	3 (12)	
Brother	1 (4)	
Sister	2 (8)	
Child	3 (12)	
Young son	2 (8)	
Adult Son	1 (4)	
Age at the time of death		66.30 (23.30)
Number of months between diagnosis and death		76.96 (121.26)
Gender (male/female)	12/13 (48/52)	
Cause of death		
Cancer	16 (64)	
Cardiovascular	5 (20)	
Neurological	3 (12)	
Homicide	1 (4)	
Nature of death		
Expected	19 (76)	
Sudden	6 (24)	
Location of death		
Metro Vancouver	14 (56)	
Elsewhere in Canada	3 (12)	
At participant's country of origin	8 (32)	

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## Procedures

The in-person meeting with each participant lasted approximately 2 hours. The author conducted the meetings with all 25 participants between March and July 2011. Twenty-one meetings took place at a conference room in a research lab at BC Children's Hospital. Four took place at a meeting room at Simon Fraser University. The language used in the meeting corresponded to the participants' preference and self-reported first language – 22 meetings were conducted in Cantonese, for those born in Hong Kong; three were conducted in Mandarin, for those born in Taiwan or Mainland China. Informed written consent from the participants was obtained at the beginning of the meeting. They were explicitly told that some of the questions might bring back negative emotions associated

with the loss, that they could request a break whenever they preferred, that they could choose not to answer certain questions if they did not feel comfortable to do so, and that they could withdraw from the study at any time.

Data collection included both quantitative and qualitative components and involved a 2-step process. First, the participants completed a battery of questionnaires on their demographic information, information about the deceased family member, psychological adjustment (level of depressive symptoms, level of anxiety symptoms, and somatic complaints), coping strategies used, and level of acculturation at the beginning of the in-person meeting to generate quantitative data for the current study. The measures chosen were well-established and commonly used in previous literature with bereaved individuals (e.g., Bonanno et al., 2002; Fried et al., 2015; Kreicbergs et al., 2004; Neimeyer et al., 2006; Worden et al., 1999). Given that the participants recruited for the current study were first-generation Chinese immigrants to Canada who did not speak English as their first language, both the original English version of the questionnaires, and the translated version in Chinese (with demonstrated cross-cultural validity) published in previous literature were made available for use. The Chinese translated versions of the questionnaires were either obtained from the test publishers who owned the copyright of the measures (e.g., the State-Trait Anxiety Inventory), or directly from the researchers who completed the translation and demonstrated their psychometric properties in peer-reviewed literature (e.g., Center for Epidemiologic Studies-Depression Scale).

Participants were asked to choose whether they would like to complete the English version or the Chinese version of the questionnaires. All 25 participants chose to complete the Chinese questionnaires. The questionnaires were then verbally administered to them by the author (instead of being completed by the participants themselves) in order to 1) build rapport and trust with the participants, given the sensitive nature of the questions on mental health and the subsequent interview on their bereavement, 2) accommodate for the different literacy level and ages in the sample, particularly for the less educated or older participants who might have trouble reading the questionnaires, and 3) accommodate for the differences in the written form of Chinese across the three Chinese regions. The Chinese translated questionnaires used in the current study were written in traditional Chinese. Traditional Chinese is used in Hong Kong and Taiwan, while simplified

Chinese is used in Mainland China. Those from Hong Kong and Taiwan will have difficulty reading and understanding simplified Chinese, and the opposite is true for those born in Mainland China. The questionnaires took approximately 30 minutes to complete.

Second, semi-structured interviews were conducted in Cantonese or Mandarin to generate qualitative data from the participants. The topics covered and the questions in the interview were developed based on previous research soliciting perspectives on palliative and bereavement care as well as their service needs (e.g., Contro et al.; 2002, D'Agostino et al., 2008; deCinque et al., 2006; Frey et al., 2013; Randhawa et al., 2003). The interview first focused on the participants' thoughts and feelings after the loss of a family member, their ways of coping, and the impact of the death on them and the rest of the family. Next, the interview focused on factors related to accessing and utilizing bereavement care services: the participants' knowledge and understanding of palliative and bereavement care, the bereavement services they were provided, whether they attended the services and why, their overall assessment and experiences with the services (e.g., what they found helpful / unhelpful), their perceived need for bereavement care services, barriers that prevented them from receiving bereavement care, as well as services they would have like to receive and ways to improve current services. Follow-up questions were asked for probing (e.g., "What did you do when that happened?"), clarification (e.g., "What did you mean when you said....."), and elaboration on the process (e.g., "Could you give me an example?" or "How did that make you feel when....."). Interviews were audio-taped with prior consent of all participants. A script of the interview questions is provided in Appendix A.

Upon completion of the study, participants were provided \$50 as honoraria. They were also given a package of bereavement resources, written in Chinese, that consisted of a brochure explaining the nature of grief, and a list of resources and support (in Chinese and English) available in the community for bereaved Chinese individuals.

## **Quantitative Measures**

### **Demographic Information**

All participants completed a background questionnaire, which collected their demographic information, as well as information related to the deceased (e.g., the deceased's country of birth, diagnosis, and year of death).

### **Psychological Functioning and Somatic Symptoms**

The following questionnaires were administered to the participants regarding their own functioning:

1. The Center for Epidemiologic Studies-Depression Scale (CES-D; Radloff, 1977) is a 20-item screening instrument that assesses depression in adults. It is one of the most widely used screening measures for depression with established reliability and validity. The Chinese version of the CES-D was developed by Chi and Boey (1992), with reliability and validity comparable to the English version. Scores above the cut-off score of 16 indicate clinically significant level of depressive symptoms. Scores between 16 and 26 suggest mild symptomatology; scores 27 and above suggest moderate to severe symptomatology. The Cronbach's alpha coefficient in the current study was 0.95.
2. The State-Trait Anxiety Inventory (STAI; Spielberger, Gorsuch, & Lishene, 1970) is a 40-item self-report questionnaire consisted of two subscales. The State Anxiety Scale (S-Anxiety) evaluates current state of anxiety, such as feelings of fear, tension, worry, and arousal. The Trait Anxiety Scale (T-Anxiety) is designed to measure an individual's general, enduring predisposition to perceive situations as threatening and respond with state anxiety. The reliability and the validity of the Chinese version have been well-established (e.g., Shek, 1988; Shek, 1993). A cut-off score of 40 was used in previous research for the Chinese version of STAI to detect clinically significant level of anxiety symptomatology (e.g., Soetanto, Chung, & Wong, 2006). Scores between 40 and 59 suggest moderate level of anxiety;



scores above 60 suggest severe level of anxiety. The Cronbach's alpha coefficient for the State Anxiety Subscale in the current study was 0.96; that for the Trait Anxiety Subscale was 0.95.

3. A researcher-developed questionnaire was used to collect information regarding somatic symptoms experienced by the participants during the past 2 weeks. The questionnaire consisted of somatic symptoms often experienced by bereaved individuals according to previous research. Participants were asked to rate the frequency of symptoms such as sleep difficulties, pain, or poor appetite on 4-point Likert scale ranging from 0 (Rarely or None of the Time) to 3 (Most of or All the time). The Cronbach's alpha coefficient in the current study was 0.92.

## **Coping**

Coping strategies were measured using the Jalowiec Coping Scale – Chinese Version (JCS). The original Jalowiec Coping Scale was developed by Jalowiec and Powers (1981) and covers 40 coping behaviours. The Chinese version was translated by Mok and Tam (2001) with reliability and validity comparable to the original version. It yields five coping subscales as named by Yeh and Chou (2007): problem-oriented (facing the problem objectively, problem-solving, or setting up a plan of action), emotion-focused (experiencing emotional reactions such as worry and guilt, or expressing emotions such as crying), support seeking (praying, seeking social support, or seeking professional help), avoidance-oriented coping (engaging in unhealthy behaviours such as smoking, bingeing and drinking), and isolating thoughts (avoiding the problem, suppressing thoughts, using distraction, or accepting the situation). The Cronbach's alpha coefficient in the current study was 0.85.

## **Acculturation**

The participants completed the Marin Short Acculturation Scale (Marin, Sabogal, Van Oss Marin, Otero-Sabogal, & Perez-Stable, 1987), a 12-item questionnaire which measures level of acculturation. Participants rated their preferred language use, media preference, and choice of friends on a 5-point bipolar scale where 1 represented one's

heritage culture (i.e., Chinese) and 5 represented the mainstream culture (i.e., North America), with a midpoint (3) of “both equally”. Scoring the questionnaire entailed averaging each participant’s ratings across all items. A score of 2.99 was recommended as the cut point; those scoring below were considered less acculturated i.e., retaining more of their heritage cultural values, while those scoring above were considered more acculturated i.e., more assimilated into the North American culture. Gupta and Yick (2001) translated the Marin Short Acculturation Scale into Chinese, and confirmed its cross-cultural reliability and validity. The Cronbach’s alpha coefficient in the current study was 0.86.

## **Analysis**

### **First Phase: Quantitative Analysis**

The first phase of data analysis focused on the quantitative data, and was largely descriptive in nature. Sample means and standard deviations were first calculated for the scores on the various questionnaires administered. Participants’ mean level of acculturation and the percentages of participants classified as “high” or “low” in acculturation on the Marin Short Acculturation Scale were calculated. With regards to the measures on psychological functioning, the percentages of participants scoring above the suggested cut-offs on the CES-D and STAI were calculated. The somatic symptoms were ranked according to mean frequency. Finally, the mean scores on the five coping subscales in the Jalowiec Coping Scale were compared using a one-way repeated measures ANOVA to examine possible differences among coping strategies in terms of frequency of use.

### **Second Phase: Qualitative Analysis**

The qualitative analysis aimed to develop an understanding of how first-generation Chinese immigrants experienced bereavement, how they navigated the health care system to access bereavement services, and what contextual factors influenced their experiences.

For the qualitative data from the interviews, the audiotaped interviews were first translated into English and transcribed by the author verbatim. Nonverbal elements such as pauses, crying and silence were also recorded in the interview transcripts. A research assistant with graduate training in social psychology and fluent in Cantonese, Mandarin and English back-translated five (20%) of the English interview transcripts into Chinese to check for accuracy in translation.

Procedures such as constant comparative analysis and various coding methods originally developed for use in the grounded theory method of Strauss and Corbin (1998) were used in the current study for analyzing the interview transcripts. It is important to emphasize that while “tools of grounded theory” were used for analyses, the current study is *not* a grounded theory study. Research on bereavement in ethnic minorities and immigrants in North America is still in its infancy. As a first step to explore this area, the current study aimed to focus on **describing** the phenomenon, **identifying patterns** and themes, and **generating hypotheses** for future research rather than theory building. More research and empirical data in this area are needed before the development of a substantive theory can be accomplished. In addition, due to logistical constraints and the ongoing difficulty in recruiting participants, a number of fundamental components that define a grounded theory study such as theoretical sampling and concurrent data collection and data analysis, were unable to be implemented (Corbin & Strauss, 2008).

Charmaz (2006) argued that “grounded theory methods need not be tied to a single method of data collection, or emerge from a specific theoretical perspective.....[or] be tied to a single epistemology” (p. 178). While the current study did not use grounded theory as a *methodology* (i.e., an overall approach to inquiry linked to a particular theoretical framework; Sandelowski, 2003), tools employed by grounded theory, as *methods* (i.e., techniques) of data analysis, can provide a systematic, step-by-step coding paradigm to guide the analysis of qualitative data (Fram, 2013; Creswell, 2007). The clear and structured approach to coding proposed by Strauss and Corbin (1998), often known as the Straussian coding paradigm, is particularly appropriate for a researcher like the author who had been well-trained in quantitative research methods but is still a novice in qualitative research. In fact, Strauss and Corbin designed their highly rigorous coding procedures and techniques specifically for “persons who are about to embark upon their

first qualitative analysis project” (Strauss & Corbin, 1990, p. 8). Another strength of adopting the Straussian method of coding is its focus on identifying social processes, interactions, and relationships among concepts (Strauss & Corbin, 1998). This is particularly appropriate for the current study which aimed to identify different contextual forces on different levels (e.g., cultural, health care system, interpersonal or personal) which are often dynamic social processes themselves, their interrelationships, and their synergistic impact on access to health care. Constant comparative analysis allows for the identification of not just the pattern itself (e.g., “How does the access to bereavement care look like for Chinese *in general*?”), but also of the pattern’s *variations* (e.g., “How do different bereaved Chinese access care differently?”), through comparing a concept’s or a pattern’s properties and dimensions under different conditions (Strauss & Corbin, 1998). Constant comparisons also help increase internal validity of the findings, as systematic comparisons and examination of commonalities and differences ensure that all data will be analyzed rather than discarded due to a perceived lack of “fit” with the researcher’s bias (Fram, 2013). Capturing, describing and conceptualizing the entire range and variations of characteristics underlying a phenomenon provide a richer description of the subject under study (Boeije, 2002). Nevertheless, the author was mindful of previous criticism of the Straussian coding method as being too prescriptive or running the risk of “forcing data into preconceived categories” (Kenny & Fourie, 2015). The coding paradigm was therefore employed as “guidelines” or “thought questions” rather than rules or “checklists” in the current study. The author made sure that she did not limit her analysis to only the conditions, concepts, or categories proposed in the Straussian paradigm. The procedures were primarily used to stimulate the author’s thinking and help her become attuned to “things to look for” when analyzing the interview transcripts.

### ***Steps to Constant Comparisons***

Strauss and Corbin (1998) referred to the process of analyzing qualitative data as *coding*, a process of first breaking data down into smaller components and labelling them, and eventually relating and combining these smaller components into larger, more abstract categories based on shared conceptual grounds (Sbaraini, Carter, Evans, & Blinkhorn, 2011). Constant comparisons were performed throughout the entire coding process in the current study according to the step-by-step approach proposed by Boeije

(2002). Comparisons occurred on several levels: within participant, between participants, between incidents and categories, and between categories.

For each participant, every incident was compared with previous incidents mentioned by the same participant in other parts of the interview, to examine consistency in the participant's report and to see if the same code would apply. For instance, if a participant said "*I distracted myself by watching TV*" in one part of the interview, while later he or she mentioned "*keeping myself busy and learning new things help me distract myself as I have no time to think about the grief*", the author would compare these two incidents of "*distract*" and the associated contexts to better understand the meaning behind the participant's narrative. Comparisons *across* interviews were also conducted; incidents or fragments from different interviews by different participants were compared to look for similarities, differences, the contexts in which the incidents occurred, and outcomes.

As the categories became more developed, incidents were compared with the characteristics of a category to determine fit and relevance. Evaluating the "fit" between incident and a pre-existing category allowed the author to check if new categories needed to be added, and ensured that the concepts were able to account for all related incidents in the data (Fram, 2013). Negative cases (i.e., incidents that did not fit into a pre-existing code or category) were carefully examined to guard against researcher bias and subjectivity, as they helped challenge the pre-existing conceptualization of categories and suggest the possibilities of new concepts, dimensions, processes, and relationships. For instance, religious affiliation was a concept that frequently came up in the interviews with the participants, with the majority of participants expressing positive attitude towards its effectiveness in helping them cope with the loss. However, a significant group of participants held completely opposite attitude towards their faith. Comparing these "negative" cases with "positive" cases helped identify the conditions, reasons and outcomes associated with these two vastly different attitudes. Similarly, categories were also compared with each other to clarify conceptual similarities, differences and interrelationships. Comparisons continued until saturation was achieved i.e., when the information provided by the participants had become redundant, and no new categories of properties, dimensions, information, or themes emerged (Sbaraini et al., 2011).

Constant comparisons improve the precision of categorization as codes and categories are added, deleted, differentiated, expanded, and collapsed (Corbin & Strauss, 1990). Examining data for similarities and differences helps refine and differentiate the categories, as well as delineating the properties and dimensions of a category, the full range of phenomena that underlay a category, the conditions under which the category applied, and relationships among categories.

### ***Steps to Coding***

The qualitative data were analyzed using the guidelines for open, axial, and selective coding proposed by Strauss and Corbin (1998). A computer program, nVivo 10, was used to facilitate the coding of interview transcripts.

### **Open Coding**

The interview transcripts were imported into nVivo 10. The transcripts were first read in their entirety to obtain a sense of the overall picture. Open coding was the first step to coding in which data were dissected, analyzed, compared, described, and categorized (Strauss & Corbin, 1998). In open coding, each transcript was reread in depth and closely examined word for word and line by line in order to break down the texts, search for patterns and categories, and assign category labels (i.e., codes) to “chunks” of data based on the meaning emerged from the data. The “chunks” of data could be single words, phrases, sentences, or even paragraphs (Miles & Huberman, 1994). Incidents such as events, issues, concerns, problems, feelings, thoughts, actions, beliefs, values, attitudes, perspectives, meanings, and interpersonal interactions formed the initial codes (Saldaña, 2013; Taylor & Gibbs, 2010). In addition to constant comparison questions (e.g., “How is this piece of information similar to or different from the previous one that was coded?”), Strauss and Corbin (1998) also proposed other questions to stimulate thinking and to guide the labelling and analysis process. *Sensitizing* questions, for example, alerted the author to what the data were indicating by asking questions such as what, who, where, when, how, why, and with what results or consequences. These questions were crucial in aiding the identification of a phenomenon’s properties and dimensions. In the current study which focused on cultural influences on behaviours, the author also asked questions suggested by Strauss and Corbin (1998) about rules, cultural values and morals, and

standards that were used by the participants to guide or explain their behaviors. Through the process of constant comparison, new data with similar indicators and concepts with previously coded data were assigned the same category label, whereas data that were dissimilar would receive a new label to reflect a different category.

In open coding, particular attention was paid to word repetitions within and between interviews, and keywords participants used to describe certain events (e.g., euphemism for “*death*”). *In vivo* coding, or using the participants’ actual language used in the interview as the code name or label for a concept, helped retain the participants’ voices in the coding process. Since the interviews in the current study were conducted in Cantonese or Mandarin Chinese, often times the *in vivo* codes were in Chinese rather than English. This was done to preserve the participants’ specific meaning, experience and intention, especially when certain “indigenous terms” (i.e., specific words from members that share the same culture; Saldaña, 2013) in Chinese may have no straightforward equivalents in English. Using the nVivo software, the author coded the interview data with labels (called “nodes” in the nVivo software) directly within the software interface. The software also allowed for easy addition, deletion, combination and / or modification of the labels. Open coding continued until all events in the transcripts were coded.

### **Axial Coding**

Axial coding is the process of “reassembling data that were fractured during open coding” (Strauss & Corbin, 1998, p. 124), in which individual codes identified in the open coding process are sorted, organized, integrated, and related to one another. In the current study, axial coding overlapped with open coding. It began once several preliminary categories had been identified in open coding and the author began to develop an initial sense of how the categories might relate to each other. The purposes of axial coding were to combine codes or categories together into larger concepts, again using the technique of constant comparison, and to begin exploring the interrelationships and conceptual linkages among categories. This was accomplished via a number of ways in the current study:

1. Grouping categories that represented the properties (“general or specific characteristics or attributes”; Strauss & Corbin, 1998, p.117) and dimensions (the range

of variations a property in a category can have) of a concept in a hierarchical manner, and subsuming them under a higher order category (i.e., they became subcategories under a larger concept),

2. Identifying the various conditions or contexts that gave rise to a situation, individuals' actions, strategies, and interactions in response to the situation, sequence, movement, changes across time and conditions, and consequences associated with a phenomenon, and

3. Grouping categories identified in open coding that shared similar characteristics or were conceptually related to form bigger thematic areas. Constant comparisons helped uncover conceptual similarities and differentiate themes (Strauss & Corbin, 1998; Scott, 2004).

The nVivo program enabled the grouping of the nodes that represented codes or labels. Nodes that shared similar features could be merged. Those that represented subcategories could be organized into a hierarchical structure under the label of a higher-order category.

### **Selective Coding**

Once open and axial coding were completed, selective coding was phased into the coding process. Strauss and Corbin (1990) previously suggested that coding could stop after axial coding if one were only interested in the identification of themes or concept development. Selective coding, as the final step of coding, is used to generate theory by integrating the major, higher-order categories, specifying their relationships, and conceptualizing the "story line" that explains the phenomenon under study. Even though the current study aimed to identify and describe bereaved Chinese immigrants' experiences rather than theory building, it was evident to the author that the major themes identified via open and axial coding were clearly intertwined, and could be arranged in order as they reflected a process participants went through in response to grief that was influenced by the larger sociocultural and system factors. Selective coding was therefore performed in the current study not for theory development but rather for organizational purposes, as a way to elucidate the relationships among the themes in a systematic



manner. This resulted in a more logical and coherent descriptive framework (rather than just a list of themes) outlining the participants' experiences with bereavement, their journeys of navigating the health care system, and the barriers along the way.

The process of selective coding began with the identification and selection of a "core category", or "the central phenomenon around which all other categories are integrated", from the categories developed during axial coding (Strauss & Corbin, 1998, p. 116). Previous literature has proposed several criteria for choosing the core category. The core category represents the central idea or the main theme of the research. It captures the participants' main concern. It reoccurs frequently in the data, meaning that "within all or almost all cases, there are indicators pointing to that concept" (Strauss & Corbin, 1998, p. 147). It should also relate meaningfully and easily with other categories (Holton, 2007). After choosing the core category and positioning it at the centre of the framework, its relationships with other categories as well as the relationships among categories were then examined. The author explored the relationships visually by drawing diagrams of different configurations of the framework, and by sorting. Index cards, each containing the name of a category, were laid out on the floor. The author sorted and rearranged the cards while asking questions regarding different aspects of the process experienced by the participants, until a conceptual map of the interrelationships that best fitted the data emerged.

## **Memoing**

Memos are the written notes or records of the researcher's thought process during analysis. In the current study, memo writing began at the start of analysis. The memos were spontaneously written in informal language and in point form, and were stored in nVivo. At the beginning of coding, memos tended to be more descriptive in nature. The author might reflect on a particular interviewee's responses, comment on comparable or divergent pieces of information across participants observed during the constant comparison process, and make note of quotes that captured her attention. As coding progressed, the level of abstraction increased, and the content of the memos began to move from description towards conceptualization. The memos became more analytical, and consisted of questions, musings, and speculations about concepts and their relationships. For example, the author recorded increasingly salient patterns and areas

that required further exploration. She reflected and elaborated on the meaning, assumptions, and values behind participants' responses, outlined the different properties and dimensions associated with a concept, and hypothesized about possible relationships among categories. By translating the author's thought process into words, memo writing helped develop and refine the ideas behind the conceptual framework of the study, and served as an audit trail that documented the analytical process.

### ***Maintenance of Rigour***

A number of strategies proposed by previous literature were employed in the current study to ensure the rigour of the qualitative research method and the trustworthiness of the results (Creswell, 2007; Saumure & Given, 2008; Kolb, 2012; Billups, 2014). The interview guide used in the current study was reviewed by members of the supervisory committee to ensure that the questions were in line with the study aim. The current sample consisted of first-generation Chinese immigrants with diverse demographic and socioeconomic backgrounds, providing a broader and deeper understanding of their bereavement experiences. Triangulation with quantitative data allowed for corroboration of qualitative findings and examination of their credibility. The use of constant comparisons and negative case analyses ensured that all the data were explored, and that disconfirming evidence was not ignored due to researcher bias. The author used a rigorous and well-recognized method of qualitative inquiry (the grounded theory coding tools developed by Strauss and Corbin), allowing for a systematic approach to data analysis. The author also kept an "audit trail" to document the research process, such as detailed procedural records and memos. Peer review and debriefing provided an "external check" of the research process and the conceptual framework developed after the coding process. A social psychologist with research interests and expertise in cross-cultural psychology coded three of the interview transcripts, and compared his codes with the author's to check for consistency. He also provided feedback on the author's conceptualization, and asked "hard questions" to challenge the author's coding, interpretations and conclusions. The author provided a rich, thick description of the participants' experiences in the write-up of the qualitative results, with detailed quotes supporting her interpretations. The author was also mindful, or reflexive, of how her own cultural background could influence the participants' behaviours during her interactions with them or introduce bias during data analysis. For instance, as a result of the cultural

value of “*zhih-yi*” and the high-context communication style in the Chinese culture, some participants kept their answers brief or used Chinese idioms without further explanations, as they assumed that the author should be able to understand them given their shared cultural background. In response, the author always asked for clarification, elaboration, and examples to illustrate what they meant. She also explicitly sought participants’ feedback on her interpretation of their words and behaviours.

### **Third Phase: Mixed Methods Analysis – Combining Qualitative Data with Quantitative Data**

A defining feature of a mixed methods study is the integration of quantitative and qualitative data in order to provide a more complete picture of the research problem (Creswell & Plano Clark, 2011). A number of salient themes that emerged from the analyses of the interview transcripts warranted further, combined analyses with quantitative data from the questionnaires. These themes included the participants’ descriptions of their grief experiences, coping methods, religious affiliation, social support, end-of-life care for the deceased family members, and access to bereavement care services.

#### ***Quantifying Qualitative Data***

The qualitative data on the aforementioned variables were quantified and transformed into categorical variables by categorizing participants based on their responses during the interview. For instance, under the variable “grief experiences”, participants were classified into six categories based on their self-reported functioning and coping success, as well as their presentation during the interviews. Certain qualitative data, such as whether a participant had taken the initiative to seek professional help, were transformed into dichotomous variables reflecting the “presence” versus “absence” of an action. The number and percentages of participants falling in each category of a categorical variable were then calculated.

#### ***Combined Statistical Analyses on Quantitative and Qualitative Data***

After quantification, the qualitative data obtained from the interview became categorical variables. Categorical data were then entered into SPSS so that statistical

analyses could be performed. By converging qualitative data from the interviews and quantitative data from the questionnaires, further analyses were performed in an attempt to answer three questions:

1. How did the participants' narrative of their grief experiences during the interview relate to their psychological functioning as measured by the quantitative questionnaires?
2. What predicted the participants' psychological outcomes i.e., grief experiences, level of depression, level of state and trait anxiety, and somatic symptoms?
3. What predicted access to various bereavement care services (pre-bereavement care, bereavement follow-up care, and bereavement interventions) and initiative to seek help?

### **Question 1: Relationships between Qualitative Description of Grief Experiences and Quantitative Measures of Psychological Functioning**

One-way ANOVAs were conducted to examine whether participants with different grief experiences also differed on their CES-D scores, STAI State Anxiety scores, STAI Trait Anxiety scores, and frequency of somatic symptoms.

### **Question 2: Predictors of Psychological Outcomes**

Further analyses were performed to explore possible predictors of the four psychological outcomes quantitatively measured in the current study: depression, state anxiety, trait anxiety, and somatic symptoms. These outcome variables were continuous in nature. The further analyses were exploratory and could not be pre-planned given the paucity of previous research examining predictors of bereavement experiences in ethnic minorities and NESB immigrants. The current study, being one of the first studies in this area, aimed to focus on hypothesis generation for future research. Yet the author was sensitive to both the possibility of inadequate power (and inflation of Type II error rate) due to small sample size, and the danger of inflation of Type I error rate when multiple comparisons were performed with no adjustment to the alpha level. The following *a priori* decisions were therefore made:

1. The variables to be examined would come from the following six areas:

a. Participants' sociodemographic characteristics (age, gender, marital status, length of bereavement, level of education, employment status, and income);

b. Participants' immigration-related characteristics (country of origin, length of residence in Canada, English fluency, and acculturation);

c. Sociodemographic and illness variables related to the deceased family members (relationship to the participant, age of death, chronicity of illness, nature of death, location of death, and whether palliative care was provided to the deceased at the end of life);

d. Participants' coping strategies (including the five coping strategies measured by the Jalowiec Coping Scale: problem-oriented coping, emotion-oriented coping, support seeking, avoidance-oriented coping, and isolating thoughts; and the four coping strategies identified based on qualitative data: taking solace in "good death", suppressing negative thoughts and emotions, focusing on restoration, and reframing the loss);

e. Participants' religious affiliation (whether one had a religious affiliation, and degree of religiosity); and

f. Participants' self-reported level of social support based on qualitative data (social sharing with family, social sharing with friends, nonverbal support from family, nonverbal support from friends).

2. For each *area* of predictors, a familywise alpha level of 0.10 was used if there were more than 2 predictor variables to be tested within each area. The more liberal alpha level was chosen in order to accommodate the small sample size and the large number of variables in the area. A familywise alpha level of 0.05 was used for the area of religious affiliation, as there were only 2 predictor variables to be tested.

3. Dunn-Sidak corrections for multiple comparisons were performed for each area of predictors. Dunn-Sidak corrections were more preferred than Bonferroni corrections as they were slightly less stringent. The formula for Dunn-Sidak Correction is:

$$\alpha \text{ per contrast} = 1 - (1 - \text{familywise } \alpha)^{1/k}$$

where k is the number of contrasts to be performed within each area.

The adjusted alpha level per contrast for the six areas are listed below:

**Table 4. Adjusted Significance Level per Contrast Based on Dunn-Sidak Corrections for Predictors of Psychological Functioning (N = 25)**

Area of Predictor Variables	Familywise $\alpha$	Contrast-based $\alpha$ (rounded to 3 decimal places)
Participants' sociodemographic characteristics	0.10	0.015
Participants' immigration-related characteristics	0.10	0.026
Deceased's sociodemographic and illness-related variables	0.10	0.017
Coping	0.10	0.012
Religious affiliation	0.05	0.025
Social support	0.10	0.026

4. Pearson correlation was used to examine the relationship between continuous predictor and outcome variables. Independent-sample t-tests or one-way ANOVA were performed to examine the relationship between categorical and continuous variables. Post-hoc comparisons using the Tukey's procedure (assuming homogeneity of variance) or the Games-Howell procedure (if the assumption of homogeneity of variance was violated) were performed if the omnibus ANOVA suggested possible statistically significant between-group differences. The analyses were univariate in nature (i.e., one predictor versus one outcome) and aimed to be exploratory, as the small sample size precluded the use of more sophisticated multivariate techniques.

### **Question 3: Factors Related to Access to Bereavement Care Services**

Further analyses, similar to those examining possible predictors of psychological functioning, were also performed to explore possible predictors of three aspects of bereavement service utilization identified in the participant interviews: 1) access to pre-bereavement care or bereavement follow-up, 2) participants' initiative to seek professional support for bereavement, and 3) access to therapeutically focused bereavement interventions. Three separate sets of analyses were run, with each aspect of bereavement service utilization being the outcome variable in each set of analyses.

Similar to the steps taken for examining possible predictors of psychological outcomes described earlier, the following *a priori* decisions were made in order to balance between the inadequate power associated with small sample size and inflation of Type I error rate due to multiple comparisons:

1. The variables to be examined would be from the following eight areas:
  - a. Participants' sociodemographic characteristics (age, gender, marital status, length of bereavement, level of education, employment status, and income);
  - b. Participants' immigration-related characteristics (country of origin, length of residence in Canada, English fluency, and acculturation);
  - c. Sociodemographic and illness variables related to the deceased family members (relationship to the participant, age of death, chronicity of illness, nature of death, location of death, and whether palliative care was provided to the deceased at the end of life);
  - d. Participants' coping strategies (including the five coping strategies measured by the Jalowiec Coping Scale: problem-oriented coping, emotion-oriented coping, support seeking, avoidance-oriented coping, and isolating thoughts; and the four coping strategies identified based on qualitative data: taking solace in "good death", suppression of negative thoughts and emotions, focusing on restoration, and reframing the loss);
  - e. Participants' religious affiliation (whether one had a religious affiliation, and degree of religiosity)
  - f. Participants' social support (social sharing with family, social sharing with friends, nonverbal support from family, nonverbal support from friends)
  - g. Psychological outcome variables (depression, state anxiety, trait anxiety, and somatic symptoms)
  - h. The other two bereavement service utilization variables that were *not* the outcome variable in question. For example, if "access to bereavement interventions" was

the outcome variable, “access to pre-bereavement care or bereavement follow-up” and “taking initiative to seek professional support” were the predictors.

2. Dunn-Sidak corrections for multiple comparisons were performed for each area of predictors. For each *area* of predictors, a familywise alpha level of 0.10 was used if there were more than two predictor variables to be tested within each area. A familywise alpha level of 0.05 was used for the area of religious affiliation and bereavement service utilization factors.

The adjusted alpha level per contrast for the eight areas are listed below:

**Table 5. Adjusted Significance Level per Contrast Based on Dunn-Sidak Corrections for Predictors of Bereavement Care Utilization (N = 25)**

<b>Area of Predictor Variables</b>	<b>Familywise <math>\alpha</math></b>	<b>Contrast-based <math>\alpha</math> (rounded to 3 decimal places)</b>
Participants' sociodemographic characteristics	0.10	0.015
Participants' immigration-related characteristics	0.10	0.026
Deceased's sociodemographic and illness-related variables	0.10	0.017
Coping	0.10	0.012
Religious affiliation	0.05	0.025
Social support	0.10	0.026
Psychological outcome variables	0.10	0.026
Bereavement service utilization variables	0.05	0.025

3. Independent-sample t-tests or one-way ANOVA were performed to examine the relationship between categorical and continuous variables. Post-hoc comparisons using the Tukey's procedure (assuming homogeneity of variance) or the Games-Howell procedure (if the assumption of homogeneity of variance was violated) were performed if the omnibus ANOVA suggested possible statistically significant between-group differences. Chi-square tests of independence were performed if both the predictor and outcome variables were categorical. Similar to the analyses examining predictors of psychological functioning, these analyses were also univariate (i.e., one predictor versus one outcome) and exploratory.



4. According to Cochran (1954), the reliability of the chi-square test is affected when any of the expected cell frequencies is less than one, or when more than 20% of the table cells have expected cell frequencies less than five. Given the sample size in the current study, the categorical predictor variables with more than two levels (marital status, level of education, employment status, participant's relationship to the deceased) yielded invalid results when the chi-square tests were used to examine their relationship with the bereavement service utilization variables. Yet alternatives to the chi-square test, such as the Fisher's exact test, were only available for 2x2 tables. As a result, these predictor variables were dichotomized by combining their categories so that each variable would only have two levels (e.g., presence vs absence, yes vs no). Similarly, the three variables on bereavement service utilization were also converted into dichotomous variables.

## Chapter 5. Results

### Quantitative Data from Questionnaires

The mean level of acculturation was 1.90 ( $SD = 0.50$ , range = 1 - 3.08). A cut-off point of 2.99 was used to classify the participants based on their level of acculturation. Among the 25 participants, only 1 (4%) scored above 2.99. Taken altogether, participants in the current sample were less acculturated in general and more strongly identified with their heritage, Chinese culture.

Table 6 presents the prevalence of depression and anxiety symptoms in the current sample. The mean score on the CES-D was 19.48 ( $SD = 14.73$ , range = 3 - 50). Fourteen of the twenty-five participants (56%) scored above the clinical cut-off of 16. Nine participants (36%) scored within the mild range of depression symptomatology, while 5 (20%) scored within the moderate to severe range.

The mean score on the STAI State Anxiety Scale was 43.60 ( $SD = 14.13$ , range = 27 - 76). Fifteen participants (60%) scored above the clinical cut-off of 40. Most of those who scored above the cut-off reported moderate level of current anxiety symptoms. Three participants (12%) were found to score within the severe range.

The mean score on the STAI Trait Anxiety Scale was 45.52 ( $SD = 12.40$ , range = 32 - 79). Sixteen participants (64%) scored above the clinical cut-off of 40. Similar to the results on the STAI State Anxiety Scale, most of those who scored above the cut-off reported moderate level of general anxiety symptoms. Four participants (16%) scored within the severe range.

Thirteen participants (52%) were identified as reporting comorbid depressive and anxiety symptoms, defined as scoring above the clinical cut-offs on both the CES-D and the STAI. Three participants (12%) scored within the "severe" range of symptomatology on CES-D, STAI State Anxiety scale **and** STAI Trait Anxiety scale.

**Table 6. Prevalence of Clinically Significant Depressive and Anxiety Symptoms and Comorbidity (N = 25)**

<b>Psychological Functioning</b>	<b><i>n</i></b>	<b>%</b>
Depression (CES-D)		
Below cut-off of 16	11	44
Equal to or above cut-off	14	56
Mild range (16-26)	9	36
Moderate to severe range ( $\geq 27$ )	5	20
State anxiety (STAI State)		
Below cut-off of 40	10	40
Equal to or above cut-off	15	60
Moderate range (40-59)	12	48
Severe range ( $\geq 60$ )	3	12
Trait anxiety (STAI Trait)		
Below cut-off of 40	9	36
Equal to or above cut-off	16	64
Moderate range (40-59)	12	48
Severe range ( $\geq 60$ )	4	16
Comorbid depression and anxiety symptoms		
Scoring above cut-off on CES-D and both STAI scales	13	52
Scoring within the severe range on CES-D and both STAI scales	3	12

Six participants (24%) reported suicidal ideation. Further risk assessments revealed that five of these participants had infrequent, fleeting thoughts of suicide with no clear plans. The remaining participant reported frequent thoughts of suicide that predated the death of the family member, but did not report any clear and imminent plan of attempts. She had attempted suicide once after becoming bereaved and was hospitalized. She had been under the care of a psychiatrist and other mental health professionals.

The mean frequency scores and standard deviations of somatic symptoms endorsed by the participants are shown in Table 7. The most frequently reported somatic symptoms (with a mean frequency score higher than 1 i.e., more than “sometimes”) were

lower back pain, muscle soreness, fatigue, forgetfulness, sleep difficulties, and headaches.

**Table 7. Mean Frequency of Somatic Symptoms in Descending Order (N = 25)**

<b>Somatic Symptoms</b>	<b>M</b>	<b>SD</b>
Lower back pain	1.88	1.09
Muscle soreness	1.88	1.09
Fatigue	1.84	1.14
Forgetfulness	1.76	0.93
Trouble staying asleep	1.40	1.26
Poor quality of sleep (shallow or light sleep, not feeling rested)	1.40	1.12
Headache	1.16	0.85
Nausea	0.92	1.00
Weakness in parts of the body	0.88	1.01
Difficulty with attention / concentration	0.88	1.01
Trouble falling asleep	0.84	1.11
Nightmares	0.84	1.03
Increase in appetite	0.80	1.00
Dizziness	0.68	1.03
Shortness of breath	0.64	0.86
Heavy feelings in extremities	0.60	0.76
Numbness or tingling	0.52	0.77
Hot or cold spells	0.48	0.59
Lump in throat	0.44	0.77
Poor appetite	0.40	0.71
Chest pain	0.40	0.58

Table 8 presents the mean scores and standard deviations for the five coping subscales in the Jalowiec Coping Scale. A one-way repeated measures ANOVA was performed to compare the coping subscale scores. Mauchly's test indicated that the assumption of sphericity was not violated,  $\chi^2(9) = 13.43, p = 0.145$ ; no correction to the degrees of freedom in the ANOVA was necessary. Results showed that there was a significant mean score difference among the five coping subscales,  $F(4, 96) = 27.54, p < 0.0001, \eta^2 = 0.44$ . Post-hoc pairwise tests using Bonferroni correction revealed that avoidance-oriented coping was the least often used coping strategy by participants; mean scores on problem-oriented coping, emotion-focused coping, support seeking, and

isolating thoughts were significantly higher than that on avoidance-oriented coping ( $p < 0.0001$  for all 4 contrasts). The mean scores on problem-oriented coping and isolating thoughts were also significantly higher than the mean score on emotion-oriented coping ( $p = 0.042$  and  $0.025$  respectively).

**Table 8. Mean Scores and Standard Deviations on the Coping Subscales of the Jalowiec Coping Scale (N = 25)**

Coping Subscale	M	SD
Problem-oriented coping	1.45	0.50
Emotion-oriented coping	0.90	0.63
Support seeking	1.35	0.65
Avoidance-oriented coping	0.21	0.40
Isolating thoughts	1.43	0.47

## Qualitative Data from Semi-Structured Interviews

Eight major categories of themes emerged from the qualitative data. *Chinese Cultural Grammar*, *Being an Immigrant in a Foreign Land*, and *Navigating Uncharted Territories in a Foreign Health Care System* underlay the contexts that influenced how the participants understood and coped with the death of their family members, how they sought and experienced support from their social networks, the health care system and the community at large, and what they perceived the barriers to accessing bereavement care to be. The core category, labelled *Bereavement as a Lonely Journey*, emerged from the intersections and interactions of these contextual processes, and represents the main concern of all the participants in the current study.

In the face of the core category, three outcome categories emerged: *Coping Strategies*, which represents the methods participants used to deal with their grief; *Religion and Spirituality*, which represents the bidirectional relationship between faith and loss, that is, how one's faith influenced the way he / she viewed death, and vice versa; and *Post-Loss Changes and Growth*, which represents the participants' perception of how they had changed and what they had learned after experiencing the death of a loved one. It is important to note that similar to the core category of *Bereavement as a Lonely*

*Journey*, these outcome categories are also embedded within the larger contextual processes related to culture, immigration, and health care system.

Finally, the category *Ideal Services for Bereaved Chinese Immigrants* is a collection of the participants' feedback to the health care system, based on their own journey of bereavement, on the services they believed would benefit bereaved Chinese immigrants, and ways to improve current services in order to reduce disparity in access to bereavement care. This category represents the participants' belief on the "ideal" ways our health care system could intervene and respond to bereaved Chinese immigrants' main concern of *Bereavement as a Lonely P.*

## **Chinese Cultural Grammar**

*Chinese Cultural Grammar* emerged as a category to reflect participants' descriptions, often spontaneous, of "*how we Chinese do things*". All the participants identified themselves as ethnically and culturally Chinese. They readily came up with a list of Chinese cultural beliefs, values, and norms on matters of death, dying and bereavement during the interviews, without explicit prompting by the author. They discussed them from the perspective of a collective, as evident by their frequent use of "we" whenever they spoke about the Chinese culture. Their description of Chinese cultural values was definitive, with a sense that such values were simply taken for granted. These cultural beliefs, values, and norms had a rule-like, dogmatic quality to them, and were stated in a matter-of-fact manner. When asked to elaborate, the participants were able to come up with examples to further illustrate their points, but struggled with explaining from where such behavioural rules originated. This is evident in the following excerpt from Participant K:

For us Chinese, it's very hard for us to open up to strangers and tell them about our bad or sad experiences. We are more conservative after all.

When asked to explain the reason why she thought "*Chinese are more conservative after all*", Participant K replied:

It's just our culture. Really don't know why that is the case.

Similarly, when discussing the difficulty with discussing one's grief with others, another participant noted that:

We Chinese find it embarrassing to talk to their closest friends or family about something like this. (Participant U)

When asked to elaborate on why the discussion of grief is considered embarrassing for Chinese, she replied:

It's just something you don't do. I can't explain it. It's our culture – these are simply things that we will not do. (Participant U)

The term “cultural grammar” was coined to describe the set of Chinese cultural rules that participants said guided and explained their thoughts, emotions, and behaviours as they coped with the loss of a family member. It serves as a “rule book” that outlines the regulations and standards of behaviours that are expected from everyone sharing the same culture. These rules are similar to grammar in a language, in that they are socialized and internalized from a young age, seen as prescriptive (i.e., one *must* abide by them as they define what is right and wrong), accepted as facts without questioning, and implicitly understood by those who share the same culture. Cultural grammar determines how an individual's behaviours should be constructed, just as linguistic grammar forms the basis of how words, clauses and sentences should be composed. There seems to be no explanation for why these grammatical rules exist – it is simply the way it is. Those who share the same cultural grammar set know how to use it and apply it in daily life, but find it inexplicable. The knowledge of such rules appears intuitive; these rules are so well-learned and so ingrained that they affect behaviours in an automatic, unconscious manner. Similar to acquiring a second language after a first language has already been established, those who did not grow up within the same cultural environment but adapt to it later in life will need to learn the other cultural grammar explicitly. For these people, the acquisition of these rules requires effort and does not come naturally. It may take time before the use of this acquired set of cultural grammar becomes fluent. Some people may never achieve the same level of native fluency compared with those who were born and raised in that culture.

*Chinese cultural grammar* has a number of properties. They include *Chinese cultural perspectives on death, communication styles, relationship rules, and culturally sanctioned coping strategies* for negative life events. These properties have direct implications for how Chinese deal with distressing emotions when grieving, and how they seek help and support from others.

### ***Chinese Cultural Perspectives on Death***

When asked how death is perceived according to Chinese cultural grammar, participants suggested a number of properties: cultural beliefs regarding death; taboo, fear and avoidance; and euphemism for death.

### **Cultural Beliefs Regarding Death**

Cultural beliefs regarding death are deeply ingrained in the Chinese culture. Participants noted that many in the culture attributed death in a family to supernatural causes such as bad luck. According to the participants, one of the causes of bad luck is bad “*feng shui*” of one’s ancestors’ grave, such as the grave site being located at an area with the wrong landscape and magnetic energy, or facing the wrong direction. A wrong grave site would put a curse on the welfare of all subsequent generations of the family. Another cause of bad luck is the choice of a wrong name for an individual: a name that does not have the right “elements” that complement a person’s destiny. Such a name is believed to be capable of harming this person in the future. Participant I, who lost her young son, explained how the death of her son was perceived by others:

You know some people.....my in-laws are already quite "modernized" in their way of thinking. They are already quite open-minded. Many who still hold onto traditional thoughts will tell you that you're cursed and are carrying bad luck around, that it's you who caused your son's death.....or that your ancestors' graves have bad feng shui, and that's why your life can't support the existence of a son.

Similarly, Participant S, who lost her adult son to cancer, recalled how she and her husband reacted in response to the news that the cancer was terminal:

We were told that this kind of cancer is terminal and very aggressive. It usually affects young people under the age of 30.....When we were in Hong Kong, we went to many fortune tellers. Some of them told me that



the ancestors of my husband's side of the family weren't properly buried, that some of them weren't even buried, so their spirits came to harm my son as revenge. So we spent some money to perform rituals to appease the spirits. Some said that the name we gave our son wasn't good. So we felt.....we wondered if it was because of that. We thought to ourselves "maybe we gave him the wrong name".

The bad luck associated with death is considered to be contagious. Anything remotely linked to the concept of death is believed to be cursed and would continue to bring bad luck to others. Participants recalled the controversy in Vancouver a few years earlier, when a group of Chinese residents protested the building of a hospice near their condominium, citing that a place associated with death and dying would bring bad feng shui and bad luck to the area. Another example was offered by Participant C, whose sister passed away during an elective surgery. Participant C described how her mother made sense of her sister's death:

My mom was critical of my sister. She was like "how come she had to pick that date for surgery?" [The date my sister picked] was around the anniversary of my dad's death. My mom was like "she really shouldn't have picked that date. Those few days have brought bad luck to her and harmed her. If she had told me earlier, I would have told her not to go through with it."

When death occurs in a family, every family member is seen to be a "carrier" of bad luck. A family member's death is therefore perceived to bring **shame** to the entire family, and this shameful event must be hidden and cannot be openly discussed. The bereaved is expected to be self-aware of one's own bad luck and, out of consideration for other people's wellbeing, should segregate oneself from others in order to prevent the spread of the bad luck to others. Some participants, for example, mentioned the cultural rule that if one was bereaved, he or she should not attend other people's birthday parties, as the bad luck from bereavement was thought to "contaminate" other people's happiness. Participants also recalled instances of social ostracism they themselves experienced, where others actively avoided them or even things they had used, as a way to prevent from being affected by the bereaved's bad luck. This is evidenced in the following excerpt by Participant S:

When my friends were looking for a place to rent, they dared not to rent the place we used to live in. I felt.....they never told me directly, but I heard from

the grapevine that they said the house must be cursed, it must have bad feng shui, which caused my son's passing.....that's what they think about me.

Participant B described her friend's reaction upon hearing the news that a common friend of theirs was recently bereaved:

Participant B: Like this one time, we were playing mahjong with a group of friends. As we were playing, one of my friends got a phone call and was told that her father just passed away in Hong Kong. Initially we already made plans to go to another friend's house to play mahjong a few days after. This other friend waited till our bereaved friend went to the bathroom, and said to us, "She is now bereaved, tell her not to come to my house!" We said, "The death happened miles away!" She replied, "It's the same. It's her dad! It's a close family member." Then I replied, "Come to my place then, I'm not afraid."

Interviewer: What do you think caused this kind of thinking?

Participant B: She just believed that cos' this friend is now bereaved.....that it's bad luck to lose a family member. If the bereaved friend visits her house, she is bringing bad luck to her as well. When I asked everyone to come to my place instead, my friends immediately said, "You need to stop and think about this first. Aren't you worried that this friend will bring bad luck to you?" I replied, "I'm not afraid, ask her to come as well. Just come to my place instead if you guys don't mind. You just need to not be afraid of dogs cos' I have two." From that experience, I learned that there are people who really care about something like this, and that's why I seldom told them about my mom's passing. They don't like talking about it. Chinese actually have beliefs like this! I don't care about this, but it turns out that there are people who just really care. I was surprised that my friend would tell us that "you guys tell her that we're changing the meeting place. Don't ever let her come to my place."

Because of shame, fear of bad luck, and fear of offending and being rejected by one's social circle, participants noted the refusal of many Chinese to talk about death, as illustrated by Participant I's comment of "*The more we talk about it, the more we're contaminated by bad luck.*" There was also an element of magical thinking, as the participants explained the cultural belief that seeing, discussing, or even thinking about

anything related to death could trigger bad luck and **cause** death. This is evidenced in the following excerpt, where Participant S explained how she wondered if a random thought of hers had somehow caused her son's death:

One time when I was attending church, and I was talking to my son's psychiatrist friend.....we didn't go to church regularly at that time. We only went if there were important events. So my son's friend said to me, "Oh [Participant S's son] got married in this church. He was ordained as a minister in this church as well. Maybe the next time I see you is when [Participant S's son]'s first child is born." I didn't know why at the time, but at that moment, the word "funeral" suddenly popped into my head. I didn't know why. It really just popped into my head out of the blue. The word "funeral". The thought of "maybe next time it's for a funeral". But at the time my son was totally healthy!.....Did I put a curse on my own son because of the thought I had?

### **Taboo, Fear, and Avoidance**

When a mere thought can be considered a possible cause of death for someone, it is not difficult to understand why participants called death the ultimate taboo topic for many Chinese. Participants described the cultural belief that death was something no one should think about, let alone talking about. Given the magical thinking that "thinking or talking about death will cause death", the logic that follows is "not thinking or talking about death can prevent death." Refusal to talk about death among Chinese was perceived by the participants as a way to control the future occurrence of such a negative life event.

Participants also noted that Chinese had an intense fear towards death, as many said that Chinese are "*very, very afraid*" of death. Such fear leads to avoidance of anything related to death, even if remotely. What constitutes "death-related topics" is extensive: illness, the possibility of death in one's family or in other people, rituals such as funeral and grave visits, drafting one's will, purchasing life insurance, or even words and numbers that sound similar to the word "death". This fear is particularly pronounced in the older generation, as many will go to great lengths to avoid anything that reminds them of mortality. Participant M recalled how her deceased mother-in-law reacted towards the death of others in the family:

When my mom passed away and we took her ash back to Vancouver for burial, [my mother-in-law] was reluctant to visit her grave. She didn't say anything, but when we got there, she was silent the whole time. I didn't pay

attention at first but later I thought to myself "Maybe an elderly person like her was afraid?" Elderly people are often fearful of and in denial about death. So she actually didn't want to go.....she couldn't deal with others' passing.....we Chinese have those special festival days where people need to visit graves to pay their respect. But she never went to any one of them, ever. Not once. Initially I thought it was strange, but then I put two and two together and realized that elderly people do not want to mention the word "death". They do not want.....I think she's scared.

Participant W discussed how her mother reacted when arranging the funeral of her deceased father:

When my dad passed away, we were told that they could put the spouse's name on the headstone in advance; they just wouldn't put a date on it. My mom adamantly refused. She absolutely refused to put her name down. Chinese are just very scared of death.

Participants raised a number of concerns about the veil of secrecy and silence over death entrenched in Chinese culture. First, they noted that due to the avoidance of death-related topics, most people in the culture were not educated about matters related to death, grief and bereavement. Grief therefore is a foreign experience to many Chinese:

Oh it is definitely problematic. We seldom talk about grief and the period of mourning. We have no idea about grief. We have never had any contact with that. (Participant X)

After the death of a family member, many participants felt that they were unprepared for the ensuing practical issues such as funeral arrangements and settling the deceased's affairs. Participants also perceived that many Chinese would be confused by the emotions associated with bereavement. The intensity and duration of grief will take them by surprise. Many do not understand what constitutes "normal grief" and "abnormal grief", which leads to a number of misconceptions about ways to manage grief. For instance, some people may think that severe, intractable grief is normal and do not require treatment, or assume that grief is something trivial and transient that people will "get over" quickly after the death of a loved one. Lack of information and understanding on the nature of grief was perceived as a barrier to help seeking and accessing bereavement care services. Participant Q illustrated this in the following excerpt:

[Chinese families] really have no idea how bad it could be. They have no idea what grief is. A lot of people assume that they will be able to deal with it. A lot of people also assume that these emotional reactions are normal. For instance, let's say the father is dead. "Oh mom? She'll be fine! She just has too much free time on her hands. Just give her something to do." But is this what she really needs? That's just our assumptions about what she needs. We are giving her what we assume she needs. But is that really what she needs?

Participant W, who had been struggling with the death of her mother, discussed how the secrecy surrounding death negatively affected her ability to cope with subsequent losses in the family:

I'm worse off now since when my grandfather passed away, my family didn't deal with it well. That's why I think I have such an intense eruption of emotions now. I never learned the proper way to deal with this. At the time, they hid the news from me as I was studying abroad. I was very close to my grandpa. When I had to leave for school, the one person I missed the most and couldn't let go of was him. We lived together at the time. But when I was studying in the UK, they just covered the whole thing up without telling me. Whenever I called home and asked about him, they would tell me that he went out for mahjong. I finally knew about it when I went home for summer holiday.

When I finally visited his grave, people were like "that man had been dead for so long already; why are you still crying and acting so sad about it?" (Crying). So when I experience the same thing again now, I have no idea how to handle it. In addition, there's now an outburst of all these suppressed emotions and memories from before. That's why I feel that there needs to be appropriate services not just for adults, but for kids in the family as well. There's this assumption among Chinese that kids don't understand anyways and so there's no need to tell them. "Oh that person has gone to visit a place that's very far away". That's the kind of excuse they always use.

Second, participants also found the reluctance to discuss death in the culture had made advance planning of medical decisions and funeral arrangements impossible, as many in the older generation simply refused to talk about it. The young ones in the family cannot bring the topic up themselves as given the cultural principle of filial piety, young members need to completely defer to the elders in the family and avoid doing anything that will offend them. Participants who suffered the death of their parents or parents-in-law said that the conversation could not happen, unless the parents or in-laws initiated the conversation themselves. This is evidenced in the following excerpt from Participant V,

who was put in a very difficult position when her mother's health care team requested a discussion of end-of-life care with her mother. She had to educate the team on how to handle this delicate matter with the Chinese population:

Towards the end of my mom's life, when she was rapidly deteriorating, they told me "you need to talk to your mom about funeral arrangements. You need to discuss with her whether she would consider hospice care". For Westerners, for the mainstream Canadian culture, this kind of discussion is pretty ordinary. "So this is how death will look like.....", etc. etc. But I told them "Sorry....." Cos' at the time, they wanted my mom to sign the do-not-resuscitate order. I just knew that this would definitely touch a raw nerve in my mom. So I asked them not to talk to my mom about it for now. I explained to them that in our culture, she would not be able to accept something like this. I discussed with the nurses there about what we could say so that she wouldn't be so sensitive about it, while at the same time we could accomplish what we wanted to do (laughed).

### **Euphemism for Death**

The discussion of offensive and taboo topics such as death necessitates the use of euphemism among Chinese. Instead of saying "death" or "died" directly, participants used a number of indirect expressions of death in the Chinese language. Some of the expressions are similar to those used in the English language. For example, participants used "passing" and "passed away" ("*hui saai*" or "*guo sun*" in Cantonese, "*qu shi*" or "*guo shi*" in Mandarin) to substitute for "death" and "die" respectively. In addition, participants used various verbs that signified "departure" as euphemism for death, such as "gone" ("*hui jor*" in Cantonese, "*qu le*" in Mandarin) and "left" ("*jau jor*" in Cantonese, "*li kai*" in Mandarin). Expressions that were milder than "passing" such as "said goodbye" ("*gong bye*" in Cantonese), "vanished" ("*mo jor*" in Cantonese), or "no longer here" ("*ng hai dou*" in Cantonese) were commonly used as well. Some participants even used the very vague expressions of "*that thing*" and "*that incident*" ("*gor yeung yeah*" or "*gor gin si*" in Cantonese) to signify "death".

### **Communication Rules**

Participants identified a number of salient features that underlie communication styles in Chinese. The majority of participants described Chinese as "*conservative*", "*introverted*", "*reserved*", "*subtle*", and "*passive*" in communication styles.

**“We are conservative, introverted and reserved.”**

By “*conservative*” and “*introverted*”, participants meant that Chinese had a disinclination to talk in general. A common phrase used by many participants was “*we do not say things out loud*”. Participants noted that when Chinese talked, the topics tended to be shallow and impersonal. One participant explained that the reasons behind the reluctance to talk were twofold: 1) denial, and 2) concerns around social harmony, particularly the impact on others when one discloses something personal:

I feel that Chinese in general believe that if we don't talk about it, we can act as if it has never happened. That's how I feel anyways. It's like "if I don't talk about it, that means I don't know about it, and everything will be fine". Or we may think "oh if I bring it up, I'll make you sad, which will make things worse". (Participant N)

A number of participants readily used “Westerners” or “Caucasians” as a comparison group, in order to illustrate that Chinese were “less likely to talk”:

Well to me, Westerners are more open and they will talk about anything and everything. We Chinese are more conservative. We seldom.....well there are things that we will just hide in our hearts and we won't dig them up to talk about them. (Participant C)

I think the sadness felt by Chinese cannot be easily expressed, verbally, by them. I think Caucasians will readily talk about their emotions fluently, without hesitation. They will say anything and everything in their heart. (Participant D)

We are just more reserved and subtle. We don't want our good experiences to be shared everywhere, let alone bad ones. This is very different from Westerners. (Participant K)

The significance of cross-cultural comparisons between oneself and “Westerners” will be further discussed in the section on *Being an Immigrant in a Foreign Land*.

Participants used the adjective “*reserved*” to describe the need for Chinese to maintain a clear and firm boundary between “public matters”, which tended to be superficial topics that were limited in scope and fit for conversation, and “private matters”, which was defined as anything personal or family-related. Private matters must be hidden from view. Participant U put it succinctly: “*for Chinese, we often keep to ourselves and try*

*our best not to let others know about our private matters.*” Participant X noted that one needed to “*pry open the mouths of Chinese*” in order to get them to talk about private matters with others.

It is interesting to note that a number of participants used the phrases “*digging it up*” or “*taking it back out*” to describe the act of speaking. To the participants, talking is a deliberate act of unearthing these “private matters” and revealing to others something buried deep within themselves. As a result, they perceived that Chinese would need more time than “Westerners” to warm up, before being able to share anything slightly personal with others. Participant A, who had been under the care of a number of physicians and mental health professionals for many years, still said the following about her current encounters with health care professionals:

I’m not someone that would openly tell others about my private matters. I always hide my private matters from others. It’s not easy for me to open up and share. So I seldom tell my doctor these things.

This was echoed by other participants. Participant W, for example, described the fear and discomfort a lot of Chinese would feel when the conversation went beyond skin deep and started to tap into “private matters”:

I think Chinese.....are afraid of airing all their private matters to outsiders. That's why they hide everything. That's why people who provide [bereavement] services will need to be very tactful. They can't keep digging and exposing everything in order to talk about them. They need to take into account the fact that Chinese may not want to go so in-depth in their discussion.

According to the participants, emotions and negative life events such as the death of a family member are some of the “private matters” to hide, to keep secret and to bury deep in one’s heart. A participant recalled her shock when she uncovered her mother’s diaries after her death, in which her mother documented her own grief when her husband (the participant’s father) passed away 20 years before:

So my sister found those diaries. It was when we read the diaries that it suddenly dawned on us that our mom had been unhappy all these years. My mom started keeping a diary after my dad passed away. Of course she would be sad [over her husband’s death], just like how we’re feeling now. I think that after my dad’s passing my mom has been.....well she lost 20



pounds. I now realize how hurt she was by her loss. But there wasn't anything we could do to help her when she was alive, since we never knew how she felt. She was reserved. She kept it all inside and would never talk about it. So she chose to write about them in her diary. When she wrote, she poured all her sad emotions into it. (Participant B)

Participant M echoed this as she saw how her husband reacted when someone tried to talk to him about his emotions:

I am going to a potluck dinner tonight with my church fellowship group for married couples. It'll be our turn to lead the opening prayer tonight, but my husband refuses to do it. He can have casual, light-hearted conversations with anyone, but if you want to dig deeper or if the conversation involves exposing his inner emotions, he will clam up and refuse to talk.

Participants observed that open discussion of negative life experiences and emotions was a foreign experience to a lot of Chinese for a number of reasons. First, participants used the word "embarrassing" to describe the disclosure of negative emotions to others. They noted that negative life experiences and emotions were seen as personal failures. Yet personal failures never pertain only to the individual according to Chinese cultural norms; they are believed to bring shame to both the individual **and** one's family. Shame then leads to a loss of "face", defined as dignity, reputation, and public image as perceived by others, for both the individual and his or her family. There is a significant fear of being negatively judged by others. As a result, there is the cultural belief that one should only discuss positive news with others, while anything negative had to be hidden, as a way to maintain "face", manage their external image, and avoid bringing shame to themselves and their families. This is evidenced in the following excerpt from Participant B, talking about how she kept her silence over negative life experiences (such as her divorce and the death of her mother) in general:

Throughout my life I have never taken the initiative to talk to people about stuff like this. Like the suffering I endured before my divorce, I never told anyone about it. My sons were so shocked to finally learn that I was so saddened by my mom's death, because I never told them anything all this time. I maintained a happy persona, never complained, never acted unhappy. Even if I was suffering a lot inside, I didn't tell anyone.

Second, participants suggested that Chinese often struggled with alexithymia, or the inability to identify and describe emotions. The act of translating one's inner, abstract

emotions into words is difficult for many Chinese, as they do not have the vocabulary to identify and describe them. This further discourages the discussion of emotions with others. Participant H used the Chinese idiom of “*pens and ink are incapable of describing it*” to describe the challenge of verbal communication of grief. “*Pens*” and “*ink*” are metaphors for “words”; the idiom means “there are simply no words to describe it”. The following excerpts illustrate these struggles:

I really feel that Chinese, as an ethnic group, do not know how to express ourselves. If a professional is not there to guide them, they really do not know how to express their emotions. (Participant B)

[Chinese] would also need more time in order to organize what they want to say. (Participant E)

I also felt that there were a lot of things that I couldn't describe clearly or could elaborate on. (Participant I)

It's very hard to explain these feelings.....even if I want to say it I don't know how to express it. I have no idea what to say.....I really don't know what to say. I really don't know. (Participant K)

Chinese people avoid talking about anything that is emotionally laden. We don't talk about it, because we don't know how to translate it into words. (Participant Q)

It's also something that is difficult to open up to talk about.....it's still something that's sad. Some people really don't know how to put it into words and tell others about it. This is especially true for Chinese as we tend to be more introverted and keep it all inside. (Participant V)

When one's culture postulates that emotions are something to hide, it implies that showing interest in or talking about someone else's emotions will be seen as a violation of interpersonal boundaries. People also become uncomfortable when others discuss their emotional experiences. This negatively impacts the kind of support one can receive from others in response to negative life events. Participant M, who worked as a mental health professional in her country of origin, recalled the responses from her friends when she told them that her mother-in-law had passed away:

All my friends did was to tell me to support my husband and my son! That was it. They then refused to talk about it, and they never brought it up themselves again. I mean.....how does one even bring that topic up? It's

very difficult.....and I think it's related to our culture. Chinese will never directly ask someone "Are you feeling sad?" It's very difficult.

Participant Q described how she used to feel about the bereaved's expression of emotions before she experienced her own loss:

Of course you're supposed to cry in private. People get annoyed if they see you cry in public. As a bystander I may think to myself "do you really need to cry so vigorously? It's just your dad who died!" Honestly this is the way I think before. In the past I had a client who just lost her father. Every time she talked about him, she cried. At that time I thought to myself "wow do you really need to overreact?" But when it was my turn to experience it, I understood how it felt. But then at times I would blame myself for "over-reacting", "do you really need to tell everyone that you're struggling with this?"

Participant Q went on to compare how her Chinese and Caucasian clients reacted differently when she talked to them about her father's death:

For instance, I'm still working and all my clients know about my dad as he had been sick for so long. Whenever I talk about him I will start crying. My Caucasian clients will then give me a hug. But I don't think Chinese will offer this kind of support through a physical act. My Chinese clients immediately shut up when they see my cry. They dare not bring up the topic when they see me the next time.

**“We are subtle.”**

By “*subtle*”, participants described the cultural rule that if communication of private matters (such as emotions, desires and affection) were to occur, it could not be done overtly. One's intended message cannot be expressed directly; rather it is implied and usually encoded in actions rather than words, and it is up to others to infer the true meaning hidden behind the code. An example participants often used to illustrate Chinese “subtlety” was the expression of affection towards family members. Participant E, for example, moved to Canada when she was in junior high and had lived in Canada for 25 years at the time of the interview. When asked about how affection was communicated in her family, she responded that she did it differently for different family members, depending on their level of acculturation:

I think for us Chinese, we seldom say "I love you" out loud. I'll say that to my children, but it is only because they are more westernized. For my other family members, I will show it, but I won't say it. (Participant E)

The cultural emphasis on covert, indirect expression of affection, however, had led to regret and guilt in a number of participants after the death of their family members. They lamented over lost opportunities to directly tell the deceased how much they loved them, but at the same time felt that they were forbidden to do so by their cultural grammar. Participant S lost her adult son to cancer and provided the following description of her regret:

After he left (euphemism for "died"), I realized that there was so much that I didn't say to him. Towards the end, when he had further deteriorated, he couldn't even speak anymore. He.....(started sobbing).....at the time he told his sister that he wished we could have praised him more. (Crying) But we Chinese.....I don't know why.....even when he did a good job, I didn't know how to praise him.

Participant B was coping with the death of her mother. When reflecting upon her relationship with her parents (both deceased at the time of the interview), she responded with the following excerpt – the number of negative words ("*not*") and modal verbs of ability ("*cannot*") and obligation ("*must*") the participant used in her response clearly demonstrates the prescriptive nature of "being subtle" in the Chinese culture; it is a rule that no one could disobey:

.....There are certain things we must avoid. Westerners' parent-child relationship is just not the same as the parent-child relationship in Chinese. Our relationship with our parents is way more subtle and reserved. We don't show it. We never say it in words. We are not used to that. It's not the same for them. They (meaning "Westerners") would probably ask, "Well why didn't you say 'I love you' to your parents? What's wrong with saying that? If you have said that out loud, everything would have been fine and you won't feel the regret." But this is not something we can do! I have never hugged my parents. This is not allowed. We cannot do it. Then they may ask, "Why can't you hug your parents? Of course you can hug your parents!" We just can't hug! You can't do it. You can't put it into words too! Like telling your dad "I love you"? We can't do it!

Since private matters cannot be directly communicated in the Chinese culture, participants recognized the incongruence between their outward appearance and their inner emotional experiences. They expressed the cultural pressure of putting up a façade

to show others that they were fine, despite their inner struggles with strongly negative emotions. What is worse, they perceived and **expected** that everyone else in the Chinese culture would do the same thing – that everyone’s overt behaviours and verbal expression would never truly reflect their thoughts and feelings. This results in the cultural practice of “*zhih-yi*”, which meant “knowing others’ true intention without them saying it out loud”. The ability to “read between the lines” is considered a virtue, an essential interpersonal skill, and a sign of personal maturity in the Chinese culture. According to the participants, interpersonal communication in the Chinese culture is largely a mind-reading exercise, where one has to ignore the superficial when inferring the true meaning behind others’ action. The inference is **not** made based on what was explicitly said or done; people know that they cannot take things at face value, as “yes” may mean “no” while “no” may mean “maybe”. Rather the inference is based on nonverbal communication (such as facial expressions), one’s personal knowledge of the other person in the social interaction, as well as the cultural knowledge of what a certain action means in the Chinese culture. A participant illustrated this with the following excerpt, when she was recalling her deceased mother’s experience in the hospice and the confusion the Chinese cultural grammar of “subtlety” had caused in her interactions with health care professionals:

The discussion with my mother around the do-not-resuscitate order got very complicated. We had to find a family friend who was a doctor, who could speak Chinese.....but it was very convoluted. I wasn't involved in that, but the way the doctor friend put it – it was a very convoluted discussion. It wasn't a direct discussion at all. But Westerners are way more open when it comes to having frank and open discussions on something like this. My mom.....I think it's something that Chinese typically do.....even though she doesn't like something, she will still stay silent (laughed). But Canadians will think "if you didn't say anything to oppose it, that means you are agreeing to it."

When my mom was in the hospital, the doctor wanted to use morphine. I looked at my mom and she had an upset look on her face. The doctor asked her "are you OK with this?". She replied "yeah OK". After the doctor had left, I asked her "are you really OK with this mom? How do you really feel?". She then replied "it's useless, it's still the same even after the injection." I then said "why didn't you say something if you actually don't want it?", but she again kept her silence and didn't answer me. In the end it was up to me to.....I ended up being her spokesperson. I was educated in Canada, but at the same time I understand how Chinese think. I know that if you don't say something, people here will just assume that you're OK with it, as Westerners tend to wear their hearts on their sleeves and vocalize everything. You need to speak your mind. But Chinese will never do that.

It's a cultural difference. But Westerners won't understand this. (Participant V)

Given the covert nature of emotions, desires and affection, their direct disclosure can be a very powerful experience for a lot of Chinese. Participant J broke down in tears and was inconsolable when recalling this interaction with his father:

When I was young I wasn't close to my father. He was a strict dad. He would spank me. But as I grew older, I had a better understanding of why he did it – he probably learned it from his own parents. Ever since I moved to Canada to pursue my education, I began to have a better appreciation of how he truly felt. I have a few examples. After finishing my first year in undergrad, I went back to Hong Kong during the summer break. My dad asked me to come to his bed and said to me – and he called me by my nickname – he said, "You're all grown up now, [Participant J's nickname]. You need to remember.....you're by yourself in Canada. You need to tell us how you're doing; don't keep it inside. Write to us. Tell us how you're doing." He said to me "even though I'm your daddy, I'm also your friend." (began to tear up and become emotional)

.....Sorry (sobbing, paused for 10 seconds). Yeah.....(too emotional to speak, stuttered) Uh.....uh.....(16 seconds later) I would never forget this moment. Never. I had never heard anything like that from him before. Another thing is – and this is what my mom told me – when I first moved to Canada, I went to live with my cousin in Kingston. My dad didn't want me to come by myself, so he came to Canada together with me. My mom later told me, "After daddy came back from Canada, every time he went somewhere, he would say to me 'I was here with [Participant J] just a few weeks ago.' He would cry after saying that, and I haven't seen your dad cry for years".

### **“We are passive.”**

By “*passive*”, the participants were alluding to the cultural grammar that Chinese would not take the initiative to assert their needs and wants and to ask for help. The notion of “passivity” and the notion of “subtlety” discussed above are highly related. “Subtlety” pertains to the practice of concealing one’s intention, needs and emotions. “Passivity” pertains to the lack of initiative, and the wait for others to read their minds and offer what they want without being asked.

Participants noted that in a social encounter, the onus fell on others to decipher what they wanted and meet their needs accordingly. This lack of personal agency to

advocate for one's welfare and to make one's needs known has significant implication for help-seeking behaviours among Chinese. Participants bluntly stated that "*there is no way Chinese will take the initiative to seek help*". They noted that there was a cultural expectation that help was not something to be asked for; others (such as health care professionals) needed to take the initiative to approach them, to explicitly tell them that they need help, and to offer help without being asked, as illustrated in the following excerpt:

Even if such services are offered, if no one tells us that we need to.....that we should receive help, that they can help us deal with these feelings, we will not take the initiative to seek services.....to actively look up ways to help ourselves solve these problems. (Participant K)

### ***Relationships Rules: Family vs "Outsiders"***

Participants described a hierarchy of interpersonal relationships consisting of two levels in general: family and "outsiders". There is a clear and impermeable boundary between these two levels of relationships; anyone who is not family by blood or by marriage is considered "outsiders". This includes close friends who may have known the participants well, and health care professionals. Relationship quality, closeness and intimacy are not the sole determinants of someone's ranking in the relationship hierarchy; in fact sometimes they are only secondary factors. Instead, consanguinity, age, family or social status, seniority, and power dynamics play a more important role. According to the participants, different levels in the relationship hierarchy call for different rules of social interaction, particularly around what one is allowed to say or what one is supposed to do.

#### **Family**

Family ranks the highest in the hierarchy of relationship among Chinese. Family relationship rule interacts with the communication rule over non-disclosure of "private matters" as follows: discussion of "private matters" should not occur in general, but if social sharing of one's "private matters" were to occur, it should be kept within one's family. What is going on within one's family, such as the death of a family member, falls within the realm of "private matters". Open discussion of such matters should therefore be reserved for family members only.

When asked to explain why only family members should be involved in such a discussion, participants first noted that family relationships were “*closer*” and that “*talking to family is simply better*”. When asked to elaborate, participants reported that 1) family members often shared a long history of living together, which helped establish a common context for family members to understand these “private matters” more easily, and 2) more importantly, family members had the **obligation** to care about another member’s private matters. This obligation makes family members feel that these private matters are **personally relevant**. Participant R explained the difference between talking to friends versus talking to her siblings regarding the death of her father in the following excerpt:

Participant R: With friends, [my discussion with them] is always superficial and nonchalant. But with my siblings, I can talk about things that are deeper and more personal, for instance my mom’s struggles, or my dad’s struggles. With friends, however, even if I were to tell them this, they might not understand it, nor would they have the same kind of patience to listen to you.....They also don’t have the obligation to sit there and listen. For siblings, however, even when we are just having a casual chat, I can still bring these problems up and talk about them. We can brainstorm ways to help my mom, or we can make plans to visit my dad’s grave.

Interviewer: What makes you think that your friends will have no patience for your stories?

Participant R: What makes you think that friends will have the patience to listen to your stories? It is none of their business as they’re not involved. All friends can do is to show that they care, such as checking in with you to see how you’re doing, but they will not go beyond that. Even if they’re willing to listen, as you keep talking, you’ll feel like you shouldn’t talk more. It’s my family’s issue, so they do not want to get involved in that. They can’t do anything to help me either. That’s why there’s no need to talk about it. Talking to friends is not helpful as it’s very superficial. I can share more with my siblings. Even though we are all married and have our own immediate families, we share the same parents. They are OUR parents. We bear the responsibility. For instance, when my dad left, all of us needed to go back in order to send him off (meaning “holding the funeral”). Friends.....all they would do is to “come bow and leave” (meaning “paying respect at the funeral”). That’s the difference. It’s not that friends don’t care. They’ll ask about it, but will stay superficial.



Even within the realm of familial relationships, certain relationships rank higher than others. Blood relations trump all other family relationships, including relationships by marriage, step relationships, and kinship by adoption. Participants often used the phrase “*one step removed*” to describe those family members who were not related by blood. Participants noted the cultural belief that the “appropriate” amount of grief one should feel towards the death of a family member depended on the **types of kinship** one had with the deceased family member, not the **quality** of the relationship. This means that according to the culture, only those who share a blood relationship should feel tremendous grief towards the loss. Even if one had shared a close, highly positive relationship with the deceased family member, he or she still should not feel as much grief if the relationship is not consanguineous. Participant B explained it succinctly: “*If you’re one step removed in terms of the types of relationship, your emotions should be one step removed as well.*” This has significant implication for how someone’s grief will be judged by others in his or her social network. Participant A, for example, reported a close relationship with her deceased father-in-law. They lived under the same roof for over 20 years. She experienced tremendous grief after the passing of her father-in-law, but received little to no support from others in the family. In fact, her sincerity was doubted and questioned by others, because she was “*just a daughter-in-law*”:

I understand that, that everyone will eventually reach death, but the feeling is different for me. My husband, for instance, did not have a lot of interaction with his father even though they lived together. My husband had to work, and when he got home from work, my father-in-law would be in bed already. In my case, however, I was always home and spending time together with him. We cooked together, we grocery shopped together, he would share with me his unhappiness. He treated me as his own daughter and I treated him as my own father, not a father-in-law. But when I told others about this, even my husband, everyone doubted me. They would doubt if I’m really this heartbroken over this death, if I’m really this sad.....they just don’t understand, but my feelings are real.

This was echoed by Participant T, who lost her adopted son:

I mean, the deceased was my adopted son – yes he was adopted, but we were very close. I actually considered him to be my biological son. Sometimes.....not a lot of friends knew about this, but at the beginning when I was in such a terrible mood, I did disclose it to my friends. Some of my friends said to me “that’s just your adopted son, why would you cry over him?”

One of the most common phrases participants used to describe the nature of family relationship was “*fulfilling my duty*”. Everyone has a role to play in the family. Performing all the jobs entailed in the familial role is one’s priority in life, and is the yardstick against which one would be socially judged by others. This is particularly evident in parent-child relationships, in which filial piety was seen as the core duty by the participants. Filial piety is usually generally understood as “respect for one’s parents and elders”, but it actually means much more than that in the Chinese culture. According to the participants, filial piety entails 1) complete obedience and submission to their parents and elders, 2) acting as a caregiver to aging parents financially, instrumentally and emotionally in order to repay the “debt” to their parents for the sacrifices parents made when raising children, and 3) producing a male heir to carry on the family lineage.

Perception of their failure to fulfill the duty of filial piety often led to tremendous guilt on the part of the participants, as well as negative social judgment, blame and ostracism by others. A few examples could illustrate this. Participant B’s mother passed away in Hong Kong. Much of Participant B’s grief consisted of guilt of being “unfilial” because she failed to “repay the debt” to her mother:

For myself, of course I couldn’t let her go. (Crying) I couldn’t let her go. I was the oldest in the family. For the past 10 plus years, I felt that I didn’t have much chance of taking care of her because I live in Canada. In contrast, she took good care of us in the past. She even helped take care of my kids when they were born. I felt that.....I can be considered as not filial.

Participant L lost her young son to cancer. She explained the importance of sons in Chinese families:

I think for Chinese families, sons are particularly important. My eldest son is gone, and he's the eldest son in both sides of the family.....lots of people in Chinese families, when they lose a child, especially a son.....for instance my aunt has 3 daughters but no son. That makes her life a living hell. She pretends to be fine in front of outsiders, but in front of family, she loves yelling at her daughters.

Participant W reported that her mother had abused her since childhood. She had been estranged from her mother for 7 years when her mother passed away:

For instance, my refusal to go back to Hong Kong to take care of my mom is considered a "mortal sin" in the eyes of others. "You rebellious, disobedient, unfilial daughter who has betrayed your mom!" – this is what they call me – "Your mom's sick don't you know?" My sister, her friends, all the relatives.....they all think that way about me. They believe that since I am single and living here by myself, why didn't I rush back to Hong Kong to take care of my mom, so that it wouldn't be such a burden on my sister?.....Chinese will think "no matter what, she's your mom. No matter how she treated you before, you still MUST go back to take care of her."

### **“Outsiders”**

Participants used a number of Chinese terms to call “outsiders” – “*mak sang yan*” in Cantonese or “*mo sheng ren*” in Mandarin, which mean “strangers”; “*oi yan*” in Cantonese or “*wai ren*” in Mandarin, which mean “outside people”; and “*gaai oi yan*” in Cantonese, which literally means “people from the street outside”. It is interesting to note that the same terms were used to describe both the people that were unknown to the participants (i.e., the real “strangers”), as well as the people known to the participants but were not family, such as friends and health care professionals. These terms clearly illustrate how distant non-family relationships are perceived in the Chinese culture.

It is therefore not difficult to understand that in the Chinese culture, discussion on “private matters”, such as emotional experiences and family matters, with people outside one’s family is strictly prohibited. The need to keep one’s silence is even more prominent when the “private matter” involves something perceived as shameful, such as the death of a family member. A number of participants used the Chinese idiom of “*news about shameful things in one’s family must be kept within the family and should not spread to outsiders*” to describe their reluctance to talk about their grief with others. Participants considered the reluctance to open up to non-family a barrier to accessing bereavement care services for many Chinese. Participant B, for example, recalled her own discomfort when she first entered therapy and had to discuss her grief with a health care professional:

Well cos’ you’re in front of a stranger. Chinese are not used to sharing their deepest thoughts and feelings with a stranger. We won’t share anything in depth with a stranger.

Participant F concurred:

Well some people really don't like sharing their feelings with others. I think this is a barrier. A lot of Chinese people don't like telling others their "family affairs". They see it as a taboo. They think it is shameful to disclose family-related matters to outsiders. I think this is a belief that's been passed down from a long time ago, the belief that you should only tell others good things, but hide bad things deep within you. Even if you tell these people that here are the services and ways to access them, they may not even want to participate because they don't want to tell outsiders so much about themselves.....Like they would often say "oh it's a family matter, it's within my family, so I don't want to tell outsiders about this".

Moreover, participants noted that the clear and firm boundary between "insiders" (i.e., self and family) and "outsiders" suggested that "outsiders" had no obligation to help them with their "private matters". Participant Q, for example, explained what a typical Chinese would think about other people's bereavement as follows:

I have lots of Caucasian clients that are willing to listen. They will say "I'm so sorry". You feel that they care. But Chinese will think "Yeah your dad has died, but that's your own problem. You still need to come to work. You'd better make sure that you don't show up for work with grief on your face".

A number of participants replied with "*I never expected others to help me with anything*" and "*others have no responsibility to take care of us*" when asked about their perception towards "outside" help, such as help from friends or professionals: Participants believed that seeking help from outsiders was selfish, as this would be seen as "*bothering others with my personal problems*":

No one has an obligation to help me. I never expected others to help me with anything. When I have no expectation on others I won't feel disappointed. (Participant B)

I think everyone has his or her own problem. No one will easily offer you help with no strings attached. Everyone is busy. We only have 24 hours in a day.....unless it's someone who's very close to you, who sees that you're not doing well, who is kind-hearted.....only then will these people take time out of their busy schedule to help you. That's reality. (Participant G)

As a result, maintaining an impression of personal fortitude and turning down offers of outside help are considered socially appropriate in the Chinese culture. Participant E, for example, made the following observation:

For Chinese, they'll often tell you "I don't need help, I'm fine, I can handle this, I have no problem" even when the world is collapsing behind them.

The cultural expectation that one should "bear his or her own cross" (i.e., resolve his or her own problem instead of relying on the help of others) breeds a strong sense of self-reliance among the participants. They firmly believed that outside help was unnecessary if they could deal with their grief by their own effort. Receiving help from others implies dependence and irresponsibility:

I want to try to resolve it myself first. I don't know if others feel this way as well. My thought is that if I can handle it myself, it's better not to bother others with my own problems. (Participant A)

I don't think there was anyone that I would consider "not helpful to me", since I don't think that you should rely on others for everything. (Participant M)

I just believe that if I can work through it myself, I shouldn't rely on others. I should just do it myself. It's the belief that if I can handle it myself, I should just handle it myself. (Participant T)

The government has no responsibility to take care of us. You can't keep criticizing the government for not doing enough. If you are capable of doing it yourself, you need to do it yourself first. (Participant H, regarding how she felt about bereavement services provided by the health care system)

### ***Culturally Sanctioned Coping Strategies for Bereavement***

When reflecting upon the Chinese cultural grammar surrounding how one should manage grief, participants reported that three coping strategies were deemed "culturally appropriate": rationalization of death, trivialization of emotions, and suppression of negative thoughts and emotions towards death.

#### **Rationalization of Death**

Participants offered two common ways Chinese use to justify the death of a loved one: attributing it to fate and destiny, and taking solace in the fact that the deceased had a "good death".

## Fatalistic View on Death

A pervasive theme in how participants explained and perceived death was the rationalization of death as a result of fate and destiny. A number of participants alluded to the concept of “heaven” (“*tin*” in Cantonese; “*tian*” in Mandarin), the core of Chinese folk religion. The meaning of “heaven” in the Chinese culture is different from that in western, Judeo-Christian cultures. “Heaven” according to Chinese is not a physical place someone goes to after death. Instead it is a deity, or a higher power, that governs the human world, decides what is moral and just, and determines everyone’s destiny. “Heaven” embodies the Taoist concept of “Tao” – the natural order of the universe. Chinese believe that a person’s life is already pre-programmed by “Heaven” the moment a person was born; the program then becomes the person’s “destiny”. What life has in store for that person however remains unknown until it happens. There is an interesting, dialectical relationship between personal agency and fate, as demonstrated by the following:

If heaven decides to play cruel tricks on you.....if heaven decides that someone has to leave, no matter how hard you try, you can't stop him / her from leaving. I would try hard, I won't sit there doing nothing. I would try my best to fulfill my duty – Through this I learn that I need to try my very best, I need to do my job diligently. If that still can't change the outcome, then we'll have to accept that. (Participant I)

The quote above suggests that there is a possibility for humans to change the course of their destiny. The only way to achieve this is by “doing good” – fulfilling one’s duty and role to the best of his or her ability. However, this still does not guarantee that a change can be effected, as “heaven” holds the ultimate decision-making power over one’s destiny. To illustrate this, participants referred to two Chinese sayings commonly used to describe the divine power of “Heaven” and fate over death: “*Matters of life and death are controlled by heaven’s will on one’s destiny*” (“*saang sei yau ming*” in Cantonese; “*sheng si you ming*” in Mandarin), and “*humans’ plans and predictions can never compete with heaven’s plans and predictions*” (“*yan suen but yu tin suen*” in Cantonese).

Attributing death to an unpredictable and uncontrollable force bigger than oneself helps the bereaved justify death as an immutable fact. Participant I used a tautology to illustrate this: “*Nothing you can do – if a person has to pass away, he or she has to pass away.*” This helps absorb the feeling of guilt, as it allows the bereaved to feel that they had

already done their best, and there was nothing more they could have done to prevent death's occurrence. Since death is already predetermined, it implies that the bereaved should cope with death by accepting reality and their own futility in changing fate. This is evidenced in the following excerpt by Participant I:

Never see it as your fault. Heaven has already determined your destiny. Everyone's road of life is already pre-set. Good fortune throughout one's life is not guaranteed. It's really just bad luck that this person got picked [to experience death]. Even in a class you'll have someone ranking first, and someone ranking last – the one ranking last is really just having bad luck. If he passes away, he passes away. There's nothing you can do. If he has to leave, no one can make him stay, right? If bad luck suddenly strikes me and I have to die, there's nothing I can do.

This was echoed by a number of participants:

I learned not to blame myself too much for this, and to accept reality. To accept that something like this is destined to happen. Everyone has his / her own fate. Maybe this is his fate. Even if I made other choices and did other things, the same outcome would have happened. It's inevitable. (Participant T)

In my father-in-law's situation, he passed away due to a brain aneurysm when he was driving home from work. We weren't prepared at all. My husband.....he appeared so calm, so calm that I was actually afraid. I asked him why he could be so calm. His outlook on life is so different from me though. He felt that he has no regret whatsoever. He felt that if it's part of destiny, you cannot avoid it. (Participant N)

### **The Concept of “Good Death”**

In addition to rationalizing death using the concept of fate, participants also reported that Chinese coped better if they knew that the deceased had had a “good death”. According to the participants, “good death” is defined by the Chinese culture as a death that occurs at old age (age 70 and above), and at a time when the person feels that he or she has completely fulfilled all of his or her duties and roles in life. In fact, a death that occurs during old age is called “*happy loss*” in Chinese (“*siu song*” or “*hey song*” in Cantonese, with “*siu*” meaning “laughing” and “*hey*” meaning “happiness”). In a “*happy loss*”, the bereaved are told that they need not feel or show any grief towards the deceased's passing. Participant P, whose mother passed away at the age of 86 (and her

death considered a “*happy loss*”), recalled his mixed feelings when he heard the following “words of comfort” from his family physician:

Even the family doctor said "oh your mom earned the extra years as a bonus already, as women usually pass away at age 80, and men at 75". Even he said that. I don't think he should have said that. Stuff like that they said.....I found it disgusting, but on the other hand I found comfort in it too, as in "right, my mom did live a long life".

With regards to circumstances surrounding death, a “good death” is one that happens quickly without the turmoil of chronic illness beforehand, such as dying in one’s sleep. In the case of death due to life-threatening illnesses, a “good death” is one that happens peacefully and comfortably with little pain and suffering, and brings relief not only to the deceased but also to the rest of the family. The death should also occur when every member of the family is present at one’s deathbed at the time of death. “Good death” is seen as a sign of good fortune and a reward for good deeds done in one’s current or past lives.

When asked to explain the significance of “good death” in helping Chinese cope with their loss, Participant M, whose mother-in-law passed away due to a sudden stroke, said:

You know to Chinese people, a quick departure is actually a sign of good fortune and a blessing. So when we notified our friends and family [of her death], their first reaction was sadness, but the second reaction was always "Oh that's actually very fortunate – I want to leave that way as well". There was no suffering, and even if there was suffering, it ended within 24 hours..... cos' our culture told us that "to die this way is very comfortable and is a blessing", I never felt the need to cry my eyes out or to feel very sad about it.

Participant M went on to explain how a “good death” benefits both the individual and the collective, in this case the family:

After her passing, a few of our relatives passed away as well. I saw how they truly suffered towards the end of their lives – not only they suffered, their family suffered too. For instance, a family member suffered a fall and was sent to an extended care facility. Each time I visited her, I could see her deteriorating even more, not just physically but mentally as well. I think she just lost the will to live since the illness has dragged on for too long. She lost interest in everything – eating, watching TV, socializing. Her two



sons took turns to take care of her since she didn't speak English. It became torturous to them as well. It's like you don't even know when it will end.

My mother-in-law was spared this painful process. She never needed to experience that emotional turmoil of getting angry or asking herself "why me?" Even that relative (who was sick and dying) said to me "I envy your mother-in-law – she left just like that", implying that she was just there waiting to die. Not only she was suffering, she had to witness the suffering of her two sons. Seeing something like this, and then looking back at what happened to my mother-in-law, I believe more firmly that my mother-in-law was blessed. Not just she was blessed – we were blessed too.

To be brutally honest, when you are already past that stage where you grieve and say all the things you wanna say to each other, but the person still survives – he / she becomes a burden. You have to take care of that person every day. You witness how that person deteriorates. It's like everyone is just waiting for the final moment to arrive. When death comes, it becomes a relief to both the dead and the survivors. That's why everyone kept saying that my mother-in-law was blessed. She wasn't very unhealthy. We never needed to take on any caregiving burden. My own siblings live here as well and they all miss my mother-in-law, but they keep saying that my mother-in-law had good fortune. It's a reward for her great behaviours in her past lives.

### **Trivialization of Emotions**

A pervasive theme in the participants' account of the assumptions most Chinese people hold regarding grief is the trivialization of negative emotions. Trivialization of emotions occurs in three different dimensions: intensity, duration, and purpose.

Participants described the cultural expectation that grief should be mild in intensity and short in duration. There is a belief that since death occurs to everybody and is a normal part of the life cycle, a typical human experience should not trigger severe emotional distress in anyone. The feeling of grief is expected to subside shortly after the death of a family member. It is also assumed that everyone always returns to the normal, baseline level of functioning after the death of a family member as "time heals all wounds". The cultural emphasis on practicality and utility further suggests that there is "no point" to grieve. Grief is perceived to be "useless" and "unnecessary" as it will not change the past and the reality that the family member is already dead. Intense, lingering emotional turmoil over the death of a loved one is therefore considered immature and even pathological.

Participants discovered these beliefs by observing how others reacted when they found out that the participants were grieving:

Everyone said, "It's been a thing in the past, you should let this go, death is something that everyone will experience".....soon after one's death, a lot of things should be put away, and the feelings should subside. (Participant A)

That's how [my husband] looked at it – "What's wrong with you guys? Time should heal all wounds and you guys should be fine now. I know you were close to your mom and you sisters have good relationships, but it's already a fact (that her mom has passed away). What's past is the past already." (Participant B)

Chinese will think that they do not need bereavement care services. They'll think "well time heals all wounds. Everything will return to normal after a period of time, so there's no need for support services".....that it'll naturally return to normal, that death is something that's bound to happen to everyone. They don't think that grief is something that deserves special attention. (Participant C)

As emotions are considered frivolous in the Chinese culture, a number of participants suspected that many Chinese immigrants would be skeptical towards the purpose, efficacy and utility of any health care services that focus on the discussion and release of emotions, something that bereavement care services often entail:

Chinese will think that there's no point talking about it – it's not like the deceased will be reborn after they talk about how they feel, and the funeral rituals are over already. They will not understand the purpose of support services. If it's for emotional support – they will wonder "how could this lead to relief of my feelings?" They will question "does crying really make me feel better?" (Participant M)

Chinese families will think "how would talking about it be helpful to me in a pragmatic way? You can't help me from a financial standpoint. You can't help me with the money for the funeral." If you tell them that this program is for providing them with financial assistance for the funeral, they will show up. If you're just simply providing emotional relief, how much of an impact will that truly make? (Participant P)

I feel that what these services could offer would only be psychological.....it's just to talk to you. We already got help on funeral arrangements. So it's basically just to talk about it. (Participant S)

## Emotional and Thought Suppression

According to the participants, the goal of bereavement as defined in the Chinese culture is to “*accept reality, let it go and get over it*”. The cultural belief that emotions are trivial leads to the assumption that controlling negative thoughts and feelings should be easy, as if they can be turned off by the flick of a switch. Emotional and thought suppression are therefore regarded as highly effective coping strategies according to the Chinese culture. Almost all of the participants had been told that the solutions to their grief were “*just don’t think about it*”, “*don’t feel sad*”, “*there is no point feeling sad*”, “*just cheer up*”, “*just find something else to do*”, and “*curb your sorrow and go with the flow*”. Coping success is defined as a lack of emotional arousal towards the family member’s death. Stoicism and the ability to suppress and control one’s emotions in the face of loss signify personal strength. Participant I, who lost her young son to cancer, took pride in herself and her husband for being able to control their emotional arousal:

I cried and cried, but I only cried the moment he passed away.....I regained control very quickly. Afterwards I would not allow myself to cry as if I was going crazy. My husband was actually the most peaceful – he never cried. He did such a good job and I found him extraordinary. He never shed a tear. He calmly watched our son pass away. Panicky people can't get things done because they are lost and confused.....When [Participant I's son] passed away, my husband was the one who started to assign tasks to people and direct them to get to work – "you go upstairs to stay with mom. You call 911." (laughed). He just started directing people to get them to do something. He's just very tough.

Given the cultural emphasis on the need to control and suppress emotions, it is important to understand what it means if someone fails to do so. Participants reported feeling fearful of the natural emotional fluctuations one would normally experience during the process of grieving. According to the participants, emotional arousal meant that they were losing control over their minds, which most Chinese would interpret as a personal failure and a sign of insanity. Receiving professional support for one’s grief further reinforces others’ belief that this person suffers from a mental illness, something that carries a lot of stigma and shame in the Chinese culture. Many participants noted that the tendency for Chinese to pathologize grief and stigmatize support for mental health could hinder their receptivity to bereavement care services. Participant A, who had a long history of depression and suicidality that was exacerbated by her grief over the death of her father-

in-law, described how she and others around her perceived her need for psychiatric treatment:

For me, I see it as a shame. If you let other people know that you need mental health treatment, they would think that you're "psycho". I would keep thinking about how others will judge me. So I'll try my best to NOT receive mental health treatment, and to suppress everything. Even now my husband still cannot accept the fact that I have "emotional problems", let alone "mental disorders". He considered it a shame of the family. He wouldn't tell anyone "oh my wife is hospitalized again". He kept his silence. If others don't ask, he doesn't tell.

Participant B sought grief therapy after the death of her father, which she found helpful, but recalled being negatively judged by her husband:

You know what my husband said? When I told him I was getting therapy, he said I was crazy! That's what your typical Chinese would think – if you need emotional support, if you seek counseling, that means you're nuts, you're mentally ill. If you have any emotional turmoil, that means you're psychotic and should be institutionalized. That's how he understood it. Honestly even till this day he still doesn't understand why I needed counseling at the time. Since this is how Chinese looks at emotions, often times we dare not to show anything on the outside, or tell anyone anything. No matter if you're happy, or unhappy.....like how unhappy I was about my mom, I never told anyone, because what if they think that I'm crazy?

Similarly, Participant E had been receiving psychological treatment, a part of which focused on the death of her brother. She recalled how her clients reacted when she told them that she was under the care of a psychologist:

Their first reaction whenever they hear something like this is "that means you are insane!" If you go see a psychologist, you are insane. The psychologist I saw had a radio show. When my clients talked about that radio show, I told them "oh yeah I go see him for therapy as well". They always gasped when they heard me say that. Their reaction already told me what they were thinking. So I always had to follow up with "no I'm not insane".

Participant T, who was a mental health professional, made the following observation:

Well individual counselling, or even group counselling, are very foreign ideas among Chinese. They are not common. I mean, many Chinese can

accept talks about diabetes, because it's about their PHYSICAL health. But when it comes to emotions, or mental health, Chinese may worry about whether others will misinterpret it. And since our community isn't very large, people worry that others would know what their struggles are. That's what Chinese in general will worry about – "If I seek help for my grief, does it mean that I'm incapable?" Many Chinese will wonder "if I go seek help, does it mean that I am incapable of managing my own emotions? That I actually will need help from the outside to help me deal with my own grief?"

Finally, Participant V described how many Chinese might misunderstand the purpose and nature of bereavement care services:

The purpose of these programs is to help you get on with your life, but people will immediately focus on the negative side. Let's say your doctor refers you to these services.....let's say your doctor said "you look unhappy, let me introduce you to this service". Some people will immediately think "are you saying I'm depressed? Are you saying something is wrong with me?" You start to wonder if that means you have an emotional disorder.....and that will be perceived as something very negative.

### **Being an Immigrant in a Foreign Land – The Need for “One of Us”**

Equipped with a set of Chinese cultural grammar from their own culture, participants entered the process of emigration to Canada. Immigration thrust them into a brand-new world consisting of people of different ethnic and cultural backgrounds, operating under different sets of cultural grammar. Through cross-cultural encounters, participants became more keenly aware of the linguistic and cultural differences between them and others residing in this foreign land. As first illustrated in the section on *Chinese Cultural Grammar*, participants readily made cross-cultural comparisons between themselves and others when discussing the standards of behaviours that underlie the Chinese culture. The description of such comparisons almost always came in the form of “*us versus them*”, as in “*We Chinese do it this way, but they Westerners (sai yan in Cantonese; xi fang ren in Mandarin) do it another way*”. It is interesting to note that the “them” in the comparison means exclusively Caucasian, as the term “Westerners” in Chinese refers to Caucasians only. This suggests that to the participants, the mainstream North American culture (which serves as a reference group for the cross-cultural comparison with Chinese culture) is largely a White culture. It is also interesting to note

that none of the participants discussed how they were **similar** to “Westerners” in terms of their cultural values and norms; they only reported differences.

It is apparent from the participants’ responses that the clash of cultures inherent in the immigration experience, and the process of cross-cultural comparison between “us Chinese” and “them Westerners” only accentuated their perceptions of between-group differences. The process of immigration showed the participants how different they were from others living in Canada. Becoming aware of how they were culturally different from others made the participants cling more to their Chinese cultural roots in the face of death and grief. Participants reported that the feeling of “being different” bred the need and preference for clustering with “one of us” (“*ji gei yan*” in Cantonese; “*zi ji ren*” in Mandarin) if they were to seek bereavement support services for their grief. The need to interact and congregate with “one of us” was an end result of the interaction between the participants’ Chinese cultural identity and their immigration experience.

### ***Who is “One of Us”?***

The concept of “one of us” is similar to the concept of ethnic match discussed earlier in the Introduction: the belief that a match between patients’ and health care professionals’ race or ethnicity will lead to better quality of care and patient satisfaction. These two concepts, however, are not identical or interchangeable according to the participants, as “one of us” goes beyond skin colour or other shared physical characteristics.

Participants’ definition of “one of us” is quite specific. To them, the defining feature of “one of us” is not race or ethnicity; “one of us” does not mean “any ethnic Chinese”. In fact, they would only consider someone as “one of us” if that person shares the same Chinese dialect, same geographical background (i.e., birth place in Asia), same cultural heritage, same immigration experience, and same cultural identity. The most pervasive theme in the participants’ definition of “one of us” is the immense intra-cultural differences within the Chinese population. Participants emphasized that “*not all Chinese are the same*”. They noted that individuals from the three Chinese regions in Asia (Hong Kong, Taiwan, and Mainland China) were so different in their backgrounds and needs that they should not be lumped into a single group of “ethnic Chinese”. Due to historical, political,

and geographical reasons, these three Chinese regions have different cultural norms, values, and practices. Even the language is not shared among these three regions. Those from Hong Kong speak Cantonese, and read and write in Traditional Chinese. Those from Taiwan also read and write in Traditional Chinese, but speak Mandarin. Those from Mainland China speak Mandarin, but read and write in Simplified Chinese. Each Chinese dialect comes with its own vocabulary that cannot be easily translated and understood by those who speak another dialect. As a result, matching based on ethnicity alone does not imply culturally sensitive services. In fact, participants perceived that the intra-cultural differences within the Chinese population would become barriers in communication, if ethnic match only took into account racial similarities:

I think.....like those from Mainland China, they will have different needs than those from other areas. Those from Hong Kong.....like among China, Hong Kong, and Taiwan, the way people feel, the way people live, their culture.....they're totally different. You cannot use the same way to treat someone from Mainland China just like how you will treat someone from Hong Kong. Their way of looking at things will be different.....we need to find out the differences among these groups in terms of their customs, how they look at death. There will be variations. (Participant D)

Differences in the health care systems of the three Chinese regions affect Chinese immigrants' knowledge and attitude towards services such as psychological treatment and bereavement care. Participant D went on to explain how historical differences between China and Hong Kong led to different understanding and acceptance of palliative care services, using the controversy of building a hospice near a condominium in Vancouver a few years earlier:

Unfortunately those who bought apartments in that area were from Mainland China. At least if they were from Hong Kong, they would have known what palliative care is. People from Mainland China have no idea what it is. They still don't have hospice services in China, and they have an even stronger fear towards death. It's a taboo topic. In Hong Kong, for historical reasons, they have had the longest history of having palliative care services. So if those people who are living in UBC were originally from Hong Kong, things might have been different. Their point of view would have been different.

Participants also perceived significant differences in communication styles and willingness to disclose "private matters" across the three regions. Two of the best excerpts

that illustrate some of these intra-cultural differences in detail, albeit longer, came from Participant E and O:

I don't know if it's ok to say that, but I think it'll be easier for Hongkongers to open up. For those from Taiwan or Mainland China, it'll be more difficult for them. I often interact with immigrants from Taiwan and China through my work. They are way more conservative. If you suggest to them that they should consider seeing a psychologist or a psychiatrist, they would be totally taken aback.....It's way easier for my clients from Hong Kong to accept this. They would say "oh that's good, it's great to talk about these things". I think those from Taiwan and China know less about this, whereas Hongkongers are more familiar with psychological help. So even we are all ethnically Chinese, we still look at this differently.....not all Chinese behave the same way. (Participant E)

I think another thing has to do with our backgrounds. People from Hong Kong, those from Taiwan, and those from China.....which group are you targeting [with bereavement care services]? Even among Chinese there are clear differences.....When you say you want to provide support services to Chinese, what language are you going to use? How will you speak to them? Do Westerners understand that not all Chinese are the same?.....You and I are both from Hong Kong, and so we will know our common background, the background in Hong Kong. Even if I don't go into detail, you will still understand what I was talking about. But talking to those from Mainland China – can you really picture what they were trying to tell you? The way they think.....what's their priority? Themselves? Money? There are so many differences in level of education, our backgrounds, the bigger environment where we grew up in.....Even among Chinese – those coming from Taiwan, versus those coming from Mainland China – their cultural backgrounds are different already. I think those from Mainland China – they have experienced things such as Cultural Revolution. They therefore may be more defensive and if you ask them to share, they will suspect that you're trying to spy on them. They wonder if you have genuine intentions. Then they are less likely to open up to you. I think many second- or third-generation Chinese are more open about [grief] already. People from Hong Kong are also better in this respect. Those from Taiwan.....their social circles tend to be very small and tight-knitted. The boundaries are more rigid. Outsiders will have a difficult time penetrating the boundaries. (Participant O)

### ***Why the Preference for “One of Us”?***

Participants identified two main reasons for their need and desire to work with a professional that is “one of us” when receiving bereavement support services: communication barriers, and cultural barriers to understanding.



## Communication Barriers

There are two dimensions to the participants' accounts of communication barriers. The first is a *linguistic barrier*, defined as one's inability to communicate with those who do not speak Chinese. This pertains to language proficiency (i.e., one's ability to use a language for speaking, listening, reading and writing), which can be considered a more basic dimension of communication. This need was identified by the participants with limited (i.e., little to no English) to surface fluency (i.e., being able to hold a simple conversation) in English. For these participants, their communication barrier had to do with their low English fluency, which made them unable to express themselves and understand what was said to them. They therefore explained that English-speaking bereavement support services would not be helpful to them, as their low English proficiency would have prevented them from participating. Working with "one of us" who could speak Chinese was seen as the only way to remove the linguistic barrier for them:

When I was in the hospital, a nurse gave me some pamphlets about some organizations we could go to seek counseling. However, the nurse told us that the services are all in English and so I didn't go seek help. I didn't read the pamphlets either since they were all in English. I don't know English at all. And that's why I didn't seek counseling as well. I think if these organizations only offer English-speaking services it's not gonna be helpful. Like me, I don't speak English, so I'll just give up even though I was told about these services. But that also means that I have lost the opportunity to receive help from others. (Participant A)

I asked if such services were available in Chinese. That person said no, that everything was in English only.....I can handle conversational, day-to-day English, but to talk about how I feel – it has to be in Chinese. At least it'll be easier for me to understand what that person was trying to tell me. It'll also be easier for me to accept his or her advice. For instance, it can already feel quite grueling if it is just ONE word that I don't understand.....if there was 1 or 2 words they said that I didn't understand, I would be stopped in my track as I wouldn't be able to fully understand what was said to me.....I cannot express my deepest feelings in English, nor can I understand fully what they say to me. I can't say to them, "Hold it, I need to look this word up in the dictionary first." It's really not direct when I have to use English. It complicates things. (Participant C)

They will not understand what's said to them. For instance, my mom (laughed).....even if she goes, it'll be totally useless to her cos' she may only understand 10% of what people are saying. It'll be totally meaningless. My mom also won't know how to express how she feels. I think she probably can't even come up with the English words to tell you "I'm very

sad". What's "sad" in English? How can I express to you how I was feeling at that time? Let's say I want to say "I can't eat" in English.....how do I even say it in English, "Empty tummy"? There's a huge language barrier. (Participant N)

If I have to have a more in-depth discussion, I won't be able to do it in English. I won't understand it. I could only do it superficially. Newer immigrants would have an even bigger need for Chinese-speaking services. Many of them do not speak English. (Participant S)

Yet interestingly, linguistic barrier was not the most important communication barrier identified by the participants. It is important to note that 60% of the participants in the current sample rated their English proficiency as fluent. All of them studied and worked in Canada. To them, the use of English was not a barrier.

Participants, regardless of English fluency, articulated that the biggest barrier to communication with someone that was not "one of us" was *transmission barrier*. To the participants, transmission is a higher-order communication need. It pertains to how one accurately translates, encodes and transmits their thoughts, emotions, and intentions to others, and ensures that the receiver of the message accurately understands its meaning.

Participants defined transmission barrier as the creation of **distance** when one had to use a non-mother tongue to discuss "*matters of the heart*" – those inner experiences that Chinese were told to bury deep within their hearts. Even for those who rated themselves as "fluent in English", they readily admitted that English was still a second language to them. To the participants, distance has three dimensions: distance from one's intended message, distance from the receiver of the message, and distance from one's true emotions. Distance results in various obstacles that impede effective communication process: participants felt that such distance made it difficult for them to clearly and precisely describe their emotions and convey their intended message.

### **Distance from the Intended Message**

This dimension of distance refers to participants' perception that the use of a second language in communication affects the clarity, accuracy, and straightforwardness of the message encoded. Participants first noted that due to non-equivalence between Chinese and English, certain terms in Chinese simply do not have an English equivalent.

This meant that they could not directly translate certain concepts into English. They also found that using Chinese, their mother tongue, gave rise to a more precise and clear message. This led to increased comfort and openness in their effort to communicate:

I'm fine with English but speaking Chinese is more comfortable. It's not about whether I'm fluent in a certain language – it's about whether I feel comfortable when talking. I feel that I can express myself better, with more clarity.....At the end of the day, Cantonese is my mother tongue. I can explain myself more clearly. I'm not saying that I can't do it with English, but it will feel like it's not quite there, like something is missing.....I'll have to think about how to say it in English, what's the right term to use.....  
(Participant I)

Like now, I can open up to you and talk about how I truly feel, since it's more precise for me to express it in Chinese. (Participant H)

Second, participants explained that even if there were equivalent terms between Chinese and English, the process of translation introduced a delay in the transmission of the message: instead of directly communicating what they wanted to say in their first language, there was now this extra step they had to take. Communication became more effortful and less automatic as a result:

To translate a word from one language to another takes time. It creates a delay, which means I won't be able to think about it or react to it quickly. It's really not direct when I have to use English. It complicates things.  
(Participant C)

### **Distance from the Audience**

Participants noted that the use of a second language created distance between them and the intended receiver of the message. Communicating with someone who spoke a different language made them feel that that person was different from them, and that they could not get close to that person. A perceived distance in the relationship resulted in skepticism about the quality of communication, as participants had little confidence that there would be mutual understanding between them and the receiver of the message. This is evidenced in the following excerpt by Participant R:

While I may understand what you are saying if you speak to me in English, it doesn't feel as intimate. I will feel that you and I are different people. If you speak English and I speak Chinese, while I'll be able to understand

what you said, it will still make me feel that we belong to different cultures and we therefore will think differently. As a result I won't feel close to you.

The feeling that "we belong to different cultures and we therefore will think differently" is just an impression that I'll have. Maybe objectively we're not really different, but I will still FEEL that "I'm Chinese, and the way I think will be different from the way Westerners think". I'll immediately have this impression. For instance, if I go to a non-Chinese family doctor, he / she may still treat me the same way as a Chinese family doctor does. And of course we can communicate, as in I understand what was said to me, and the doctor would also understand what I said.....but why do I still prefer a Chinese doctor? Cos' it has to do with how I feel about it. I'm sure that there's no major difference between a non-Chinese doctor and a Chinese doctor, but why do I still prefer a Chinese doctor? It's cos' of the sense of closeness I feel when working with someone that I think is similar to me, and my trust that you are going to understand what I am truly communicating to you. (Participant R)

### **Distance from Emotions**

To the participants, the most significant transmission barrier caused by the use of a second language is the distance from their real emotions. Participants firmly believed that it was "*impossible*" to use English to communicate their emotions, regardless of their level of English fluency. They used the phrases "*hitting deep into my flesh*" ("*yap yuk*" in Cantonese) and "*clinging to my skin*" ("*tip sun*" in Cantonese) to describe how they felt when they used their first language to talk about their emotions – using Chinese is simply more intimate. They explained that using a second language to discuss emotions created a barrier between what they said, heard or read and what they truly felt. The emotional impact of such communication became attenuated as a result. The distance from their emotions made them feel that the communication was less complete, direct and accurate. The message felt generic and superficial rather than personally relevant. The words used never seemed right. It felt as if something was missing, since the English words did not seem to truly capture and reflect their underlying emotions. Some participants even said that if they had to communicate how they felt using a second language, their emotions would change as a result, since the English words would distort the emotions they felt. To the participants, the distance between what was said and how they truly felt would mean that others would not fully understand their genuine emotions:

I think for any counseling services, they must be provided in a way that feels like they "cling to my skin". We have to be able to communicate. If the

services are in English, people may not be able to fully express what they really mean. So services in English will not be as good. (Participant B)

Of course, for us Chinese, using Cantonese to talk about feelings is way more precise as it feels it really hits deep into my flesh. If I were to use English, I will feel that the conversation can never get deep. We don't speak English as our native language, and as a result our usage of English will never be native-like or intuitive. We are OK if we were to talk about something superficial, but if we are to talk about what's in the bottom of our hearts, it often feels as if we don't have the right vocabulary for it. Others therefore may not fully grasp what you truly want to communicate. That's why it's important to speak to someone who shares the same language, someone who sounds just like me, cos' that will make me feel that this person will understand what I'm really trying to say. (Participant R)

### **Cultural Barriers to Understanding**

Many participants expressed their skepticism about quality of care and the strength of the therapeutic relationship if bereavement care services were provided by non-Chinese professionals. Their strong skepticism stemmed from their lack of confidence in non-Chinese health care professionals' ability to **understand** their bereavement experience due to cultural barriers. Participants firmly believed that only "one of us" – an ethnic Chinese who shares the same dialect, cultural heritage, and immigration experience – would be able to understand them.

Participants readily identified a number of ways that they believed made "Westerners" different from Chinese: their openness, their ease and comfort in overt, spontaneous expression and discussion of emotions, their frequent use of physical intimacy (such as hugs) to convey care and affection, their freedom to express their individuality without fear of negative judgment by others, and their initiative in seeking help and accessing health care services. They also felt that "Westerners" and Chinese do not share the same cultural beliefs regarding death or the same fear towards death, nor do they share the same coping strategies for the loss of a family member. Participants steadfastly believed that such cross-cultural differences would prevent professionals who did not share the same Chinese heritage from appreciating their concerns, feelings, preferences and needs during bereavement – factors seen as implicit, intuitive, and culturally determined.

Participants who suffered from parental and spousal death were particularly concerned about cross-cultural differences in the nature and importance of familial relationships. They firmly believed that Westerners did not place the same value on family relationships. They assumed that since Western cultures celebrated individualism over collective interests, family relationships in the mainstream Caucasian culture were going to be casual, and devoid of attachment, commitment, and responsibility to each other. As a result, participants felt that Westerners would not be able to understand the enormous weight of family duties Chinese must carry on their shoulders. For instance, they believed that Westerners would not understand the need for Chinese to obey and defer to their parents, the need to repay their parents' effort in raising a family, the emphasis on fulfilling one's duty and roles in a family, and the negative social consequences of defying these cultural rules. Some participants who lost their parents even commented that Westerners would not be able to understand why parental death often led to tremendous guilt among Chinese due to their perceived failure to fulfill their responsibilities as sons and daughters, as well as the blame, stigma, and social ostracism from others if they are judged to be "unfilial".

Participants expressed their preference for high context communication, a concept previously described in the Introduction – indirect, covert messages with hidden, implied meaning that can only be understood by "reading between the lines" – in contrast to the straightforward and open communication style held by "Westerners". "*Zhih-yi*", the cultural grammar that the receiver in the communication process should be able to decipher the meaning of the message without being directly told, is paramount to the building of a trusting and comfortable therapeutic alliance as well as treatment success. To the participants, "*zhih-yi*" means genuine understanding. It implies that the professional is able to go beyond the literal, superficial meaning of the participants' spoken words to recognize their real intention. Participants also emphasized the need for professionals to understand them immediately, despite minimal explanation on their part. Such accurate and spontaneous understanding can occur only if the professionals have internalized and embraced the same set of cultural grammar.

It is interesting to note that the participants saw cross-cultural differences in absolute terms rather than relative, that is, they believed that the cultural values Chinese

embrace were completely **absent** in Western cultures. They seemed unable to entertain the possibility that the same values could be present in the Western cultures, just that different cultures embraced these values to a different degree.

A consequence of looking at cross-cultural differences in absolute, black-and-white terms is that participants expressed a high level of discomfort and mistrust when they had to discuss matters related to death and grief with a non-Chinese. Participants explained that without a shared cultural heritage and relevant cultural knowledge, it would be impossible for people from other ethnic groups to understand the meaning, motivation and constraints behind their behaviours, many of which were culture-bound. Such understanding is not based on book knowledge but rather experiential knowledge – the experience of being born and raised in the Chinese culture.

According to the participants, “the feeling of being understood” is paramount to the success in motivating Chinese to access bereavement care services. Knowing that they will be understood allows them to develop a sense of trust, confidence, closeness and comfort when working with a health care professional. They need to feel absolutely confident that their disclosure will be understood by the other party, and that the advice provided will be helpful and relevant, in order for them to overcome their fear and the strong cultural restriction against the expression of emotions and verbal discussion of grief. They therefore feel reluctant to open up to someone whom they cannot trust to understand their needs, thoughts, emotions, and behaviours.

Several excerpts from the participants help illustrate their skepticism towards non-Chinese individuals’ ability to understand and support them during the grieving process. Participant L was married to a Caucasian husband. In the following excerpt, she tried to explain how the Chinese view on parents, family, and parent-child relationships was very different from that in the Western culture, and why her husband failed to understand her grief over the death of her mother:

Given that my husband is a “foreigner”, I don't think someone from the Western culture could ever develop any sense of close affinity with my mom. I think Western culture..... given our different cultural backgrounds and upbringing, I wonder if they would truly understand our way of thinking, our feelings. I think if I use Chinese [to talk about my feelings], the other

person would be better able to understand me – I'm assuming that the other person is of Chinese descent. Cos' for westerners, mom is just mom. The sadness.....they would wonder why my sadness is so profound. But the Chinese view on parents, family, and parent-child relationships is very different from that in Western culture. Our view is that our parents took care of us since our birth. As a result, we need to "return the favour" and do the best we can for our parents. But this is not necessary true for Westerners. To them, "Oh as adults, we are independent and a separate entity from our parents." They may not look at parent-child relationship in such an in-depth way as we do. To them, "parents" are merely a component in the family. It's different from the kind of respect we have. That's one of the reasons why I don't think my husband could understand why "it's been so long and you're still so sad". They won't be able to understand the importance of "parents" in a family.

Other participants shared the same perception on the inability of non-Chinese individuals to understand Chinese people due to a lack of shared cultural heritage:

If we talk about the idea of filial piety, Westerners may not share the same background – for instance, they may have moved out at age 18.....they won't be able to understand this relationship we have with our parents.....or this tendency to not talk about death and grief. (Participant O)

I guess culture can play a role. For instance, I may tell [the professional] something, but maybe in his / her culture, that's something that's considered trivial. Then I may feel that I cannot communicate with this person, when this person's understanding of the issue is not the same as mine. I may feel that this person doesn't really get me. That's why I may think it won't help. But if we share the same culture – if we share the same values, such as our tendency to keep things to ourselves – when I say something, that person may feel the same way and say "oh yeah that's true for me as well". It's the kind of understanding I need. Westerners may just go hit the bar and drink some beer. Once they get drunk they can speak to anyone. That's not something we do as Chinese. I don't go get drunk. I don't talk to random strangers about something like this. I won't go talk to the waiter about it. (Participant Y)

A number of participants explained the need for professionals to possess the skill of “*zhih-yi*”. They expected the professionals to understand them immediately without the need for further explanation:

Like when I told you (meaning the author), about how Chinese avoid the death and the bereaved, you understand immediately. People from other cultures won't get this at all. They will not understand the reason behind this avoidance.....if the therapist is “one of us”, it's so much easier to feel



at ease and comfortable around him or her. He or she speaks our language, and understands our culture. There are things that I just need to briefly mention but both of us will understand right away. You don't need to go into a lengthy explanation. To me that's important. Let's say if you ask me to see a therapist of Japanese descent. Even if the therapist can speak Chinese, he / she still won't be able to understand! (Participant B)

The most important thing is to find someone who can truly understand how I feel. At least when I talk to you (the author), you understand what I'm talking about. If I have to explain things over and over again, it's very taxing. (Participant I)

You and I are both from Hong Kong, and so we will know our common background, the background in Hong Kong. Even if I didn't go into detail, you will still understand what I was talking about. (Participant Q)

For example there are things that are big "no no's" when it comes to talking to my mom. I can try to explain this to a Caucasian friend but I don't think he / she will get it; whereas if I'm talking to someone like you, you get it right away without any further explanation or elaboration from me. That's what makes the difference. (Participant V)

Interestingly, the strongest skepticism was voiced by participants who had received grief therapy from non-Chinese professionals. Their therapy experiences failed to eliminate their doubt; instead it reinforced their lack of confidence. These participants reported mixed feelings towards the quality of services they received. They used the phrase "*not hitting deep into my flesh*" to describe their therapeutic experiences. They felt that their non-Chinese therapists never understood certain unique aspects of the Chinese culture. They also felt that professionals from a different cultural background might give advice that Chinese may find culturally inappropriate. Participant U, for example, received individual counselling from a Caucasian therapist after losing his wife to cancer. He entered therapy to learn how to adjust to the life of a single father and to better relate to his daughter, yet he felt that the clash of cultural values had led to disagreements between him and his therapist over his clinical judgments and therapeutic recommendations:

For instance, talking about my kid.....it didn't feel like it hit me deep in the flesh. When we talked about how to discipline my daughter, he would tell me to let my daughter handle her own affairs and I shouldn't get involved, that I didn't need to be worried, but my point of view was different. I felt that he didn't really understand.....well maybe he did understand, but his point of view was different from mine. For us Chinese, education is a priority, extracurriculars like swimming or learning musical instruments are priorities, but from his perspective, I was putting too much pressure on my

daughter. He would interpret this as my “anxiety”. But Chinese culture is different.....especially Hong Kong. For us, studying is her major responsibility. But they would see us as being too anxious and over-involved.

His other suggestion – to just let my daughter be and let her handle her own stuff – that’s very different from how we think as Chinese. Of course, eventually I’ll have to let her go as she’ll go to Calgary to study, but for Chinese, we all want to stay close to our kids and want to monitor them. But Westerners do not agree with this approach. He told me, “Just let her study elsewhere! She doesn’t need to go to UBC or SFU. Going out of town is the same thing; you can just visit her, and she can visit you.” Westerners tend to give their kids a free rein. They can just let their kids go.....But for Chinese, we just have a totally different mindset.

Similarly, Participant W explained that despite her fluent English, she still did not feel that her Caucasian psychiatrist could fully understand the extent of her grief and her main concerns:

Things that involve the Chinese culture – parents, family, relatives, face – my psychiatrist may understand it at a superficial, general level, but when we go deeper in the conversation, he still looks at these concepts from a Western culture point of view. I don’t think he really understands Chinese cultural values. That’s why when I told him what was troubling me, he wanted to help, but he couldn’t fully grasp what they meant.

For instance, this concept of face.....or the concept of "complete deference to your parents", "filial piety", "complete obedience" as a child. These things don’t exist in the Western culture. Even the solutions they offer.....for instance, for Chinese, if someone put food in front of you, especially if it’s from the elders in the family, you MUST eat it. You cannot say no to the elders. People from Western cultures do not see saying no to these people as a problem. For instance, my refusal to go back to Hong Kong to take care of my mom was considered a "mortal sin" in the eyes of others.....But people from Western cultures don’t understand this at all. My psychiatrist said that I needed to live my own life, that I needed to put myself as the priority – "if you’re unwell, how can you take care of others?" I mean, I could accept that when I was there listening to it, but when I was back to Hong Kong, my biggest difficulty had to do with my relatives and friends, how they judged me. My psychiatrist does not understand this at all.

### ***Implications for Bereavement Care Services***

Regardless of English proficiency, all but two participants expressed a preference for Chinese-speaking bereavement care services. To them, receiving care from “one of

us” helps remove communication and cultural barriers to accessing these services. They also suggested that Chinese will be more receptive to bereavement care services if they know that Chinese-speaking professionals are available, as it would be easier to build trust and confidence in the therapeutic relationship if they are working with “one of us”. They firmly believed that only “one of us” can truly understand how Chinese feel about death and grief. Participants readily admitted that their skepticism was a subjective feeling. However, the thoughts of “we are different” and “they will not understand us” are automatically triggered in every cross-cultural encounter, a process that the participants felt they had no control over:

Of course it's a subjective feeling, but it will make it very difficult. Also, if we belong to different ethnic groups, just by looking at that person I can already tell that we are different. This already makes me suspect that he or she will not understand what I'm saying. I therefore will lose confidence in that person. (Participant R)

While two participants preferred English-speaking services, it is interesting to note that the reason for their preference still reflects the Chinese cultural grammar on the need to suppress emotional experience. The two participants readily agreed that not using one's native language to talk about emotions meant that the discussion would not “*hit them in their flesh*”. However, that was exactly what they liked. These two participants used the adjectives “*embarrassing*” and “*disgusting*” to describe the experience of emotions. Using English, a second language, to discuss their grief allowed them to create a psychological distance from those negative emotions, which put them more at ease with their emotional experiences:

Sometimes when I chatted with my husband, I actually found that him not understanding Chinese is a good thing. I think I will actually feel more comfortable speaking in a different language when talking to a stranger if I need to talk about my emotions. Whenever I talk about emotions, I actually feel way more comfortable talking about them in English. It just feels way less.....disgusting. I find it way easier talking about emotions in English. If I were to talk about emotions using Cantonese, I feel that it would “hit deep into my flesh”. I can't stand that as that makes me feel yucky and uncomfortable. (Participant N)

Sometimes I feel that “well maybe using English to express myself is less embarrassing”.....Speaking Chinese does “hit deeper into my flesh”, but English is less embarrassing. Often when I think about sad experiences, I

notice that my thoughts are all in English. Using English allows me to keep a distance between myself and my emotions. (Participant W)

In light of these communication and cultural barriers, some participants were adamant that “no one will show up” if bereavement care services were delivered by “Westerners” in English only:

I think there has to be a shared language. If these services are offered by Caucasians, many people will not show up. Just knowing that these services are in English would already stop them in their tracks. (Participant E)

Honestly if you tell me that these services exist but only in English, I won't come cos' I don't want to bother with English. (Participant I)

Offering it in Chinese is critical. Even if such services exist, if they're in English, I dare not show up. (Participant K)

They will not go at all.....unless it's offered by Chinese, unless it's a Chinese approaching you telling you about these services. (Participant N)

If the brochures are in English only, I won't even bother reading them. I won't touch them even if they are lying around. (Participant X)

## **Navigating Uncharted Territories in a Foreign Medical System**

The causes of death for the participants' family members varied. Some were expected after a chronic, tumultuous course of a life-threatening illness; others were sudden, unexpected, and sometimes difficult to accept, such as homicide. The deceased family members also varied in their geographical locations of death. While most passed away in Canada, almost one-third died in the participants' countries of origin. Participants whose family members suffered life-threatening illnesses before their passing tended to have a longer period of interaction with a wider variety of health care professionals and settings, and report significant caregiving strain. Those whose family members died of unexpected causes had more exposure to acute care, and reported shorter and fewer interactions with health care professionals. Yet regardless of the nature and location of death, illness and death of their loved ones invariably plunged the participants into the Canadian health care system, a medical system that was foreign to them.

Being immigrants to Canada, participants entered the Canadian health care system with a set of expectations based on their knowledge of and prior experiences with health care in their countries of origin. According to the participants, the health care systems in Hong Kong, Taiwan and Mainland China (thereafter known as “Chinese health care system”) are characterized by hierarchical and paternalistic professional-patient relationships, efficiency, emphasis on cure rather than quality of life, and prioritization of resources based on cost minimization rather than patient need.

***Participants’ Expectations on the Roles of Health Care Users and Health Care Professionals – “The Experts Talk, We Listen and Nod”***

Participants noted that in the Chinese health care system, there is a significant power difference between health care professionals and health care users. Health care professionals are seen as the experts who possess specialized knowledge. They therefore tend to play an authoritarian role in their interactions with patients and family members. The power of decision-making rests in the professionals’ hands. Professionals determine what, when and how health care will be delivered. There is a unidirectional flow of information from professionals to health care users, but not the other way around. Health care professionals tend to present patients and family members with selected information only.

Given the paternalistic model of care in their countries of origin, participants expected to play a passive role in health care decision making. They deferred to the experts because “the professionals know best”. Their job as patients and / or family members was to provide assent only. Participants whose family members passed away in their countries of origin recalled being confused, as they often were not told the diagnosis, prognosis, and the reasons for the professionals’ choice of treatment procedures for their family members. Yet none of them asked questions for clarification or understanding; they simply acquiesced. This is evidenced in the following excerpt from Participant G, whose mother passed away in Hong Kong due to colon cancer:

My mother had a feeding tube inserted at the time. I really regret this as I didn't know that you cannot remove it. She died due to the feeding tube. The tube punctured her internal organs. She bled so much. I cried out loud and my mom could no longer speak. From that moment on till her death,

my mom never opened her eyes again. She never spoke again. You can tell how regretful I feel about this.

At the time the doctors said my mom needed the feeding tube. I didn't know anything about it, so whatever they said was whatever we agreed to. After they put the feeding tube in, they kept pumping her with liquid diet. Initially I thought that once I could get my mom to try eating again, they would remove the tube. It turned out not to be the case. I was so angry. The doctors never explained it to me. They assigned someone new to do the insertion. She bled so much during the procedure. How could I not be angry? My mom kept crying for help until she lost her voice.

Participants tended to regard themselves as a recipient of care rather than a partner in care in the Chinese health care system. They explained that initiative from patients and / or family members to seek help and request health care services was unexpected and rare for a number of reasons. First, the role of passivity they were expected to play in health care decision-making precluded the need to take initiative. Second, the Chinese cultural emphasis of respect and obedience towards authority figures, together with the paternalistic role of health care professionals, made participants reluctant to take initiative for fear of offending those higher in the relationship hierarchy and violating social rules. Third, the expectation for patients and family members to stay passive was also consistent with the Chinese cultural grammar on communication styles; directly and overtly asserting ones' needs would have violated the cultural rule that communication should be subtle and keep one's intention implicit and vague.

Assuming a passive role in health care in their countries of origin resulted in **poor health-related knowledge and understanding** among participants, as there was a belief that health-related knowledge should belong exclusively to professionals or the "experts". The most pervasive theme of participants' health care experience back home was "we *didn't know*". They did not have enough knowledge to help them perceive, evaluate and respond to symptoms. They had little awareness of available services for their family members. They were confused over the roles and responsibilities of various health care professionals. They were hardly aware of the nature and purpose of the treatment procedures their loved ones underwent. Some of them were even confused over the types of settings for patient care – they did not know what certain facilities or hospital wards were for. They also had trouble understanding information presented to them by health care professionals. This further exacerbated the participants' passivity, as they had no

foundation of knowledge allowing them to take charge of their and their family members' health.

The following excerpt from Participant L, whose mother passed away in Hong Kong due to cancer, demonstrated her state of confusion over her mother's condition and the health care received. First, whether her mother suffered from Alzheimer's remained a mystery to her to this day, since she had trouble differentiating between normal and pathological aging despite the worsening of her mother's symptoms. She also did not know how to properly respond to her mother's illness:

In general, we weren't very sure about what was going on. But we noticed that we could no longer provide her with adequate care at home.....We did know that she was forgetful. She had had memory problems for years already. We didn't know anything.....but then it got to the point where she started to develop hallucinations. She kept saying that the floor was covered by bugs and therefore she refused to go out. She refused to go out for dinner with me, as she kept saying that people would break into the house, that she had to stay behind to guard the house. At the time she kept losing the house keys already. We thought that it was a normal part of aging, that it was just your ordinary "forgetfulness". All we could do was to help her, to comfort her when she got confused, to tell her not to get frustrated, to be empathic, to search for things that she had lost, or to reassure her that it's OK to lose things. But these couldn't help her at all, as I found out later.

Participant L further commented on her lack of knowledge and understanding of her mother's illness, her confusion over the procedures, and her helplessness over her inability to ask questions regarding her mother's care:

I suspect that the doctors already had a lot of information in their hands, but we were kept in the dark. We really had no idea what had caused her difficulties – was it cancer? Or was it dementia? I think Chinese often think that it's important NOT to say too much, that doctors should just go about doing their thing without communicating with the families, but as the family, we had no understanding whatsoever.....Of course I know that sometimes it's hard to predict the future, but we really need to have more knowledge and understanding of the patient's real prognosis. This is a huge regret of mine. We really had no idea why she was hospitalized, why she wasn't eating.....so many things we didn't know at all. The doctors.....they never gave a definitive diagnosis of dementia. A psychiatrist came to examine her. But when they came talk to us about our mom's condition, we didn't really understand what was going on.

The strangest thing was the psychiatric consult they arranged for my mom. They said they needed a psychiatrist to check on her. But my mom had dementia.....but then I'm not a health care professional. I thought she had it, but I couldn't say 100% that she definitely had it. I don't know if having a psychiatrist to do the evaluation is appropriate or not. But there were all these confusing things.....that made you feel helpless. [The psychiatrist] was someone sent by the hospital, so you couldn't question it like "but my mom has this [condition], she doesn't have that [other condition]."

### ***Participants' Expectations on End-of-Life Care***

Participants noted that medical professionals in the Chinese medical system oscillated between a relentless pursuit of curative treatments and a "getting rid of patients" attitude.

### **Cure and Life-Sustaining Treatments, Not Quality of Life**

Participants reported a number of invasive procedures performed on their family members at the end-of-life stage by professionals in their countries of origin, such as force-feeding and intubation. Do-not-resuscitate orders appeared non-existent there. Patients' quality of life did not seem to factor in the decision-making process. Yet participants expected such aggressive treatments to be the norm of end-of-life care. They interpreted the professionals' focus on cure and resuscitation as a display of effort and ethics, that the professionals were trying their best to save the lives of their loved ones. They also mistook it as a sign that their family members were not dying, since the professionals gave them an impression of ongoing active treatment. This, coupled with the withholding of information by health care professionals, implied that participants had little awareness of their family members' real health status. They therefore were taken off guard when their loved ones passed away. Participant L, who had been bereaved for 3 years at the time of the interview, remained baffled by her mother's death. She continued to perceive her mother's passing due to cancer as "sudden death":

Then one day, I didn't know why.....the hospital was shifting things around and they suddenly told us that they had to move mommy to that hospital in Wanchai.....(Crying) They never explained to me why mommy had to move, or what that hospital was for. We just thought that maybe something happened and they had to move patients around.



That ward.....just a day or two after mommy was sent there, we already witnessed the death of two patients. I really didn't understand.....like this patient in the bed beside my mom's.....just this minute someone was feeding him, then the next minute he was no longer here. But it was still a hospital. They still provided care. There were nurses and doctors. But we never had any psychological preparation for this. We really thought that "oh maybe mommy would stay here for a while". We didn't even think about when she would be discharged, or things that would happen after. We were totally confused about how long she would be staying, or what she needed, or what we needed to bring to her.

At the time my mom refused to eat. (Crying again) She refused to swallow. They still sent specialists over to see if there was something blocking her esophagus. I really don't understand.....they were still treating her! But is her difficulty swallowing a sign that maybe her body has shut down already? Maybe that's something common for people who are gravely ill? I was by her side when the doctors came to examine her esophagus. We didn't really understand.....it happened so suddenly. They were still dealing with her feeding problem at the time.....did they REALLY not know that this was going to happen? It didn't take her long to leave – just 2-3 weeks later. I just feel that – could they have.....there were lots of things.....like, they were doing all these things for my mom, which gave us this false impression that "oh they are doing such a great job, they are still constantly doing check-ups on mommy." But it turned out that what they were doing wasn't even relevant.

### **Withdrawal of Care as a Resource Allocation Strategy**

Conversely, some participants noted that the tides quickly changed once the professionals decided that nothing could be **overtly** done. The emphasis on efficiency and cost control in the Chinese medical system meant that any further treatment or hospitalization would be seen as “a waste of resources”. Participants noticed an immediate withdrawal of care and resources after being bluntly told that the patient was just “waiting to die”. No follow-up care with a focus on comfort, pain control and improving quality of life was provided. Participant W, for example, described the conversation she and her family had with the professionals in charge of her mother's care:

Well they put it bluntly, "Oh she's in the terminal stage already, so even if she's dying, we will not save her, and you need to understand that." They got my sister to sign something. Then they asked, "Does she have any other family members? Have all the family members come back to be by her deathbed?" They were very cold-blooded. They had no regard for our feelings. It was all very matter-of-fact. "Yeah is everyone here? Yes? Yeah then it's about time". Something like that. "Well we won't do anything to

save her. She looks like she's suffering. Analgesics won't help anyways." Stuff like that that they said.....I mean, before being transferred to this hospital, my mom stayed at another hospital. She was told "well you can't just go home, then come back, then go home, then keep coming back. This is not the ER. We can't keep you here. We have no room for you. We have to move you." And then she was just thrown to this other hospital where she passed away. And there was no follow-up whatsoever. Once my mom passed away, that's it. Nothing else from them.

Participant B recalled having a similar conversation on the need to “properly allocate health care resources” with a nurse before her mother’s death due to heart disease in Hong Kong:

My sister has a friend whose niece works as a nurse at [a Hong Kong hospital]. The niece got in touch with us, as a friend, before my mom passed away. She told us that cos’ my mom was old, she was just a “geriatric case”. Therefore there was nothing else the hospital could offer to us. They simply didn’t have enough resources for everyone. My understanding was that since she’s old, the hospital did not want to devote any further resources on her. The resources need to be reserved for the young only.

Participants were surprisingly accepting of such a strategy for allocation of health care resources: instead of equity in access, they expected that certain patients would be prioritized over others. One participant described it as “*that’s the way it is in Hong Kong*”. They appeared to endorse the same philosophy of efficiency and cost minimization that underlies the Chinese health care system, and agreed that health care resources needed to be carefully and sparingly allocated in order to minimize waste. They saw the health care system as one that was stretched beyond its limit. As a result, they entered the health care system expecting staff shortage, little time and attention devoted to them by health care professionals, poor quality of care, and little to no services.

### ***Participants’ Expectations on Bereavement Care Services – “No Expectation, Since Bereavement Care Services Don’t Exist”***

The majority of participants from Hong Kong and Taiwan had moved to Canada before bereavement care services were first introduced there in the 1990’s. The current services in Hong Kong and Taiwan remain limited in scope and are not universally offered by health care facilities. Immigrants from Hong Kong and Taiwan likely will not have heard anything regarding bereavement care services from their relatives and friends back home,

since the general public still has little awareness on their existence. On the other hand, participants from Mainland China noted that such services were not provided in their homeland. As a result, participants had no idea that bereavement care services even exist.

Participants whose family members passed away in their countries of origin recalled the lack of follow-up contact from health care professionals. They reported that once their family members were deceased, the professionals “washed their hands of them” – their duty of care ended immediately after the patient’s death. The only job left for them to do, according to the participants, was to issue the death certificate:

Absolutely nothing! All we did was to get the body out of the hospital. The hospital didn’t offer anything to us.....the doctors would never contact us afterwards to follow up! I knew that already when I was still working in the hospitals in Hong Kong. [Follow-up contact] would never happen.....I have no idea how things work here, but in Hong Kong, their motto is “when a person dies, it’s over, and it has nothing to do with us anymore. Just go downstairs to get the death certificate”. That’s it. No one will care about how you are anymore. (Participant D)

Honestly in China they do not have any services available to bereaved families. Basically once my mom has passed away, they washed their hands of us.....all they did was to issue the death certificate. (Participant K)

Such [follow-up] contact doesn't exist in Hong Kong.....no one provided any follow-up. Once my dad’s passing was certified, hospital, doctors, nurses.....they felt that their job was complete already. It’s finished. They no longer need to contact you. Whatever you need to do afterwards, they pass it over to Vital Statistics. It’s your job to deal with the tasks that come after.....My dad’s doctor did speak to my mom and my sister. All the doctor said was "Your dad has left". Then he just issued the death certificate. He gave a brief explanation of "yeah he had a sudden heart attack". From the moment he certified my dad's passing and issued the death certificate, his job was done. (Participant R)

No one mentioned anything about bereavement support. There was no pamphlet, no information provided.....all we got from them afterwards was a bill (laughed). (Participant W)

Participants’ lack of knowledge on the existence of bereavement care services, together with their lack of experience with receiving this type of care, gave rise to a lack of expectation for any form of follow-up support and services related to bereavement from health care professionals after the death of a family member.

In summary, participants entered the Canadian health care system with **a lack of health-related knowledge in general**, as well as the following expectations on the principles and practices of health care:

1. The health care team is the authority that has complete control over treatment decision-making. They are the experts who know best;
2. Patients and / or family members must play a passive role. Taking initiative, whether it is asking for clarification, seeking help, asserting their needs, or requesting services, is unnecessary and possibly offensive to health care professionals;
3. End-of-life care should focus on cure and life-sustaining treatments. The pursuit of curative treatments at the expense of quality of life is a reflection of the health care team's competence and caring attitude towards their patients;
4. Health care resources must be conserved if a patient is approaching the end of life, since further allocation of resources is simply a waste; and,
5. There will not be any further contact or bereavement support from health care professionals after the death of a loved one, since a) the professionals' job ends right at the moment of death, and b) bereavement support services do not exist.

### ***Misalignments of Expectations between Chinese Immigrant Health Care Users and the Canadian Health Care System***

Participants found themselves having to navigate the Canadian health care system at a time when they were the most vulnerable and confused: facing the death of a loved one. Their experiences with Canadian health care, however, can be characterized by numerous **misalignments of expectations**. Participants were confronted with a foreign health care system with philosophy and practices that were either unknown to them or completely at odds with their expectations. The clash of expectations between them as health care users and the health care system led to a number of negative health care experiences, misconceptions towards health care services, and barriers to accessing bereavement care services among Chinese immigrants.

### **Paternalism vs Egalitarianism in Professional-Patient Relationships**

Coming from a culture where health care professionals are seen as experts with specialized knowledge in health care, a number of participants reported being dissatisfied

with the clinical skills of their family members' health care teams. In the Canadian health care system where the model of care emphasizes egalitarianism and collaboration, patients and health care professionals are expected to be equal partners in fostering health. The clinical encounter, therefore, is seldom a unilateral one where the "experts" do all the talking while the patients silently acquiesce. Patients are expected to participate in the assessment process. Information gathering by asking patients questions, a thorough review of symptoms and concerns, and detailed history taking before making a diagnosis and treatment recommendations are typical of any professional-patient interaction. The participants of the current study, however, interpreted the professionals' need to ask question as incompetence. They appeared to have the assumption that health care professionals, being the "experts", should be able to come up with solutions by their own effort without the need for patient participation. Asking patients to offer detailed information or to report their medical history was seen as "irrelevant" and a lack of professionalism:

I received follow-up visits from community health nurses since I just gave birth. And (sigh) I had to repeat the same story.....they asked me again what [her son] went through. They apologized and said that they didn't know what conditions my son had. **Aren't you supposed to know ALL the pediatric conditions?.....**I was very surprised. I don't know if my expectation is too high. And they even.....they asked me to tell them what procedures he underwent, what was actually done during the procedure.....My God it was torturous to me. I'm so tired of talking, so tired of explaining, and you as a professional are asking me about things like this? Aren't you supposed to do your own homework? Aren't you a nurse?.....**Don't ask me all these questions before telling me what the answer is.** (Participant I)

It is evident that participants did not see themselves as an equal partner in health care. Instead they expressed a need for definitive answers and concrete instructions from health care professionals – they simply wanted to be told explicitly and exactly what was going on and what they needed to do, rather than professionals asking them what they would like to do. They had little tolerance for uncertainty during the diagnostic process. They saw illness and health as a static rather than a dynamic process, and did not seem to understand that a patient's clinical picture was ever-changing, and therefore no one could be 100% sure of what exactly would happen. This is particularly true during the end-of-life phase, where prognosis and life expectancy are often difficult to predict. Professionals' failure to "tell them exactly what to do and what is going to happen",

however, was again perceived as a sign of incompetence, defensiveness, and evasion of responsibility:

I called NurseLink when my son got sick. I felt that they were just BS-ing.....It really pissed me off.....I just wanted them to TELL ME what I needed to do. Stop asking me questions. Just give me a straight answer right away.....But they can't even give me a straight answer when I asked "So this is what happened, what should I do next?" (Participant I)

When my dad was sick, those so-called "specialists"....."Oh we are not sure.".....They would never tell you exactly what cancer it was. They never gave you a firm answer. I think maybe they didn't want to be responsible. (Participant P)

We as the family of the patient would really want to know what's next, what were the next steps to take, but I feel that the doctors here don't really do that.....They don't really tell you what is going to happen. The doctors here keep everything confidential.....but we need that guidance. I don't know what kind of training doctors received here, if they are not allowed to talk about what the prognosis is. They won't tell you how many weeks you have left. All they said [to my father] was "hope to see you next time". His next appointment was a month later, but they couldn't even promise that he would have that much time left. All you could do was to speculate that, based on what they said, it [his death] would happen within this month. Can't they make their communication clearer? Can't they be a bit less defensive when they offer us professional opinions? I want to have clear guidance from them.....I just want them to tell me, in simple terms, what needs to be done, and I'll just agree to it. I don't understand why they cannot give us anything definitive. Are they afraid of getting into trouble? Are they afraid that they may mislead someone? (Participant Q)

### **Passivity vs Autonomy and Initiative**

A related dimension is how participants' expectation of being passive in treatment decision-making clashed with the emphasis on patient autonomy and initiative in the Canadian health care system. In Western medical systems, respect for individuals' autonomy is the most important and fundamental principle in medical ethics. A number of procedures were developed to reflect this value, such as informed consent, the right of a patient to refuse treatment, and deference to the wishes of the patient on treatment decisions.

While informed consent has been a ubiquitous practice in the Canadian health care system, it remains a foreign concept to many first-generation immigrants such as the

participants in the current study. Informed consent requires the patient to be active in decision-making, to have the capacity to understand the information provided and make treatment decisions after a cost-benefit analysis, and to make independent decision without coercion or undue influence. Participants, coming from a culture where they were expected to play a passive role in health care and to accept whatever treatment decision that was imposed on them by paternalistic health care professionals, felt bewildered by the freedom and power bestowed on them by Canadian health care professionals in treatment decision-making.

Participants first noted that their health-related knowledge was inadequate to support them to make sound treatment decisions. They admitted feeling less “health literate” compared with “Westerners” (i.e., those from the mainstream culture). Yet health care professionals might have overestimated their level of knowledge and familiarity with health care services, and therefore provided insufficient guidance to help them navigate the decision-making process:

I just think they gave us too many choices, but there wasn't enough support to help us navigate through all the choices. They just threw a bunch of numbers at us and I had no idea what they were about. Maybe for Westerners they know more about these than us. For Chinese, we know less about these things; we receive less information about these things. Maybe it's us who didn't open our eyes to the information available. We often ignore these things. (Participant Q)

The lack of health-related knowledge is evident from the participants' narrative of their loved ones' health care experiences before death. For instance, they appeared to be confused over the roles different professionals played – they did not know what certain professionals were called, and what their responsibilities were. Participant P, for example, was describing to the author how his mother's “social worker” took care of her when asked why he did not take the initiative to contact the social worker for bereavement support. It was towards the end of the conversation that the author realized that the professional he was talking about was not a social worker:

I never thought about contacting the social worker again. My impression at the time was that – she worked for the hospital, and I thought that it was only for my mom's care, as my mom was unable to bathe herself at the

time, **so we were told that a social worker would come bathe her several times a week.**

It was also evident from the participants' narratives of their family members' illness trajectories that they had poor knowledge and a number of misconceptions on the nature of medical diagnoses and associated symptoms. As a result, they had trouble understanding the explanation on etiology and disease process given by health care professionals. Participant P, for instance, was confused by the meaning of "metastasis". He could not make the distinction between primary and secondary site of cancer. He insisted on wanting to know "exactly which **one** was the organ with cancer", since he believed that attacking the "root" of the cancer would lead to a cure. His need for a concrete, definitive answer on the site of cancer is illustrated below:

To be honest to this day I still don't know if she had lung cancer or liver cancer. When it happened to my mom, I asked them whether it was lung cancer or liver cancer. Their answer was that it was lung cancer metastasized to her liver. That's why we focused on her lungs and bought her cancer drugs specifically for her lungs. But it turned out that it was her liver. But what did she really have? It wasn't liver cancer, it wasn't carcinoma.....I don't even know what that was. All they could say was that it had metastasized. We went to her family doctor and her family doctor said the same thing.

Those who know how cancer spreads in human bodies will recognize that the cancer no longer fits in only one diagnostic category after a metastasis has occurred – it is no longer just "lung cancer" or "liver cancer". Participant P's misconception on how cancer progresses led to his need to attribute metastatic cancer to only one organ. Since he was told that the cancer spread from the lungs to the liver, he thought that lung cancer was the root of the problem, and treatment focusing on the lungs should work. This resulted in misunderstanding on the health care team's explanation on the nature of his mother's condition, its severity, its consequences, and appropriate treatment options. Inadequate health-related knowledge therefore negatively impacts participants' capacity to make sound treatment decisions and provide informed consent, since their lack of knowledge prevents them from comprehending the information provided and appreciating the consequences of their choices.



Second, participants' expectation of being passive in decision-making led to the misunderstanding that the emphasis on autonomy and informed consent was a way for professionals to "pass the buck". They felt that it should have been the professionals' job to make decisions, not them. As a result, asking them to play an active role and giving them the ultimate say in the choice of treatment was perceived as an attempt for professionals to "dodge the bullet" – to avoid being involved and accepting responsibility in the care they provided. They believed that when patients held the power in making health care decisions, professionals could then protect themselves if something went wrong; they could simply shift the blame onto the patients. Participants also did not feel that they had a real choice on whether or not they should go through the procedure. This is evidenced from the following excerpt by Participant Q, as she described how a technician sought informed consent from her father before he underwent a PET scan:

I think they put too much emphasis on human rights. One time I was very angry – my dad had an appointment for a PET scan. I had no idea what it was. During the appointment, a technician brought us a bunch of forms to sign, telling us what the PET scan was, that we had the right not to go through with it, what the program was, that it was a new program in BC, etc. etc. After reading all that, I got very angry. Why would you explain all these to us after you've set up an appointment with us? Isn't this a waste of my time? I'm here already. Do I really have a choice not to go through with it? Aren't you treating us as guinea pigs when you tell us that this is a new program? Why would you set up an appointment first, and then explain all these things to me afterwards?.....I just think that a lot of the stuff they do isn't concrete enough, isn't clear enough. They said that it's for human rights, but I think they tell you everything about the procedure and tell you that it's up to you to decide because they just want to protect themselves. They want to put the ball in our court. Why should I be the one to decide this? I'm the ignorant one; it should have been you giving us your expert opinion. I just feel that they didn't want to bear the responsibility or any possible consequences. Maybe it's their culture or their professional ethics, that they need to explain everything and let you decide, but for us Chinese immigrants, we are used to just passively receive.

From the excerpt, Participant Q did not seem to understand why they were provided with all the information pertaining to the procedure and the treatment program, which is the first step in any standard procedure in seeking informed consent. She saw it as a waste of their time; attending the appointment, she believed, was a clear enough sign that they were consenting to the procedure. It is also interesting to note how she described her expectation of professionals being the active one in decision-making rather than the

patients – she readily admitted to being “the ignorant one”, explained that it should have been the professionals’ job to make decisions since they were the “experts”, and alluded to how Chinese immigrants were used to “passively receive” rather than actively participate in treatment decisions. The need for a concrete and clear answer is also antagonistic to the process of informed consent. Informed consent is the outcome of a cost-benefit analysis. It is inherently messy, and involves probability rather than absolute certainty. As a result, patient autonomy was interpreted by Participant Q as “putting too much emphasis on human rights” and allowing professionals to evade liability, rather than a way to respect a person’s dignity and autonomy.

Third, a clash of expectation over “who should reach out to whom first” between health care professionals and users put the participants in a difficult position with regards to gaining access to health care services. Participants were taught to play a passive role in the health care system back home; taking initiative was interpreted as challenging the authority of health care professionals and ran the risk of offending the “experts”. Participants therefore expected the professionals to take the initiative. With regards to bereavement support, they assumed that it was standard practice for professionals to reach out and take care of them, as the “experts” should be able to figure out what they need and proactively offer them services:

I assume that if someone has passed away, social workers will definitely be following up with family members. That's what I think. I assume that social workers will come visit you and tell you what you need to do. Or for instance, after I gave birth, I got a huge package of brochures that talked about every possible scenario – what's the number to call if this or that happens etc. I would expect the hospitals here to do the same for bereaved families, that they will provide the same kind of information package to them. (Participant E)

Such an assumption, however, is far from the reality of the Canadian health care system. Given the emphasis on patient autonomy, Canadian health care professionals expect health care users to take the initiative in seeking help. The onus is on the users to be their own advocate, to ask questions, to assert their needs, and to actively request services. The misalignment of expectation between health care professionals and users over where initiative lies prevents bereaved Chinese immigrants from receiving appropriate bereavement care, as each side is waiting for the other to make the first move.

## **Life-Sustaining Treatments vs Quality of Life – Knowledge, Experience, and Perception of Palliative Care**

Qualitative analysis emphasizes the discovery of patterns and processes in human experience. Numbers are usually of secondary importance. However, knowing the proportion of participants who reported certain experiences helps establish a context for better understanding of the patterns. As a result, the current section, and the following section on bereavement care, will involve the report of numbers.

### **Knowledge of Palliative Care**

All but three participants were aware of palliative care. Their knowledge of the purpose of palliative care was shallow in general. The majority of participants who knew of palliative care defined palliative care exclusively as end-of-life care, but were unable to elaborate further. Only 10 participants were aware of one or more goals of palliative care: ensuring quality of life, minimizing suffering, preserving dignity, pain and symptom management, and providing family support and time to be together. When asked about the types of palliative care, participants defined palliative care services as “staying in a facility”, such as a residential hospice or the palliative care ward in a hospital. None of them was aware that home care was a form of palliative care, even though 7 participants’ deceased family members had received such care before their passing. Three participants misunderstood palliative care as “*a place that would help with funeral arrangements*”, “*a place where they get you to join a religion*”, or “*having a case manager that controls every aspect of care and makes all the treatment decisions*”.

### **Experience with Palliative Care**

Slightly more than half of the sample reported having experience with palliative care, but the level of experience was highly unequally distributed within the sample, depending on the geographical location of death. Among the 17 family members who passed away in Canada, 14 passed away due to chronic, life-threatening illnesses such as cancer. Among them, all but two family members had received palliative care towards the end of life. In contrast, while 5 out of the 8 family members who passed away outside Canada suffered from a chronic illness, only 1 participant’s family member had received end-of-life palliative care. The types of palliative care services received included hospice

care, home care, home death, in-hospital palliative care, or a combination of these services (e.g., receiving home care first, but passing away at a hospice).

### **Perception towards Hospice and Hospital-Based Palliative Care**

Participants' perceptions of the palliative care services their loved ones received was highly influenced by how well they understood and agreed with the philosophy of palliative care.

#### ***Positive View on Palliative Care***

Participants who felt positive about palliative care were able to understand and accept that there came a point in a person's illness trajectory that active treatment would no longer bring about a cure. Despite their sadness upon realizing this, they were able to shift their goal of care to the minimization of pain and suffering for their loved ones. These participants appreciated that palliative care had allowed them to spend quality time with the patients before their passing. They were able to visit anytime they wanted, and stay together with the patients for as long as they wished. Many were able to fulfill last wishes and create lasting memories:

I was happy about being able to spend time together with my dad. We did a lot of things that we never got to do before. I cut his hair using a shaver he bought. I cut his toenails. I never did that before. There were lots of happy memories (starting to tear up). (Participant J)

My sons are truly great sons. I told them, "Daddy is dying soon. Whatever you want to tell him, don't wait anymore, you need to tell him ASAP." One night, my son told me that he went back to the hospice, held his dad and cried for an hour. He apologized to his dad for being angry and ignoring him before. Of course my husband wasn't mad. My son poured his heart out in the end. (Participant X)

Participants who perceived hospice and hospital-based palliative care positively were happy with the quality of care provided. They described hospices as a "*calm*", "*peaceful*", and "*comfortable*" place. Some praised the hospices' physical environment and layout, such as having a garden outside, private patient rooms, big windows, and separate rooms and kitchens for family members if they needed respite. They also described staff members as "*kind*", "*nice*", "*knowing how to talk to us*", "*knowing how to use humour*", and "*managing the place so well that it wasn't ugly or repulsive at all*". Others noted that they

felt more at ease and reassured knowing that medical professionals were available on site and responsible for providing care. This helped lift the caregiving burden from family members, as many felt that they did not know enough to provide quality care to their loved ones. Most importantly, participants felt happy and relieved when they witnessed how their family members were able to spend the last journey of their lives in a comfortable and dignified manner because of palliative care's focus on quality of life. Participant Q, for example, described how the hospice staff reacted in a respectful manner when they saw the huge tumour located at her father's private area:

When I walked into his room, I accidentally saw his tumour – the way the tumour looked really scared me.....the tumour was huge, like the size of a pomelo. When my dad, who was very, very thin at the time, had a huge, huge, greyish tumour, so huge that it actually pushed his penis upward.....I was so saddened by it. But the nurses didn't make a big deal out of it. They just naturally grabbed a blanket and covered him, so that he wouldn't feel embarrassed.....They just covered him up so naturally, without making a big deal out of it, and continued to talk as if nothing has happened. I felt that this was very respectful and it gave him dignity. It gave me a sense of comfort knowing that the health care workers here would safeguard my father's dignity.

She proceeded to describe how moved the family was by palliative care's focus on symptom management:

I felt that they treated my dad as a human being, not an animal. Towards the end, they told us that they could place a pump in him for pain control. The first question out of my dad's mouth was "Is it going to be a waste on me?" I totally understand where my dad was coming from – "I'm dying already, are you guys allowed to waste all these resources and money on me? Why would you waste so much energy and effort on me, when no one knows what would happen to me in the next month?" I translated what my dad was thinking into English and told his doctor. The doctor said – and I found this very touching – "Yes, it's an expensive procedure, since the pump will be in you permanently. No one will take it back out again, not even after your death. But if this pump can help you, even if it's for 6 months, we think it's worth it." Wow at that moment my heart was melted. I felt that they would do anything for the patient, for his dignity, for his quality of life. This really moved me.

Participant H saw it as a sign of good fortune that her husband managed to receive palliative care before his passing. She saw how much her deceased husband appreciated palliative care, which in turn made her desire the same services for herself:

After getting settled there, he saw that the nurses treated him well, and he got his own room. He finally said to me, "I'm very happy here. I have no other demands. I am happy here. I sleep well at night. I feel at peace." I really like palliative care. I often say "it'll be good if I can receive the same kind of care when it's my turn, if I can meet their criteria for admission." Not everyone can receive palliative care you know?

### ***Negative View on Palliative Care***

For those participants who viewed palliative care negatively, the principles underlying palliative care were in conflict with their health care beliefs and expectations. These participants strongly endorsed the focus on sustaining life at all cost over preserving quality of life found in their home countries' medical systems. They defined health care as a pursuit of cure, down to the last minute and last breath of someone's life. Seeing professionals actively treat and resuscitate their family members helped sustain a sense of hope. As a result, they were unable to understand and accept it when told by health care professionals that curative treatments would no longer be helpful to their loved ones. They refused to believe that nothing more could be done. To them, withdrawal of curative treatment and referral to palliative care was patient abandonment. Palliative care represented professionals "giving up" on their loved ones, refusing to put their best effort into saving their lives, and sentencing their family members to death. It took away their hope that maybe their loved ones' condition would somehow become reversible, or that miracles could happen:

Well when I was in Hong Kong, I had no idea what [palliative care] was. I first got to know about it in Canada. In Hong Kong, doctors would do anything and everything – even at the very last minute, they will continue to save you. Things are different here.....For me, palliative care means that you're hopeless already.....it's basically a death sentence. Things are different in Hong Kong. They'll try their best to save you. But here, once they diagnose you [with a terminal illness], they will not put any effort into you anymore. To me.....or to Chinese in general, it's something we find hard to adjust to.

At the end of the day I can't resign myself to the fact that.....that they would refuse to save her till the very last minute. To Chinese, it means that the doctors have forsaken the patient. I think that way too, that they have forsaken my wife. I feel very despondent about this. It's just different in Hong Kong. They will try their best till the very, very end. You can see it for yourself that they are actively doing things for you. Even if they are just leaving her in the hospital, you still feel like "oh but they're keeping her in

the hospital!" But sending her to a hospice.....in your mind you know that they've announced a death sentence. I really find it hard to adjust to that. (Participant U)

Not understanding why health care professionals would "refuse to save" their family members, these participants tried to make sense of palliative care from a health care policy perspective. They defined palliative care as a money-saving strategy from the government due to scarcity in health care resources. They believed that there must have been an official government or hospital policy to simply give up on patients they deemed "hopeless", such as elderly patients or those with terminal illnesses, so that they could minimize waste and allocate resources to other patients that were "worth saving". Coming from a collectivist culture, however, participants consoled themselves by believing that sacrificing their loved one's lives was for society's greater good:

I think for the most part – and this is how I look at it – the main purpose of palliative care is that they don't want you to occupy a bed in the hospital. It's for diverting people to another facility. To me it's all about the lack of resources. Basically once they give you a death sentence, they want to send you away, so that you're not getting in the way of other patients who need to be admitted. But I think it's helpful to society. In the end resources are limited in society. You're indeed occupying a bed. (Participant U)

So 3 days after surgery, my brother-in-law called me and said that the doctor said "it's over, you guys need to come see your sister for the last time" (Crying). I immediately rushed to see her. My brother-in-law told me that they would need to withdraw life support soon. They also couldn't keep the blood transfusion going as it had no use. Her organs were failing already. I think they stopped the blood transfusion so that they wouldn't be wasting more blood on my sister. (Participant C)

We talked to [the professionals] about it, but they still insisted on not providing any curative treatment, as they claimed that "not providing treatment is better than providing treatment", that "she may not be able to withstand the treatment, which could hasten her passing." I really can't stop feeling that they have given up on her due to her old age. So even before she passed away, everyone had already given up on her when they saw her being so old already. Of course I would want them to improve their services, but in a socialist country like ours, it's very difficult since the budget for health care is not enough. They may want to do a better job but maybe there's this policy.....a policy that says when the patient is old, you shouldn't save him or her.....But I understand their perspective – it's a lack of funding. I don't know.....it's just my guess. I think they will save someone who's young but won't save someone like my mom who was old.....I think that it has something to do with the budget deficits in health

care – It's my feeling OK? – that if you're someone younger, they will put more effort into treating you. If you're old, they'd rather save the money, since to them, "you've already lived long enough". (Participant P)

As a result of their mistrust and disappointment towards the health care system, these participants misinterpreted typical procedures in palliative care that aimed to increase comfort, such as symptom management and withdrawal of aggressive interventions, as a way for professionals and the government to hasten their family members' death:

At the time my mom had multiple health problems. Her family doctor actually cut the dosage of her diabetes medication in half. And when the doctor told us that she wouldn't live past that night, they unplugged everything – oxygen, IV, everything was gone. They kept saying she wouldn't survive till the next day, but in the end she did. I think [the professionals] did this to say "oh if you won't die naturally, we will do something to hasten your death by starving you or dehydrating you". She was like that for 24 hours. (Participant P)

A few hours before my mom's passing, I spoke on the phone with her. Since I wasn't physically there, I could only hear from others after the fact about what happened to my mom a few hours before her passing. My understanding was that the hospice administered an overdose of morphine.....I call it an "overdose"; it's my interpretation. That's why she fell into a coma during her sleep, and then stopped breathing. (Participant V)

Believing that health care professionals had forsaken their family members, these participants felt that they needed to "take things into their own hands", and would go to great lengths to do so. They continued to look for a cure either by pursuing health care elsewhere, such as seeking help from the US or their countries of origin, or by using alternative and complementary therapies such as traditional Chinese medicine. Some even purchased drugs from overseas to administer to their ill family members:

I started to blame [the health care professionals] for this. Why didn't they prescribe any treatment for my mother? She was so old already. Even till now we still believe that the BC Cancer Agency didn't do enough to save her. I think they thought that she was so old already and so they could just ignore her. They didn't prescribe anything for her. My brother is a practising physician in Taiwan. He asked the oncologists over there about the drugs to get for treatment of lung cancer. So in the end we decided to pay out of pocket to get these drugs for her [from Taiwan]. (Participant P)



Taking care of my husband was very difficult. Like visiting traditional Chinese doctors – he would go to anyone that was recommended to him. We might need to go to three different doctors in a day. One of his traditional Chinese doctors gave him over 10 types of herbs. Each of them required a different way of preparation. I had to first pan fry one, then put honey on another, then boil a third one in water, and then steam another one in the rice cooker. Then I had to boil all of them for 2 hours. I then needed to remove two bowls worth of liquid from the concoction, and boil the remaining liquid for 3 hours. But it didn't end there. Three hours later, I had to add two more ingredients, then add back the two bowls of liquid, and boil it for another 45 minutes. I had to keep stirring it too. My husband had to soak his feet since they were always cold. Some of the ingredients for his soak were poisonous, and I had to pre-treat them first. (Participant X)

It is evident from the participants' narrative that differences in opinion on end-of-life care and goals of treatment can drive a wedge between family members. Those who wanted cure and life-sustaining treatments for the patients often blamed the death on the family members who supported the withdrawal of care. Participant P, for example, described how his eldest brother's choice of care for their mother was perceived by others in the family:

When my mom was hospitalized, one of my brothers immediately rushed back to Vancouver. At the time she was in a coma already. Since he's a doctor, he has some medical knowledge. He said that.....since the tumour in her liver had ruptured, he told us that we could inject some medication into her liver and that should wake her up. My eldest brother, however, kept saying "no let's not bother". So my two younger brothers felt that my eldest brother chose to let her die without doing anything to save her. (Participant P)

Participant X's husband suffered from an inherited, aggressive form of muscular dystrophy before his death. At the time, her husband's family members kept pressuring them to seek curative treatment at all cost, including a visit to a remote hospital in Mainland China. Participant X and her husband refused. She no longer kept contact with her in-laws after his death, as she was hurt by a heated phone conversation with her parents-in-law, during which she was blamed for causing her husband's death by refusing to seek medical help from China:

[My father-in-law] was like "Even if there's just a tiny glimpse of hope, you need to go treat this." My husband refused to listen to it anymore, so he gave the phone to me. My mother-in-law then started yelling at me by

saying "Why did you choose to move to Canada? What's the point of that? It's because you guys emigrated that my son ends up like this!" She was taking her anger out on me, "We told you to come back for treatment but you refused! You're just playing Russian's Roulette with my son's life!"

Why didn't they respect our wishes? Why did they insist that we must go to China for treatment? If he had indeed gone to China, I'm sure he would have passed away even quicker. I asked them why they couldn't let us make our own decisions. Why were they so insistent and unreasonable in their way of forcing their wishes on us? They are all educated people. Why did they keep forcing us to do things according to their wishes? I told them clearly what our decision was, but they couldn't take no for an answer. The two elders [i.e., her in-laws] yelled at me as if they had gone crazy.

Even if the patient has expressed their wish to forego treatment, the rest of the family may refuse to accept it and insist on pursuing more aggressive interventions. This creates more pain and suffering not only for the patient, but for the entire family as well. The wife of Participant Y, for example, had been struggling with brain cancer for over 20 years before her eventual death at age 49. Participant Y closed the family business in order to be her full-time caregiver. After being told by local physicians that they were running out of options to treat his wife's brain tumour, he and his wife preferred to forego curative treatments. Their children, however, were unable to accept their decision and begged them to seek treatment elsewhere. In the end, the family took an arduous journey to seek help from a hospital in New York, paying for the expensive travel expenses, hospital bills, and medications by mortgaging their family home. Unfortunately, the treatment eventually failed and aggravated his wife's suffering. Reflecting on this experience, Participant Y considered their trip to New York a traumatizing experience and expressed a deep sense of regret. He felt that they had wasted precious time in a blind pursuit of ineffective treatment, when they could have put whatever remaining time his wife had to better use:

I witnessed how difficult my wife's struggles were towards the end of her life. It was tragic for her. She suffered so much. She made that decision to continue treatment only because her kids begged her to. Those 40-something days we spent in New York.....even to this day my son and I refuse to visit New York again because of this. The painful experience we had there has made us too scared to visit New York again. We were trapped between the four walls in that hotel for 40 days. It was test after test, test after test. The wait was grueling. My wife was in tears all the time, saying that she wanted to leave. It felt like the wait was going to be

indefinite. But then we didn't want to go home with nothing to show for it. That period of time in New York was so painful for us.

I knew it was ridiculous, but at that time I would try anything and everything to try to cure her. But then after what happened to my wife.....I remembered that the social worker at BCCA told me that nowadays people are not trying to pursue longevity or to spend the last few years of your life pursuing a cure. It's meaningless to get an extra year or two. However, it's about accepting that there's no cure, letting everything go, and leading a happy, carefree life during the last few years of your life.

At that time we really planned.....I told her wherever she wanted to go, I would go with her. Even if she wanted to travel, I would go with her. We would go anywhere we wanted – even if we were just camping out in the wilderness, watching sunset together with her would bring me lasting memory and would bring us happiness.....But then in the end it was the kids who kept begging her to seek treatment, who kept saying that they didn't want to lose their mom so soon. They said that we must try our very best to seek a cure for her. That's why we acquiesced. But now I realized that the doctors here were right all along. In the end there really was nothing we could do. When the doctors said that the treatment you seek won't be very effective, it's time to let everything go and focus your energy on doing things that make you happy.

### ***Bereavement Care: Knowledge, Experience, Perception, and Access***

It is evident from the participants' narratives that a lack of knowledge resulted in the largest barrier to accessing bereavement care services for bereaved Chinese immigrants. Chinese immigrants presented with significant information needs as they struggled with a lack of awareness and knowledge in bereavement care and the proper routes to access help. Their information needs, however, had been unmet by the health care system and health care professionals due to a lack of public education and promotional efforts, a lack of consistent and prolonged staff-initiated contact (both before and after the death), a lack of proper, clear, personal and timely introduction to existing services by health care professionals, and the professionals' lack of awareness on culturally appropriate services available in the community. A mismatch in timing between the emergence of need and the availability of services further deterred bereaved Chinese immigrants from seeking help. The interplay between health care users and professionals, in which both parties failed to recognize and meet each others' expectation and needs, had led to significant gaps in services and inequitable access to bereavement care for Chinese immigrants.

## **“We Don’t Know What Bereavement Care Is!” – Participants’ Lack of Knowledge in Bereavement Care**

Participants unanimously identified a lack of knowledge in bereavement care as the biggest obstacle preventing them and other bereaved Chinese immigrants from accessing bereavement care services. They described three dimensions to their “lack of knowledge”:

### ***Not knowing bereavement care exists***

The first dimension is a lack of awareness, or a lack of knowledge on the *existence* of bereavement care services. As previously discussed, participants emigrated to Canada from regions where bereavement care remains unknown or non-existent. It is not surprising to find that compared with palliative care, participants had significantly less awareness and knowledge in bereavement care services. Sixteen out of 25 participants (64%) said they had “*never heard of*” bereavement care services. Interestingly, among these participants, 10 had actually received some forms of bereavement care services in Canada but never realized that such services were a form of bereavement support provided by the health care system.

For the remaining nine participants who said they knew about bereavement care services, one participant did not know about bereavement care until after enrolling in the current study, when she was informed by her sister about these services during a phone conversation. Two participants were health care professionals themselves and as a result had heard of bereavement care. Four reported having no awareness of such services until learning about them for the first time from the author’s radio shows. Among these four participants, one had actually received more comprehensive bereavement care support from the hospital with pre-bereavement care and regular post-death follow-up, yet she never made the connection that they were bereavement care services. In the end, only two participants learned about bereavement care from information provided by health care professionals before the death of their family members.

All of the participants, regardless of whether they had received professional support for their grief, said that they and/or most people in the Chinese community “*have no idea such services exist*”. Coming from regions where professional support after the

death of a family member is unheard of, participants did not have the concept of “bereavement care” nor an expectation for professional help after the loss of a family member. Many participants said that they “*could never have imagined that such services exist*”. As Participant P explained when asked about why she and other Chinese seldom access bereavement care, “*When I don’t even know that such services exist, how can I access them?*” In fact, those participants struggling with significant grief yet never sought help said that if they had known about the availability of bereavement care before, they would have participated:

Actually it was after I heard your show on the radio (laughed).....I started thinking about it after listening to what you said, and realized that “hey, actually these services could be really helpful”. But at the time [when I was grieving] I didn’t know such services were available. It’s really after hearing you talk on the radio and knowing about these services, I started thinking about them and realized that they would have been very helpful. But 2 years ago we had no idea. No one told us about any of this 2 years ago. (Participant F)

It's a matter of knowledge. If I had known that such services exist, I would have found it to be a good source of support. I would have participated. But I didn't know about them. (Participant O)

### ***Not knowing what bereavement care is***

Participants’ lack of knowledge also pertains to not knowing the nature of bereavement care i.e., what bereavement care entails. Since the majority of participants were not aware of bereavement care, they were asked to speculate on the purpose and nature of such services. Their answers revealed that their knowledge was limited. They defined bereavement care only in terms of “offering emotional support”. They thought that bereavement care only entails therapeutic-focused interventions such as support groups or psychotherapy. For those who were aware of bereavement care, their knowledge of the purpose and nature of such services was limited in scope as well. Similar to those who had “never heard of” bereavement care, participants who were aware of bereavement care also defined bereavement care services exclusively as “counselling” or support groups for emotional support. None of their definitions included anticipatory grief services and/or follow-up services such as planning for loss, staff-initiated contacts, or educational materials on grief and ways to contact support services.

### ***Not knowing how to access bereavement care services***

Finally, participants reported a lack of knowledge on the steps to take to access bereavement care services. They noted that they would have no idea where to begin if they were asked to seek bereavement support. They did not know which organizations offered help, what resources were available, what routes to take to obtain more information about available services, or whom to approach in order to gain access to care. Even the two participants who were health care professionals admitted that although they knew of bereavement care, they had no idea what organizations to contact and how to access services. Participants reported that they did not know what these support services were called, since the words “bereavement care” did not exist in their vocabulary. As a result, they had no idea what to search for if they were to look up information about it:

Well no one knows about these services or ways to access them. Even if you know such services exist, you will not know the ways to look them up or to access them. To me that's the biggest difficulty. You can't even Google it on the internet when you can't even tell the search engine what to look for, since you don't even know what keywords you should enter into the search box. You don't even know where to start! (Participant F)

Participants reported feeling lost when navigating the Canadian medical system to gain access to bereavement care due to their lack of knowledge on the availability of resources and ways to seek help. They attributed their lack of knowledge and resourcefulness to their status as first-generation immigrants to a new country:

Honestly I have no idea what organizations to approach to get help. As an immigrant from the outside, I don't really know what organizations here are responsible to do what.....for instance, if I were still in Hong Kong.....I grew up there, so I would know what organizations would be available, who I should approach to get help, what phone numbers I should call, who would be the people that can help.....but emigrating to a brand-new environment, I really have no idea who to approach in order to seek help. For immigrants like us, there are many things that we need to adjust to when we move to a new country; there are lots of things that we just don't know about. If you ask me to access bereavement care, I don't even know what phone number to call. I don't know what that department is called in English. I don't know if it requires a doctor's referral. I don't know how to look for them, who to look for, which organization is closest to my home and the most convenient to access. How do I even go about doing it – Do I just walk into the place and say "Oh I'm very sad, I need help"? (Participant C)

## **“No One Ever Told Us about or Offered Us Bereavement Care Services!” – Health Care System’s Failure to Satisfy Participants’ Information Needs and Gaps in Service Delivery**

Participants’ descriptions of their interactions with health care professionals and their bereavement experiences reveal that the significant need for information in bereaved Chinese immigrants was not recognized or addressed by the Canadian health care system. The most frequent phrase used by the participants was “*no one ever told us about this*”.

By “*no one*”, participants were describing two major sources of information that failed to educate and introduce them to bereavement care services. First, participants were frustrated by the lack of public education and promotional efforts regarding bereavement care services in the Chinese community. They believed that many bereaved Chinese individuals were silently suffering and were desperate for information on available support services and ways to access them. They also noted that Chinese immigrants mostly relied on Chinese-language media in Canada, seminars offered by Chinese-speaking professionals at community centres or immigrant services organizations, as well as word of mouth to obtain health-related information. Yet they could not find any information regarding grief and bereavement care from Chinese newspapers, TV or radio. Those who had attended Chinese community health fairs noted that bereavement care services had never been a part of the program. Participants noted that the lack of public education and promotion on bereavement care perpetuated the lack of knowledge and low health literacy among Chinese immigrants. They felt that if the whole community were kept in the dark regarding the availability of bereavement services, they would be unable to educate and encourage each other to seek help.

Second, participants reported a lack of proper education and introduction to bereavement care services by health care professionals. In general, participants’ experiences with being introduced to or offered bereavement services by professionals were highly inconsistent, depending on the locations of death and the age of the deceased.

Staff-initiated pre-bereavement support (for those whose loved ones suffered from chronic, life-threatening conditions before death) and bereavement follow-up care can be

considered “front-line” bereavement care services. Through these services, bereaved (or soon-to-be-bereaved) family members are, often for the first time, educated about grief, introduced to available bereavement support services, and provided with information on ways to access care if needs arise. Pre-bereavement support and bereavement follow-up also serve an important “gate-keeping” function, as professionals can use such contact to assess family members’ functioning, so that they can decide whether more intensive follow-up, referrals, or formal bereavement interventions are necessary.

For the eight participants whose family members passed away outside Canada, no pre-bereavement support or staff-initiated bereavement follow-up was ever provided to them or other survivors. Participants noted that offering bereavement support was not a standard practice in their countries of origin’s health care system. They also reported that even if they were referred to therapeutic interventions such as support groups or psychotherapy, they would not have been able to participate anyway since their stay in their countries of origin was not long enough for them to seek help there. Upon their return to Canada, they did not expect local organizations to provide them with bereavement support, since they 1) did not know such services exist in Canada, and 2) assumed that only those who lost their loved ones in Canada would be eligible for such services.

For the 17 participants who lost their family members in Canada, it is evident from their experiences that pre-bereavement support and bereavement follow-up care had not been consistently provided. Six participants said that they had never received bereavement support before or after losing their loved ones. These participants had never been approached by professionals and informed of the existence of bereavement support services. They never received any educational materials or information packages from the hospitals or hospices. No one ever called to follow up and check in with them after the death of their family members. In fact, the death often marked the end of contact from health care professionals. Despite the lack of support and follow-up contact by health care professionals, three participants initiated post-death contact with the professionals themselves, either by paying a visit to thank them for their care, or by making a donation to the facilities. Since participants never expected bereavement care services to begin with, the lack of contact and introduction to services by health care professionals reinforced participants’ belief that bereavement support did not exist.



For the remaining 11 participants who had received some form of bereavement care services, their experiences with bereavement support differed depending on the age of the deceased family members. Participant I, the mother of an 8-month-old child who died of cancer, is the only participant in the entire sample who had received comprehensive bereavement support services that began before her son's death and continued for an extended period of time post-death: an assessment of her emotional functioning and bereavement needs prior to her son's death, pre- and post-death informational support such as provision of brochures on grief and therapeutic services available, and regular follow-up contact via mail and invitation to annual memorial services after the death had occurred. However, she declined these follow-up services after her son's death due to relocation to another province.

Compared with Participant I, the other 10 participants whose deceased family members were adults reported limited experiences with bereavement support pre- and post-death. Even though the family members of nine of these participants passed away due to chronic life-threatening conditions such as cancer or degenerative neurological disorder, only one recalled receiving some limited staff-initiated pre-bereavement support – a social worker provided him with some brochures on funeral arrangement and a list of available support services before his wife passed away from cancer. In addition, one participant noted that even though the staff never initiated contact or offered bereavement support to her, she came across information on grief and bereavement by chance prior to her family member's death, as she saw some educational pamphlets lying around at the hospice and took one to read.

For others, the pre-bereavement contacts they had with professionals pertained mostly to patient care only. The information provided to them by health care professionals focused exclusively on the end-of-life care for the patients. Participants recalled that the information they received mainly surrounded ways for them to care for the dying patients (e.g., how to administer analgesics or to provide breathing support at home, or how to take care of the patients' daily needs). Participants therefore felt that they were only seen as caregivers rather than someone who was going to suffer the loss of a family member. Health care professionals paid little attention to their needs and wellbeing as survivors, and provided no information to prepare them for the death and its aftermath:

I remember reading some pamphlets in the palliative care ward. They talked about home care and services provided if the patient moves home instead of staying in the palliative care ward. They were mostly about how to take care of the patient, but nothing about the care for surviving family members after someone's passing. So all I've read about was support services for patients under hospice home care. I don't know that there are actually support services for surviving family members as well. (Participant H)

We received nothing at all. Even when we were at the hospital, or at the hospice.....I think someone came to talk to us, but it wasn't about services for us. It was only about palliative care for daddy – how they would take care of daddy, the kinds of services they would offer. We didn't receive any information about us as family members. (Participant N)

The hospital trained me to be [my wife's] caregiver – changing her sheets, helping her get up, changing her diapers. But they never told me anything about what would come AFTER. They only focused on the things that would happen BEFORE – the care before her passing, all the things I need to do, the day-to-day caregiving. (Participant Y)

With regards to bereavement follow-up post-death, these 10 participants reported highly diverse experiences. No follow-up was provided to the participant who discovered the educational pamphlets by chance prior to her loved one's death. The remaining nine participants received limited bereavement support confined to a single follow-up attempt only.

It is evident from the participants' narratives that they had never been properly introduced to and educated about bereavement care services by health care professionals during follow-up contacts. Among those who had received some bereavement follow-up, for example, five can be considered "passive recipients of care" – bereavement follow-up services were provided to them without their prior knowledge, consent, request, or even participation. These follow-up services tended to be "compassionate" in nature, that is, the follow-up contact was intended for the health care professionals to show care. The follow-up activities included receiving one brief "welfare check" phone call from staff, receiving one sympathy card in the mail, staff attendance at the funeral, or being notified that the hospice lighted a commemorative candle for the deceased. Since the purpose of such services was for health care professionals to show care, the professionals were the ones who decided what and when services would be provided, and initiated the services at their discretion. Often times the "contacts" the participants received were merely "notification of

services performed” – being told that a candle was lighted, seeing staff members show up at the funeral without being asked, or receiving a sympathy card in the mail. The only thing the participants could do was to accept these services. Yet at the same time these participants were never told that bereavement follow-up was to be expected; none of them knew beforehand that there would be further contact from health care professionals after their family members’ death. They therefore failed to recognize such staff-initiated follow-up contact as a form of bereavement support because they had never been informed so. The contact with staff was usually brief (e.g., one quick welfare-check phone call) or indirect (e.g., sympathy cards). Since the purpose of these contacts was never explicitly explained to the participants, misinterpretation ensued. For instance, those who received follow-up phone calls thought that the call was for the professionals to close the patient file rather than to show care. As a result, they kept the phone conversation brief and nonchalant, never disclosing to the callers how they truly felt about the loss.

On the other hand, four participants received bereavement follow-up intended to provide information on other bereavement support services that required their active participation. Two recalled being told by a professional in person that grief counselling was available after the death of their loved ones. One received a letter inviting her to attend the hospice’s annual memorial service. The participant who received brochures from a social worker prior to the death of his wife also received brochures from the hospice containing information on available intervention programs after her death, and was verbally told that the hospice held support groups for the bereaved. However, these participants felt that health care professionals had overestimated their’ pre-existing knowledge on bereavement services. As a result, professionals simply **informed** them of the availability of services, rather than **educating** them on these services. For instance, those who received information on counselling and support groups were only told of these services’ existence, but not their purposes, nature, and benefits. The participant who was invited to the annual memorial service by mail recalled that the letter never explained what the “gathering” was for. Since she received the letter in December, she assumed that she was invited to a Christmas party and therefore declined to participate. Follow-up contact with staff members was also described as brief, narrow in scope, and ill-timed. The two participants who were approached by professionals in person were told about grief counselling without first being assessed to determine if they truly required therapeutically

focused interventions. They were led to believe that psychotherapy was the only form of bereavement support available since they were not introduced to other available services. One of the participants was approached by a nurse during her own hospitalization after a suicide attempt. The other participant was quickly notified of the availability of grief counselling in the hospital hallway, at a time when the family just decided to withdraw life support. As a result, these two participants were unable to retain the information presented to them as they were too distressed and distracted during the conversation with hospital staff.

In addition, a common experience for the three participants who received information on bereavement interventions was that – after being told that counselling or support groups for the bereaved existed, they were immediately told by health care professionals that such services were only offered in English, even though Chinese-speaking services were actually available through a number of community-based agencies and mental health professionals in Greater Vancouver. As previously discussed, participants expressed a need for working with “one of us” if they were to receive bereavement care – a professional who shares the same Chinese dialect, similar immigration history, and similar cultural background, in order for bereaved Chinese immigrants to break through linguistic, communication and cultural barriers. To these participants, being told that bereavement support was only available in English was no different from being told that support was unavailable to them:

When I was in the hospital, a nurse gave me some information about some organizations we could go to seek counseling. However, the nurse told us that the services were all in English and so I didn't go seek help.....The nurse told me that no one knew how to speak Chinese in these organizations, and that's why I didn't go. I don't know English at all. If they had told me, at the time, that there was Chinese-speaking service available, I probably would have gone to seek help there. But when the first thing out of their mouth was “English only”, I immediately thought to myself “well then there is no point for me to consider this”, and I would not continue to follow up on this. (Participant A)

The person who talked to us was a “Westerner”. To me, no matter how hard I try to express my feelings and thoughts to a foreigner, I will not be able to do it in a comprehensive manner. I don't think he or she will be able to understand what's deep within my heart. Or maybe he or she is trying to teach me what to do – but I may not even understand what he or she is saying since it will be in English. I asked if such services were available in

Chinese. That person said no, that everything was in English only. (Participant C)

The hospice mostly served “Westerners”. At the time they told me that there were “groups”. They also gave me some information, printed on one or two pieces of paper. They told me that I could join these groups, to have a discussion, to share information.....the group would have 6-7 people, all bereaved, and we would chat. But they were all in English – the groups were in English, and so were the informational leaflets. I mean, everyone who worked at that hospice was a Westerner. (Participant U)

As a result, none of these participants accessed the bereavement interventions suggested to them by the health care staff.

### **“The Timing is Wrong” – Mismatch in Timing Between the Emergence of Needs and the Availability of Bereavement Care Services**

Participants perceived an issue with “wrong timing”, as they noted a mismatch between the time when they needed bereavement care services the most, and the time when support services (if any) were offered to them. A common theme in the participants’ narratives of their bereavement is the delayed onset of grief emotions. They described feeling “*fine*”, “*strong*”, and “*rational*” immediately after the death of a family member, as their minds were occupied by funeral arrangements and settling their loved ones’ affairs. Being busy and task-oriented kept their emotions at bay. Participants therefore had a poor gauge of how intense their grief was and how well they could cope with the loss, as many described feeling “able to handle it” at the time:

In order to [bury my mother next to my father], the three of us (i.e., the three surviving children) did a lot of running around trying to get a lot of things done. So at that time we had no time to feel sad over it, or to have any thoughts about it. The three of us only talked about what we needed to do, but not how we felt. There was no tear, no sadness.....even during my mom's funeral service, we held it at the church.....yes we did cry, but during those few weeks, all I did was to throw myself into the funeral arrangements, doing my best for mommy. (Participant L)

At that MOMENT we appeared that we could handle it, like my brother-in-law.....it's been 2 years already, but he's still very sad. Maybe at that time when it happened, he was indeed able to handle it, cos' it looked to me that he was so rational, that he was so calm and tackled this in such an organized, step-by-step manner, thinking about the TASKS that he had to do. (Participant C)

I think I was more rational back then. I thought that I would be able to survive this. But.....well during the 6 months after, I was very busy. Funeral, CPP, death certificate, pension.....just lots of things to deal with. During those 6 months I actually felt very strong. Looking back – and it's almost 2 years now – I was better at handling it during the first 6 months. Maybe it had something to do with how many things I had to deal with at the time. I was busy with the house, busy with my daughter.....so many things. I was able to get past the first 6 months because I was so busy, and there were so many things that needed me to handle them – things that I had to handle in person, or via the phone. So many things. I think that occupied my time. It made me feel less lonely. (Participant U)

Given their false sense of wellbeing and ability to cope, participants naturally concluded that bereavement support was unnecessary to them. They were so focused on settling the affair of their loved ones that they had no time nor space to think about their own needs. To them, seeking bereavement support was not their priority at the time. Yet bereavement follow-up contact with surviving family members from health care professionals, if offered, usually occurs during the immediate period of time that follows the death. As a result, participants admitted that they, and likely most Chinese, would have told the professionals that they felt fine and did not require any further support services if they received follow-up contact during that time:

A nurse did call me up to follow up [after the death], asking me how I was doing. Just one phone call. At that time I really felt OK, so I just thanked her and left it at that. (Participant V, who received a follow-up phone call from the hospital after the death of her mother)

I really didn't pay attention to it at the time. I was too busy, and that never crossed my mind. I was just dealing with it one day at a time – I will deal with it when it happens. I only took a quick glance at the brochures. At the time that wasn't my biggest concern, since I was so busy with other things and didn't have the room to think about these things. At the time I felt that I would be able to survive this. I was just trying my best to put up with it. (Participant U, reflecting on the brochures on grief and bereavement services he received after the death of his wife)

After someone passes away, the survivors often do not have the time or the mental state to think about getting support. All they can think about is to prepare for the funeral and to settle everything. They never have the quiet down time to think "oh I need counselling". This is not their priority. (Participant M)

If you reach out to them shortly after that incident (*euphemism for death*) happened, they likely will tell you they're fine at that moment. (Participant E)

The onset of grief was insidious for a number of participants. They were taken by surprise when grief hit them in full force after "the dust had settled". They noted that it was after the funeral, when all the practical matters had subsided, that they finally had the time to reflect on the loss. Their mood began to deteriorate, as emotions such as sadness, yearning, and regret finally emerged. The physical absence of their deceased family members in the house they once shared made the participants realize that their loved ones no longer existed, life was no longer the same, and nothing could ever fill the void they left behind:

So everything went smoothly when it came to funeral arrangements. But when everything was settled, you suddenly realize that you miss her as you've lost this person forever. (Participant M)

What was strange was – when I was in Hong Kong dealing with her funeral arrangements, I actually felt OK at that time. I felt relieved since I felt that she no longer needed to suffer. It's like she finally freed herself from the pain and suffering. I was happy for her, cos' she no longer needed to suffer. This sense of loss wasn't particularly prominent at that time. But the sense of loss appeared after the funeral was over, when I started reflecting on what had happened, and asking myself whether there was anything more I could have done, or whether I could have done these things earlier.....maybe her quality of life would haven't been better. (Participant L)

That period of time right after someone has left.....initially you feel fine. During the first month you are so busy, so busy to the point that you get dizzy. After the funeral arrangements and settling the person's affairs, you finally get a break. So you really feel that nothing is wrong during that period of time. You may feel relieved. You may think to yourself "well yes my wife is no longer here. Maybe I can finally relax a bit." But then after you feel relaxed, you feel empty. Once you realize that there's this void in your life, you start getting depressed. But then no one is around to console you, to help you look at it from a different perspective, to help you resolve this. You can't find a solution. This gets more serious when you get to the 3rd or 4th month after the death of your loved one. And these symptoms get insidiously worse. Initially you don't really realize how serious they are. But then you may be taking a stroll outside and see another couple walking together, but you're walking alone. You see that they have white hair already but they still get to walk together. They get to spend lives together when their hair turns white. But you don't get to do that yourself. That's when these feelings gradually become more and more severe. Then finally

you get to a point when you can no longer stand it. (Participant Y, reflecting on the death of his wife)

Participants' delayed grief led to a delayed realization of their need for formal support and a delayed effort in seeking help. Yet at the same time, any staff-initiated follow-up contact with the surviving family members would have ceased by then. Contrary to the recommendation in the literature which encouraged multiple contacts over a longer period of time (e.g., 1 year post-death), participants' experiences with bereavement follow-up care, if offered, were in the form of a limited, one-time contact immediately following the death. If participants had refused further follow-up or did not respond when the professionals contacted them for the first time, they would have missed the only opportunity to receive staff-initiated bereavement support. Participants were then left to seek help themselves without professional guidance, at a time when they were struggling with low mood and intense grief. As a result, participants often ended up with no professional support at the time when they needed it the most:

I've tried so hard to look for help but I couldn't find anything. I think health care professionals only focus on the care before someone passes away. After my wife left, every professional broke off contact with me. I had no idea where to seek help. I had no idea what I should do. I had no direction at all. (Participant Y)

When it was over, when the dust has settled, that's when the emotions deep in one's heart emerge. That's the time you need to express these feelings, to let them out, but I never had a chance to. (Participant C)

When you are grieving, you won't take the initiative to go look for services.....When it happens, you feel utterly shattered. So whatever is offered to me at the time I need it will be whatever I'll receive.....When we are at our lowest, don't expect us to call around and look for services ourselves. That's actually the moment that we need support the most. You don't even have the motivation to pour yourself a glass of water at that moment. (Participant N)

Even if [support] exists, if it's up to me to reach out to them.....when I am already feeling crappy? If someone takes the initiative to reach out to me, I may accept that. But if I am already feeling so bad, and yet I still need to take the initiative to search for help from outside organizations? I don't think anyone would do that. At least I won't do that.....I can't do that given how badly I felt at the time. (Participant R)



### **“If You Want Something, You Have to Ask for It, and Ask for it Correctly” – Who Received Professional Support for Bereavement in the End?**

In the Canadian health care system, initiative lies with those who need help. Those who want help are expected to take the first step by “seeking help”. In the current study, quantitative data revealed that 17 participants (68%) scored above the clinical cut-offs on measures of depression and/or anxiety, suggesting a level of symptomatology that was likely significant and warranted further clinical investigation and possibly treatment. Among them, however, only eight participants (32% of the sample) took some form of initiative to seek formal help. In the end, 5 of these 8 participants (20% of the sample) received formal therapeutic support for grief from professionals. In addition, two participants who did not report significant depression or anxiety symptoms during the meeting with the author said that they had taken the initiative to seek help for their grief at the time when it was the most intense, but only one received formal support.

Participants’ narratives of their help-seeking experiences suggest that it is not enough to simply “take initiative”; the nature of such effort predicts eventual success in receiving formal support. For those who had taken the initiative to seek help, three different types of initiative were evident. First, some participants were already under the care of a mental health professional, for reasons unrelated to grief, at the time of their family members’ death. For them, initiative took the form of asking for “add-on services” i.e., having their therapists or psychiatrists add therapeutic support specific for grief during their regular appointments. Second, some participants sought help from their family physicians, who diagnosed them with major depression and/or an anxiety disorder and subsequently referred them to either psychiatry or community-based mental health organizations for psychotherapy. Third, some participants described an “informal”, nonspecific, and haphazard way of seeking help. For these participants, their “initiative” consisted of brief, random searches on the internet, checking bulletin boards in community centres or public libraries to see if help was available, or visiting hospitals in the hope of running into professionals that could provide help. A closer look at the data suggests that how one takes initiative makes a difference. Those who managed to receive help for grief in the end tended to be those who were already receiving mental health services, or those who knew that they needed to directly approach their family physicians for diagnosis and referral. Of the seven participants who displayed such effort, for example, all but one

managed to receive formal bereavement interventions from health care professionals. In contrast, those who used a more random, indirect and ineffective way of seeking help all failed to receive professional help for their grief.

### **Core Concern: Bereavement as a Lonely Journey**

Multiple factors at multiple levels – culture, immigration, and health care system – interact and prevent many bereaved Chinese immigrants from accessing bereavement care services. Their absence or non-participation in such services, however, are often taken as a sign that bereaved Chinese have received adequate naturally occurring social support from family and friends and therefore do not need agency-provided support from the health care system. Yet for all of the participants in the current study, the most frequent way they described their grief experience was how lonely they felt in the journey of bereavement. Their profound sense of loneliness is exemplified by quotes such as “*no one has supported me*”, “*I am facing this alone*”, “*I have no one to talk to about this*”, “*I can only rely on myself*”, or, as Participant D eloquently put it, “*I feel like I’m the only soldier fighting this battle*”. Participants’ narratives revealed three major dimensions of their loneliness: physical, social, and existential.

#### ***Physical Loneliness***

Physical loneliness pertains to participants’ sense of solitude due to the physical absence of the loved one who has passed away. It reflects the end result of death – the deceased has ceased to exist, and the departure is permanent and irreversible. This feeling is most pronounced among participants who had lost their spouses, and those who used to reside with their now-deceased parents. Many now felt alone in the house. The house became a constant reminder of the time they used to spend together, and the fact that their family members were “no longer here”. This gave rise to a sense of “incompleteness” among the participants – that the death of their family members left an unfillable void in their lives:

When I'm home, when I read [my husband's] writing.....I still keep the chair he used at our dining table. I sometimes sit in his chair. When we have dinner now, his seat is empty. I just feel incomplete.....A piece of the puzzle is missing. A part of my day is missing. Something is missing. (Participant H)

My first feeling is – it's so obvious that someone is no longer here. It used to be my dad who yelled from upstairs telling us to come down for dinner while my mom was cooking. All of a sudden I feel this sense of loss. Another thing is – there's no longer a male voice in the house. Before my dad's passing, whenever we came home, we would hear my dad watching TV upstairs. Now there's no longer any noise from the TV upstairs. Something is missing.....my house wasn't bustling with activities to begin with. Now it feels even more desolate. (Participant J)

Everything in the house has quieted down. In the past, when I got home from work every day, my dad would have prepared dinner. I could complain to him. I could talk to him about anything. But now this no longer exists. It's as if this regular programme on TV has been cancelled (crying). My dad loved reading and watching movies. So whenever I had questions when I read or watched movies, I knew that I could ask my dad and he would readily give me an answer. My sense of loss has to do with – even if I open my mouth now, no one will answer me. (continued to cry, paused for 30 seconds) (Participant Q)

I was in that house all by myself. I was sleeping on my mom's bed – we got a new mattress but it was the same bed. And I was alone.....before, I would buy lots of food, and mom and I would watch TV together. Now I was just by myself. And at that particular moment I was thinking "Mommy was supposed to be sitting on the sofa, right beside me. We should be eating popsicles together, or eating papayas together".....and she would have been so happy.....These memories just all came back out.....Now I still have these feelings whenever I'm alone. I feel lonely. It's not helplessness, but loneliness. I will think to myself "oh so this is how loneliness feels". In the past I have never felt this way. (Participant D)

Participants reported feeling bizarre that their lives went on while their loved ones' lives did not. Being alone often led to the perception that they were left behind by the deceased. A number of participants noted that their family members had "the easy way out" by dying, as the survivors were the ones that truly suffered:

I often talk to [my husband's] picture. He was smiling in the picture. I sometimes said to him "You must be happy now, but I'm the one suffering. I'm the one you left behind." (Participant H)

The surviving people are the ones who suffer. Dying is not painful. We who are still alive are the ones suffering. (Participant I)

The way I view death is.....like, when I go to funerals now, I seldom cry. I don't feel sad towards the dead. I only feel sad towards those who are still alive, those who need to be taken care of. (Participant S)

Feeling that they were the ones abandoned on Earth by their loved ones, participants believed that they had no choice but to continue to live life “as usual”, even though life had become a painful experience they were forced to endure:

I have no choice but to survive. I need to keep living. Being alive is a painful experience for all of us, and everyone is crawling towards death anyways. Just that some people get to the finish line earlier than others, and people like us may need to crawl and crawl for a long time until we get there. All we can do is to keep crawling (laughed). (Participant I)

I told my dad that I would continue to live my life as usual.....(paused for 5 seconds, tear up, voice shaking) “Of course I'll miss you, but I'll carry on as usual.” I have no choice but to accept reality, and continue on my life journey. I have to continue to live my day-to-day life. I can't break down and cry in the middle of work. I have to get to work early.....A day will go by quickly just like that. When I get home at night, I grade assignments. I watch TV. That's a wrap. (Participant J)

The physical absence of the deceased family members also meant that the participants had to “pick up behind them” and assumed the roles their loved ones used to play. The stress and burden related to role transitions further reinforced the participants’ sense of loneliness as they were left to take over new, unfamiliar tasks without the company and guidance of their deceased family members:

Since my mom has Alzheimer's.....when my dad was still here, he was the one who bore the brunt of her illness, whereas we kids were the ones that made fun of her. In front of us, my dad would embellish or tone things down a bit. But now my dad, who had shielded us from the truth, is gone. We kids now bear the brunt of my mom's aggression. So it feels as if I have changed the channel on my TV, and am now watching a different TV programme. I am now the one to cheer my mom up. I don't know what my dad did to make her happy.....now it feels like it's a different way of relating to her. (Participant Q)

I was quite dependent on [my wife]. She made all the decisions.....I really had no opinion of my own. All the decisions were made by her. I was responsible for household chores, but she was the one who instructed me to do them. After she left, I became “lazy”.....I had no motivation. It's like I've lost the locomotive – I've lost the drive to do things. My wife was the primary caregiver. She had a closer relationship with our daughter than I did. After my wife passed away, this adjustment period between me and my daughter had created a lot of headache for me. She didn't talk about it, and I didn't either. We kept our silence. Some of my friends told me to communicate with my daughter more, but it's difficult for me since we didn't talk much before. (Participant U)

Last year, my daughter got pregnant. You know often times mothers would be there to take care of their pregnant daughters, but since her mom was no longer here, I needed to learn how to take care of my daughter as a father. My life practically revolved around my family – taking care of my daughter, learning how to make soup, asking others how to take care of my daughter after she had given birth.....these are things that my wife would have done in the past.....and I had to learn from scratch. Then I would think to myself, "If my wife were still here, this would have been what a mother would do". But now that my wife is not here, I as the father will need to adopt her role to take care of our daughter. (Participant Y)

### ***Social Loneliness***

Social loneliness refers to participants' perception of the absence of an engaging social network to offer help and support during bereavement. Participants described two elements in their experiences of social loneliness: 1) loss of social network, and 2) nonexistent to inferior support from their social networks.

### **Loss of Social Network**

Some participants reported a loss of social network due to immigration, isolation, and social withdrawal. Participants whose family members (mostly parents) passed away outside Canada regarded their siblings and other members in their families of origin as a major source of support. The process of immigration, however, had led to geographical dispersion of family members. These participants often reported that they were the only ones in the family residing in Canada; others in the family either still resided in their countries of origin, or had emigrated to other countries in the world. While participants tried maintaining contact via technology (e.g., phone, email, or Skype) or short-term visits, geographical distance made it impossible for them to immediately attend to each other when support was needed. "Not having family here" made participants feel lonely as they needed to deal with grief by themselves:

When I was in Hong Kong dealing with [my mother's] funeral arrangements, I was able to see my relatives again at the time, and I was able to spend a lot of time together with my family. I was actually happy about that at the time. After I came back to Vancouver by myself, I often felt lonely (crying). Cos' I have no family here. This sense of loss wasn't very intense when I was still in Hong Kong, but after I came back, and when things happened to me and I started feeling lonely, I naturally started to think about my mom (crying) (Participant L).

I realized that I have no one else in this world – I no longer have a dad, and I no longer have a mom. I only have my sister left, but she's in Hong Kong. And I am single. Being alone in this world is a very scary thing (Participant W).

Participant W further explained that due to geographical distance between her and her sister, she was reluctant to open up to her sister for fear of burdening her:

I will keep telling myself not to think further, as this will create too much trouble for others. My sister is also single. I remember she asked me not to [harm myself]. She said, "If you keep thinking this way, what's gonna happen to me?" I don't want my sister to be worried. Like, all these emotions I had, all these thoughts – I won't share them with my sister cos' I'm here and she's there. She's already very worried about me. I don't want her to be more worried.

Some participants longed for contact with others after their loss, but quickly realized that their social network no longer existed. This is commonly seen among those who needed to take care of their sick family members before their eventual death; caregiving resulted in social isolation. Participant Y, a widower who took care of his wife for over a decade before she passed away, found that he had lost all his friends because he was unable to maintain contact with them due to his caregiving duties. Despite his desire to reach out to others for help, he had no one to talk to:

After my wife had left, I was in so much pain. I was so upset. I locked myself inside my home for over a year. I lost all my friends during the time when my wife was sick, since I couldn't go have lunch with them, I couldn't go play golf with them, I couldn't go play mahjong with them.....every time when they invited me to do something, I couldn't make it. Eventually I lost all my friends since I had no time for socializing. As a result I have no friends to talk to about this sense of loss. I have no one that I can socialize with. Not even one person.

On the other hand, some participants observed that they had become socially withdrawn after the loss. They had lost all interest in socializing due to low mood:

When I came home from work, when I finally sat down, I didn't even want to pick up the phone when it rang. People were asking where I was. I didn't answer the phone. I hid in my room. I didn't want to go out. I didn't even talk to my sons. I went straight to my room after dinner. I would hide in my room, watching TV or sitting in front of the computer. Honestly there were times that I wasn't watching anything in particular. I was just staring at the

TV or monitor.....Even when people were calling I couldn't wait to hang up; I would keep the conversation superficial. Those who called said "well it's obvious that you don't want to talk". Well I indeed didn't want to talk. It wasn't like that in the past. I could chat for hours on anything and everything. I also stopped going out with people. This is very important. In the past, every Sunday, I would go to church with friends. After church we would hang out, eat.....now I don't even go to church anymore. I want to be alone. I don't want to see anyone. I don't want to talk to them. I don't feel like socializing at all. (Participant D)

Participant U described his inner struggle trying to combat the compulsion of wanting to withdraw from the world after losing his wife to cancer:

I know that I must.....I need to go to church more. I need to see more people. But then my mood is.....maybe you can call them my "inner demons". They often get in the way and block me from going out to see other people. I would try.....and since my daughter goes to church too, this forces me to go. It pushes me to go. But then I have all these excuses for not going. "Oh I'm feeling a little bit sick, so I won't go." Then my church friends will call and ask how I was doing, why I didn't come, etc. So I will push myself to make sure that I must show up. But then if my daughter is going to church for her own activities, where it's just her and her friends, I'll use it as an excuse not to go.

Participant Y explained the vicious cycle involving grief, social withdrawal and loneliness:

When [your grief] gets more serious, you naturally want to go in hiding. In the end it can get to the point that you don't even want to leave the house. You don't want to see any strangers. When you go out, you see other families who are happy and complete, while you've lost someone in your family. Sooner or later you become more withdrawn and disconnected. You are less likely to get out and participate in other activities. You don't want to see others since you don't know what to say when others ask you about where your family member is. But the more you do this, the more you push yourself into a corner and the more you feel like you are trapped.

### **Nonexistent to Inferior Social Support from Families and/or Friends**

It is evident that the kind of social support most frequently provided to the participants was nonverbal in nature. Participants noted that family members and friends often showed support through "acts of kindness". Some of these helpful actions were instrumental, such as helping with household chores. The majority of these actions, however, pertained to emotional support – participants noted that their family members

showed support by spending more time with them, taking time off from work so that they could attend funerals out of town, being more “well-behaved” or affectionate, or offering help without being asked, as evident in the following excerpt from Participant B:

Participant B: Support from family is very important too. When that bad thing (euphemism for “death”) happened to my mom, my sons and my husband immediately bought tickets back to Hong Kong to see how they could help. They were very supportive of me and I felt lucky that I had their support.

Interviewer: How did you find that supportive?

Participant B: Like how they immediately came back to Hong Kong. My son really loved grandma. Just recently he said “I should go visit grandma” – his paternal grandma is in Toronto now. What he said made me feel that he has grown up and become more mature, that he understands that he needs to start treasuring the family members that are still alive. To me, they demonstrated that they were there to support me through their actions. Especially my son, cos’ I didn’t expect him to go back.

Similarly, Participant H said:

Whenever we visited [my husband’s] grave.....my oldest daughter is a Christian but she knows that her dad prefers incense. So she bought incense to pay respect to him. My daughters took me to my doctor’s appointments. Whenever I tell them that I don’t feel well, they take time off work to take me to my doctor. They made time for me. I feel that they are fulfilling their duty to take care of me.

Nonverbal support from friends was in the form of attending funerals, inviting them to spend time together, visiting them at home, or making “memory books” or “prayer books” for the deceased. Participant X considered her friends to be the people most supportive to her during her journey of bereavement through practical support and “small gestures”:

Practical help, such as mowing the lawn for me. It’s a very tangible kind of support. That’s a task I couldn’t deal with at the time. Or household chores – they offered to clean my house and cook for me. Practical support is very helpful. Or even sitting beside me, even if I didn’t want to talk. Or cry together. Or pray together. These seem minor, but this already can bring changes to people’s hearts. This is very comforting. It doesn’t need to be



any grand gesture. The most important thing is to let people feel that they're not alone. (Participant X)

Yet receiving nonverbal social support was not enough to make participants feel supported through their journey of bereavement. The predominant theme when describing their attempts in coping with loss was that there was no outside help. Many participants still replied with “*no one*” or “*myself only*” when the author asked “*who were the people that helped you the most*”. It appears that participants gauged social support more in terms of the amount, nature, and quality of their **social sharing**, or **verbal communication** of grief, with others in their social networks. Those who were the happiest about the social support they had received were the ones that were able to honestly and openly speak to a family member or a friend about their grief, **and** receive helpful responses in return. For the majority of participants, however, such social sharing was either nonexistent or of poor quality. This is likely due to the Chinese social grammar around emotions, communication and relationships.

### **Social Sharing of Grief**

It is interesting to note that only two participants saw the social sharing of grief as “pointless” and therefore had no desire to talk about their loss with friends or family. One participant felt that talking had no impact on her emotions:

My friends encouraged me to talk to them. They said "Tell us. Talk to us. Talking about it lessens the burden on you". Well I don't think so, cos' talking never lessens the burden on me. The emotions are still there. Just talking about it doesn't help me. (Participant G)

Coming from a pragmatic perspective, another participant defined verbal communication of grief as “just talk” – talking served no purpose since it would not change the fact that her loved one had passed away:

I talk to [my siblings] on the phone, but we won't bring up my dad's passing again. We just have casual chats with each other, talking about happy things. We won't intentionally or seriously discuss my dad's departure. Since daddy has already left, all the funeral rituals have been completed, all the final arrangements on his affairs have been made. His departure is a fact. That's why there's no need to talk about it, to study it or to examine it in detail. (Participant R)

All other participants expressed a desire to talk about grief, yet were equally hesitant to do so for two reasons in general. First, consistent with the Chinese cultural grammar on emotional suppression, participants reported significant fear towards the emotional arousal resulting from the discussion of grief. Fear of one's emotional experience and public display of emotions often led to more effort to suppress their grief and to avoid any triggers of negative emotions and unhappy memories, such as the social sharing of their loss and bereavement. Participant O explained why no one in her family talked about her mother's death and their grief:

We are too afraid. We dare not to bring it up, cos' we know that if we bring it up, it triggers all the sadness in us. I never bring it up cos' I don't want to trigger the sadness in me.

Some participants outright refused to talk about it despite being invited to do so, because of their fear of crying (and doing so in public), as evident in the following excerpts from Participants O and P:

It's also easy for me to get emotional over it again. I have avoided seeing my friends for a long time. Whenever I see them, if they ask me how I am doing, I will not be able to hold back tears. Don't talk to me about it. Don't even bring it up. I get easily triggered. Even asking me how I am doing can be a trigger – Never ask people how they're doing. Don't do it. For me at least. (Participant O)

I told my friends that I didn't want to talk about it; let's just focus on work. I asked them not to ask me.....My mom died, I took 2 weeks off, so don't ask me anything, just leave it. I was actually afraid of people showing their care, as it would only bring up something that's sad.....I didn't want to cry. I didn't want to cry in front of them. Whenever people bring it up I will cry, so let's just talk business. (Participant P)

Second, when participants attempted to initiate a conversation about their grief, they noticed that others in their social network avoided it because of their fear of the participants' emotional display.

I tried chatting with.....like with our relatives, they would immediately tell me "don't think too much about this". Sometimes I would reminisce on how [my son] was like when he was alive. But many people refused to talk about it with me. They avoided bringing it up cos' they couldn't deal with my crying. (Participant S)

Participants attributed the fear from their social network to the fact that many Chinese do not know how to handle other people's emotional outbursts. Many also do not know how to be helpful and supportive. They struggle with not having the right vocabulary to comfort others, or not knowing what is the right thing to do in response to grief. This makes them worried about unintentionally aggravating someone's grief due to their lack of knowledge. Looking at it from their family's or friends' perspective, participants were empathic about how uncomfortable their families or friends must have felt when the participants tried to initiate a conversation about grief:

It's not like I'm intentionally hurting someone, but this indeed is something that comes with tremendous grief. What if you start crying when you talk about it? What should I do when you start crying? I have no idea how to deal with your emotional reactions. (Participant Q)

They may think "oh if I bring it up, I'll make you sad, which will make things worse". So even if you have friends or family, the level of support you can get from them can really vary. (Participant N)

If it is me who has a very good friend whose family member has passed away, the most I will be able to do is to check in with them, see how they're doing, ask them out.....just to take their minds off of it, to give them this space to cheer them up. That's all I can do to be helpful. I definitely will not take the initiative to ask about their grief or to ask them to share their feelings with me. Cos' I don't know.....I don't know how my friend would react if I ask. Will this make him or her sad? I have no idea how to console him or her. I feel that I don't have the professional knowledge to do so. All I can say is "Don't be sad, that person has passed, there's no point being sad, you need to focus on living your life. Your parents will be able to take comfort in that in heaven." That's the most I can say. I really don't know what I can do to console others. That's the most I can do. That's why I would never bring this topic up myself. (Participant K)

Sometimes it's hard to try to console others. If you bring it up, you may make [the bereaved] feel worse. So when you spend time with them, you may choose to do other things to distract them, cos' you don't want to bring it up again or talk about the deceased. Cos' if they talk about it, they always end up crying. Recently, my co-worker's father passed away. All I could say to console her was "he suffered from lots of health problems. He had cancer and Parkinson's Disease. He was on dialysis. So to him, it's a relief." That's all I could say to make her feel better. Or "well he had so many health problems, and you had been taking care of him for years as well. It was very tough for you too". That's all I could say. (Participant S)

In addition, participants' experiences of social sharing with family are qualitatively different from that with friends – not only in terms of what happened, but also in terms of what contributed to those differences.

### **Social Sharing with Family**

Participants' experience of social sharing with family was dominated by a feeling of *ambivalence*. Consistent with the Chinese cultural grammar on relationships and communication – that if communication of private matters were to occur, it must be limited to family members – participants expressed a stronger preference to speak to family members than friends about their grief. The status of family members as “insiders” and ranking higher in terms of relationship closeness is supposed to facilitate more open disclosure of emotions. Yet paradoxically, participants most often described their experience with social sharing with family members as “*we never really talked about it*”. “*We never really talked about it*” had different meaning for different participants. Some participants reported that they never attempted to discuss their grief with family members regardless of how close they were. For some participants, when they said they “*never really talked about it*” with their family members, they did not mean that they never expressed their grief in words. Rather, they meant that they never managed to *sustain* a conversation on the loss with their families. For some participants, “*we*” stood for “*the entire family*”. By “*we never really talked about it*”, they meant that they could only talk to a highly selected few of their family members, rather than everyone in the family, about their grief.

Participants described a number of barriers to social sharing of grief with family. They observed that even within the same family, reactions to the death of a loved one highly varied across individuals due to differences in one's perspectives towards death, and in the nature and quality of one's relationships with the deceased family member. The individual differences in the responses to loss within a family meant that participants could not indiscriminately disclose their grief to anyone in the family, since not everyone felt the same way about the death:

My oldest brother-in-law was very close to his dad, so among the three sons, I have to say that the ones most saddened by this were him and my husband. As for my second brother-in-law.....well I think he is not the kind

of people that is very emotional. He won't show his emotions. I still remember that during the funeral, my second brother-in-law didn't even cry. He acted so calm. He was so quiet, as if he was totally accepting this as fact. My husband and his oldest brother were bawling their eyes out. They couldn't keep it to themselves.....especially when they had to get on stage to give the eulogy and reflect on their dad's life. They kept crying while doing it. But my second brother-in-law appeared so peaceful. But then different people often react differently.....it really depends on the individual. (Participant F)

For my older brother.....I think he was probably unhappy, but he had a tumultuous relationship with my dad and they used to argue a lot. So I guess for him, it's more like "oh it's good that I have less conflict in my life now". It really depends on the relationship. Since my older brother often argued with my dad, even if he was unhappy, the intensity of his sadness was definitely not as strong as mine. (Participant N)

Well my siblings.....My eldest brother didn't feel anything, as he believed that "oh it's time for her to go already". My sister.....she was the one who took care of my mom in Hong Kong, so she also had the guilty feeling of "I could have done better" all the time. My third and fourth siblings felt nothing.....I think it depends on how close you felt towards the one who had passed away. My fourth brother even went on vacation [when mom died]. As for me, I just kept thinking "how come I didn't do a better job?" My sixth brother was very saddened by this as he's a physician. He felt "I managed to save so many people but how come I can't save my own mother?" I think he completely broke down when my mom left. He cried his eyes out. (Participant P)

At the same time, participants also struggled with deciding who the appropriate *target* of disclosure within the family should be, since they had trouble recognizing how others *genuinely* feel about the death. What made accurate judgment of another family member's grief so difficult was the incongruence between outward appearance and inner emotional experience found in many Chinese, as a result of the Chinese cultural grammar on being "subtle" in one's communication. One of the most common ways participants illustrated their confusion over other family members' true level of grief was "*I cannot tell from the outside how he / she really feels*":

I couldn't tell from the outside whether there's anything wrong with my sister when I was in Hong Kong last year. I couldn't tell from the outside whether my sons were unhappy. (Participant B, on how the death of her mother affected others in the family)

I can't say that my mom isn't an emotional person, but I also don't think she's as emotionally sensitive as me though. I just really can't tell. (Participant J, who lost his father)

My son never said anything.....honestly I couldn't even figure out what he was thinking. He didn't cry at all. I wanted to talk to him about it but he acted like.....On the surface he didn't act sad. He never talked to us about this either. So I'm a bit worried about him cos' I can't tell what he's thinking. This is someone who had played a significant role in his life. (Participant M, on how the death of her mother affected her son, who was very close to grandma)

And for Chinese.....even among family members, I sometimes wonder how hurt they were by this. For instance, I wonder how hurt my older brother is by this, how hurt my sister is, or how hurt my younger brother is. I guess we are all wounded by this, but we differ in the way we express our hurt. Expressing it is easier for me; I just cry out loud. I don't cover it up. But then I looked at my brothers – they did cry, but they looked as if nothing has happened after crying. Then I start to wonder how they truly feel. I just don't think they are ever able to express their true emotions. I think this is particularly true for Chinese. (Participant Q, who lost her father)

She acted tough on the surface. I have no idea how she truly feels when it's late at night and she's by herself, but on the surface she seemed strong. (Participant S, talking about how the death of her son affected her daughter)

It is clear that these participants made a distinction between “what goes on the surface” and “what really goes on underneath” – they knew that they could not “judge a book by its cover”. They knew that there was a mismatch between one’s outward appearance and inner emotional turmoil. However, they had trouble discerning what that hidden emotion was. Participant O, for instance, said that while everyone in the family made assumptions about each other’s functioning, “*actually no one really knows how each other is doing*”. Participants felt vulnerable to the risk of opening up to someone who did not share the same reaction towards the loss and might therefore be incapable of understanding their grief.

Some participants avoided talking about their grief out of a sense of duty to protect other family members from further grief. They worried that disclosure of their grief might harm others, since it might trigger negative emotions in their family members and exacerbate their suffering. They also believed that, even if they initiated a conversation

about grief, others in the family would not be able to provide them with adequate support anyway since everyone in the family was grieving:

(Crying).....These are things that had already happened; they were all in the past. If I dig up the past and talk about it now, will it create a burden on them? Would this make them feel like.....I'm not saying that I want to avoid being responsible, but I also wonder if I would make them feel uncomfortable. I know that each of us wanted to try our best to offer the best to our mom (crying), but.....I don't know how they would react. I also don't want to negatively impact them by bringing these things up again. I don't know if their grief has already subsided. I don't want to dig this up again. (Participant L)

I dare not tell [my family] anything. To my sons.....I'm afraid that if I tell them how I feel, I will make them unhappy too. (Participant B)

Even after [my wife] had passed away, I still didn't talk to anyone in my family, cos' everyone has been suffering. Even my kids had been suffering. Everyone wants to avoid this problem. None of us will ever bring it up. We just keep everything inside our hearts. We won't talk about it. We dare not talk about it at all. If we ever talk about it, if we ever dig it up, we don't know if anyone will feel uncomfortable for a few days after. That's why we have never talked about it.....I feel that talking about it will only make everyone suffer. (Participant Y)

In the case of my family, when [the death] happened, it was also a major blow to them. Everyone was hurting. It was a huge blow to their emotions too. So I think it's very difficult.....I think everyone is sad, so how can they support you when they also need support themselves? Honestly how can you own family counsel you and support you through this? It's very difficult. When everyone is sad how can we support each other? (Participant A)

Some participants found it difficult to initiate social sharing of grief with family because they perceived that others avoided talking about the loss, either by avoiding to initiate a conversation about the loss, or by avoiding to interact with the participants when they were distressed. As a result they did not feel comfortable starting a conversation about grief because they were able to tell that such a discussion was clearly not welcomed by their family members:

[My relatives and I] are in touch but they will not ask me about [the loss of my son]. They never ask about how I'm feeling. They will not bring it up out of the blue. (Participant S)

There had been no support from [my sons]. They never asked me about how I felt about losing my mother. (Participant B)

As for my husband.....when he saw me crying, he never did anything. He would just walk away and let me cry as much as I wanted. He didn't do anything special for me. (Participant C)

A number of participants initiated a conversation about their loss with family members, only to receive highly negative responses in return. Sustained conversation on grief was therefore impossible, as their family members clearly did not want to reciprocate. Participants immediately clammed up; they understood the social clue that such a discussion was unwelcomed, or that it would never become in-depth. Poor responses from family also discouraged any future attempts by the participants to talk about their grief. Negative responses from family members tended to be dismissive, rude, shallow, or cliché:

My husband said, "Wow it's been a long time ago! Why do you still remember stuff like that? Isn't it over already? It's already in the past! And your mom really wanted to 'leave' (euphemism for "die") at the time. It's her wish. She asked you for help remember? Now she got what she wanted already. Isn't it a good thing?" That's how he comforted me. (Participant B)

When I tried talking to my sister, all she said was "stop thinking about it. Just go exercise or do other things." Sometimes she even yelled at me, "Why are you always talking about it, why are you always thinking about it?" She got irritated. That shut me up right away. All I want is to.....we are siblings, we grew up together, we spent a significant amount of time together. I would think that we must be the closest, but it turns out not to be the case. I find it incredibly hurtful. I tried talking to my husband as well, and his response was always "just stop thinking about it. Go find something to do. Go cook. Go do laundry. Go clean the house." That really irritated me. I didn't get any empathy from them. They just didn't feel the same way. They never offered any advice. All they would say was "just go do something else, throw yourself into housework". It really irritated me as I felt that we were not in sync. (Participant C)

My daughters kept telling me "Don't dwell on it. In dad's family, most people didn't enjoy a long life anyways. Daddy lived past 80, so he was already lucky." (Participant H)

I mean, the only reason why I brought it up with my husband was that I was feeling upset at the time. I usually kept everything to myself. The whole experience felt like it was just me sitting there talking to myself, and he just happened to sit beside me when I was talking. He wasn't there to comfort me and help me resolve this, or to relieve my pain. All he said was "just don't think of it that way. It wasn't your fault.".....I mean, he gave me a response, but I didn't find it helpful. It wasn't like I could have a conversation with him about it. (Participant L)



[My husband] refused to talk about [my son]. I tried to bring it up, but he told me to stop talking. He didn't want to talk about it. (Participant S)

Actually [my family] didn't do much to support me at all, come to think of it. All my husband said was "your dad was old. This is a normal part of life." That's the kind of "comforting" words he offered. But I thought to myself "this is so cliché, who doesn't know that?" (laughed) I mean, I knew what he said is right, but feeling sad and missing my dad is something else. (Participant R)

For those who successfully talked about their grief with family members, in-depth and fruitful social sharing was usually limited to a selected few members within their nuclear families. To them, other family members either did not understand their grief, or could not be trusted. For example, Participant I, who lost her infant son to cancer, only found talking to her husband supportive because others did not share the same parent-child bond:

Honestly, I find it difficult to talk to my family about this, with the exception of my husband. My husband's aunt, his cousins, my mother-in-law – they don't understand how I feel at all. They only know that I'm very sad, that my heart is aching, but that's it.....If you actually don't really understand where I'm coming from, talking about it is just a waste of my time and breath. Yes we may all be talking about grief, but only parents truly grieve. Only those who were the closest, or those who raised the child, will truly grieve.

Participant J continued to reside with his mother after the death of his father. He reported that he could only have an in-depth conversation about his grief with his wife. In contrast, he noted that he avoided talking to his mother because of her tendency to misinterpret what he said, and her inability to keep the information confidential:

Well with my wife, I can discuss all the things I told you today. I never did that with my mom though.....We stay superficial. Let's say that the depth of the things I told you today is a 4 out of 5. I actually would only stay at 1 or 2 out of 5 with my mom. I'm afraid that my mom.....(paused for 5 seconds, looking for the right words) I think she will distort what I said. She will add her own opinions on it, distorting what I said, while claiming that the distorted version is what I've actually said. I found this very dangerous. Then she would tell others the distorted version – she can't keep it within the family and instead will tell it to someone else. That's why I can't tell her so much.

## Social Sharing with Friends

Participants' experience with social sharing of grief with their friends was dominated by the participants' and their friends' *mutual need to maintain distance*. Compared with speaking to one's family about grief, social sharing with friends was even more rare and difficult for participants. Participants felt even more reluctant to initiate a conversation about their grief with friends than with family, while at the same time their friends actively avoided discussing the participants' grief. Fewer participants reported being able to have an in-depth conversation about their grief with friends. There was also a unique aspect to the experience of social sharing of grief with friends that was not observed in that with family – participants who recalled speaking to friends about their grief most often described their experience as “*we all stayed shallow*”.

Chinese cultural grammar on relationships and communication contains a different and likely more stringent set of rules for interacting with friends. To the participants, friends fall into the “outsider” category of relationships. *Distance* is the defining feature of such relationships:

At a certain point in your life, you can no longer have any heart-to-heart talk with friends. You can't really tell them anything.....You just dare not be honest with them. You dare not tell them so much about you. You have no idea if they want to listen to you. You have to keep a distance. I really cannot open up like that to a friend. (Participant B)

As previously discussed, cultural rules stipulate that disclosure of personal, private matters to all “outsiders” needs to be kept to a minimum, regardless of emotional closeness or quality of relationship. Open and honest discussion of taboo topics such as the death of a family member and one's negative emotions with an “outsider” is considered a serious boundary violation in the Chinese culture. The risk of negative social consequences after such a disclosure therefore runs significantly higher with friends than with family. As a result, participants reported a tendency to downplay or hide their grief in front of “outsiders”, for fear of burdening others with their personal problems, offending others, being negatively judged, or being disliked:

That's why I learned to avoid the topic as well. I don't want to open my mouth to tell my friends about my experience, only to realize that others do not want to know about this cos' they feel disgusted and offended by the

taboo topic. It's not because I personally see [grief and loss] as a taboo; I'm worried about other people's reactions. This is why whenever people asked me about my mom, I would reply "Oh it's all in the past, it's over, I'm fine." I don't want to tell them too much. If that's their mindset, there's no point talking to them about how I feel. (Participant B)

I just think it's unnecessary for [me and my friends] to talk about [my son] and I don't need them to cheer me up. And you know, there are things that you just know in your heart – like even if I tell my friends, I feel that they will think to themselves, "She's always telling us her unhappy experiences. What's the point of telling me these things?" I think that'll only make me extremely unpopular – that my friends will feel disgusted and then avoid me. My friends will stop liking me. Maybe they are worrying about their own problems. Everyone has his / her own burden to bear. Maybe they're overwhelmed by their own problems already. How can I share my burden and grief with them? (Participant I)

Others may think "wow you're just a pest aren't you?" They will think that you're so annoying. Everyone has his or her own share of problems already. Many of them have their own families or kids to worry about. To them, my life is great – I'm single, I don't have any burden from family. (Participant W)

You don't know what others may think about you. You will have a lot of second guessing and mind-reading – "If I tell people how I feel, will they think that I'm weak?" (Participant T)

You don't know what others may think – "Are you trying to gain sympathy by talking? Are you trying to take advantage of us?" I'm afraid that's how others will look at me. (Participant Y)

At the same time, some participants observed that their friends engaged in the same avoidant behaviours as they did. They often described their friends' responses to their loss as "*no one ever asked me about it*", "*no one reached out to me*", or "*they do not want to discuss it with me*". Being ethnically Chinese, their friends abided by the same set of Chinese cultural grammar that regulates relationships and communication as well. This means that not only the participants saw their friends as outsiders, their friends also saw *themselves* as outsiders, which implied that it was socially inappropriate for them to initiate a conversation about others' "family matters" or private emotions:

I never talked about [my grief] with friends cos' they never brought it up. They never asked me how I felt. (Participant F)

For instance, when I told my friends about my experience – actually many never approached me to talk about it in the first place – I felt that they

avoided the topic. They acted as if they were in denial, as if my dad was still alive. They never talked about it.....they would not ask me how I felt about my dad's passing or bring up the topic themselves. (Participant N)

Yet a unique feature of social sharing with friends (that was not observed in the participants' social sharing with family) is that most of those who managed to have a conversation about their grief with friends described it as a "shallow conversation" – a conversation in which participants and their friends alluded to the subject of death in a brief, subtle, covert, and superficial manner, while maintaining personal distance. Participants noted that their friends would indirectly "check in" with them, such as saying "hi", asking them "how are you", or making innocuous comments such as "you seem better today". Participants were able to read between the lines and recognize these comments as their friends' subtle way to refer to their loss. However, their friends' questions always remained at a superficial level. They seldom followed up with more in-depth questions concerning the participants' emotional wellbeing. Participants therefore understood it as a sign that their friends were not truly interested in having an in-depth conversation on grief:

They didn't really show any support.....most of them would just say hi to me and leave it at that. But we don't really bring it up deliberately. It's just a topic that may come up in conversations, like them saying "you seem better today", or "you seem happier than last week". But we've never talked about it directly. (Participant C)

They would ask me how I was. But "how are you?" is the level they stayed at. They would not ask any follow-up questions. They would not dig deep. They would not discuss with me further. They never asked me, "What made you upset?", or looked at the loss with me in-depth like what my husband would do. They wouldn't even say, "Oh it was great that you managed to spend time with your dad [before his passing]". They would not analyze it together with me. (Participant N)

I guess they had sympathy for me, but our conversations were mostly superficial, like "How are you?" (Participant Y)

They asked me how I was doing, but they kept it superficial. They didn't really want to discuss it with me anyways. (Participant I)

Participants' interpretation that their friends did not genuinely intend to initiate and sustain a conversation on grief was further confirmed by their friends' superficial and cliché responses if they ever brought up their losses. This fueled participants' skepticism towards

the purpose and effectiveness of social sharing with friends. Shallow conversations on grief with friends were simply “useless”:

The only thing my friends said was “everyone will experience this”.  
(Participant A)

The most my friends did was to check in with me. Told me not to think about this too much.....you know, those superficial stuff. (Participant B)

All they would tell me is “stop thinking too much about it”. I mean, I would say the same thing to others too, but it does not “hit me in the flesh” and is not helpful. It’s useless. (Participant D)

I sometimes told my friend how I feel over the phone. She would tell me “don’t think too much. Those were the cards you were dealt. That’s life.”  
(Participants H)

What can friends really offer? All they said was “Oh [your mother] was so old already. This means it was a ‘happy loss!’” You know, the same old same old. Well I already knew this stuff. I knew she was old. That’s why I didn’t find that helpful at all. (Participant P)

That’s what everyone said to me, “oh just take it easy”, “just get over and accept it”, “oh don’t be so pessimistic”, “oh just go travel and distract yourself”, “oh just come out more and have dim sum”, “oh just come out more and exercise”. I mean, it was helpful in the sense that it showed that they cared. But on the other hand, the stuff that they said was so cliché! It’s just stuff that people would say over and over. Yeah I felt that they cared, but they were just repeating themselves over and over. They had good intention, but I didn’t feel that they were helpful in a tangible, actual way. The generic, empty “oh just take it easy”.....I mean, I know how to say that too, “oh your life is long, it’ll be fine eventually, just go find someone else”. It’s very easy to say these things, but the recipient of these suggestions often feel that these suggestions were totally meaningless and nonspecific.  
(Participant U)

Participant W found her friends’ attempt to stay shallow and divert the topic hurtful and unsupportive, as their cliché responses clearly showed that their friends did not understand her loss. Speaking to friends only aggravated her sense of loneliness:

Talking to others – the result was disastrous. I tried to talk to my friends, but I could tell that they didn’t really understand. Of course they would always try to come up with something to console me, but those words made no sense to me. Things like “think positive”, “well you still have this and this and this.....you still have a sister”, etc. I already feel that I have no one else besides myself, that I’m the only one left alive in this whole wide world, but

they still said to me "oh but you still have this, and you still have this", etc. I have this feeling of the world collapsing around me, this very lonely feeling, the feeling of being abandoned.....my friends absolutely cannot comprehend what it's like for me. They said to me "Oh I'd rather be single just like you. It's so much better by yourself", "Well you're actually doing great, I'd rather be you.".....that I'm so free, that I have all the time in the world. They want me to feel that I'm actually doing very well, but I don't feel that way at all. They can't help me anyways.

From their friends' superficial questions and cliché responses, participants got the social clue that their friends were likely not genuinely interested in a conversation on death – the “checking in” was simply a gesture to be polite and to show care, but not an invitation for further discussion. Since it appeared that their friends preferred to keep a distance, participants concluded that the only socially appropriate way for them to respond was to stay shallow as well:

I just acted tough. I always told the other churchgoers “I'm OK, don't worry.”  
(Participant J)

My girlfriends..... I would talk to them in general terms, such as "yeah [my mom] was very sick before. It's great now cos' she no longer suffers." That's the extent I could go with them. Just staying on the surface. (Participant L)

When I talk to friends, all I would say is that "he has left".....in a matter-of-fact way, a superficial way. I will say "oh yeah, my mom is in Hong Kong by herself. My dad has left" in a calm, nonchalant way. (Participant R)

Similar to participants' experience with social sharing with family, those who successfully had an in-depth, helpful discussion of grief with friends were able to do so only with a highly selected group of close friends. The strength of their friendship helped them overcome the cultural constraints on communication and the need to maintain a distance from “outsiders”. Trust and mutual understanding inherent in a close friendship also helped participants feel that the conversation was helpful:

I talk more if they are my close friends. The acquaintances, I'll just thank them for showing they care and reassure them that I'm OK. But with close friends, the conversation can get pretty deep.....as deep as what we're having now. So I do have friends I can talk to about this. (Participant J)

I had way deeper conversations with my best friend. I was comfortable telling her my feelings and what's bothering me. (Participant H)

My friends played the role of providing support in lieu of more formal support from professionals. Initially I did wonder if I should seek counselling, since my workplace offers counselling for employees. However, I chose not to because I was lucky that I have had enough social support. I can only talk to those friends that I can trust. They need to make me feel comfortable and secure in confiding in them. My friends know me very well. I am so grateful that I was able to talk to them. Speaking to them has been incredibly supportive for me – It was helpful in terms of emotional support. When something like this happened, I felt guilty and often blamed myself for it. But after talking with my friends, I realized that it had nothing to do with me, since they were able to provide me with a more comprehensive view on what happened. (Participant T)

### ***Existential Loneliness***

*Bereavement is a very individual journey.* (Participant D)

Existential loneliness refers to the participants' belief of the "fundamental separateness of human existence and experiences as selves" (Ettema, Derksen, & van Leeuwen, 2010). To the participants, this "separateness" represents the very essence of human nature: that everyone is a separate entity from others. This implies that one can directly access the workings of his or her own mind but not the workings of others' minds. One's understanding of others, via empathy, is to simulate the mental states of others (i.e., what others are truly feeling or experiencing). Yet mental simulation is never a *perfect* replication, since private experiences that are unique to others may not be directly accessible. Participants seemed to suggest that given empathy's failure to provide a perfect replication of their mental state, others can never truly understand their grief experience. In addition, participants alluded to their belief of "*you are not me*" i.e., that no one can "live someone else's life". Every aspect of human experience – ups and downs, happiness and sadness, health and illness, life and death – therefore belongs to, and only to, the person who is living that life. Others can only "look from the outside in". To the participants, this means that human existence, by definition, is a lonely experience – every individual is ultimately alone in this world, and is ultimately the only person responsible for his or her experiences and actions.

In the case of bereavement, participants noted that even if others in their social network try to be supportive, they still feel lonely and isolated because they, and only they,

are the ones experiencing the pain and the aftermath of a loved one's death. Participants used a common Chinese idiom of "*you never know how much a needle prick hurts unless it is your flesh being poked into*" (*jam ng gat dou yuk ng ji tung* in Cantonese) to illustrate their belief that empathy does not exist in grief – even if others claim to understand what the participants are going through, they actually cannot truly understand because "*they are not me; they are not the ones experiencing it*".

Even if I tell other people how I feel, they still cannot feel it; only I myself can feel it. (Participant A)

It's easy for people to say "don't be sad about it", but doing it.....honestly "you never know how much a needle hurts if it is not your flesh that is poked". Even if these people try their hardest, with their most sincere intention, to talk you out of your sadness, it's still you who is experiencing it. (Participant H)

**I feel that others are on a different wavelength.** They want me to do well, but the things they say to me feel like they are from a different TV channel – it's not my channel.....Whenever I feel that the way a person looks at things is different from mine, whenever I feel that our perspectives are different, I know that they don't understand at all. I feel that I'm way past that already, but they are still talking about things that are over here – that is not even what I'm really concerned with anymore. I appreciate their intention, but what they offer is missing the mark. (Participant Q)

Even if I talk to my family or friends, they will feel nothing. All they can say is "oh poor you", but they never know how that truly feels like. They'll claim "oh I know you're devastated, I know it's tragic", but it doesn't hit them in the flesh. They're just listening to someone else's story. There's the saying that "you never know how much a needle prick hurts unless it is your flesh being poked into". **To others, it is like watching a sad movie, but they cannot feel it as if it is them experiencing it.** That's why they won't understand what I am feeling. (Participant I)

Given the participants' belief that no one can truly share or understand other people's life experiences and realities, bereavement is always going to be an individual journey to them. They noted that despite others' intentions to help, the responsibility of resolving grief still fell squarely on their own shoulders – it is their lives, and others cannot live their lives for them. Taking ownership of one's own private experiences means taking responsibility for themselves and their actions. Participants felt that ultimately they could only rely on themselves to face their own grief, to process it, to understand it, to change their perspective, and to get unstuck:



I think in the end, I still have to face it by myself. Sooner or later, you have to face it, you have to accept it, even though you're very sad. That's why I will not think about whether others are helpful or unhelpful to me. At the end of the day, it's up to me to learn how to face this, how to accept this. (Participant A)

At the end of the day I can only rely on myself. Yes, talking about it with others may help release some of the emotions at that moment, but once you get home, you have to face [the loss] yourself, you have to face the things [the deceased] had left behind. (Participant X)

Honestly nothing and no one else can truly help. It's up to you to resolve it and find closure. It takes time, and you need to figure out by yourself how you can deal with this. Others can't really help you with this. It's very difficult. **You can only rely on yourself to get through this. No one can help you, not even those closest to you, cos' the thoughts you have are yours. The actions you do are yours. Others can't help you with that.** They can tell you not to get into a downward spiral in your thoughts, but only you can control your thoughts. That's why you can only rely on yourself to get out of this. You can't rely on others to help you. Others can't help you much. They can only console you on a superficial level, but it is up to you to take their advice to heart and implement them. (Participant R)

To be honest with you.....nothing can truly help. Yes my husband offered me a different perspective to think about [my loss], but **the ultimate responsibility falls on me – that it's still up to me to figure it out. So my own effort is actually the most important.** Yes you can try to speak to people around you, but at the end of the day, you will remain unhappy if you cannot resolve this yourself. It's up to you to pull yourself out of it. You need to rely on yourself to do that. (Participant N)

At the end of the day.....through my self-help process, I learned that it's.....**it's your life; your feelings, whether happy or unhappy, are yours as well.** Even if everyone around you wants to help you, if you refuse to help yourself, no one can help you. Yes other people may know that you're unhappy, but ultimately it's still up to you to help yourself. (Participant V)

## **Responses to the Lonely Journey of Bereavement**

Participants' responses to bereavement fell into three major categories: coping strategies, religion and spirituality, and personal changes and growth post-loss.

## ***Coping Strategies***

Participants reported four main strategies for coping with their losses: taking solace in their family member's "good death", suppressing negative thoughts and emotions, focusing on restoration, and reframing the loss. Many of these strategies are highly consistent with the culturally sanctioned coping strategies according to Chinese cultural rules: rationalizing the death, trivializing negative emotions, and suppressing negative thoughts and emotions.

### **Taking Solace in "Good Death"**

Participants reported that they felt more at peace if their family members had a "good death" as defined by the Chinese culture – a pain-free, comfortable death that alleviates everyone's suffering. Those who lost their family members to a chronic illness often found it painful to witness the deterioration of their loved ones before death finally struck. Successful pain and symptom management was of utmost importance to the wellbeing of not only the patients, but their families as well. Participants found relief in knowing that 1) their family members did not suffer or were not in pain before death, or 2) death put an end to the suffering of their ill family members:

I was very grateful that [my father] was never in pain throughout the entire period. Never in pain. That's why a lot of people said that it was amazing. Especially for pancreatic cancer.....many people said that it's very painful. The only time he complained of a little bit of pain was when he ate too much and was too full. So I felt that we were so blessed. (Participant J)

It was when he relapsed and when he developed other complications such as diabetes and hernia, that's when I could see him truly deteriorating. This was the hardest part – witnessing that he was feeling so unwell, but he could no longer undergo surgery. The only thing we took comfort in was that he was not in pain. That was very helpful to my mom and to us, as that made us feel less sad. (Participant N)

I keep telling myself that [my son] is no longer suffering. During those last few months, he couldn't sleep. He had to sit up all the time since he couldn't breathe when lying down. I prayed at the time that "if you are making him suffer like this, I'd rather that he leave earlier, so that he won't suffer as much". (Participant S)

When [my mother] was approaching end of life, I felt that.....when it was happening to your closest family member, when you saw that her quality of

life wasn't great.....death is a relief to her. That's why I would tell myself that. (Participant V)

In the case of sudden deaths, participants were glad that death came quickly and the deceased family member was never in pain. They felt blessed that their loved ones and the rest of the family were spared of the devastating suffering they would have experienced if the cause of death was a chronic life-threatening illness instead:

The comforting thing is that [my dad] left comfortably. He didn't suffer. He never experienced the turmoil of chronic illnesses. He left when he was riding the MTR (the subway system in Hong Kong). He left happily as he didn't suffer. He looked so peaceful when I saw him in the funeral home. He didn't look like he had suffered. It was as if he was asleep. I was happy for him as I felt that he was comfortable. (Participant R, whose father passed away after having a massive heart attack)

I cope by telling myself that [my mother] actually didn't suffer. It wasn't like she was hospitalized and had to be carried around from one place to another. She wasn't in pain. She wasn't demented or had trouble controlling her own actions. It would be even worse if she were like that. I just told myself that she had a good "departure". It helped relieve some emotions. (Participant D, whose mother passed away in her sleep)

For those participants who had lost their parents, they took solace in the fact that the deceased had lived a long and full life, fulfilled his or her roles and duties, and accomplished everything he or she could before death:

My husband felt that we should look at daddy from the perspective of – has he done what he was supposed to do in life? My husband even said to me, that if he himself were to leave right here and now, he would just ask himself whether he has completed everything he should have done, whether he has any regrets, whether he has fulfilled his purpose in life.....whether it has been a full life. That's how he helped me see why my dad's passing wasn't such a terrible thing. (Participant N)

Participants also felt that they coped better if there was no "unfinished business" associated with the death – they were able to spend time with the deceased before the death occurred, saying what they wanted to say, doing what they wanted to do, and having a proper goodbye. There was no lingering regret after death:

I told my sister how much I love her. I felt that this was something I did right. I didn't miss the chance to tell her. (Participant C)

When I chatted with my dad at the hospital, we were able to say whatever we wanted to say to each other (sobbing). I was able to talk to him, and he was able to talk to me. We could reminisce our past together. We got to spend time together. (Participant N)

### **Suppressing Negative Thoughts and Emotions**

To many Chinese, the only way to cope with death is to “*curb your sorrow and go with the flow*” – the most widely used saying in the Chinese culture to comfort those in mourning. As a result, a number of participants reported that the only tool in their repertoire of coping strategies was thought and emotional suppression:

Honestly, I can only say.....(sob).....it's just about me suppressing these feelings. Suppressing, suppressing.....so it's been very tough. So I don't think I have ever done anything specific to "cope" with this. All I did was to suppress these feelings. To avoid thinking about them. Just avoid talking and opening up about this grief. **But honestly I think suppression is a last resort kind of thing (the literal translation of what the participant said was "the only solution when you have no solution"), cos' I actually have no other options.** (Participant K)

Many participants reported having a fear of being sad. As a result, they devoted much energy on trivializing and controlling negative thoughts and emotions. Some participants suppressed their thoughts by directly telling themselves not to think about the death, as shown in the following excerpts by Participants C and I:

I will tell myself not to think about the loss. My daughter and I decided together that we will stop thinking about it, stop crying about it – if we stop thinking about it, there's no need for us to cry about it again. (Participant C)

I don't think about these painful experiences. I think life is already painful; let's not think about painful things as well. It's torturous. Just like I don't like watching tragedy on TV – being human is already painful enough. (Participant I)

A number of participants reported “being busy” as one of their coping strategies. Upon further queries, however, it is clear that “being busy” was simply a way to distract themselves in order to suppress any thoughts towards their loss:

I force myself to do things that are “regular”. I force myself to exercise every day. I enrolled in a bunch of classes. I force myself to learn new things. I learned calligraphy. That's what I do on my day off. I have even started

playing video games. I just force myself to find something to do every day. I dance every morning at 9. When I am so busy, when I keep such a regular schedule, it leaves no time for me to think about anything else. I do have some free time at home in the afternoon, but luckily I have two puppies. Just taking care of them keeps me busy. passing. When I'm so busy, I can forget it. I can stop thinking about it. (Participant B)

When I go to work I'm totally devoted. I will forget these things. That's why I must continue working. I have tons of stuff to do, so I don't even think about it. (Participant D)

If I'm very sad or feeling troubled by things, I'll listen to music.....using music to distract myself. I'll also keep myself very, very busy. I make myself very busy so that I'll have no time to think about it. (Participant K)

I've also told others to watch scary movies (laughed). When you get very scared, you will then forget what was bothering you. Personally I prefer comedy.....basically anything that captivates you, takes away 100% of your attention, will be effective. Or travelling. Or playing mahjong – basically anything that can distract you. (Participant X)

Some participants actively avoided any reminders of the deceased, as a way to suppress any possible triggers of negative memories and emotions:

Even though it's been over a year, I am still afraid of going upstairs, cos' [my father-in-law] lived upstairs. And that's why I still have not had a chance to pack up his belongings, cos' every time when I tried to pack up his stuff I would start thinking about him. I have actually tried to pack up his stuff but I would give up very quickly. (Participant A)

There was this one time when my son, all of a sudden, said that there was a message on the answering machine for me. He was pushing some buttons trying to show me the message, but then all of a sudden a recording of a conversation between me and my mom popped up. It was from a long time ago. When I heard her voice, I burst into tears uncontrollably. I had to stop the machine immediately and dared not to listen to it anymore. (Participant B)

I tried to return to the church I used to go to. I went back twice. Each time I couldn't stop crying. In the end I had to switch to a different church cos' I used to sit together with my mom at church. We went to fellowship together. We worshipped together. We went to Sunday school together.....So going to a different church is an act of avoidance, now that I come to think of it. People in this new church don't know me. I can just be there to worship. I can leave right away once church is over. (Participant O)

Despite the cultural belief in its effectiveness, participants unanimously found thought and emotional suppression unhelpful and inconducive to healing. To them, grief is an active volcano or an open wound. Suppression is merely a band-aid that covers the pain, but it does not lead to true resolution:

I just feel that often times Chinese don't know how to deal with negative emotions. The only way we know is to distract ourselves, to not think about it. When you do these things, you may feel that it's effective at that particular moment and you feel fine. But those emotions just accumulate and one day they'll erupt as they have never been resolved. Once they erupt, it'll spill everywhere and you don't know how to deal with them. (Participant W)

Actually suppressing it is not a good thing. It's a coping strategy I used but it's not a good thing to do. When you suppress your emotions.....others often think that I'm doing OK. My sisters think that I'm doing OK. My son also thinks that I'm doing OK. But look at how I'm today when I talk about this? It shows that I'm not healed yet. If a wound has healed, it won't bleed when someone touches it. But for me, every time I touch it now, it still bleeds. This tells me that my wound hasn't healed. The new skin hasn't formed. It remains an open wound. (Participant O)

Well all these things I have done only act like a band-aid to cover up the wound. It may look like that I have gotten over this. But I feel that the wound still remains when I lift the band-aid up. I'm not there yet. I know that I'm not OK (cried). (Participant B)

In fact, a number of participants readily admitted that they were only pretending to be well. They noted that the more they tried to put a lid on their emotions, the more uncontrollable the emotions became. At the same time, they struggled with a lack of alternative coping strategies to suppression:

I hide everything inside, to the point that I can't bear with it anymore. All we can do is to hide everything, let's not talk about it, but the emotions boil inside us. (Participant A)

No matter how unhappy I am inside, on the surface I have to stay strong. I have to suppress everything. But now I feel that I've faked being strong for so long, I've already collapsed on the inside. I can no longer suppress it. (Participant D)

I will tell myself not to think about the loss. Forcing myself to think about Jesus makes me feel better. However, when I get to bed, I'll think of her.....well actually, even saying the words "sister" will make my heart ache. I will feel sad. My tears will come out uncontrollably. (Participant B)

It's been 2 years already but every time I talk about it, I realize that I'm still trapped in these emotions (starting to sob). It's like I'm dealing with a volcano. All I could do was to suppress everything, but it will actually erupt any minute now. Any minute now. (Participant K)

Participant C wondered if she was suffering from a mood disorder when her grief remained unresolved for such a long time despite her best effort to suppress it. She was particularly worried about the long-term implication for her health:

"To put it aside" or "just don't think about it"....."just don't think about it, time heals all wounds, you'll be fine after a while".....this belief that "setting it aside" is an effective solution.....basically these feelings are just set aside but they have never been resolved, and we actually have no idea how to resolve them. Like me, I just set these emotions aside, but I actually never truly worked through them and resolved them. I never sought help or talked to someone about these and learned how to resolve this. That's why I always thought to myself (crying) – my sister left so quickly. Am I depressed? And how will my emotional turmoil affect my future wellbeing?

Participant L proposed a possible explanation on the ineffectiveness of suppression as a coping strategy by pointing out the dialectical relationship between “feeling sad” and “feeling healed”. Despite the Chinese cultural belief that one can feel better only by avoiding feeling sad, she noted the opposite was true for her: that one has to first go through the painful process of experiencing and expressing negative emotions before he or she will genuinely feel better:

Every time when I think of my loss.....even if I didn't have a chance to talk about it out loud, but every time I cry about it, I feel a little bit better. That's why to suppress and bottle up these feelings is a problem. It's not about how much time has passed, or how many years have passed. Suppressing these emotions does not make them disappear. I don't think it's right to not bring it up or to never talk about it, thinking that "if we don't talk about it, we can pretend that it has never happened, that it's already resolved". That's not a healthy way to deal with it.

Participant I concurred when she described how she coped with the death of her infant son – allowing herself to confront the loss and expressing negative emotions helped improve her mood:

I do feel worse when I look at his photo albums, but crying after looking at them makes me feel better. One day, I took his photo albums out to look. The photo albums were like videotapes that recorded every moment of his

life from birth till the end. As I was looking through the albums, it was as if I saw his entire life flashing before my eyes. Oh gosh.....I cried vigorously. I was pregnant at the time. I was scared and didn't know what to do. But after crying, I felt relieved.

### **Focusing on Restoration**

“Being busy” does not always mean suppression or avoidance of grief to participants. Instead, “being busy” can represent efforts towards restoring a normal, regular life after the death of a loved one. Participants still felt “distracted” from their grief in this form of “being busy”. Yet what distinguishes “being busy as a way to restore” from “being busy as a way to suppress” is its confrontative, proactive, and present- and future-oriented nature – the focus is on facing the reality of the loss, adjusting to the absence of their deceased loved ones, getting on with one’s daily life, developing new skills or even a new identity, and reconstructing a sense of normalcy after the death.

Some participants restored their lives by resuming normal routines. It was a way to show themselves that life went on despite their loss. Forcing themselves to do something helped combat the low level of energy and motivation commonly observed among the bereaved. For those participants who were mothers, their children helped reorient their focus from the past back to the present:

At the time my mood was terrible and I had no appetite. But I forced myself to eat a little bit. I continued to volunteer, go out with friends, or go shopping. I made a huge and deliberate effort to get myself out of the house, even if it's just for a short stroll around the block. I still continued to carry out my day to day activities. If I had to work that day, I insisted on going to work. I continued to keep a regular schedule. (Participant T)

I threw myself back into work and my own family. I kept telling myself that life has to move on. Your kids need you to be there for them. So I don't think that I ever felt very low in my mood. (Participant V)

Whenever I thought about my kids, I realized that I need to pull myself together. If I continue to stay in this depressing past and keep crying, what will happen to my kids? Who can take care of them? They really helped redirect my attention back to my current life. (Participant N)

Some participants coped by learning something new. It helps reconnect them to the rest of the world and gives them a new goal to pursue:



I coped by learning new things. My Chinese opera instructor taught me new songs and arranged some performances for me. I didn't just learn new songs – I needed to perform. I realize that I needed to bear the responsibility of performing well. That's why I think you need to learn new things. You need to feel that you're responsible for something – that forces you to get out of the hole since there are things you need to do. (Participant P)

Before [my son's death], I was very healthy. After it happened, I was sick all the time. I realized that I couldn't let this continue. So I started volunteering and taking courses. I learned how to use a computer. I took a course on job search. Things then became a bit better. I tried to look for work again. I wasn't just hiding at home all the time. Getting out of the house and getting in touch with the rest of the world again was really helpful. (Participant S)

Participants who took care of their family members before their death often described caregiving as an isolating experience, since they needed to attend to their loved ones' needs at the expense of their own lives. Doing something different and learning new things after their family members' death helped them re-expand their world and rediscover their interests. It helped them realize that life was bigger than their loss:

I started pushing myself out of the house to meet new friends, to push myself out of this quandary. That's why since May I've been participating in a lot of activities organized by SUCCESS such as lawn tennis, hiking, and short trips. I felt that I needed to get out more. (Participant Y)

I have a large social network.....sometimes there's so much socializing that I had to put a stop to it (laughed). I also exercise. I found what my true interests are. I attended classes to learn new things. I think you need to rediscover your own worth. You need to find out what your own interests are. Even if you have lost this major relationship in your life, you can still divert your attention and emotion to something else. You can still lead a wonderful life. (Participant X)

## **Reframing the Loss**

Participants reported various forms of cognitive coping strategies in managing their grief. These strategies are termed "reframing" as they involved changing one's perspective or mindset. Participants used the phrase "*lam tung*" in Cantonese or "*xiang tung*" in Mandarin to denote the thought process of cognitive reframing in response to their family members' death. There is no one-word equivalent for this phrase in English, but it is possible to understand what it means by looking at the individual words in the phrase.

"*Lam*" or "*xiang*" in Chinese stand for "to think". "*Tung*" on the other hand means to unclog, to pass through, or to achieve clarity. "*Tung*" is therefore similar to the Eureka moment in English, the sudden understanding of a concept that was previously incomprehensible. "*Lam tung*" implies that one's thought process is the key to achieve clarity (i.e., "*tung*"), but it cannot be any random thought process.

Participants used the phrase "*winding down into a bull's horn*" ("*gyun ngau gok jim*" in Cantonese, "*zuan niu jiao jian*" in Mandarin) to describe their typical thought process during bereavement. It is similar to the concept of a "downward thought spiral" – a bull's horn is wide at its opening but becomes narrower towards the tip. By "*winding down into a bull's horn*", participants meant that the more they thought about their loss, the more they became narrow-minded, pessimistic and trapped in their negative thoughts. "*Lam tung*" is the tool to "unwind out of the horn". It combats the downward spiral by confronting and accepting reality, changing one's way of interpreting the loss, using humour, and making social comparisons.

Participants noted that the process of "*lam tung*" was predicated upon one's willingness to face and accept reality – to acknowledge that the loss had happened, and that there was nothing anyone can do to change it. One also needed to accept that negative emotions are bound to occur and are a normal part of the grieving process:

Of course you will feel sad regardless of whether the deceased family member treated you well. You cannot change the fact that the deceased was your family. You're blood-related no matter what. I think facing and accepting reality is key. In the case of my dad, he had an incurable illness. There was no treatment available. You can only accept reality, and continue on with your life journey. (Participant J)

I would look at [my son's] photos. I do not hide them. I think it's important to face it. The most correct attitude is to face reality. I would never tell myself "He's gone already, let's not think about him". You can't pretend that it has never happened. It's impossible, and you shouldn't. (Participant I)

It's about facing and understanding the circumstances surrounding what happened. What happened has already happened. The deceased has already gone. There's nothing you can do. Yes from an emotional perspective you're very unhappy, but you still have things that you still need to do. You need to move on. (Participant V)

“*Lam tung*” also involves finding an alternative interpretation of the loss:

I would feel guilty about not being able to take care of my mom before she passed away, but the rational side of my mind would say, “Well you didn’t do that intentionally. You didn’t want this to happen too. You didn’t have a choice”. (Participant B)

I was able to think about [my son’s death] from a more positive angle, to process it, to change my perspective, and to get unstuck completely. It is all about how optimistic you are, and whether you can see the bigger picture. You need to look at things from another perspective. Honestly, of course it would have been wonderful if I had given birth to a healthy baby. But since that was not the case, the only thing I could do is to think about it differently. Positively. Optimistically. This made me feel less sad. Yes, this moment you are hurting so much, but you need to see that this is a relief to the deceased, that the deceased is finally comfortable now. Sometimes death is just another level of being – they just went to a different world. It’s not an end. They may actually be happier – even happier than you are – when they are in that world. You need to think positively and happily. (Participant I)

I sometimes will think to myself “I should have done a better job, I should have treated my mom this way instead, it would have been better if I had done that instead”. Those feelings of guilt would drown me. But I always jump back out by reminding myself that there were things I did right. Be more positive. (Participant O)

It is interesting that a few participants defined “changing one’s perspective” as “positive thinking”. Positive thinking is not only about finding the silver lining in a terrible situation though; having a sense of humour also helps lighten the emotional load of death:

My husband and I have a great sense of humour and often joke around. We tease each other a lot (laughed). For example, my husband always says, “Oh I think [our son] is nearby.” I always reply, “Yeah right, as if [our son] still has time to care about your business. I’m sure he’s already happily chasing after girls in Heaven!” We talk about death with a sense of humour. We will joke about it by telling each other “Don’t you ever come into my dream once you’re gone – I don’t want you disturbing my sleep!” (laughed). (Participant I)

Being the surviving children, the five of us often joke with each other saying, “It’s a great thing that our dad didn’t leave any money behind for us (laughed). We are still on speaking terms because there is no inheritance for us to fight over!” See, after my dad’s passing, we’ll bring something like this up and turn it into a joke. We want to create a positive environment, so that we won’t constantly mope around saying “oh no daddy is gone now”. Instead we say to each other, “It’s good that daddy didn’t leave us

anything". It is about having a sense of humour about it, and looking at it from a positive point of view. You turn it into something positive, so that we can stop feeling sad about it. Sometimes I would feel sad thinking about daddy's passing, but then I would think about the stuff we said to each other and find humour in it. (Participant R)

Participants also reframed the impact of their loss by engaging in downward social comparisons. They compared their own circumstances with people who were less fortunate, and realized that despite their loss, they were still better off than many others:

My husband said, "Your dad was in his 70's when he passed away. He already lived a full life and accomplished everything he should. What if the same thing happens to one of our friends, someone who just got married or has a young child? What's sadder, what happened to you or what happened to our friend?" This really helped me as he was able to offer a different perspective to look at my loss. (Participant N)

I witnessed how terrible it was for the other kids who were staying at the oncology ward. Many lost all of their hair. The atmosphere was gloomy; everyone stayed at their rooms. I saw a boy – around 10-year-old I guess – who underwent surgery to remove a tumour in his brain, but the surgery affected his impulse control and intelligence. Seeing something like this, I realized that there were many, many people who were very unfortunate. I'm not the most unfortunate one. These parents suffer more than I do. I am already better off than they are. (Participant I)

When I saw others.....like when I saw the news about the earthquake in Japan, I became more emotional than others. I told myself, "These people have suffered more than I do". I now often think to myself, "Many people are worse off than we are. At least we're OK financially." (Participant S, on losing his adult son)

### ***Religion and Spirituality***

The majority of participants reported belonging to a religion. For many of them, their religious affiliation became a major source of support in the face of loss. In fact, they described being even more religious after the death of their loved ones:

Now I no longer take my medication. Instead I totally devote myself to my religion. I pray. I listen to the teachings and sermons by great priests. I feel that I am now living in prayers. That's the turning point and that's the only thing that has helped. It's not easy but I need to keep doing it. It's difficult to keep it up, but I pray to God for the ability to persist till my last breath. I go to church every day rain or shine. I rely on the priests in my church. I'll

confess to them that I can't cope anymore, and they will teach me the prayers I can say. (Participant G)

Participants who found their religions helpful offered a number of reasons behind the growth in their religiosity. First, religions allow them to feel that death does not represent the end of one's life. The teachings of most organized religions invariably include a concept of "heaven", a place where the dead will go to live, and some version of an afterlife, whether it is in the form of an immortal soul or rebirth. This allowed the bereaved participants to think that, despite their departure from Earth, their deceased family members actually continued to exist in another world. To the participants, their loved ones were immortal, and their lives were never destroyed by death due to the belief of "life after death". This also implies that their relationships were never severed by death:

After moving to Canada I began learning more about Buddhism. I like their teachings. Buddhism talks about reincarnation, how when one life ends, another life will be reborn. I think religion can really be helpful in this regard. I mean the legitimate ones – Catholicism, Buddhism, Protestantism, Islam – cos' they often talk about life after death. During my mom's funeral mass, the monk said "don't sorrow, she only left this world to be in another world. She used another key to open the door to another world". I think that is a great way to put it.....to know that the end of one life is the beginning of another life. That even when lives end on this Earth, in heaven they become other lives.....to know that life hasn't really ended. These things make me feel better. (Participant P)

I believe that even though our bodies have vanished, our spirits, our souls, are forever, as I'm Catholic. They are never destroyed. Since our souls last forever, I'll be at peace if I know that [my sister] is at a place where she's peaceful and contented.....I hope that I can have an everlasting relationship with my sister. That's why I pray for her every day. (Participant G)

Second, the religious belief that their loved ones were still "alive" in another world provided the participants with a forward-looking perspective and hope for the future. To them, the absence of their family members was temporary. In the end, they would all reunite in "heaven". In fact, many participants used their experience of immigration as a metaphor to death – the deceased family members have only "emigrated" to a different world; the survivors will get to join them at a later time, when it is their turn to "leave":

I also remember what my pastor said – that [my sister] was just on a plane going somewhere else. But we will reunite in Heaven. She will be there to

greet me. I will get to see her again. This is just going to be a temporary separation. That got me thinking back to the time when my sister left for Canada by plane. Unlike the last time, this time she won't write to me anymore (crying) and can't call me anymore (crying).....but then it got me into thinking – sooner or later I will.....just like what happened to us, I also emigrated to Canada, I moved to where she moved to. This means that sooner or later we will end up in the same place again, as long as I do not sin. Then we will see each other again in Heaven. (Participant C)

I think the most important thing is – I'm a Christian. I know that I will see him again in the future. This is.....it gives me a lot of peace and calms my emotions. (Participant J)

So my husband told me that this is not a separation. Yes [my father and I] are separated for now, but we will all reunite in the end. I find that very helpful. That gives me hope. That gives me something to look forward to.....that we will see each other again in the future. I remember saying to my dad before he passed away, "It's just like when we emigrated to Canada – you came here first to look at the place, before moving all of us over. So it's basically the same thing now, as you are going there first to check it out and see how it's like. When it's our turn to go, we'll be together again." (Participant N)

Third, most religions portray “heaven” as a place free of pain and suffering. For those whose family members passed away after a difficult course of life-threatening illness, knowing that their loved ones were finally healthy, happy and at peace brought tremendous comfort. For those who previously experienced other deaths in the family, “heaven” was a place that allowed all the deceased family members to reunite as well:

I hold onto this idea tightly – how wonderful to be up there in Heaven! People don't want to come back if they are up there, even when that means they have to leave behind their wives and young kids! This gives me a huge sense of comfort – if people are so happy up there, there's no point for me to be worried about my husband anymore. There's also something to look forward to – we will see each other again in this great place in the future. This really helped release my grief and brought me great comfort. (Participant X)

[My mother-in-law] was religious too, which is helpful as we believe that she is now finally reunited with her husband. My father-in-law passed away years ago, before I married into the family. He died early due to cancer. We buried them together. Due to our religion, we believe that they will meet again, and so we think that they must be very happy now and free of any suffering.....that she finally meets her life partner again after all these years. So that's why it feels different.....that I never experienced the grief others might experience. (Participant M)

Fourth, religions alleviated the participants' sense of helplessness and powerlessness in response to death through rituals. Knowing that their deceased loved ones were still "alive" elsewhere, participants felt that they could continue to do something for the dead by performing various religious rituals. This allowed them to maintain a bond with their loved ones. Those who felt guilty about "not doing enough" for their deceased family members also saw rituals as a way to make amends. Through rituals that were purported to "benefit" the dead, participants felt that they managed to make up for things they did not get to do before the death:

I pray for her every day. I go to church every day. I do good on her behalf. I keep going to church, talking to my priests, attending masses.....whatever I think will benefit her, I'll do it. I make donations for the poor. I do it in her memory. I do it for her. I donate at church. I do it for her soul. (Participant G)

Religion gives me something to hold onto, that hope for the future. To hope that [the deceased] are actually doing even better. Things that we do now.....even though we didn't do a good enough job when they were alive, we hope that after their death we can do a better job for them. I often visit the Buddhist temple for atonement, for confessing the wrongs I did. Before my mom's passing I tried to become a vegetarian as a form of blessing for her, but that didn't last long. I went back to eating meat often. After my mom's passing, I decided to become a vegetarian once and for all. It's for "parinamana" – the idea that my own good deeds can be transferred to her as well, in order to help her. This is my way to atone the wrongs I did. (Participant P)

In contrast, a number of participants noted that their faith was significantly challenged by their family members' death. These participants' relationship with the "higher power" became fraught with ambivalence, disillusionment, and anger. They began to adopt a "realist" stance against the "blind faith" which is often necessary if one wants to be truly devout. They questioned religious teachings and the religious causal attribution often used to explain their family members' death (e.g., "it is God's plan"), as they struggled to make sense of why tragedy still happened to good people like them. This is evident in the following excerpt by Participant S, who became increasingly angry during the interview when she discussed her religious beliefs with the author:

Before this happened, we were not Christians. We didn't believe in God, but we knew that [our son's] wish was for us to believe in God. Shortly before his death, his pastor asked us to become Christians, and so we

complied. But after we did so, he quickly passed away. I think I was too naive. I really thought that his "God" would perform a miracle. After he left, I really regretted being a Christian. I never believed in God. Even now I don't believe. At the time I did say that I would accept God into my life.....and I truly wanted to. But I find their teachings contradictory. Sometimes when I listened to sermons and the pastor asked more people to go study theology, to go on missions.....I would think to myself, "What's the point of studying that? You still make [my son] die so soon!" (raising her voice, acting angry) So I will keep thinking about things to argue back. You (meaning God) have no reason to take him away.....[My son] was so devoted to you, he wholeheartedly believed in you, he did all these things for you, he worked hard to spread the words of the church.....but you still want him to leave so soon. Right? To me.....I find it very problematic. I have no idea why this happened. I totally blame this on God. If there's God, why would He have this plan? How could God punish [my son] like that?

After he passed away, I tried to read the Bible and listen to sermons, but I only did it for him. From my perspective, there's no God. It's just something that helps you feel better psychologically. It's the same for every religion. For example, every religion teaches you to do good. This makes you feel better psychologically. So it's like a form of psychological counselling. But is it really true that there's a god? Like the teaching "God loves everyone", I feel disgusted. I don't think so. I just don't see how God loves humanity.

Other participants reported similar struggles. Their religious affiliation did nothing to help them cope with the death of a loved one. To them, their faith had caused more harm than good, as it only led to more questions about why the death happened to their loved ones:

To put it in a nice way – I don't think the church understands what I'm going through, as they believe that [my son] has just returned to Heaven. Well but.....(laughed).....this passage to Heaven has created so much pain. People put it so lightly, "Oh he's just going to Heaven, he's returning to God's embrace". Yeah it's easy for YOU to say. Maybe his return to Heaven is "good" to a certain extent, but don't tell me as if it's 100% great. It's just something you say to yourself to make yourself feel better. (Participant I)

In terms of religion, I feel that I'm at the fringe of it.....sometimes I really want to believe, to have faith, to believe that it's God's plan and that we will see each other again one day. But sometimes there's a huge question mark in my mind. Why did so many bad things happen to me? Why me? Why is it so unfair? I have doubts. I struggle between believing and not believing. I feel that it's a precarious position, cos' if I lose this one thing that's holding my life together, I don't know how to continue to live. So I'm just desperately holding onto it. I desperately want to believe. It's a big part of my life. But then I have lots of questions, lots of devils floating around asking "why" "why" "why". (Participant W)



I don't understand why God chose us, why God would let this happen to us. We were just your typical middle-class family. Why would it pick my wife and let something like this happen to her? Why did He choose us to let us experience such difficulties? To me that's so unfair. Why was my family chosen? We sacrificed a lot to come here.....after over 10 years of a smooth, calm life, why did it suddenly happen? Why did she get sick? This has caused so many relationship problems between me and my daughter, and lots of terrible things that happened to my family. Why is it so unfair? I thought that this is harvest time for me and my wife after working so long. But when it's time for us to harvest, she isn't here to enjoy it. (Participant U)

Interestingly, these participants continued to attend religious events, but only for social reasons: to accompany their family members, to meet friends, or to make new friends. Participating in these events served as a pastime and a way to distract themselves from their grief:

(Sounded hesitant) If I don't need to work on Sundays I will go to church, but my heart doesn't feel the same as others. I won't do it the way they do it, thanking God for everything. I go only because my daughter goes regularly. Sometimes it's just nice to listen to the sermons. The pastor has a sense of humour. I'm there to listen to his teachings. I'm trying to learn so that my heart will feel the same way they do. This may make me feel happier and more peaceful.....to have more positive thoughts. (Participant S)

I returned to church as many of my friends recommended it. They wanted me to come out to socialize more. I got to know many friends who are Protestant as well. They all recommended that I should come out and join the church functions more, as they didn't want me to live in a socially withdrawn world. I tried my best to go. I think it was a good thing for me. I started reading the Bible. I got closer to the friends from church as we started to talk more and participated in more activities together. So now every Friday I make it compulsory to go to church. I feel lucky that the church and my friends are there to help me. Of course the church has an agenda of its own – they socialize with you cos' they want to convert you to their faith, but there's a positive side to it, as they're genuine in their effort to help you. Their intention is good – to help and to love. Whether you accept their religion or not, however, is another thing. Of course someone may say to me "oh you're just using them".....but you can't say that I'm just taking advantage of them. After losing a loved one, you're in such a terrible mood. Studying the Bible can serve as a distraction – it diverts your time and attention away from the sadness. You also gain something by talking to friends you meet at church. (Participant U)

## **Post-Loss Changes and Growth**

Death of a family member was such a significant life event that many participants reported a subsequent change in their outlook on life and a sense of personal growth after the loss. Participants had the sudden realization that life is fragile and constantly in flux, and that nothing should be taken for granted in life. They described it using the Chinese term of “*mo sheung*” in Cantonese, or “*wu chang*” in Mandarin, which literally means “nothing is ever constant”:

I realize that nothing is ever a given in life. There are things in life that would just.....Chinese call it “nothing is ever constant in life” (“*mo sheung*”). Things can disappear or be taken away from you in an instant. That’s why there are things in life that I’ve learned to let go. (Participant B)

I just feel that life is so helpless and constantly changing. You know there used to be this old saying in Cantonese, “*yat ye laai laai cheung, tiu meng chap chap seu*”? It means that nighttime feels so long, but in contrast our lives are very short and fragile. You never know when you’ll be gone. (Participant H)

For a number of participants, the feeling of “*mo sheung*” had led to a sense of pessimism towards their future. Death has brought about shattered dreams, and life has become utterly uncontrollable. Coupled with the realization of their own mortality, they believed that it was futile to make any plans for the future, because life could take everything away in the blink of an eye:

I now realize that I’m getting old. What will my future look like? I start to feel pessimistic all of a sudden. I feel that I’m getting closer and closer to death day by day. I have given up all hope and tried not to think about it anymore. Before my mom’s death, I would have many plans. There are so many things I wanna do and wanna try. But now I will just give up and forget it. I won’t think about them anymore. (Participant D)

I realize that there are things you simply cannot predict or imagine beforehand. My husband and I used to have these plans.....we have two kids. Our daughter has graduated from college and found a job. We have paid off the mortgage on our house. Life was good and we were at peace. I had these plans that if [my son] ever had kids, I could take care of my grandkids for him. We had all these plans. But.....now we have nothing. It’s not up to us to plan or think about the future anymore. Things never end up the same way as you originally planned. No way could we have imagined.....I find it very ironic that (sobbing).....before [my son] got sick, my boss asked me when I would like to take time off. At the time, [my son]

was planning to start a family already. I told my boss, "I have no idea. I'm waiting for my daughter-in-law to get pregnant. Once I hear the news I'll request time off." I really couldn't imagine that in the end, I took time off because my son had to have surgery. My son ended up having cancer instead of having a child. So now I will no longer have such an optimistic and positive outlook. A lot of things.....maybe life will decide to play a cruel trick on you and doesn't grant you what you want. Lots of things are unpredictable. I've become more pessimistic. In the past, I always felt that life had treated me well. Although we weren't rich, we had a stable life. Both of our kids were great kids. I was contented. Now I have nothing.....and I've stopped planning into the future. (Participant S)

For other participants, however, the unpredictability and fragility of life resulted in personal growth in many aspects. First, it motivated them to "seize the day", as they learned that they need to do everything they want to do before it is too late:

"Carpe diem" definitely. Whatever you want to do, if you have time, do it now, don't wait. For example, don't wait till you get old before you travel. Seize whatever time you have today to do what you want to do. (Participant F)

In the past I wouldn't treasure life as much. Now I have this fear of losing people around me all of a sudden. I feel that I may lose someone in the blink of an eye. So last time when I underwent surgery myself, even though I had no idea if I would end up OK, I seized the opportunity to say what I wanted to say, and to do what I wanted to do. After doing that I felt at peace. So now I will say whatever I want to say right away. I won't hide and not tell others.....unless it's something hurtful. No one knows what will happen tomorrow. (Participant C)

My outlook on life has changed. My mom was very, very hardworking. But now I learn that work is not your life; work shouldn't be your everything. "Carpe diem" is the lesson I learned. Yes you need to work hard, but you also need to rest when it's time to rest. (Participant V)

Second, participants noted that the death of their family members led to a philosophy of life called "*tai ho*" or "*tai fa*" in Cantonese ("*kan kai*" or "*kan hua*" in Mandarin). "*Tai ho*" or "*tai fa*" can be loosely translated as "letting go", but it is not about letting go of the deceased. Instead, "*tai ho*" or "*tai fa*" pertain to the realization that since life is not under human control, it is important to learn to "go with the flow" rather than forcing things to happen or wanting things that one is not destined to have in life. It is about letting go of the desire to control life's outcomes. Participants described themselves as becoming less rigid and stubborn, less demanding on themselves and others, and more

accepting of imperfection and negative life experiences. By “taking life easy”, they were able to become more relaxed and less worried about what the future might hold:

I used to be so hung up on my kids’ academic performance, and their career accomplishments. My mom’s passing made me realize that.....even if I try to plan their lives or to think about what they should be doing, it’s futile. They have to make their own choices in order to feel no regrets, right? Another thing is – at the time I thought my life was so great! I had a mom, I had my sisters.....but I could lose them all of a sudden. It’s so fragile. That’s why I am no longer as “stuck” or insistent on certain things. I’ve always been stubborn. Like my kids. Since their childhood I made them get tutoring on math, on English.....I pushed them to the point that they would lose their mind. Now I look back and realize that I cannot force them to follow only this path I’ve planned for them and not let them deviate from it. (Participant B)

I think because of [my deceased son], I learn to adjust my expectation towards my other kids. In the past I would wish that my kids could excel in everything, and grow up to be the cream of the crop. But now I no longer think that way. I just want them to be happy. I want to be able to teach them to be independent and self-reliant. I want them to live a life of service to others. (Participant I)

I just realize that – no one know what will happen tomorrow. So whenever I start to get very worried about something, I’ll tell myself "who knows what’s gonna happen the next minute? What’s the point of worrying?" Maybe the tide would turn the next minute, then you would have wasted your energy on worrying. (Participant M)

Third, the death of a family member led to an improvement in the relationships participants had with others. Since life is short and fragile, a person can be alive one minute but vanish the next minute. Participants therefore had learned to treasure people around them when they were still alive:

When we are still alive, we need to treasure what we have – not just our parents, but our friends, coworkers.....like those inspiring messages I saw on the internet, "Treasure the time you spend with your friends". Or even your spouse, your children, when you can still spend time together, treasure it. Don’t regret it afterwards. (Participant P)

I now learn that we need to “treasure the person in front of us” right now. When you have the opportunity to spend time with your family, you need to treasure it. I now treasure everything I have even more so than before. (Participant R)

From this I have learned what it means by "treasuring the time with your children". Now that I have two more kids, I take care of them myself. I won't hire a nanny. That's why I didn't go back to work.....I need to treasure the time that I can still spend with them. My husband understands this too. So we make sure we spend as much time as we can with them. When my husband comes home from work, he spends as much time with them as possible, and will wait till they are in bed before he starts dealing with his own work. (Participant I)

When your family members are still around, spend more time with them. They actually can leave (laughed). For instance, my dad is still here. My sisters, my brother.....these relationships are precious. (Participant O)

Fourth, some participants found that their tragic experiences helped them become more charitable and empathic. Having suffered themselves, they found it easier to understand the suffering of others, and felt more motivated to help:

I want to live a life of service to others. During my stay at the hospital, I witnessed how many people really needed help from others. I would want my kids to volunteer. I now donate rather than throwing things away. I give more to charities. There are just so many people in need. (Participant I)

I want to volunteer at organizations that serve the bereaved, as I want to help others too. I want to use my own experience to help others. (Participant Y)

I now understand how [the bereaved] feel.....or those with family members who suddenly passed away, or those who passed away due to a terminal illness.....I read about these stories all the time in the newspaper.....and I have empathy for the survivors. I can put myself in their shoes. I feel that we are in the same situation together. (Participant H)

Finally, the passing of a family member helped demystify and normalize death for both the participants and the rest of their families. This allowed them to overcome the rigid Chinese cultural rules prohibiting the discussion of death. Participants noted that they and their family members became less fearful of death. They were more open to making advance preparation for death, such as discussing their preferences with family members, having a will, and purchasing burial plots. Participants noted that even the older members of the family, who tended to be more traditional and more likely to see death as a taboo, were more accepting of such honest discussion on death:

After our son has passed away, my husband and I bought burial plots for ourselves. Then this started spreading to lots of other people – my mother-

in-law bought one, then our friends bought theirs.....when you have experienced something like this, you start making preparations beforehand. My parents are in their 70's and they are very traditionally Chinese in their way of thinking. This is such a taboo to them.....But I talked to my parents about it and they surprisingly replied "oh sure, let's do that, no problem". So now everyone has made preparations already (laughed). In the past it was totally a taboo, but after this happened, everyone became more open (laughed). It's no longer a taboo. We started having frank discussions about how our parents want their funerals to look like, or what arrangements they want to see. (Participant I)

In the past, death was a taboo topic in my family. After what happened to my dad, we have become less avoidant and no longer avoid the topic. In the past I was scared of going to funeral homes. But when I was dealing with my dad's funeral, I realized that it wasn't a big deal at all. Now I no longer have this fear when I visit funeral homes. To me it's just a place.....a place for you to pay respect to the body, a place where you get stuff done. It is a huge change for me. And in the past I always avoided talking about preparations for death, but after what happened to my dad, I asked with my mom, in an open and honest manner, "What are your wishes and plans when this happens to you?" I brought this up myself. I would not have done that in the past. My dad passed away so suddenly.....he never told us what his wishes were or made any arrangements. After this happened, when I suggested to my mom that she should start pre-planning for it, she was able to accept it. She finally realized that if you leave so suddenly with no final words or prior arrangement, those surviving you will have no idea what arrangement they should make to best reflect your wishes. Now I manage to have an open discussion with my mom. We now learn to face reality. Even for us as children, we are no longer avoidant. I'm happy that we can now discuss this openly and clearly. It's no longer that much of a taboo topic, since my dad has already left, and we already went through all the arrangements one needs to make after death. Our experience showed us that there's nothing to be fearful of. This is something that everyone will experience. You can't avoid it and you can't be scared. Of course no one wants to talk about this, but reality is reality. It's a normal part of our life cycle. (Participant R)

## **Ideal Services for Bereaved Chinese Immigrants**

*I think it's a bad thing not to talk about it, but talking about it.....like in my case, I never talked about it but I also feel that I'm not healed yet. But who can I really talk to about this? How do I really heal myself? I haven't really dealt with it yet. (Participant O)*

*I feel totally helpless. I feel that there has been no support, no help. There's no one around me that could help me. Where else can I do then to seek help? I'm just desperate to hold onto anything. I feel as if I'm lost in a huge forest and there's no one to help me. Or on a remote island. I also have no*

*idea where to go to seek help, especially when I feel so disconnected from the rest of the world, when I haven't been participating in any social or community activities for years. My only social contacts were limited to my mom, my sister, and my daughter. (Participant Y)*

*I relied on self-help in order to get out of grief, but it's not really a.....it was actually a huge struggle. It felt like I had fallen into a well and I could only rely on myself to climb back up. If someone could drop a rope down to pull me up, it would have made the whole process so much easier. I won't die if no one drops me a rope down to save me as I'll find my own way to get back up, but the process would have been faster and not as difficult if someone were there to help me. (Participant V)*

### **Goals of Bereavement Care Services as Perceived by Bereaved Chinese Immigrants**

Participants unanimously agreed that there is a tremendous need for bereavement care services for bereaved Chinese immigrants due to their own suffering and the suffering they witnessed in other bereaved individuals. This is true even for those who felt that they did not need services for themselves. They proposed three goals that they believed bereavement care should achieve:

### **Information Support on the Experience of Grief and Available Bereavement Care Services**

The most urgently needed bereavement care service identified by an overwhelming majority of participants is the provision of information on grief, ranging from the nature of grief, to its impact on physical, psychological, social, and occupational functioning, ways to cope, and support services available in the community should the bereaved require further assistance and more specialized intervention. Participants unanimously agreed that their lack of awareness and knowledge on grief-related matters and the existence of bereavement care services had deprived them of the opportunity to receive the care essential to their health and wellbeing after the loss of a loved one. At the same time, they felt that they were put in an unfair and unfeasible position by being asked to take the initiative to seek bereavement care support, when they did not have the concept of "grief" or "bereavement care", did not know that help exists, and did not expect bereavement support from health care professionals:

One thing I noticed was – and that was something I said to the chaplain in the hospice as well – I had to take the initiative to ask first, before they would provide me with information. But what if I didn't ask because I didn't know? There was no one that approached me instead and provided me with information. It was up to me to ask for it. (Participant X)

Participants also expressed that health care professionals should not assume that Chinese do not need bereavement care services simply based on low utilization rate. They recognized that while the need for formal, therapeutic-focused bereavement care might vary across individuals, services should still remain available to bereaved Chinese immigrants, and everyone should still have equal access to information regardless of needs. At the very least, they believed that professionals should inform them of available services, and let the bereaved individuals decide if they needed help. Providing information, to them, is the first step to removing barriers in accessing services:

The services needed will vary across individuals as they may do things differently or have different family backgrounds. So I can't say whether there's a general need for such services. I don't know. I can only say that it's better to have these services than not having them. If such services exist, those who feel that they need it can access them. Those who don't feel they need it of course won't knock on your doors, but at least you're there. You also can't say no one needs such services either. There are people who'll need it, and right now they have no idea how to seek help. They have no idea how to find you. That means even if services exist, these services are of no use to them. (Participant R)

It really depends on the individual. Of course, if you have told this person about these services, but he or she chooses not to take it, there's nothing you can say. It's like, I've already taught you all the steps you need to take, but if you can't do them, that's fine. But if you are not offering anything, that's something else. (Participant U)

### **Informational Support on Funeral Arrangements and Estate Settlement**

Participants would also welcome information on funeral arrangements and ways to settle the deceased's affairs. Many of them reported that it was their first time arranging a funeral when their loved ones died. They therefore had no idea how to begin tackling this, and would like to have concrete directions on what they needed to do:

Many people have never arranged a funeral. Many don't know how to get started. For instance, my sister-in-law had no idea how to do it as well. What happened was that – a clan association in Chinatown came over to



help her. Their members told her where to go to do what, how she should deal with the casket, etc. They were there to instruct her on how to do it. I think it's true for everybody – if you are bereaved, you often feel helpless and lost in addition to feeling sad. If someone can provide you with guidelines on how to do it, it would have been very helpful. (Participant E)

And not just to deal with the survivors' emotions – they also need help with funeral arrangements, the steps one needs to take to get things done. How do you arrange a funeral? Where do you go? What do you do? This is something that they really need information on. They really need lots of pamphlets in their hands, pamphlets that tell them where to go, phone numbers, addresses.....where the funeral homes are, which home you should go with what religion affiliation.....information is of utmost importance. You actually need to tell them what they should know (laugh), then you go into detail on what they need to do, where to go to do what, what you should do first – for instance, you need a death certificate first, or something like that. Many people are confused about this. (Participant I)

I think they will benefit the most from having someone teach them how to make funeral arrangements. People will find it helpful if you tell them things that they need to deal with after a person's passing, such as filing tax returns. I think after someone's passing, the surviving members often feel the most lost when they need to deal with all the funeral arrangements and put the deceased's affairs in order. They want to do it appropriately. They also don't want to get into trouble with the government around estate matters. So they actually will benefit from some guidance around that before the patient's passing. (Participant J)

Things like applying for death certificates, funeral arrangements, all these applications you need to make, settling her finances.....there are lots of things to deal with. These are things you MUST deal with, no matter how you feel that day. These are big problems – how to handle these practical things, how to apply for things, how to get the money out.....if you don't know how to do it, you really don't know how to do it. Even accountants may not know what you should do in this case. But if there are support services that teach you the steps you need to take, what the best strategies are, that would be a lot better. (Participant U)

### **Emotional Support from a Professional**

With regards to more therapeutically focused services, participants identified a tremendous need for the bereaved to talk to someone as a way to relieve pain. Yet “emotional support” goes beyond “emotional catharsis” or “getting it out of the system”. Participants noted that bereaved Chinese would need guidance to learn how to express emotions (e.g., putting emotions into words, allowing themselves to feel emotions). Consistent with the Chinese cultural emphasis on practicality and utility, they also wanted

practical strategies for managing emotions and changing their perspectives. Participants firmly believed that bereavement care services are effective only if they are provided by professionals.

What distinguishes professional support from peer support is the training professionals had received. Participants believed that professional training is a must in order for someone to understand what the bereaved are going through, and to know the “right” things to say or do in response to grief. To them, these are specialized skills that only professionals can offer:

We need someone with a psychology background that can understand our sadness, and maybe help us with releasing these emotions, and offer us suggestions on things that we could do in addition to just talking about it. Maybe things like deep breathing, or meditation, or yoga.....concrete things that we can do to distract us, to pull us out of that downward spiral of thoughts. (Participant L)

I think [professionals] can help me process this and change my way of thinking about it. They can help me get through those lowest times – those times when I was so moody, when I couldn't get anything done – if someone could say to me "well you need to try this. You can't keep thinking about your daddy's passing. You can't just stay sad", or if someone could offer alternative solutions, I think I would have found that very helpful. I think it can help me get out of the rock bottom, having someone who's well-trained, who can listen to you, and who can console you. (Participant N)

Since I've undergone therapy before, I realize that having someone to talk to when something major like this happens is a great thing. Sometimes the way we think about things may be different from how a professional would look at it. I think professionals can help you gain a different perspective. (Participant E)

[My therapist] offered practical suggestions, things that you can actually do and implement, such as how to fill up your time during the day. Sometimes you really don't know where to begin and what steps to take. But they were able to give me concrete ideas, and help me plan the day. (Participant W)

I want to learn how to manage my emotions. But I want practical guidance. I don't just want a bunch of theories. That's useless. I want to know what I can actually DO. For instance, I want to learn actual skills, like writing down our feelings, or other practical coping strategies. But many people need someone to tell them what to do, since they have no idea themselves what to do. (Participant Y)

Another difference between professional support and peer support is the level of trust and confidence clients have when working with a health care professional. Professionals have the duty to safeguard their clients' confidentiality. To be effective in their work, they also need to be objective and non-judgmental. Participants therefore felt that they would feel more free and comfortable to open up and express negative emotions in the safety of the treatment room:

At the time I had a lot of guilty feelings. I think it's important to process these emotions with someone. That's why I think it's important to have professional support in this area – sort of more counselling-focused, a place where you feel that you can talk about these emotions freely and comfortably, even when you are talking about emotions such as anger towards the surviving family members.....you can freely talk about them without worrying that others will judge you. If there are actually professionals available, with whom I know that I can freely share whatever thoughts and feelings I have, I will find it incredibly helpful. (Participant T)

With the right environment, and with the right person, some people can really open up and talk about things that they really want to talk about but have no one to talk to. Many Chinese find it embarrassing to share these with their family members or close friends. If you provide an environment where they can talk about their emotions and release them, it'll be very helpful. (Participant V)

Participant B, who had undergone grief therapy, recalled how speaking to a stranger who was bound to keep information confidential allowed her to process her grief in-depth with someone, without the fear of negative social consequences:

Well Chinese do not want to talk, they don't want to share everything that's within themselves. Honestly I was not used to it at first. But when it was a one-on-one situation, I felt more comfortable. I understood the rules that guide [a mental health professional's] line of work, like confidentiality, that he or she won't share what I said with others. Confidentiality is very important. I wasn't worried. Honestly before I started counseling I didn't know about this. Once I started I felt that the experience was quite positive. Chinese are not used to sharing their deepest thoughts and feelings with a stranger. We won't share anything in depth with a stranger. But then later I realize that.....it's only in a situation like this will you be able to talk about things that are deep within you. If it's your friends, you actually cannot do that. Only with a stranger will you be able to share anything deep. You never know when your friend will tell others what you have just told him or her. You don't know if people will resent it when you bring up a taboo topic. That's why having professional support is so important, cos' in a situation like that I wouldn't be afraid to tell my counselor anything.

## ***Strategies to Promote Utilization and Address Gaps in Current Bereavement Care Services***

### **“Everyone needs to know about this” – Public Education and Promotion of Bereavement Care Services as Primary Prevention**

To the participants, public education and promotion targeting the local Chinese community is the key to reduce the disparities in access and improve the utilization of bereavement care services by bereaved Chinese immigrants in Canada. Participants defined these public health efforts as a form of primary prevention – learning more about grief and bereavement care services **before** death occurs helps promote healthier adjustment to loss and reduce the risk for negative sequelae of bereavement. Through education, Chinese immigrants can be more mentally prepared for their losses, become better-informed health care users, and feel less lonely in the journey of bereavement with the knowledge that help is available should they need it:

You need to let people know earlier. You need to let people know about these services before bad things happen. Of course I know it's difficult – when nothing has happened to your family yet, it's hard for people to approach you to talk about it. But I think "planning for a rainy day" is actually a good thing. You may not need it now, but when it finally happens to you, you may suddenly remember "oh there's this organization that provides support". At least you know. Of course many people don't want to hear it, they don't want to think about it beforehand.....but I actually find it helpful that in the back of your head you know about these organizations, that when something happens to you, at least you already know that there are organizations that can help you. (Participant N)

Many people dare not tell others that someone in their family is dying. It'll be shocking to them if they wait till the person has passed away before receiving information. They need to know beforehand what they will face. It will really make a difference. (Participant D)

You need to let people know about these services beforehand. Even if one's mom is still alive right now, maybe she will pass away 3 years later and the surviving family member will still remember that these services exist. Typically people don't like to hear anything about this, but when they finally experience someone's death, if they have something like a brochure to hold onto, maybe later they'll take that brochure out again and be reminded that there are services for them. (Participant M)

Since the majority of participants identified the lack of knowledge on the existence of bereavement care as the biggest obstacle to accessing services, they naturally urged

for increased, public educational and promotional efforts to address the knowledge gaps in bereavement care among Chinese immigrants, and to raise awareness on the current bereavement support services available and the routes to take to access them:

So to me, letting people know about these services is of utmost priority. If no one knows about them, no one will seek them out. Often times our clients told us that they came because someone told them about our program, that they were told that there were programs available to help them. (Participant T, who is a mental health professional herself)

I really think you guys need to widely advertise this. There needs to be more promotion on the current bereavement care services in the Chinese community. People also need to know the fees.....what are the phone numbers they can call.....are there any direct routes to take, things they can do, the actual steps to take to seek these services out. (Participant C)

At the same time, participants also believed that public education should not only focus on the existence and availability of bereavement care services. In fact, educational efforts may need to start from the basics: explaining the nature of grief and bereavement care, explaining how to recognize symptoms, normalizing grief, and reducing the fear and stigma associated with death, expression of negative emotions and help-seeking:

A person often has to feel that "OK I can no longer deal with this by myself. I can no longer hold myself together" before he or she realizes the need to seek help. This is actually a huge barrier. Can they recognize that they're already at their breaking point? I think this needs to be part of the promotion – telling people "when you are experiencing these things, like if you're in a lot of stress, or in a lot of physical pain, or if you're crying all the time, these are the warning signs." I think many people take these things for granted as they would think to themselves, "Of course I will feel this way, it's normal to feel this way after losing a loved one". There is also the assumption that one must hide his or her grief. Of course you're supposed to cry in private. People get annoyed if they see you cry in public. This means you can't just educate the ones who have lost their loved ones; you also need to educate the other people around them. (Participant Q)

I think a lot of the promotional efforts will need to focus on educating them about how seeking help is a way to help yourself and your family, and that's why it's important not to be afraid of going to a support group. Let them know that it is OK to attend these groups. Don't be ashamed of it. (Participant F)

I think part of the educational effort has to be – to educate others that some people really need these services, and you shouldn't discriminate against

them. You also need to let those people who need services know that there are people ready to support them, that they're not alone. (Participant G)

Participants believed that public education and promotional efforts must extend outside the walls of hospitals and hospices. Many highlighted the power of advertising bereavement care services through the local Chinese media, funeral homes and local immigrant support organizations such as SUCCESS:

A lot of people read Chinese newspapers. I know you have to pay in order to advertise in newspapers, but I think it's important for people to know about these services. Or like radio station.....a lot of elderly people listen to the radio only, so if someone can go on the radio to talk about services that would be great. (Participant A)

Do more seminars! SUCCESS often has a number of seminars on health, like heart disease prevention, smoking cessation.....Is it possible to have more of those on palliative care? This applies to bereavement care too – like if you do a seminar, a lot of people who are bereaved or have family members who are dying will show up. It will get them to think about whether they need services. But now there isn't anything. It's really worth a try to do seminars in the Chinese community. SUCCESS does a lot of promotion of their health seminars and a lot of people attend those. The seminars are always full. (Participant D)

I think you guys need to prepare some pamphlets and ask funeral homes to give them out. Placing pamphlets in funeral homes is particularly important. When people are sitting at the funeral grieving, if they see these brochures, they are more likely to consider signing up for these services. At least they'll know what phone number to call. You need to emphasize that these services are provided in Cantonese or Mandarin. Let them know that if they want to talk, they can contact these people. They need to know that such services exist. These families often will spend at least a day or 2 at the funeral home. They don't really have much to do anyways and they'll have time to read these pamphlets. Or TV – whether it's Chinese TV or English TV – they have these programs that talk about community services. Have someone introduce these programs to the audience. Talk about it more frequently, maybe once every 3 months. (Participant M)

Can we start from funeral homes if you need to find a way to access this population? For instance, the Richmond Funeral Home serves a lot of Chinese individuals. Just provide some brochures to the funeral homes so that they can help distribute them to the families who are there, since funeral homes are a stop for everyone that is arranging a funeral. In the brochure, it'll be helpful to list what resources are available to help these families, the help available for supporting people's emotional needs, and where they can go to ask more questions. (Participant Q)

## **“Please help us before our loved ones pass away” – Pre-Bereavement Services as Secondary Prevention**

Participants identified a need for health care professionals to consistently provide pre-bereavement services that involve assessing needs, educating them on grief and bereavement care, and providing information on available resources when they are working with those facing the impending loss of a loved one. Participants recognized the need for early intervention by professionals given the emergence of anticipatory grief long before death eventually occurs. They considered pre-bereavement services a form of secondary prevention – health care professionals can detect those at-risk and intervene early during their frequent interaction with a dying patient’s family members:

Educate family members about the death and dying process. Help people mentally prepare for what would happen. The process has to begin before death occurs. If this is done well, they may not need such a long period of support and care from professionals after the loss. (Participant B)

If you feel that this family member is displaying symptoms when you interact with him / her, you need to take the initiative to help them. Don't wait till the problem has snowballed before you reach out to them. I mean....."bereavement care services" sounds as if it's something that's offered only AFTER someone has already lost a loved one. But the emotions often appear way before the person passes away. This is especially true when the loved one is sick – you witness his / her struggles from the moment he / she gets sick to the final moment. This period of time is actually very tough. Don't wait till the patient has passed away before you offer services. You need to support them through the entire journey. (Participant V)

Participants believed that the best time to “catch” and provide information to family members is during a patient’s hospitalization, when family members are still physically present in the health care facilities. Participants also highlighted the need for “memory aids” – tangible tools such as brochures on grief and available services, or fridge magnets with phone numbers that someone can hold onto after speaking to a professional. These can remind surviving family members that help exists even after they have left the hospital, when they finally realize their needs for services:

Hospitals shouldn't wait till the patient is no longer here before they reach out to families and provide information. You need to get in touch, drop off some brochures, and educate the families on the services available when the patient first got admitted, or within a few days of admission at the latest.

You need to provide more information to the family members. You need to educate them. And it would be so helpful if somebody, like a social worker, could have approached us when we were still in the hospital, to let us know about these services. Or to send a social worker over to us at the very beginning, even if it's just to drop off some brochures or give us some information. (Participant F)

If professionals wait till that incident (euphemism for "death") happens before talking to people, they are likely going to say that they're fine at that moment and do not need help. That's why you need to talk to them before it happens, and leave a bunch of brochures for them, so that they have something to hold onto. If down the road something happens, they would remember "right, there's someone that can help me". For instance, after I gave birth, they have these fridge magnets with the phone number of the newborn hotline. You can call anytime if anything happens. You get to talk to nurses directly. Of course they may need to refer you to someone else, but at least you know that "if I run into any difficulty, someone is there to help me." (Participant E)

#### **"Professionals need to make the first move"**

With regards to the delivery of bereavement care services to Chinese immigrants, participants believed that health care professionals need to take the initiative to reach out to family members and proactively provide help, rather than waiting for family members to ask for help. Participants felt that they were dealt a double blow to their level of motivation – a lack of knowledge in bereavement care, combined with debilitating grief, often prevent the bereaved from making the first move in help-seeking:

I didn't know anything about available support for families! Maybe we didn't pay attention, but when you are grieving, it's impossible to take the initiative to go look for services, unless you have "done your homework" before it happens..... as in, if you know that your family member is leaving soon, you search for these services in advance before it happens. (Participant N)

Regardless of whether the survivor is a spouse, a child, or others in the family.....during the mourning period, we shut down and withdrew. I think most people would just close themselves off. On top of that, after such a long period of caregiving, I felt so detached from the rest of the world.....and when I was already so disconnected to what's happening in the world, I really had no idea what services exist. (Participant Y)

While participants recognized the emphasis on individual autonomy in the Canadian health care system, they also noted that the passive nature of many Chinese people might make it difficult for them to make the first move and assert their needs. They



therefore felt that many Chinese people needed to be “pushed”. “Pushing” does not mean coercion. It simply means professionals working with Chinese immigrants need to take the lead in reaching out, initiating a conversation about grief, motivating them to get help, and providing more explicit instructions and guidance on how to do so:

At the beginning I didn't even want to cook or eat. I didn't even know what kind of help I really wanted at the time. I couldn't tell anyone what would be helpful to me at that time. My mood was at an all time low. I didn't know what I wanted. So I guess during that period of time.....I would want someone to reach out to me, to regularly give me a call even when I didn't feel like talking.....To have someone who has a very good understanding of what usually happens at that stage, who knows the kinds of emotions are expected during that particular stage, to reach out to me just to help me, instead of asking me what I wanted, cos' I really had no idea what I wanted. (Participant W)

Caucasians will really expect other people to help them. They will take the initiative to seek help. Chinese.....you have to push them. You need to give them a trigger.....like me, hearing what you said on the radio the other day was what prompted me to take action. If I didn't hear about this, I would have ignored it. If you give them a trigger, they will come. You just need to make the first move to let people know about these services. You're not pushing them deliberately, but sometimes with the right lead, they will talk about it. (Participant B)

A number of participants also criticized the “passive” approach to patient education in health care – that often times health care professionals assume that they have done their job educating patients simply by leaving brochures behind, and expecting those in need to take the initiative to pick them up and read them. To the participants, there needs to be more “human touch” to education and service delivery – to have someone approach the families in-person, communicate to them directly, and personally introduce them to bereavement care services:

[Health care professionals] need to give out pamphlets without being asked. Or can hospitals have a designated staff member to meet and greet families regularly to introduce these services to them? I think if you don't have someone to approach the family members, just putting brochures up on notice boards won't be as effective. (Participant N)

Chinese families.....they will not take the initiative to seek out or ask for services. That's why doctors are very important, or nurses, or other health care professionals.....they need to take the initiative to offer them services, to tell them that these services are available. That would have been much

better. Don't assume that just because you have left some brochures in the room, these people will take the initiative to take them and learn about these services. Most Chinese people don't do that. (Participant V)

At the hospice, it was up to us to pick up the brochures and read them ourselves. There were lots of brochures just lying around in the hospice. There were some that talked about the process of dying. But then it was totally up to me to get them and read them myself. Honestly, I would have preferred someone, for example the chaplain, to read TO me what was said in the brochure, instead of me reading it myself. I would rather have someone tell me what's available instead of expecting me to discover them myself. (Participant X)

Some participants used their experience with after-birth care as an example to illustrate their idea of “professional-led initiative”. They noted that after giving birth, their information was sent to the public health units in their communities. Public health nurses then took the initiative to reach out to the new mothers, to check in with them, and to proactively provide information and referral to other services. They considered it a good model for the delivery of bereavement care:

I think for Chinese, there's this delayed response when it comes to seeking help. That's why I think if professionals can take the initiative to approach these people, it will be a lot better. For instance, after I gave birth, there were community nurses who got in touch with me. They visited me at home to see if I was doing OK and if I had encountered any trouble. I find this approach a lot better. (Participant E)

**“Please maintain contact with us even after we had left the hospital, and don't take no for an answer” – The Importance of Continued Bereavement Follow-up**

Most participants identified the first 6 months after bereavement as the most emotionally difficult period of time for them. Those still struggling with their losses attributed their prolonged grief and suffering to the lack of timely professional follow-up and intervention after the death of their loved ones:

If someone had provided some services during the most difficult time, maybe [the bereaved] would have felt a bit better, and therefore would not have such a long and difficult course like me, dragging the negative emotions out for so many years. (Participant A)

If within the first 6 months, someone had come to help me, to console me, to lead me out of this difficult situation, to suggest other activities I could have participated in.....maybe the negative consequences wouldn't be as

bad as they are now. Maybe I won't be waking up at 4am every night. Maybe I won't still feel so anxious even though it's been a year and a half later already. (Participant Y)

For most participants, their contact with health care professionals ceased immediately after the death of a family member. For the few who received some form of post-death follow-up from professionals, the contact was usually time-limited and short-lived, and was filled with ambiguous intent. Participants expressed a desire for multiple, longer, and more frequent follow-up contacts by health care professionals for three reasons. First, follow-up contacts serve to “establish a presence”. They demonstrate to the bereaved that help is available, and that someone from the health care system cares about the wellbeing of the surviving family members:

The first call is just a way to initiate contact. It helps establish in that person's mind that you're available. He / she will still remember you even after the funeral. If you wait too long before reaching out, they will find it strange to talk about it again. The best timing to connect is within 1 to 2 days after the death. Just ask about funeral arrangements. It's just a way to show that you care. Then there needs to be more follow-up phone calls. Slowly make your way into their hearts, to see what they need. (Participant D)

Second, multiple contacts help overcome one of the barriers to help-seeking identified by the participants earlier – the mismatch between timing and need for services. As previously discussed, participants believed that most Chinese would have denied their need for support services during the first follow-up contact. As a result, participants suggested that professionals “should not take no for an answer”, that is, they should not accept the first refusal at face value and cease further contacts. Only if follow-up continues will the professionals be able to catch those who do not recognize their needs immediately after their losses:

I think there needs to be longer, more frequent follow-ups by social workers. Don't just do it once, and don't stop just because they tell you they don't need your services. Don't just give up and say “oh they told me they don't need it, so I'll stop calling”. (Participant E)

They also need to be mindful that some people may claim that they do not need help, but they actually do need help. Don't just go by what they said out loud. (Participant W)

Even just making a phone call to check in – "How are you? We are thinking of you." You may feel that the person answering the phone is not interested or is ignoring you at first, but it will become helpful in the end if you can continue to reach out to the bereaved like that. (Participant J)

Third, multiple contacts help build trust and familiarity, allowing those in need to feel comfortable disclosing their emotional difficulties and seeking more formal bereavement support. Participants used the phrase "*letting you into their hearts*" to describe the level of trust many Chinese need to have with a professional, in order for them to open up, to overcome the shame and stigma associated with negative emotions, to admit that they need help, and to become receptive to therapeutic support:

I think it's important to have someone to talk about how you feel, but.....it really depends on whether that Chinese person lets you into his / her heart. Patience is key. If the professional is very patient and follows the family in a caring, thoughtful manner, I think everyone will have a moment of weakness, and at that moment, if they realize that you're genuinely there to help.....after a long period of time, they will be willing to open up. (Participant E)

For Chinese, I think they don't want to look bad and admit that they have failed. They would want to hide it from others. Like me, I won't tell new friends I met at church about my experiences either. I won't do it until I know them well. I will want to hide it. Only when I feel close enough to that person will I begin to disclose things about myself. That's a very common value in our culture – that we really need to get to know someone, feel close to someone, before we will share private things about ourselves. It's different for Westerners – they tend to be more open. Chinese tend to keep everything to themselves until they feel that they've known you very, very well, that you are someone with similar mindset, someone whom they can talk to and someone who would listen to them. That's when sharing will occur. (Participant U)

Initially I did refuse to talk to anyone about it. But what if there had been a social worker who visited me often and wanted to help resolve this with me? I would have talked to him or her once we became familiar with each other. If there had been a social worker or an organization that had been in touch with me from the start, I would have been happy to talk to them. But there has to be some trust established first. I need to know that person well first. I won't open up to strangers. (Participant Y)

### **“You need to approach Chinese in an indirect, implicit manner”**

Participants noted that professionals need to be very tactful and implicit when they try to initiate a conversation around death and dying with Chinese immigrants, in order to overcome the stigma and fear surrounding death and negative emotions, and the cultural value on keeping personal matters private. They believed that being too upfront at the outset would only be met with resistance:

I think if you start off by saying, “You need to come in, and we’ll talk about your emotions”, you’ll scare them off and people won’t come. You cannot start off by being so direct, going deep into their hearts, or asking questions that are too deep or personal. Chinese people will outright refuse to let you in. You cannot be so direct with Chinese people.....and I’m talking about your typical Chinese family.....For your typical Chinese family, you have to take the indirect route, and gain entry into their hearts step by step. (Participant D)

Taking it slow, being patient, “starting from the surface and slowly making your way down” are the keys to “make one’s way” into the hearts of bereaved Chinese according to the participants. Participant D used the Cantonese term “*chim yi mak fa*” (meaning “slowly, silently, unobtrusively, and inconspicuously creating lasting changes”) to describe the process of educating Chinese immigrants and changing their attitudes towards death-related matters, palliative care and bereavement care. Participants believed that professionals need to normalize these topics and downplay their significance if they want to engage Chinese immigrants. To educate Chinese immigrants on palliative care, for example, professionals can combine their efforts with other health promotion efforts to make it less of a taboo:

Make palliative care the same as other health-related services – like smoking cessation promotion, or illness prevention – do your promotion as part of a bigger project on health promotion in general. Palliative care doesn’t need to be singled out. For example, every year SUCCESS will have a big seminar series on health. You just need to group palliative care as part of this. If you single it out, like if you just talk about palliative care, it will scare people off. But if you group it up with something else, it’ll be less of a taboo. Or commercials.....just insert this into your typical commercial time slots. Don’t need to make a big deal about it. People will get the message this way. I think people really need education that slowly permeates. You really need to do it indirectly with Chinese. (Participant D)

Similarly, to promote participation in support groups among bereaved Chinese, participants noted that organizers need to make them “a bit less serious”. Group leaders can consider emphasizing the social nature of such groups rather than the therapeutic aspect at the outset. Serving food is always a welcomed gesture to “lighten the mood”:

Just get a room in a community centre, and have people meet once a week.....just get people to come, have a regular weekly gathering, enjoy some cookies and coffee, and chat. The first time is always the hardest. But if you can get them to come once, they'll come the second time around. Once they have come once, it will become a habit. They will feel like "Why don't I come again next time, just to have someone to chat with, it's not like I have something better to do." They can see it as an opportunity to get out of the house. I think you can even promote it as a way to meet new people..... let's not make it so heavy, so "life and death". Make it a social gathering. (Participant F)

**“Please provide services that are sensitive to our communication and cultural needs”**

From their experiences navigating the Canadian health care system, participants were often surprised by the lack of ethnic and linguistic diversity among health care professionals, which did not reflect the demographics of Vancouver. Many health care professionals may believe that the availability of interpreters is enough to overcome communication and cultural barriers to accessing bereavement care. While interpreters help address linguistic barriers for those with limited English fluency (i.e., to translate another language into English), participants felt that the use of interpreters might exacerbate transmission barriers, as having a “middle person” relay a message makes the speaker feel even more disconnected from the audience. They were also concerned about confidentiality; one can no longer feel safe disclosing private matters when there is another person in the room:

If it requires translation, it creates a certain degree of disconnection. For instance, some of my church friends said "Well what if we are not fluent in English and require someone to translate for us? Then this translator will be sitting in the same room?" It changes the dynamics. It creates distance, as there's now someone else in between you and the counsellor. And most importantly, there's now another person that knows about things that you want to keep private. It's natural that there are things we want to keep confidential right? That's not good. So maybe the solution is to have a Chinese-speaking counsellor. Maybe there are. At least it makes the communication more direct. (Participant U)

In light of the linguistic, transmission and cultural barriers previously identified, participants unanimously expressed the wish to work with professionals who share the same cultural heritage and can speak their language. Most of them preferred working with “Chinese professionals” – someone who is bilingual in English and Chinese, and can offer services using the participants’ first language. Many felt that more bereaved Chinese immigrants would have accessed bereavement care if they had received information written in Chinese, or had been approached by a Chinese-speaking professional in the first place:

If these services are offered in the languages that they speak, that would be very helpful. Or if they could hire professionals who are bilingual, who can speak both Chinese and English, it would make things so much easier. For instance, getting people to join support groups can definitely be difficult, but if the group leader or the instructor is Chinese, I think people will come. (Participant F)

I feel that the government is already working hard to improve health care access for Chinese. For instance, I see that the mammogram service here – it’s in both English and Chinese, so they’re doing something already. But when it comes to bereavement services.....they really need to do more to target the Chinese population – from a language perspective, to have Chinese professionals to come out to offer such services. (Participant K)

Participants recognized that multilingual staff might not always be available in health care facilities, but they found that even having brochures on grief and available services written or translated in Chinese would have been tremendously helpful:

Put some pamphlets in the hospital, in Chinese, cos’ there are people who do not speak English at all. Put some pamphlets in SUCCESS and nursing homes. If you have something written in Chinese, it will automatically attract my attention. I will automatically want to read it. (Participant B)

Well at least put some brochures in hospitals to let people know about these services..... brochures that are publicly displayed, that people can freely take to read. I would hope that at least the brochures will be in both Chinese and English. (Participant F)

Finally, participants believed that better education on cultural competence for health care professionals would allow them to provide better, more culturally appropriate bereavement care to ethnic minority groups. They also hoped that professionals could

become more educated about the existence of bereavement care services provided in other languages in the community:

If they can have professionals that know how to work with ethnic minorities, professionals that truly understand someone's cultural background, it would have been so much better. Like my psychiatrist – he's great in so many respect, with the exception that there are things about my culture that he does not understand at all. (Participant W)

It's not just about promoting these services among Chinese people – non-Chinese health care professionals need to know about these services too, so that they are aware of services that are offered in other languages. This is important as they are the people that have the most frequent contact with bereaved individuals. (Participant V)

## **Merging Quantitative and Qualitative Data**

### **Quantifying Qualitative Data**

#### ***Grief Experiences***

All participants described their grief experiences when interviewed by the author. Their grief experiences could be classified into six subtypes:

1. Minimal grief: Four participants (16%) reported little sadness or other long-lasting negative emotions associated with the loss of the family member. They appeared calm during the interview, and maybe even cheerful at times. None of them cried during the interview, even when recalling the deceased and the loss.

2. Integrated grief: Four participants (16%) described their current mood as “*fine*” or “*I have recovered*”. During the interview they reported sadness associated with the loss and expressed emotions in a way that was consistent with their narrative (e.g., they would cry when recalling painful memories associated with the loss). However, they were able to quickly recover from the crying and manage their negative emotions. They also spontaneously reported positive aspects associated with the loss, such as personal growth. A typical narrative of grief from these participants was “*I am fine in my day-to-day functioning. I may feel a little bit of sadness if the thought of the deceased suddenly pops into my head, but I also recall the happy times I used to have with him or her.*”



3. Improving grief: Two participants (8%) described their current mood as *“I still feel sad, but I am already a lot better than before. I am not at my lowest point anymore”*, or *“I have been feeling so much better already, but the thought of the deceased may suddenly appear, and I feel bad all over again”*. Those in the “improving” category tended to report more sadness than those in the “integrated grief” category. They also seldom reported positive aspects of the loss.

4. Paradoxical grief: Three participants (12%) were classified into this category. The defining characteristic of these participants is the disjunction between their presentation and the narration of their grief. All of these participants appeared flat and detached, with little emotional arousal during the interview. However, the verbal description of their grief was full of intense negative emotions. For instance, one participant in this category described his grief as *“I won’t be surprised if my mood remains terrible until the day I die”*. The way he said it, however, was nonchalant, flat, and incongruent with the intensity of the statement he just made. The predominant emotions experienced by the participants in this category tended to be anger, bitterness, and cynicism.

5. Concealed grief: Four participants (16%) fell in this category. Almost all of the participants in this category used a *“band-aid”* metaphor when describing their grief. They reported that they were barely covering up their grief and pretending to be fine, but the grief felt like an open sore, or a volcano waiting to erupt. They mostly coped by denial, avoidance, and suppression of emotions. When asked to recall their loss during the interview, they often broke down into uncontrollable emotional outbursts. They admitted that they had never truly “resolved” the grief, and felt that they had no real solutions or alternatives.

6. Intense grief: Eight participants (32%) were classified as having intense grief. The narrative of these participants was dominated by intense sadness, guilt, regret, and a sense that they were “hanging by a thread”. Long, frequent crying spells during the interviews were common. The intense grief significantly interfered with their daily functioning, with little to no coping strategies to counteract it. These participants often reported losing the motivation to live. Many reported feeling “stuck” at the moment of loss

and constantly had intrusive thoughts about the deceased. They were unable to move on and come to terms with the death.

### ***Coping Strategies***

Four major coping strategies had been reported by the participants during the interview: taking solace in the deceased's "good death", suppressing negative emotions and thoughts, focusing on restoration, and reframing the loss. Thirteen participants (52%) reported that they coped by taking solace in the belief that the deceased family members had a "good death". Twelve participants (48%) reported using emotional and thought suppression. Adopting a focus on restoration was used by 13 participants (52%). Finally, 12 participants (48%) reported that they reframed the loss by changing their perspectives.

### ***Religious Affiliation***

The majority of participants ( $n = 20$ , 80%) reported some form of religious affiliation. Eighteen participants (72%) belonged to the Christian faith (Catholicism or Protestantism). Two (8%) were Buddhists.

Participants were also classified according to their self-reported degree of religiosity, as shown in Table 9. The majority of participants who were religious considered themselves devout ( $n = 13$ , 52%). They regularly attended church or performed Buddhist rituals, read scriptures, and found religious teachings useful in helping them cope with the loss of a family member. Seven participants (28%) displayed an ambivalent attitude towards their religious affiliation. Some said they never attended church, while others attended church for social reasons but admitted that they did not really believe in the religion. Some reported feeling angry at God for causing the death of their loved ones.

**Table 9. Degree of Religiosity ( $N = 25$ )**

<b>Degree of Religiosity</b>	<b><i>n</i></b>	<b>%</b>
Not religious	5	20
Ambivalent	7	28
Devout	13	52

## **Social Support**

The participants were classified on four dimensions of social support: 1) social sharing of grief with family members, 2) social sharing of grief with friends, 3) nonverbal support from family, and 4) nonverbal support from friends.

### **Social Sharing within Family**

Table 10 presents the degree of social sharing of grief (i.e., verbal discussion of grief) with the participants' family members. The majority of the participants (48%) reported little to no social sharing of grief with their families. They either had no other family member to confide in ( $n = 1$ , 4%), avoided talking to family members about their grief ( $n = 7$ , 28%), or tried to open up but other family members avoided the topic or gave unsupportive responses such as yelling at them, dismissing their emotions, or telling them to "get over it" ( $n = 4$ , 16%). Thirty-six percent of participants were able to identify a limited set (i.e., 1 or 2) of family members with whom they could have a more in-depth and supportive discussion on their bereavement. Finally, 16% identified a wider range of family members (i.e., more than 2) that they could speak openly about their grief.

**Table 10. Level of Social Sharing of Grief with Family (N = 25)**

<b>Social Sharing</b>	<b><i>n</i></b>	<b>%</b>
Little to no social sharing	12	48
Social sharing with a limited number of family members	9	36
Social sharing with a wider range of family members	4	16

### **Social Sharing with Friends**

Table 11 presents the degree of social sharing of grief participants had with their friends. Similar to the findings on social sharing with family, the majority of the participants (44%) also reported little to no social sharing of grief with their friends. They either had no friends to confide in ( $n = 2$ , 8%), avoided talking to family members about their grief ( $n = 6$ , 24%), or tried to initiate a conversation but their friends avoided the topic ( $n = 3$ , 9%). Thirty-two percent of participants described their discussion with friends as limited and shallow. For instance, their friends might ask subtle, indirect questions to check on their wellbeing without going in-depth, and participants responded with superficial answers and

did not continue the conversation. Twelve percent of participants had one or two close friends that they could discuss their grief in depth. Another 12% reported having a number of close friends that they could openly speak to regarding their grief.

**Table 11. Level of Social Sharing of Grief with Friends (N = 25)**

<b>Social Sharing</b>	<b><i>n</i></b>	<b>%</b>
Little to no social sharing	11	44
Shallow sharing	8	32
Social sharing with a limited number of friends	3	12
Social sharing with a wider range of friends	3	12

### **Nonverbal Support from Family and Friends**

Eleven participants (44%) reported receiving nonverbal support from family members, such as taking care of household chores, spending more time with them, taking time off from work so that they could attend funerals out of town, being more “well-behaved” or affectionate, or offering help without being asked.

### **Nonverbal Support from Friends**

Eight participants (32%) reported receiving nonverbal social support from friends, in the form of attending funerals, inviting them to spend time together, making “memory books” or “prayer books” for the deceased, or offering practical help such as cooking, babysitting, landscaping and cleaning.

### ***End-of-Life Care for the Deceased Patients***

The type of end-of-life care received by the deceased (based on participant report) varied, as shown in Table 12. Slightly over half of the deceased family members ( $n = 13$ , 52%) received some form of palliative care support during the last days of their lives. The services received included hospice care, home death, a combination of hospice in-home care support and transfer to hospice at the very last days of life, or a combination of in-hospital palliative care followed by a transfer to a hospice. Close to half ( $n = 12$ , 48%) of the deceased family members still spent their last days in an acute care hospital.

**Table 12. Types of End-of-Life Care Offered to the Deceased Family Members (N = 25)**

End-of-Life Care	<i>n</i>	%
Acute hospital care	12	48
Hospice care	5	20
Combination of hospice home support and hospice care	4	16
Home death	3	12
Combination of in-hospital palliative care and hospice care	1	4

In terms of the predictors of the likelihood of receiving palliative care before death, there was a significant relationship between geographical location of death and types of end-of-life care received,  $\chi^2(1, N = 25) = 7.35, p = 0.007$ . Death within Canada was associated with a higher likelihood of receiving palliative care prior to death. Among the eight deceased family members who died outside of Canada (i.e., in the participants' countries of origin), for example, only one received hospice care; the rest passed away in an acute care hospital. For the 17 deceased family members who died within Canada, only five passed away at an acute care setting, with the rest receiving some forms of palliative care towards the end of their lives. Intuitively, the nature of death was associated with the types of end-of-life care received,  $\chi^2(1, N = 25) = 8.55, p = 0.003$ ; sudden deaths were inversely related to the likelihood of receiving palliative care. Causes of death were also associated with the types of end-of-life care received,  $\chi^2(3, N = 25) = 10.31, p = 0.016$ . Those who died of cancer were more likely to have received palliative care, while those who died of cardiovascular causes were less likely to have received palliative care, probably because the majority of cardiovascular deaths in the current sample were sudden in nature (i.e., heart attacks). Age of death and chronicity of health conditions (i.e., time elapsed between diagnosis and death) were not associated with the likelihood of receiving palliative care towards the end of life,  $t(23) = -0.81$  and  $-1.04, p = 0.43$  and  $0.31, d = -0.32$  and  $-0.42$  respectively.

Further analyses were performed to examine the relationship between geographical location of death and types of end-of-life care. A significant relationship between geographical location of death and causes of death was found,  $\chi^2(3, N = 25) = 10.12, p = 0.018$ . Cancer deaths were more likely to have occurred within Canada, while

cardiovascular deaths were more likely to have occurred outside of Canada. No significant relationship between geographical location of death and nature of death (expected vs sudden) was observed,  $\chi^2(1, N = 25) = 1.18, p = 0.28$ .

### ***Bereavement Service Utilization***

Three factors related to participants' utilization of bereavement services warranted further quantitative analyses: whether the participants were offered pre-bereavement care and/or bereavement follow-up care, whether the participants took the initiative to seek bereavement support, and whether participants received any bereavement interventions in the end.

#### **Access to Pre-Bereavement Care and Bereavement Follow-Up**

Pre-bereavement care and bereavement follow-up care were not consistently offered to the participants. The majority of participants ( $n = 14, 56\%$ ) never received any pre-bereavement support or bereavement follow-up care, as shown in Table 13. These participants noted that no health care professionals ever approached them before or after the death of their family members to provide information or support. They also were never told of available bereavement support services. Among these participants, the family members of 8 of them (32%) passed away outside Canada.

For the remaining 11 participants (44%) who recalled receiving some forms of pre-bereavement care and/or bereavement follow-up, their experiences widely varied. One participant came across information on grief by chance, but no professional-initiated pre-bereavement or bereavement follow-up care was offered to her. Five participants (20%) were passive recipients of bereavement follow-up care as they were merely notified that services were provided to them (e.g., being told that a memorial candle was lighted, or receiving a sympathy card in the mail) without their prior knowledge and expectation of follow-up. The five remaining participants (20%) were provided information on services that required their active participation (e.g., attending support groups) but they declined to access such services.

**Table 13. Access to Pre-bereavement and/or Bereavement Follow-up (N = 25)**

<b>Introduction to Services</b>	<b><i>n</i></b>	<b>%</b>
No services offered	14	56
Received information by chance	1	4
Passive recipients	5	20
Declined active participation	5	20

### **Initiative to Seek Professional Bereavement Support**

Ten participants (40%) reported making an effort to seek professional support for bereavement, while the rest ( $n = 15$ , 60%) said that they never took any initiative to seek help. Among those who had taken initiative to seek bereavement support services, the nature of their effort varied. Three of them (9%) were already under the care of a physician or a mental health professional for other pre-existing conditions before they took the initiative to seek services. As a result, they requested bereavement support as an “add-on” during their regular medical follow-up visits or therapy sessions. Four participants (16%) sought help from their family physicians. For the remaining 3 participants (12%), their effort was more informal or even passive in nature. One participant made a search on the internet for information on bereavement support but did not follow through. Two made a visit to the hospital after the death of their family members, hoping that they would run into health care professionals they knew in order to get information about bereavement support.

### **Access to Bereavement Interventions**

Table 14 presents the types of bereavement interventions participants eventually received. The majority of participants (76%) never received any professional bereavement interventions. Those who sought help for their bereavement as part of their regular follow-up with their physicians or mental health professionals all received continued care. Three participants (12%) who sought help from their family physicians were referred to outpatient psychiatric or psychological treatments.

**Table 14. Access to Bereavement Interventions (N = 25)**

<b>Service</b>	<b><i>n</i></b>	<b>%</b>
No intervention	19	76
Continued care	3	12
Outpatient psychiatric or psychological treatment	3	12

Figure 1 (for participants who lost their family members in Canada) and 2 (for participants who lost their family members outside Canada) outline the participants' journey of navigating the health care system for bereavement support, the eventual outcomes, and "caseness" of depression and/or anxiety i.e., whether a participant scored above or below clinical cut-off on measures of depression and/or anxiety in the current research.



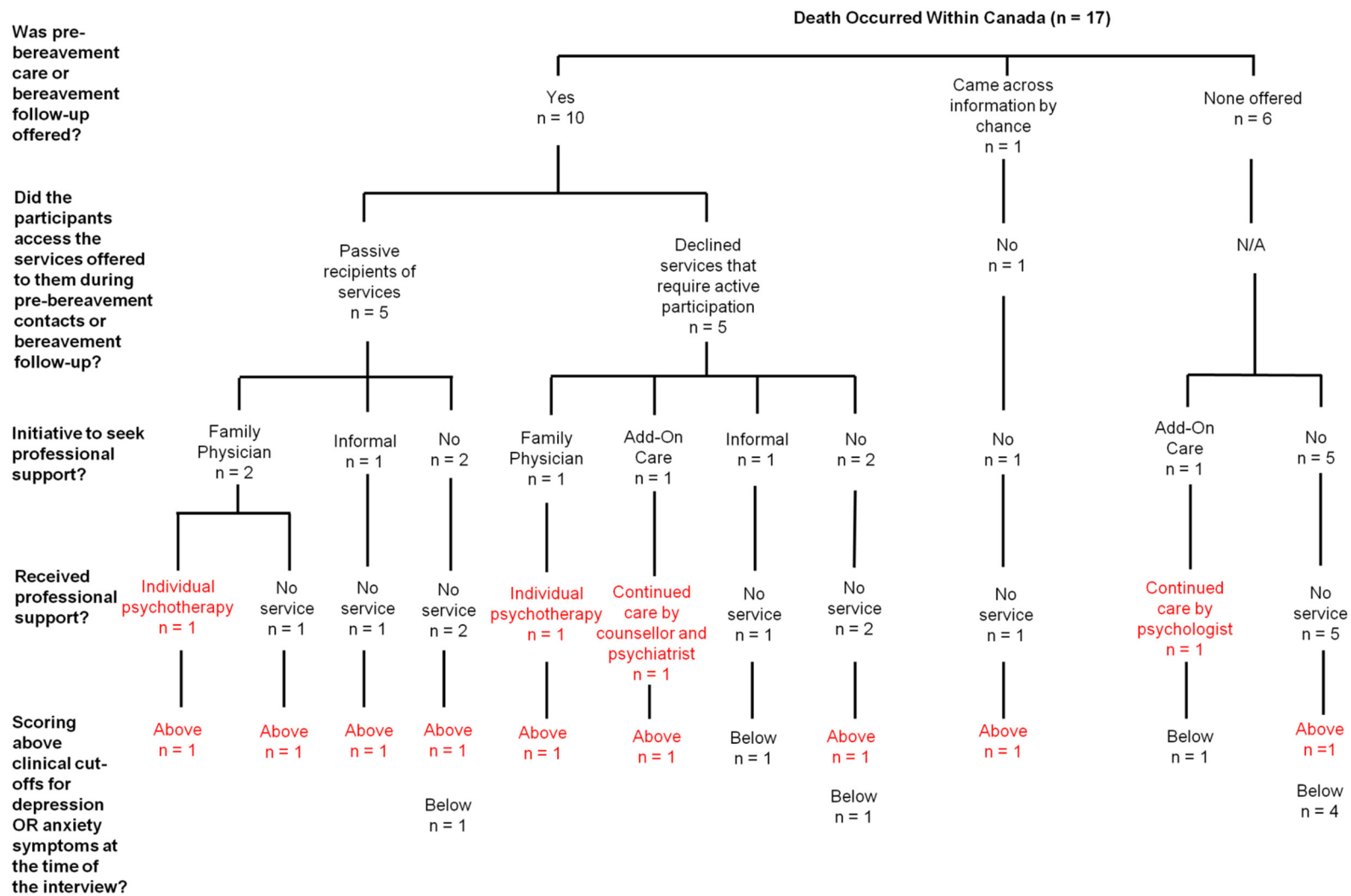


Figure 1. The process of accessing and utilizing bereavement care for bereaved Chinese immigrants whose family members passed away in Canada.

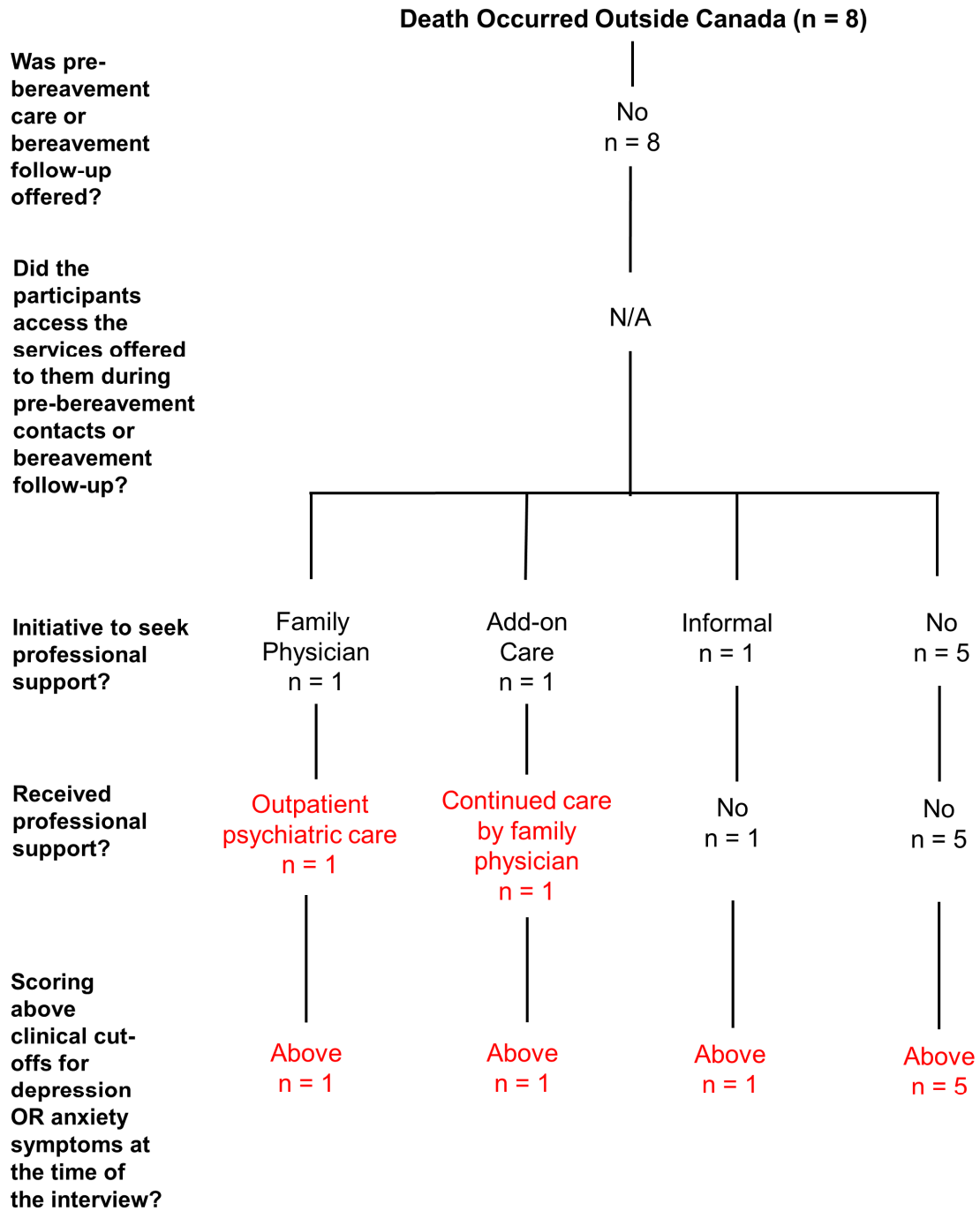


Figure 2. The process of accessing and utilizing bereavement care for bereaved Chinese immigrants whose family members passed away outside of Canada.

## Combined Statistical Analyses on Quantitative and Qualitative Data

### **Question 1: Relationships between Grief Experiences Reported in Interviews and Self-Reported Psychological Functioning in Questionnaires**

Table 15 presents the mean depression scores (as measured by CES-D) and standard deviations for the six subtypes of grief experiences reported by the participants during the interview. A one-way ANOVA revealed that there was a significant difference in mean depression scores among the participants based on the different grief experiences reported during the interview. Since the assumption of homogeneity of variance was violated, the obtained Welch's adjusted F ratio was used,  $F(5, 7.56) = 6.04$ ,  $p = 0.015$ ,  $\omega^2 = 0.30$ . Games-Howell post-hoc procedures revealed that those who reported continued intense grief had a significantly higher mean depression score than those with minimal grief, those with integrated grief, and those with concealed grief ( $d = 2.03, 2.33, \text{ and } 1.94$  respectively).

**Table 15. Means and Standard Deviations of CES-D Scores Across Subtypes of Grief Experience (N = 25)**

Grief Experience	Depression	
	<i>M</i>	<i>SD</i>
Minimal grief	9.75	9.74
Integrated grief	9.25	5.32
Improving grief	22.50	2.12
Paradoxical grief	12.67	4.04
Concealed grief	12.00	8.04
Intense grief	35.00	14.67

Table 16 presents the mean state anxiety scores (as measured by STAI State Anxiety Scale) and standard deviations for the six subtypes of grief experiences. A one-way ANOVA revealed that there was a significant difference in mean state anxiety scores across grief experiences subtypes during the interview,  $F(5, 19) = 5.68$ ,  $p = 0.002$ ,  $\eta^2 = 0.60$ . Similar to the results on depressive symptoms, Tukey post-hoc procedures revealed that those who reported continued intense grief had a significantly higher mean state anxiety score than those with minimal grief, those with integrated grief, and those who were covering up their grief ( $d = 2.38, 2.03, \text{ and } 2.14$  respectively)

**Table 16. Means and Standard Deviations of STAI State Anxiety Scores Across Subtypes of Grief Experience (N = 25)**

Grief Experience	State Anxiety	
	<i>M</i>	<i>SD</i>
Minimal grief	32.25	6.65
Integrated grief	36.00	6.78
Improving grief	49.50	9.19
Paradoxical grief	38.33	7.02
Concealed grief	34.75	6.85
Intense grief	58.00	13.77

Table 17 lists the means and standard deviations of trait anxiety scores across the grief experience subtypes. A one-way ANOVA (using Welch's adjusted ratio due to violation of homogeneity of variance assumption) failed to detect any statistically significant difference in mean STAI trait anxiety scores among the grief experience subtypes, Welch's  $F(5,6.11) = 2.26$ ,  $p = 0.172$ ,  $\omega^2 = 0.20$ .

**Table 17. Means and Standard Deviations of STAI Trait Anxiety Scores Across Subtypes of Grief Experience (N = 25)**

Grief Experience	Trait Anxiety	
	<i>M</i>	<i>SD</i>
Minimal grief	36.50	5.07
Integrated grief	40.75	3.69
Improving grief	47.50	4.95
Paradoxical grief	40.00	6.93
Concealed grief	39.25	6.75
Intense grief	57.12	14.94

Table 18 presents the means and standard deviations of somatic symptom scores across the grief experience subtypes. A one-way ANOVA also failed to detect any statistically significant difference in mean somatic symptom scores among the grief experience subtypes,  $F(5,19) = 1.38$ ,  $p = 0.277$ ,  $\eta^2 = 0.27$ .

**Table 18. Means and Standard Deviations of Somatic Symptom Scores Across Subtypes of Grief Experience (N = 25)**

Grief Experience	Somatic Symptoms	
	<i>M</i>	<i>SD</i>
Minimal grief	14.75	14.24
Integrated grief	14.50	8.96
Improving grief	27.00	12.73
Paradoxical grief	11.67	3.06
Concealed grief	23.50	14.48
Intense grief	27.00	12.05

### ***Question 2: Predictors of Psychological Outcomes***

#### **Predicting Level of Depressive Symptoms**

Table 19 presents results from the univariate analyses on predictors of depressive symptoms. In terms of demographic characteristics, there was a significant difference in mean depression scores across different educational levels of the participants. Those whose educational level was below high school had higher mean depression scores than those who finished high school and those with post-secondary education (college or trade schools, and university undergraduate education). Employment status also made a significant difference – those who were retired or on leave had a higher mean depression score than those who were still working (full-time or part-time) or those who were full-time homemakers. With regards to coping strategies, emotion-oriented coping as measured on the JCS had a positive relationship with level of depression – the more one engaged in emotion-oriented coping, the higher the depression score. Conversely, taking solace in the belief that the deceased had a “good death” and reframing the loss by changing one’s perspectives were inversely related to depression – those who engaged in these coping strategies had significantly lower mean depression scores than those who did not report doing so. Finally, among the types of social support, only discussing one’s grief with family members was significantly associated with level of depression. Those who reported little to no social sharing with family had a significantly higher mean depression score than those who managed to discuss their grief with a limited number or with a wide range of family members.

**Table 19. Univariate Analyses on Predictors of Depression**

Variable	Statistic	<i>p</i>	ES*
Participants' sociodemographic characteristics			
Age	$r(25) = 0.37$	0.065	
Gender	$t(23) = 1.04$	0.308	0.50
Marital status	$F(3, 21) = 3.06$	0.052	0.30
Length of bereavement (in months)	$r(25) = -0.06$	0.762	
Level of education	$F(4, 20) = 5.87$	<b>0.003**</b>	0.54
Employment status	$F(3, 21) = 5.65$	<b>0.005**</b>	0.45
Income	$F(3, 21) = 0.90$	0.342	0.11
Participants' immigration-related characteristics			
Country of origin (Hong Kong vs not Hong Kong)	$t(23) = -1.43$	0.166	0.82
Length of residence in Canada	$r(25) = 0.07$	0.743	
English fluency (Fluent English vs not fluent)	$t(23) = -1.24$	0.228	0.43
Acculturation	$r(25) = -0.14$	0.496	
Deceased's sociodemographic and illness-related variables			
Relationship to the participant	$F(4, 20) = 0.58$	0.678	0.10
Age of death	$r(25) = 0.12$	0.562	
Time between diagnosis and death (in months)	$r(25) = 0.09$	0.660	
Nature of death (predictable vs sudden)	$t(23) = 0.62$	0.539	0.34
Location of death (within or outside Canada)	$t(23) = -1.50$	0.148	0.66
Whether palliative care was provided	$t(19.57) = 0.65$	0.523	0.26
Coping			
JCS problem-oriented coping	$r(25) = -0.15$	0.462	
JCS emotion-oriented coping	$r(25) = 0.74$	<b>&lt;0.001**</b>	
JCS support seeking	$r(25) = -0.15$	0.481	
JCS avoidance-oriented coping	$r(25) = 0.34$	0.095	
JCS isolating thoughts	$r(25) = 0.08$	0.706	
Suppression	$t(23) = 0.49$	0.630	0.19
Focusing on restoration	$t(23) = -0.33$	0.747	0.13
Taking solace in "good death"	$t(23) = -2.77$	<b>0.011**</b>	1.53
Cognitive reframing	$t(15.64) = -4.14$	<b>0.001**</b>	1.63

Religious affiliation			
Whether one had a religious affiliation	$t(4.75) = 1.12$	0.142	0.63
Degree of religiosity	$F(2, 22) = 1.41$	0.266	0.11
Social support			
Discussion of loss with family	Welch's $F(2, 10) = 7.21$	<b>0.012**</b>	0.33
Discussion of loss with friends	Welch's $F(3, 7.56) = 0.99$	0.448	0.57
Nonverbal support from family	$t(23) = 0.55$	0.590	1.53
Nonverbal support from friends	$t(23) = 2.00$	0.057	0.95

\* Effect size in terms of Cohen's  $d$  (for independent-sample  $t$ -tests), eta squared (for one-way ANOVA), or adjusted omega squared (for Welch's  $F$  tests).

\*\* Statistically significant results after Dunn-Sidak corrections.

### Predicting Level of State Anxiety

Table 20 presents results from the univariate analyses on predictors of state anxiety. In terms of demographic characteristics, there was a significant difference in mean state anxiety scores across different categories of employment status. Those who were retired or on leave had a higher mean state anxiety score than those who were working full-time. With regards to coping strategies, JCS emotion-oriented coping and cognitive reframing were found to predict level of state anxiety. The more one engaged in emotion-oriented coping, the higher the state anxiety. The reverse was true for cognitive reframing – those who engaged in this strategy reported lower level of state anxiety. Similar to the findings on the relationship between social support and depressive symptoms, only discussing one's grief was significantly associated with level of state anxiety – those who reported little to no social sharing with family had a significantly higher mean state anxiety score than those who could talk to a wide range of family members about their grief.

**Table 20. Univariate Analyses on Predictors of State Anxiety**

Variable	Statistic	$p$	ES*
Participants' sociodemographic characteristics			
Age	$r(25) = 0.36$	0.075	
Gender	$t(23) = 0.21$	0.834	0.12

Marital status	F(3, 21) = 2.98	0.055	0.30
Length of bereavement (in months)	r(25) = -0.09	0.671	
Level of education	F(4, 20) = 2.48	0.077	0.33
Employment status	F(3, 21) = 4.36	<b>0.015**</b>	0.38
Income	F(3, 21) = 0.55	0.657	0.07
Participants' immigration-related characteristics			
Country of origin (Hong Kong vs not Hong Kong)	t(23) = -1.24	0.227	0.65
Length of residence in Canada	r(25) = 0.10	0.628	
English fluency (Fluent English vs not fluent)	t(23) = -1.23	0.233	0.49
Acculturation	r(25) = -0.05	0.799	
Deceased's sociodemographic and illness-related variables			
Relationship to the participant	F(4, 20) = 0.18	0.948	0.03
Age of death	r(25) = 0.17	0.405	
Time between diagnosis and death (in months)	r(25) = 0.02	0.923	
Nature of death (predictable vs sudden)	t(23) = 0.71	0.486	0.36
Location of death (within or outside Canada)	t(23) = -1.93	0.066	0.81
Whether palliative care was provided	t(23) = 0.88	0.388	0.35
Coping			
JCS problem-oriented coping	r(25) = -0.14	0.507	
JCS emotion-oriented coping	r(25) = 0.72	<b>&lt;0.001**</b>	
JCS support seeking	r(25) = -0.10	0.644	
JCS avoidance-oriented coping	r(25) = 0.31	0.133	
JCS isolating thoughts	r(25) = -0.12	0.573	
Suppression	t(23) = 0.30	0.767	0.12
Focusing on restoration	t(23) = -0.30	0.767	0.12
Taking solace in "good death"	t(15.93) = -2.06	0.056	0.84
Cognitive reframing	t(16.62) = -3.11	<b>0.007**</b>	1.23
Religious affiliation			
Whether one had a religious affiliation	t(23) = 0.92	0.369	0.41
Degree of religiosity	F(2, 22) = 1.02	0.377	0.08
Social support			



Discussion of loss with family	F(2, 22) = 4.80	<b>0.019**</b>	0.30
Discussion of loss with friends	F(3, 21) = 1.52	0.238	0.18
Nonverbal support from family	t(23) = 0.16	0.877	0.06
Nonverbal support from friends	t(23) = 2.02	0.055	0.96

\* Effect size in terms of Cohen's d (for independent-sample t-tests), eta squared (for one-way ANOVA), or adjusted omega squared (for Welch's F tests).

\*\* Statistically significant results after Dunn-Sidak corrections.

### Predicting Level of Trait Anxiety

Table 21 presents results from the univariate analyses on predictors of trait anxiety. In terms of demographic characteristics, there was a significant difference in mean trait anxiety scores across different categories of employment status. Those who were retired or on leave had a higher mean trait anxiety score than those who were working full-time, working part-time, or working as a full-time homemaker. Similar to previous findings on coping strategies, JCS emotion-oriented coping and cognitive reframing were also found to predict level of trait anxiety. The more one engaged in emotion-oriented coping, the higher the trait anxiety. Those who reported that they coped with the loss by changing their perspectives had significantly lower mean trait anxiety score than those who did not report doing so.

**Table 21. Univariate Analyses on Predictors of Trait Anxiety**

Variable	Statistic	p	ES*
Participants' sociodemographic characteristics			
Age	r(25) = 0.33	0.105	
Gender	t(23) = 0.21	0.834	0.11
Marital status	F(3, 21) = 3.53	0.032	0.34
Length of bereavement (in months)	r(25) = -0.02	0.928	
Level of education	F(4, 20) = 2.96	0.045	0.37
Employment status	F(3, 21) = 6.64	<b>0.003**</b>	0.49
Income	F(3, 21) = 0.91	0.454	0.11
Participants' immigration-related characteristics			
Country of origin (Hong Kong vs not Hong Kong)	t(23) = -1.24	0.227	0.65
Length of residence in Canada	r(25) = 0.09	0.687	
English fluency (Fluent English vs not fluent)	t(23) = -1.23	0.233	0.49

Acculturation	$r(25) = -0.08$	0.714	
Deceased's sociodemographic and illness-related variables			
Relationship to the participant	$F(4, 20) = 0.18$	0.945	0.04
Age of death	$r(25) = 0.17$	0.405	
Time between diagnosis and death (in months)	$r(25) = 0.02$	0.923	
Nature of death (predictable vs sudden)	$t(23) = 0.71$	0.486	0.36
Location of death (within or outside Canada)	$t(23) = -1.89$	0.720	0.77
Whether palliative care was provided	$t(23) = 0.91$	0.373	0.37
Coping			
JCS problem-oriented coping	$r(25) = -0.28$	0.179	
JCS emotion-oriented coping	$r(25) = 0.78$	<b>&lt;0.001**</b>	
JCS support seeking	$r(25) = -0.09$	0.678	
JCS avoidance-oriented coping	$r(25) = 0.34$	0.100	
JCS isolating thoughts	$r(25) = -0.05$	0.796	
Suppression	$t(23) = 0.06$	0.956	0.50
Focusing on restoration	$t(23) = 0.20$	0.845	0.08
Taking solace in "good death"	$t(14.11) = -2.67$	0.021	1.05
Cognitive reframing	$t(15.53) = -3.19$	<b>0.006**</b>	1.26
Religious affiliation			
Whether one had a religious affiliation	$t(4.75) = 1.11$	0.278	0.50
Degree of religiosity	$F(2, 22) = 1.33$	0.285	0.11
Social support			
Discussion of loss with family	Welch's $F(2, 10.08) = 4.44$	0.041	0.22
Discussion of loss with friends	Welch's $F(3, 7.56) = 1.77$	0.237	0.08
Nonverbal support from family	$t(23) = -0.18$	0.857	0.07
Nonverbal support from friends	$t(23) = -1.69$	0.104	0.81

\* Effect size in terms of Cohen's d (for independent-sample t-tests), eta squared (for one-way ANOVA), or adjusted omega squared (for Welch's F tests).

\*\* Statistically significant results after Dunn-Sidak corrections.

## Predicting Level of Somatic Symptoms

Table 22 presents results from the univariate analyses on predictors of somatic symptoms. Country of birth was related to the frequency of somatic symptoms. Those who were born in Hong Kong reported somatic symptoms significantly less frequently than those who were born in Taiwan or Mainland China. With regards to coping strategies, JCS emotion-oriented coping had a positive relationship with somatic symptoms – the more one engaged in emotion-oriented coping, the more frequently he or she experienced somatic symptoms. Conversely, cognitive reframing of the loss was negatively related to frequency of somatic symptoms, as those who reported using this coping strategy experienced somatic symptoms less frequently than those who did not report doing so. Finally, among the types of social support, discussing one’s grief with family again emerged as a significant predictor. Those who reported little to no social sharing with family, on average, experienced somatic symptoms more frequently than those who managed to discuss their grief with a limited number or with a wide range of family members.

**Table 22. Univariate Analyses on Predictors of Somatic Symptoms**

Variable	Statistic	<i>p</i>	ES*
Participants' sociodemographic characteristics			
Age	$r(25) = 0.12$	0.583	
Gender	$t(23) = -0.46$	0.650	0.24
Marital status	$F(3, 21) = 0.47$	0.705	0.06
Length of bereavement (in months)	$r(25) = 0.07$	0.747	
Level of education	$F(4, 20) = 3.04$	0.041	0.38
Employment status	$F(3, 21) = 1.52$	0.239	0.18
Income	$F(3, 21) = 1.91$	0.159	0.21
Participants' immigration-related characteristics			
Country of origin (Hong Kong vs not Hong Kong)	$t(23) = -3.82$	<b>0.001**</b>	2.88
Length of residence in Canada	$r(25) = -0.15$	0.474	
English fluency (Fluent English vs not fluent)	$t(13.60) = -0.71$	0.492	0.30
Acculturation	$r(25) = -0.24$	0.256	
Deceased's sociodemographic and illness-related variables			

Relationship to the participant	Welch's F(4, 5.64) = 0.39	0.809	0.08
Age of death	r(25) = -0.07	0.748	
Time between diagnosis and death (in months)	r(25) = 0.17	0.417	
Nature of death (predictable vs sudden)	t(23) = 0.18	0.859	0.08
Location of death (within or outside Canada)	t(23) = -1.112	0.276	0.49
Whether palliative care was provided	t(23) = -0.46	0.650	0.24
<b>Coping</b>			
JCS problem-oriented coping	r(25) = 0.10	0.645	
JCS emotion-oriented coping	r(25) = 0.58	<b>0.002**</b>	
JCS support seeking	r(25) = -0.10	0.643	
JCS avoidance-oriented coping	r(25) = 0.48	0.016	
JCS isolating thoughts	r(25) = 0.03	0.904	
Suppression	t(23) = 1.93	0.066	0.79
Focusing on restoration	t(23) = -1.19	0.246	0.48
Taking solace in "good death"	t(23) = -2.43	0.023	0.97
Changing perspective	t(23) = -3.37	<b>0.003**</b>	1.36
<b>Religious affiliation</b>			
Whether one had a religious affiliation	t(4.52) = 0.97	0.382	0.56
Degree of religiosity	Welch's F(2, 9.11) = 0.44	0.655	0.05
<b>Social support</b>			
Discussion of loss with family	Welch's F(2, 14.58) = 21.83	<b>&lt;0.001**</b>	0.62
Discussion of loss with friends	F(3, 21) = 0.73	0.545	0.09
Nonverbal support from family	t(23) = 0.32	0.752	0.13
Nonverbal support from friends	t(23) = -0.45	0.658	0.18

\* Effect size in terms of Cohen's d (for independent-sample t-tests), eta squared (for one-way ANOVA), or adjusted omega squared (for Welch's F tests).

\*\* Statistically significant results after Dunn-Sidak corrections.

### Question 3: Factors Related to Bereavement Service Utilization

#### Factors Related to Access to Pre-Bereavement and/or Bereavement Follow-Up Care

Table 23 presents results from the univariate analyses on factors related to whether the participants received pre-bereavement and/or bereavement follow-up care. Only two variables were found to be statistically significant: the location of death of the deceased family members, and whether the deceased family members received palliative care before their passing. Those whose family members passed away outside Canada were significantly less likely to have received pre-bereavement and/or bereavement follow-up care. Those participants whose deceased family members received palliative care before death were significantly more likely to have received pre-bereavement and/or bereavement follow-up support. It is interesting to note that whether one received pre-bereavement and/or bereavement follow-up care was **not** related to his/her initiative to seek professional support, nor was it related to later access of bereavement interventions.

**Table 23. Univariate Analyses on Factors Related to Access to Pre-Bereavement and/or Bereavement Follow-Up Care**

Variable	t	$\chi^2$	p	ES <sup>A</sup>
Participants' sociodemographic characteristics				
Age	0.27		0.791	0.11
Length of bereavement (in months)	0.76		0.455	0.31
Gender		*	1.000	0.05
Marital status (Married vs Not Married)		*	1.000	0.07
Level of education ( $\leq$ high school vs post-secondary education)		*	0.177	0.09
Employment status (Working vs Not Working)		*	1.000	0.05
Income		*	0.227	0.30
Participants' immigration-related characteristics				
Length of residence in Canada	-0.62		0.542	0.26
Acculturation	-1.49		0.149	0.60
Country of origin (Hong Kong vs not Hong Kong)		*	1.000	0.08

English fluency (Fluent English vs not fluent)		*	0.697	0.10
Deceased's sociodemographic and illness-related variables				
Age of death	-1.52		0.141	0.60
Time between diagnosis and death (in months)	0.84		0.408	0.33
Relationship to the participant (parents vs non-parents)		3.38	0.066	0.37
Nature of death (predictable vs sudden)		*	0.180	0.31
Location of death (within or outside Canada)		*	<b>0.003**</b>	0.61
Whether palliative care was provided		11.91	<b>0.001**</b>	0.69
Coping				
JCS problem-oriented coping	-0.72		0.481	0.29
JCS emotion-oriented coping	0.30		0.770	0.12
JCS support seeking	0.40		0.694	0.16
JCS avoidance-oriented coping	-0.35		0.732	0.14
JCS isolating thoughts	-0.59		0.561	0.23
Suppression		*	0.407	0.19
Focusing on restoration		*	0.428	0.21
Taking solace in "good death"		1.07	0.302	0.21
Changing perspective		1.07	0.302	0.21
Religious affiliation				
Whether one had a religious affiliation		*	1.000	0.04
Degree of religiosity (Not religious /ambivalent vs devout)		1.92	0.165	0.28
Social support				
Discussion of loss with family		0.05	0.821	0.05
Discussion of loss with friends		*	0.350	0.26
Nonverbal support from family		*	1.000	0.03
Nonverbal support from friends		*	1.000	0.08
Psychological outcomes				
Depression	0.13		0.901	0.05

State anxiety	-0.02		0.987	0.00
Trait anxiety	0.04		0.968	0.02
Somatic symptoms	0.16		0.875	0.06
Other factors of bereavement service utilization				
Taking initiative to seek bereavement support		*	0.241	0.26
Whether the participants received bereavement interventions		*	1.000	0.07

\* Fisher's exact test was used in this comparison since more than 20% of the cells had expected cell frequency less than 5, thus violating one of the assumptions of the chi-square test of independence; as a result, no chi-square value was available as the Fisher's exact test only provided a p-value but not the test statistic.

\*\* Statistically significant results after Dunn-Sidak corrections.

^ Effect size in terms of Cohen's d (for independent-sample t-tests) or Cramer's V (for chi-square test of independence or Fisher's exact test)

### Factors Related to Participants' Initiative to Seek Professional Bereavement Support

A number of variables were found to be significantly related to one's initiative to seek professional support after the death of a family member as presented in Table 24. First, social sharing of grief with family negatively correlated with the initiative to seek professional support, as those who reported little to no discussion of grief with family members were more likely to take initiative to seek bereavement support from professionals. Psychological morbidity was positively related to initiative taking as well. Those who had taken initiative to seek help had significantly higher mean depression, state anxiety, and trait anxiety scores than those who had not. Finally, whether one was previously offered pre-bereavement and/or bereavement follow-up care did **not** predict subsequent initiative to seek professional help. However, whether one had taken the initiative to seek help was significantly related to whether one would receive bereavement interventions in the end. Those who received services in the end were more likely to be the ones who proactively sought help in the first place.

**Table 24. Univariate Analyses on Factors Related to Participants' Initiative to Seek Professional Support**

Variable	t	$\chi^2$	p	ES <sup>Δ</sup>
Participants' sociodemographic characteristics				
Age	-0.22		0.831	0.10
Length of bereavement (in months)	-0.47		0.642	0.20
Gender		*	1.000	0.09
Marital status (Married vs Not Married)		*	0.122	0.33
Level of education (≤ high school vs post-secondary education)		*	1.000	0.04
Employment status (Working vs Not Working)		*	0.017	0.54
Income		*	0.697	0.10
Participants' immigration-related characteristics				
Length of residence in Canada	-0.04		0.970	0.01
Acculturation	0.07		0.948	0.03
Country of origin (Hong Kong vs not Hong Kong)		*	0.543	0.20
English fluency (Fluent English vs not fluent)		*	1.000	0.00
Deceased's sociodemographic and illness-related variables				
Age of death	-2.15		0.042	0.82
Time between diagnosis and death (in months)	-1.21		0.238	0.52
Relationship to the participant (parents vs non-parents)		*	0.041	0.46
Nature of death (predictable vs sudden)		*	0.345	0.27
Location of death (within or outside Canada)		*	1.000	0.04
Whether palliative care was provided		*	0.226	0.29
Coping				
JCS problem-oriented coping	-0.42		0.677	0.17
JCS emotion-oriented coping	2.16		0.053	0.94
JCS support seeking	1.11		0.278	0.46



JCS avoidance-oriented coping	1.75		0.110	0.77
JCS isolating thoughts	0.34		0.734	0.15
Suppression		*	0.659	0.15
Focusing on restoration		*	0.688	0.13
Taking solace in “good death”		*	0.015	0.52
Changing perspective		*	0.111	0.36
Religious affiliation				
Whether one had a religious affiliation		*	1.000	0.00
Degree of religiosity (Not religious /ambivalent vs devout)		*	0.428	0.20
Social support				
Discussion of loss with family		*	<b>0.015**</b>	0.52
Discussion of loss with friends		*	0.175	0.31
Nonverbal support from family		*	1.000	0.07
Nonverbal support from friends		*	0.402	0.21
Psychological outcomes				
Depression	2.68		<b>0.022**</b>	1.17
State anxiety	2.57		<b>0.025**</b>	1.11
Trait anxiety	2.81		<b>0.017**</b>	1.23
Somatic symptoms	2.24		0.035	0.91
Other factors of bereavement service utilization				
Access to pre-bereavement and/or bereavement follow-up care		*	0.241	0.26
Whether the participants received bereavement interventions		*	<b>&lt;0.001**</b>	0.69

\* Fisher’s exact test was used in this comparison since more than 20% of the cells had expected cell frequency less than 5, thus violating one of the assumptions of the chi-square test of independence; as a result, no chi-square value was available as the Fisher’s exact test only provided a *p*-value but not the test statistic.

\*\* Statistically significant results after Dunn-Sidak corrections.

△ Effect size in terms of Cohen’s *d* (for independent-sample *t*-tests) or Cramer’s *V* (for chi-square test of independence or Fisher’s exact test)

## Factors Related to Access to Professional Bereavement Interventions

A number of variables were significantly related to whether one successfully received formal therapeutic bereavement interventions in the end, as shown in Table 25. Psychological morbidity was positively related to whether professional therapeutic interventions were provided. Those who received professional help had significantly higher mean depression, state anxiety, and trait anxiety scores than those who had not. As previously reported, whether one previously received pre-bereavement and/or bereavement follow-up care did not predict whether one received professional bereavement interventions in the end. Initiative to seek help, however, strongly predicted subsequent access of bereavement interventions.

**Table 25. Univariate Analyses on Factors Related to Access to Professional Bereavement Interventions**

Variable	t	$\chi^2$	p	ES <sup>Δ</sup>
Participants' sociodemographic characteristics				
Age	-0.32		0.750	0.18
Length of bereavement (in months)	-1.92		0.067	0.68
Gender		*	1.000	0.01
Marital status (Married vs Not Married)		*	0.653	0.12
Level of education ( $\leq$ high school vs post-secondary education)		*	1.000	0.07
Employment status (Working vs Not Working)		*	0.234	0.27
Income		*	1.000	0.07
Participants' immigration-related characteristics				
Length of residence in Canada	0.91		0.375	0.41
Acculturation	0.32		0.352	0.15
Country of origin (Hong Kong vs not Hong Kong)		*	1.000	0.08
English fluency (Fluent English vs not fluent)		*	1.000	0.08
Deceased's sociodemographic and illness-related variables				
Age of death	0.08		0.935	0.04

Time between diagnosis and death (in months)	-1.20		0.241	0.68
Relationship to the participant (parents vs non-parents)		*	0.645	0.17
Nature of death (predictable vs sudden)		*	0.278	0.32
Location of death (within or outside Canada)		*	1.000	0.02
Whether palliative care was provided		*	0.645	0.17
<b>Coping</b>				
JCS problem-oriented coping	-0.55		0.585	0.29
JCS emotion-oriented coping	1.51		0.187	0.83
JCS support seeking	0.83		0.416	0.44
JCS avoidance-oriented coping	0.85		0.405	0.41
JCS isolating thoughts	-0.22		0.826	0.11
Suppression		*	0.645	0.17
Focusing on restoration		*	1.000	0.02
Taking solace in "good death"		*	0.073	0.40
Changing perspective		*	0.160	0.35
<b>Religious affiliation</b>				
Whether one had a religious affiliation		*	1.000	0.05
Degree of religiosity (Not religious /ambivalent vs devout)		*	0.378	0.21
<b>Social support</b>				
Discussion of loss with family		*	0.073	0.40
Discussion of loss with friends		*	1.000	0.10
Nonverbal support from family		*	0.661	0.12
Nonverbal support from friends		*	0.129	0.39
<b>Psychological outcomes</b>				
Depression	2.72		<b>0.012**</b>	1.09
State Anxiety	3.22		<b>0.004**</b>	1.21
Trait Anxiety	3.39		<b>0.003**</b>	1.26
Somatic Symptoms	0.49		0.627	0.22

Other factors of bereavement service utilization			
Access to pre-bereavement and/or bereavement follow-up care	*	1.000	0.07
Taking initiative to seek bereavement support	*	<b>0.001**</b>	0.69

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\* Fisher's exact test was used in this comparison since more than 20% of the cells had expected cell frequency less than 5, thus violating one of the assumptions of the chi-square test of independence; as a result, no chi-square value was available as the Fisher's exact test only provided a *p*-value but not the test statistic.

\*\* Statistically significant results after Dunn-Sidak corrections.

^ Effect size in terms of Cohen's *d* (for independent-sample *t*-tests) or Cramer's *V* (for chi-square test of independence or Fisher's exact test)

## Chapter 6. Discussion

*First, from our perspective, I think it's important that "when in Rome, do as the Romans do". As we have moved and settled here, it's important for us to learn and accept the Western culture. Of course it's a learning process.....to learn, and to understand. On the other hand, Canada is a multicultural country. I think.....if bereavement services exist, can the mainstream culture understand and accept that Chinese, or Asians – let's not just limit this to ourselves but let's talk about Asians in general – have our own cultural values? I'm not saying that our cultural values are bad – actually they are good in certain ways. We are reserved. We are humble. In the Western culture where openness is emphasized, of course we need to learn to be open, but on the other hand I would hope that they can understand our reserved personality. Both sides need to learn from each other and accept each other, so that we can integrate into one another.*  
(Participant K)

To the author's knowledge, the current study is the first study to examine the psychological and health outcomes of bereavement as well as the knowledge, perception, access, and needs of bereavement care services in a diverse, community sample of bereaved Chinese immigrants in Canada. One of the strengths of the current study is the composition of its sample – all the participants are first-generation Chinese-Canadian immigrants who speak Chinese as their primary language and have retained strong roots in their Chinese heritage culture. This group of individuals either seldom participates in or is typically excluded from bereavement research. The current study managed to access this population and directly solicit their perspectives on death and bereavement care, which are considered some of the most forbidden topics of discussion in the Chinese culture.

This study was initially inspired by a research question based on the clinical observation that bereaved Chinese immigrants were underrepresented among users of bereavement care services. While some may assume that the low utilization rate of a health care service reflects a lack of need (e.g., that bereaved Chinese immigrants do not need professional support because they are adjusting well to the loss as a whole, and/or are well-supported by their personal coping resources and social network), the current study provides both quantitative and qualitative evidence that challenge this assumption. Bereaved Chinese immigrants demonstrate a need for professional support for

psychological functioning based on their scores on quantitative measures of psychological morbidity. Qualitative data based on bereaved Chinese immigrants' own narrative reports also suggest that they encounter numerous barriers to accessing bereavement care despite their need for professional help. Their bereavement needs have been unmet by their own social networks, as well as by the health care system as a whole, for a variety of reasons.

## **Psychological Functioning and Grief Experiences of Bereaved Chinese Immigrants**

Previous research examining the health and psychological outcomes associated with bereavement utilized predominantly Caucasian participants, with few studies examining cross-cultural differences or focusing on a specific non-Caucasian ethnic group (Shah & Meeks, 2012; Stahl & Schulz, 2014). Results of the current study reveal that 56% to 64% of bereaved Chinese immigrants in the sample reported elevated depressive and anxiety symptoms, with 52% reporting comorbid symptoms. With regards to depression, 36% of the participants scored within the mild range, while 20% scored within the moderate to severe range. With regards to anxiety, 48% of the participants reported moderate level of current (state) as well as general (trait) anxiety, while 12-16% scored within the severe range. These findings are similar to the prevalence rates of depressive and anxiety symptoms reported in previous research utilizing Caucasian or multiethnic samples (with the majority of participants being Caucasian). For instance, previous studies reveal that 25% to 45% of bereaved individuals report mild levels of depressive symptoms, and 10% to 20% display severe symptoms (Stroebe et al., 2007; Zisook & Kendler, 2007). Studies examining the prevalence of various anxiety disorders in the wake of bereavement report a wider range of prevalence rates, depending on the anxiety disorder diagnosed, the length of bereavement, and the nature of the sample. In Jacobs et al.'s (1990) longitudinal study examining bereavement-related anxiety disorders in a community sample of widows and widowers identified using death records, 25% of the sample met criteria for at least one anxiety disorder at 6-month post-loss. The rate rose to 50% at 12-month post-loss. In Simon et al.'s (2007) treatment study of complicated grief in a clinical sample of participants displaying significant level of grief, 62% were found to have at least

one current anxiety disorder, while 69% reported at least one lifetime anxiety disorder. Participants in the current study also reported physical health complaints that are similar to those reported in previous research, such as pain, low energy, and poor sleep quality (Stahl & Schulz, 2014; Stroebe et al., 2007). Taken altogether, these findings challenge the “clinical folklore” that bereaved Chinese immigrants adjust so well to the loss of a family member that they do not need bereavement care services. At the very least, they display a need for professional support and intervention at a level that is similar to what has been observed in the mainstream population.

Previous research has suggested that even though grief, depression and anxiety often co-occur and share overlapping features, they are distinct concepts (Shah & Meeks, 2012; Shear et al., 2013; Shear & Skritskaya, 2012). The unavailability of a Chinese translated and validated measure of grief at the time of data collection precludes a quantitative, norm-reference assessment of the participants’ grief in the current study. As a result, the participants’ self-reports of their grief experiences during the interview were coded, as a first step to categorize the patterns of grief displayed by bereaved Chinese immigrants. Six patterns have been identified: minimal grief, improved grief, integrated grief, paradoxical grief, concealed grief and intense grief. The pattern most frequently observed is intense grief. Bereaved Chinese immigrants in this category present with symptoms that are consistent with complicated grief, a condition characterized by intense yearning and longing for the loved one, persistent intrusive thoughts about the deceased, difficulty finding meaning in life, and frequent, intense grief symptoms which cause distress and impairment (Zisook et al., 2014). Patterns of concealed grief and paradoxical grief are similar in the sense that they reflect an incongruence between emotional experience and emotional display typically observed in collectivist cultures. Bereaved Chinese immigrants displaying these patterns of grief may present as stoic or calm, but underneath this surface are intense negative emotions associated with the loss, ranging from sadness to anger. These patterns are likely related to the Chinese display rules that curb emotional expressivity, and the tendency of bereaved Chinese immigrants to manage grief by emotional suppression, a coping strategy that is culturally sanctioned and promoted. Integrated grief, on the other hand, is often seen as a sign of “recovery” in the bereavement literature (Zisook & Shear, 2009). It is characterized by well-modulated levels of arousal and calmness. While there may be surges of sadness when the bereaved is reminded of

his / her loss, they are attenuated within a short period of time. Individuals who display this pattern are better able to come to terms with the loss, experience positive emotions, and exhibit a renewed appreciation for life, personal growth, and enhanced coping skills. The pattern of improving grief likely represents an intermediate stage in the road to recovery – bereaved Chinese immigrants who display this pattern notice that their mood has greatly improved, and the intensity of acute grief has begun to subside. However, they are less effective in managing their emotions compared with those with integrated grief.

The triangulation of quantitative and qualitative data leads to several interesting findings. First, it lends some support to the validity of the pattern of “intense grief”, as those who report continued intense grief also have significantly higher mean depression and state anxiety scores than those with minimal grief and integrated grief. Second, despite the observation during the interview that those with concealed grief displayed an intense level of distress that was commensurate with those with intense grief, their mean depression and state anxiety scores are significantly lower than those with intense grief. The disjunction between the results on rating scales and qualitative observations may be related to rapport and trust building. During data collection, the questionnaires on psychological functioning were administered first, followed by a semi-structured interview that was at least 1 hour long. Given bereaved Chinese immigrants’ need to develop a trusting relationship with an outsider before expression of negative emotions can occur, the impersonal nature of rating one’s emotional state on a questionnaire administered by a stranger likely made early disclosure of distress difficult, resulting in underreporting of symptoms. Once the participants became more familiar with and had more confidence in the interviewer who shared a similar cultural and linguistic background with them, they felt more comfortable and honest in the discussion and displays of negative emotions. This suggests that assessments of bereavement needs that only utilize screening measures for psychological functioning without follow-up clinical interviews (a situation that often occurs in busy clinical practices or acute care settings, where professionals need a quick, straightforward, and numerical estimate of a person’s psychological functioning) may miss a group of individuals who suffer from tremendous grief but may not reveal so on quantitative measures.



## **Barriers to Bereavement Care for Bereaved Chinese Immigrants**

Given their significant need for professional support, why do bereaved Chinese immigrants continue to be underrepresented among users of bereavement care services? Qualitative data from the current study suggest that while bereaved Chinese immigrants unanimously agree that they have a tremendous need for bereavement care services, they face numerous barriers to accessing bereavement care. Barriers to accessing bereavement services are multidimensional and exist on multiple levels, ranging from culture, health care system (i.e., structural factors related to health care delivery such as funding, policies, and organizations), health care practitioner, to personal factors such as immigration history, as well as knowledge, beliefs, expectation and attitudes towards health care. It is important to note each of these barriers to bereavement care, if considered individually, is likely not unique to Chinese immigrants. For instance, there are people from other ethnocultural backgrounds that prefer an avoidant coping style, or lack health-related knowledge and health literacy. System barriers, such as a lack of funding, are generic barriers that affect every user of the Canadian health care system. What sets the “Chinese experience” apart is the combination and dynamic interactions among all these factors. The synergistic influence of these risk factors is what makes Chinese immigrants more vulnerable to the negative sequelae of bereavement, and makes access to bereavement care even more difficult for them. It is also important to note that a number of the barriers identified in the current study, such as “language barriers” or “knowledge barriers”, have also been identified by previous research examining cross-cultural differences in ethnic disparities in health care access as well (e.g., Evans et al., 2013; Frey et al., 2012). What sets the current study apart from the previous research is its ability to offer a richer, more in-depth understanding on the meaning behind these labels from the perspectives of bereaved Chinese immigrants (e.g., what specifically underlies a “language barrier” for Chinese, or what “ethnic match” means to Chinese when accessing health care). The use of the qualitative method and the Straussian coding paradigm has allowed for better clarification, expansion and enrichment of these concepts.

## Chinese Cultural Grammar as Barriers to Bereavement Care

The ways the participants described the Chinese culture are consistent with findings from previous anthropological and cross-cultural psychology research which describes the Chinese culture as highly collectivistic, interdependent, and tight. In this culture, the rights and wellbeing of the collective trump those of an individual. Cultural norms are prescriptive and absolute. The importance of interpersonal relationships implies the need to avoid saying or doing things that may upset others. Given how important conformity, interpersonal relationships and the maintenance of social harmony are in the Chinese culture, violation of cultural norms (i.e., being the “odd one out” in a group) can be fear-provoking as such action is associated with dire social consequences.

The data suggest that a number of rules in the Chinese cultural grammar form the standard of behaviours that define 1) how death should be understood, 2) whether, what, how, and with whom one can discuss his / her grief experience, and 3) how one should cope with the death of a family member. Some of these rules are more specific to death (e.g., cultural beliefs surrounding death), while others are more general as they govern a broader spectrum of behaviours (e.g., the rules surrounding communication styles guide social-communicative behaviours in general, whether or not such behaviours are death-related). Yet many of these rules are incompatible with the nature, principles, and practices of bereavement care services, and may put Chinese at a disadvantage when coping with grief.

In the Chinese culture, cultural beliefs regarding death suggest that death is a taboo. Talking about it runs the risk of attracting bad luck, bringing shame to one's family, offending others, and causing social ostracism. The rule over communication styles suggests that direct, overt discussion of private matters such as the death of a family member and one's emotions is socially and culturally inappropriate. Such matters must therefore be discussed covertly using innuendos and euphemisms, and it is up to the listeners to “*zhih-yi*”, or “mind read” in order to decipher the true meaning behind the words. The rules over relationships in the Chinese culture further suggest that if discussion of grief were to occur, it must be limited within the realm of one's family; talking about one's grief with outsiders is forbidden. Emotions are seen as something unhealthy that must be avoided and controlled. Grief is considered useless and unnecessary as it will not

change the immutable reality that someone has died. Talking about grief is therefore pointless and "making a mountain out of molehill". Receiving outside help is indicative of one's failure to control emotions, which is then interpreted as a sign of pathology and mental illness. As a result, any attempt to seek outside help on one's negative emotions, such as through accessing bereavement care services, is stigmatized by many Chinese in the culture.

Moreover, participants' perceptions of Chinese cultural values and norms suggest that the Chinese culture stipulates the concealment, trivialization, avoidance, and suppression of personal needs, experiences, and desires for the sake of social harmony and the collective good. The culturally condoned ways of coping with grief are rationalization, trivialization of grief, and thought and emotion suppression, rather than talking and emotional catharsis. Yet bereavement care services almost always involve a reminder of the family member's death, emotional arousal, an explicit discussion of death with an outsider, and a release of negative emotions (Reid, Field, Payne, & Relf, 2006b). Grief interventions usually adopt a loss- and emotion-focused approach rather than problem-focused, entailing the repeated retelling of the loss, having an imaginary conversation with the deceased, and confronting avoided situations (Schulz, Hebert, & Boerner, 2008). Chinese cultural rules clearly run counter to bereavement care services' emphasis on openness to emotional experiences, and past research has shown that individuals with more avoidant or instrumental coping styles tend to respond more poorly to such interventions (Jordan & Neimeyer, 2003). Experiences from professionals offering bereavement care in Hong Kong also confirm that direct discussion of emotions can lead to early dropout (Chan & Chow, 2006). Often times practitioners in Hong Kong need to downplay the focus on emotions in order to motivate bereaved Hong Kong Chinese to initiate treatment and maintain attendance. They also need to adopt a solution-focused approach and emphasize the practical benefits of therapy rather than emotional catharsis. They need to discuss matters such as appetite, quality of sleep and somatic symptoms as an oblique way to address the bereaved's emotional needs.

The veil of secrecy and the habit of suppressing emotions may mean that strong emotional arousal is a foreign and scary experience to many Chinese. Many participants suggest that Chinese in general struggle with alexithymia (the inability to identify and

describe their emotions) and are often confused about how to interpret the meaning behind emotional arousal. Many Chinese are therefore put in a particularly vulnerable position when they experience the death of a family member. They are often utterly unprepared for the ensuing emotional turmoil, do not know how to make sense of their grief, and are provided with few tools by their culture to cope with bereavement. They also may fail to recognize that their symptoms are a sign of a more serious health problem, or that their grief has taken a turn for the worse and begun to negatively impact their daily functioning (Fong & Yeung, 2012). Furthermore, since help is culturally considered something to be offered rather than to ask for, the passivity over seeking help and asserting one's needs discourages any initiative to seek professional bereavement support. These factors have likely contributed to the high number of participants in the current study who scored above clinical cut-offs on measures of psychological morbidity, but had never made any effort to seek professional help.

### **Immigration Experiences as Barriers to Bereavement Care**

Findings from the current study suggest that Chinese immigrants' heritage cultural grammar is tested when they enter the process of immigration. For this group of first-generation Chinese immigrants who still firmly identify with their heritage culture, their immigration experience accentuates cross-cultural differences rather than cross-cultural similarities. The ethnic and cultural diversity in Canada has only made them realize how different they are from the rest of the population (and particularly the "Western", Caucasian population). This feeling of being an "alien" in a foreign land can make them hold stronger to Chinese cultural grammar when dealing with matters related to death and grief.

Bereaved Chinese immigrants have overwhelmingly expressed a preference for working with Chinese professionals if they were to seek bereavement care services. They refer to their preferred Chinese professionals as "one of us" – someone who is not only similar in ethnicity and Chinese dialect used, but also share the same birth place, values, immigration experience and cultural identity. "One of us" therefore does not mean "any Chinese", as the immense intra-cultural differences among the three Chinese regions (Hong Kong, Taiwan, and Mainland China) are perceived to impede within-group

communication. Since the population of Chinese immigrants is not a homogenous group, bereaved Chinese immigrants believe that ethnic match based on shared racial characteristics (i.e., Chinese) is not enough to guarantee mutual understanding and better quality of bereavement care. This view is consistent with findings from previous research examining the relationships among ethnic match, intra-group diversity, and mental health treatment outcomes. For example, Mok, Lai, and colleagues (2003) examined how Chinese Canadians utilized “ethnically sensitive mental health services” offered by a specialized cross-cultural outpatient psychiatric clinic in Vancouver. They found that despite an ethnic match between patients and psychiatrists (i.e., both being ethnically Chinese and speaking the same dialect), Mandarin-speaking patients who emigrated from Taiwan and Mainland China were twice as likely to prematurely terminate treatment compared with their Hong Kong-born Cantonese-speaking and Canadian-born English-speaking counterparts. The authors suggest that culturally sensitive practice needs to go beyond language and ethnic matching, as intra-ethnic variations in “invisible” cultural characteristics such as values, traditions, upbringing and immigration experiences between health care providers and the patients can still negatively impact accessibility of services and treatment success. The current study also supports the existence of intra-cultural differences among Chinese depending on their countries of origin. Participants from Taiwan and China (Chinese regions that are more conservative in values) tend to report more somatic symptoms related to grief than their counterparts from Hong Kong (a more westernized region due to prior British rule), a finding consistent with previous research which finds that Chinese individuals who hold a more traditional view on psychological functioning tend to report more somatic symptoms as an indirect way to express emotions (e.g., Ryder et al., 2008).

Two major barriers drive bereaved Chinese immigrants’ preference for working with a professional that is “one of us” when accessing bereavement care: communication barrier, and cultural barrier to understanding. Previous research examining barriers to health care access in immigrant and ethnic minority groups often equates “communication barrier” or “language barrier” to the health care users’ poor English proficiency (i.e. barrier exists because health care users cannot meet the expectation of using English to communicate during a clinical encounter with health care professionals, the majority of whom are English-speaking only). The current study suggests that such definition is likely

too simplistic. For those who do not speak fluent English, their “language barrier” is indeed a result of their limited English fluency or inability to use the English language, such as not being able to understand what was said to them and not knowing how to express themselves in English. Yet bereaved Chinese immigrants who speak fluent English (who formed the majority of the current sample) still report encountering a “language barrier” to the access of bereavement care services. For these individuals, their biggest barrier in communication is a transmission barrier, defined as a perception of distance caused by the use of one’s second language to discuss emotions, regardless of English fluency. Three dimensions underlie the feeling of distance: distance from one’s intended message, as they feel unable to communicate in a clear, direct and accurate manner using a second language; distance from the audience, as they doubt that someone who is clearly different from them will be able to understand what they want to convey; and distance from their emotions, as using English to discuss emotions may distort their meaning and creates a psychological distance from one’s genuine feelings. For English-speaking Chinese immigrants, “language barrier” reflects cross-cultural communication challenges at a deeper level that goes beyond the usage of a language. They pertain more to the accurate encoding, conveying, and decoding of intended meanings when one is communicating about abstract concepts such as emotions using a language that is not one’s native tongue.

With regards to cultural barrier to understanding, bereaved Chinese immigrants are adamant that it is “impossible” for professionals who do not share the same cultural background with them to understand their needs and feelings during bereavement. This is likely due to their perception of cultural incompatibility, that is, the absolute cross-cultural differences between Chinese and “Westerners” in aspects such as perspectives on death, emotional expression and help-seeking behaviours, communication styles, and family values. Genuine understanding from health care professionals is defined by their ability to go beyond the literal meaning of a patient’s words, and to immediately and accurately understand what a patient wants to convey based on a few words uttered, without the need for further explanation. Such a level of automatic, precise understanding is predicated upon a shared cultural background, which necessitates the professionals being “one of us”. Bereaved Chinese immigrants’ skepticism over cross-cultural understanding clearly stems from the high-context communication style prevalent in the Chinese culture,

in which meaning is conveyed implicitly and cannot be accurately interpreted without a deep understanding of the cultural context.

An interesting finding is that the participants who voiced most concern with the cultural barrier to understanding were those who had received bereavement care services from non-Chinese professionals. They reported mixed feelings towards the quality of care they had received, and were able to speak from experience regarding how the cross-cultural differences between them and their therapists led to misunderstanding and failure to receive culturally appropriate therapeutic recommendations. For example, the participant who sought help from her psychiatrist over the death of her mother noted that the psychiatrist was unable to understand her distress over being an “unfilial” daughter and the ensuing negative social judgments due to her refusal to care for her abusive mother towards the end of her life. Coming from an individualistic culture, the psychiatrist recommended the participant to make her own wellness a priority over other people’s perception of her. Previous research on bereavement care needs in predominantly Caucasian samples has supported the view that adults grieving for the death of a parent have the lowest risk of developing complicated grief (e.g., Aoun et al., 2015). In the Chinese culture, however, the centrality of the value of “filial piety” implies that taking care of one’s ill parents is socially expected (Chan & Chang, 2000). This gives rise to a strong sense of duty in the adult children in the family, and contributes to tremendous guilt, self-blame, and blame by others if one fails at this role. The death of a parent, even if expected, can still be perceived as unexpected, untimely and traumatic due to the bereaved’s perception that they have not done enough for their deceased parents (Chan & Chow, 2006). Not sharing the same cultural roots and view on familial relationships might have made it difficult for the psychiatrist to appreciate the participant’s main concern and respond in a culturally sensitive way. The feeling of “being understood” is therefore the key to encourage Chinese individuals to access bereavement care services. Only if they are assured that they will be understood by the professionals will they be able to develop trust, confidence, closeness and comfort in the therapeutic relationship, thereby allowing them to overcome their fear and cultural rules restricting them from openly discussing grief and expressing negative emotions with an outsider.

## **Barriers to Bereavement Care When Navigating a Foreign Medical System**

The current study suggests that as they navigate a foreign medical system, bereaved Chinese immigrants encounter significant barriers to accessing bereavement care on multiple levels – personal barriers, health care provider barriers, and system barriers.

On a personal level, many first-generation Chinese Canadians, being immigrants to a foreign country, have brought with them a set of health-related values, beliefs, knowledge, expectations, and practices based on their experiences with health care “back home”. This is the framework they use to understand health, illness, death, and dying, as well as the practices in the Canadian medical system. Most Chinese immigrants used to receive health care from a system endorsing a paternalistic model of professional-patient relationships, where users are expected to acquiesce even if they are confused about the diagnoses and treatment plans offered by professionals. The role of a health care user is to be a passive recipient. Health care professionals, being “experts”, assume the lead in decision-making and provision of care.

Chinese immigrants intersect with the Canadian health care system during one of the most stressful life events – the illness and / or death of a family member. They encounter a health care system which emphasizes egalitarianism over paternalism, autonomy and initiative over passivity, respect for dignity over a relentless pursuit for cure, and quality of life over quantity. These values, beliefs and practices are often unknown to them or are in conflict with their expectations of what health care should look like. Chinese immigrants’ attempts to interpret the philosophy and practices of the Canadian medical system based on their pre-existing knowledge, understanding and expectations of health care from their countries of origin have resulted in a number of misconceptions and negative health care experiences, such as the belief that palliative care is a cost-saving measure sanctioned by the hospital and/or the government, or that health care professionals have colluded to hasten their loved ones’ death.

One of the most salient themes in bereaved Chinese immigrants’ reports of health care experiences is their profound deficit in health-related knowledge, a finding that is



consistent with results from previous research examining immigrants from non-English-speaking background's and ethnic minority groups' level of knowledge in palliative and bereavement care (Enguidanos et al., 2013; Frey et al., 2013; Kreling et al., 2010). The severe gap in knowledge is likely one of the consequences of playing a passive role in health care in their countries of origin. Chinese immigrants have trouble obtaining, processing, and understanding health information, and are unaware of health care services available to them. The lack of knowledge negatively impacts their sense of agency in health care decision-making, as the ability to take initiative and actively participate in health care requires a sound knowledge base. Being new to Canada also means that Chinese immigrants often lack knowledge in the health care services offered in this country and the ways to access them.

### ***Lack of Knowledge in Bereavement Care as the Biggest Barrier to Access***

For bereaved Chinese immigrants, the biggest obstacle to accessing bereavement care is their lack of knowledge in this service – not being aware that bereavement care exists, not knowing what it is, and not knowing the steps to take to access such services. This is in contrast to findings from previous research examining utilization patterns of bereavement care in the mainstream population, in which the majority of bereaved individuals who never used bereavement care services attribute their non-use to an absence of need – either they feel that they are adjusting well to the loss, or that they have received enough support from their informal social networks (e.g., Cherlin et al., 2007). “A lack of awareness of bereavement care services” as a reason for non-participation is reported by a small minority only (less than 3% in the Cherlin et al. study).

The current study reveals that the majority of bereaved Chinese immigrants have “*never heard of*” bereavement care and “*have no idea such services exist*”. Even though some individuals had received bereavement care, they did not realize that the services they were provided with were bereavement support services. Since bereavement care remains non-existent or largely unknown to the public in their countries of origin, the concept of “bereavement care” does not exist in the minds of most Chinese immigrants. They are not aware that such services exist, and do not expect any follow-up contact or dedicated services from professionals to support them after their loss. Moreover, bereaved Chinese immigrants have limited knowledge on the nature and content of bereavement

care, and the routes to take to access such services. They tend to define bereavement care as synonymous with “counselling” or “emotional support”. They do not know from whom, where, and how to seek support for grief. The lack of resourcefulness and familiarity with health care services available in Canada make bereaved Chinese immigrants feel utterly lost as they navigate a foreign medical system to gain access to bereavement care at one of the lowest points in their lives. Lack of awareness and knowledge can result in mistrust and misconceptions about the nature, quality, and accessibility of bereavement care services (Calanzani et al., 2013).

***Lack of Knowledge Exacerbated by the Inconsistent Delivery of Pre-bereavement Support and Bereavement Follow-Up, and a Lack of Public Education***

On a health care provider and system level, bereaved Chinese immigrants’ significant gap in knowledge and information needs have not been recognized and addressed by health care professionals or the Canadian health care system, as evidenced by the participants’ frequent use of the phrase “*no one ever told us about bereavement care*”. In addition to low awareness of services, lack of information provided by professionals in culturally appropriate formats and languages has constantly been identified as a barrier to health care service use in previous research on ethnic disparities in health care access (e.g., Evans et al., 2012). Findings from the current study reveal that bereaved Chinese immigrants’ experiences with pre-bereavement care and bereavement follow-up, which are professional-initiated services that serve an important educational and health promotion function, have been highly heterogeneous. The inconsistent delivery of these services means that health care professionals may have missed the golden opportunity to clarify misconceptions, provide information, and educate bereaved Chinese immigrants about grief and bereavement support.

A number of participants whose family members passed away in Canada never received any pre-bereavement services nor bereavement follow-up from health care professionals – no one ever informed them of the existence of bereavement support services, no educational materials on grief and bereavement were ever provided, and no follow-up care was offered. The lack of contact from health care professionals helps perpetuate bereaved Chinese immigrants’ knowledge deficit on grief, bereavement and

available intervention programs, and reinforces their expectation that bereavement care services do not exist.

For those who have received some form of pre-bereavement care or bereavement follow-up (with the exception of the bereaved mother who lost her infant son to cancer), the delivery of care is perceived to be poor and fails to fulfill its educational purpose. Despite the fact that most of these participants lost their loved ones to chronic life-threatening illnesses (which implied continued contact with the patients' health care professionals prior to death), only one participant received limited pre-bereavement care which entailed the provision of educational brochures. One participant came across educational materials on grief by chance only. A proper, detailed introduction to bereavement care services by health care professionals is sorely lacking. In fact, much of the family members' conversations with health care professionals at the end-of-life stage centred around patient care. Little attention was devoted to the family members' own wellbeing.

Health care professionals' follow-up contact with surviving family members after the death of a patient tends to be random, brief, erratic, inadequate and ill-timed. Bereavement follow-up usually constitutes a one-time contact by professionals only. Some participants received staff-initiated follow-up contact "out of the blue", with little explanation on its purpose. Some were merely **informed** of the existence of bereavement interventions rather than being **educated** about them, as they were again provided with little explanation on the purpose, nature and benefits of bereavement care. Some were provided with erroneous information by health care professionals (e.g., being told that only English-speaking bereavement care services were available). Pre-bereavement grief support or bereavement follow-up, if offered, are often provided at the wrong time – either at a time when bereaved Chinese immigrants feel the most overwhelmed and distracted, or when they are busy with funeral arrangements and therefore are insulated from their grief. This leads to a significant mismatch between the time support is provided and the time their need for support emerged. Research conducted in Hong Kong suggests that emotions of bereaved Chinese often do not emerge until after burial arrangements are complete (Chan & Chow, 2006). The current research confirms that Chinese immigrants in Canada also report a delayed grief response which emerges only after the funeral is

over and all dust is settled. When bereavement follow-up is limited to a one-time contact rather than a continued effort, professionals would have ceased contact by the time Chinese immigrants realize that they need help. This means that Chinese immigrants are often left to their own devices to seek support.

In addition, there has been a lack of public education and promotional efforts to raise awareness in the Chinese community with regards to death, dying, grief, and the availability of bereavement care services. As a result, the Chinese community at large has been kept in the dark about these services, making information support through word-of-mouth among family members and peers impossible. Bereaved Chinese immigrants whose family members passed away in their countries of origin never get to learn that bereavement support is available in Canada, and that they are eligible for services even if their loved ones did not pass away here.

A combination of system-level factors and practitioner-level factors likely contributes to the highly fragmented and inadequate delivery of bereavement care to bereaved Chinese immigrants. While practice guidelines for palliative care services have always recognized bereavement care as a core element and noted the obligation for institutions and professionals to provide some level of bereavement care to the surviving family members, they seldom specify the nature of services to be provided (Holtzlander, 2008). Little consensus exists over what constitutes “bereavement care”, how care should be delivered, and for how long should services continue (Barry et al., 2012; Reid, Field, Payne, & Relf, 2006a). No recommended format, practice standards or standardized model of care has been developed specifically for bereavement care in many countries of the world, including Canada and the United States. It is often left to the discretion of individual facilities to figure out the best approach, based on their individual circumstances, to administer care. As a result, whether bereavement care is provided and what services are offered vary across programs and settings, and not all services are available (Barry et al., 2012). Reid and colleagues (2006b), in their survey of five hospices in England, found that while they all made initial contact with bereaved family members shortly after death and provided verbal and written information about bereavement, ongoing follow-up support and therapeutically focused services were not consistently provided. Those with more complex bereavement needs were therefore not adequately supported. Billings and

Colton (1999) interviewed 51 bereaved family members to understand their patterns of access to bereavement follow-up at a tertiary care hospital in the United States, and found that only 62% of the participants had post-death contact with the hospital staff, 26% of which was initiated by the participants themselves. Contact was limited to one instance and consisted of a note, phone call, follow-up visits, or chance hallway meetings and office visits when the family members went for their own medical appointment. No repeated or sustained follow-up was offered. Lichtenthal and colleagues (2015), in their comprehensive review of hospital-based bereavement care programs for family members who suffer the loss of a child to cancer, noted that follow-up attempts by a particular medical team were inconsistent due to lack of standard of care. Some families were never contacted, and programs highly varied in terms of their definition of “bereavement care” and services provided. In the face of erratic delivery of bereavement care in the health care system, bereaved NESB immigrants and individuals from ethnic minority groups, who already experience a range of cultural and linguistic barriers to health care in general, are more likely to suffer from suboptimal care or even an absence of care.

The structure of the Canadian health care system also contributes to the inconsistent delivery of bereavement care. Health care is a provincial responsibility (Canadian Cancer Society, 2015). Every province is further divided into several health regions, each with its own regional health care board or authority that oversees health care facilities within its boundary. Different health regions have different needs and prioritize palliative and bereavement care differently. The decentralization of health care in Canada makes it difficult to create nation-wide policies and practice standards for bereavement care (Crooks, 2009). Uneven distribution of resources across and within health authorities in the province also leads to inequities and variability in the provision of services (Select Standing Committee on Health, 2016). As a result, services one can access in a particular municipality may be different from another.

Without a systematic, nation-wide approach to bereavement care, it is then up to individual organizations to develop their own bereavement services. Many do not have a facility-wide, centralized bereavement program to coordinate care and to ensure consistent delivery of services. “Bereavement care” then becomes a hodgepodge of practices as different facilities, or even different clinical units within the same facility, may

have different definitions on what constitutes bereavement support and are providing vastly different services. The type of bereavement care provided is often determined based on the characteristics of the health care facility itself and the deceased patient such as age and cause of death, rather than the needs of the bereaved. For instance, palliative care facilities such as stand-alone hospices tend to have longer-term relationships and more frequent interactions with the patients and their families, allowing for better assessment of needs that can begin at the point of admission. There is also a longer continuation of care – most hospices offer active bereavement support of up to 1 year, with the possibility of surviving family members returning for services beyond the 1-year mark (deJong-berg & deVlaming, 2005). In addition, health care facilities that serve the pediatric population tend to have the most formal policies and comprehensive mechanisms for bereavement support, with pre-bereavement care, continuation of support for at least 1 year and staff-initiated follow-up contact at regular intervals (e.g., IWK Health Centre, 2014; The Hospital for Sick Children, 2011; Stevenson et al., 2016). In contrast, acute, tertiary-care hospitals (where the majority of deaths usually occur) are less likely to offer organized, long-term bereavement services (Canadian Institute for Health Information, 2007; Morris & Block, 2015). Staff working at these facilities are usually busy managing crisis situations and attending to the immediate medical needs of patients. This leaves little time and resources for them to attend to the care of bereaved survivors. Even if individual programs within the hospital attempt to provide bereavement service, services are usually limited to a brief, one-time contact only due to patient volume (Morris & Block, 2015). The current study lends support to these observations. The only person who had received comprehensive and prolonged pre-bereavement support and bereavement follow-up is the participant who lost her infant son to cancer. Combined analyses of quantitative and qualitative data also find that those whose deceased family members had received palliative care prior to death are more likely to have been offered pre-bereavement care and bereavement follow-up.

The lack of health care funding further complicates the delivery of bereavement care in Canada. The literature often calls for continued support for bereaved family members, which should begin with pre-bereavement discussion and continue for at least 12 months following the loss (Holtslander, 2008). The Canada Health Act, however, covers palliative and end-of-life care for patients and their family caregivers over a period

of several months only. No dedicated funding for bereavement support is available from the government (Lang et al., 2015). Once the patient dies, remuneration to health care facilities and practitioners for their work supporting family members immediately stops. Funding resumes only if bereaved family members become “patients” themselves and access the health care system with a grief-related health problem. This funding gap leads to a disjointed delivery of bereavement care and a lack of continuity of care for surviving family members. It also means that bereavement care is reactive rather than preventive, as no compensation (and thus no service) is available unless bereaved family members develop clinically significant symptoms and become “sick” enough to qualify for services.

With many provinces and their respective health care authorities running a budget deficit, health care funding freeze or cuts often lead to resource restrictions and service cuts. Since there is no designated funding for bereavement support, the provision of such services has to come from the operating funds for palliative care. Yet palliative care itself also suffers from funding cuts since it is not considered a core service in many provinces (Crooks, 2009). Many organizations that provide palliative care such as hospices rely on donations and user fees to supplement their budgets (North Okanagan Hospice Society, 2011). A scarcity of resources for palliative care means that available funding must first be allocated for direct patient care rather than for patients’ family members. Bereavement support is relegated to an optional service within the domain of palliative care, and is usually the first to be curtailed due to resource restrictions (Holtslander, 2008; Lang et al., 2015). Many current bereavement support programs are now run by community-based non-profit organizations, relying on privately raised funds and unpaid volunteers to sustain services (Wilson & Playfair, 2016). The lack of funding also means that special services that cater to minority groups, such as providing linguistically and culturally appropriate educational materials, are difficult to justify and become even less of a priority (Reese & Beckwith, 2015).

Without a clear mandate from the government and health care facilities to provide bereavement care and address ethnic disparities in access, delivery of bereavement services to ethnic minorities and NESB immigrants depends largely on individual professionals’ own “goodwill” and interest in 1) providing bereavement care, and 2) providing bereavement care to culturally diverse groups. Yet to some health care

professionals, their duty of care pertains only to the patient but not his / her family members, and such duty ends at the moment of the patient's passing (Buppert, 2015; Tse, Wu, Suen, Ko, & Yung, 2006). Some professionals exhibit a disjunction between their attitude towards bereavement care and their actual practices. In a survey of Canadian oncologists and palliative care physicians on their practices of bereavement follow-up, while over 84% of physicians expressed a desire to meet a deceased patient's family members, most engaged in "passive bereavement practices" only, such as making themselves available to answer phone calls from family members. With regards to "active bereavement practices" that require initiative on their part (e.g., making a phone call or sending a condolence card), only 33.3% of the physicians surveyed routinely engaged in such practices, and only 10% routinely referred bereaved family members to bereavement support program or bereavement counselling (Chau, Zimmerman, Ma, Taback, & Krzyzanowska, 2009). In a similar survey, despite the finding that 89% of physicians who responded expressed a strong interest in meeting bereaved family members, 72% rarely or never initiated family meetings, and only 38.7% would attend family-initiated meetings (Kusano et al., 2012). Logistical barriers, such as a lack of time, a lack of resources, strained manpower, and a heavy burden of patients with advanced illness, are associated with less frequent bereavement support practices (Chan et al., 2013; Chau et al., 2009). Professionals' discomfort also negatively predicts their likelihood of providing bereavement care. A lack of training, skills and confidence in the management of grief makes staff feel overwhelmed and ill-equipped to provide bereavement care as they fear that they may not know what to say or may make a mistake (Donovan et al., 2015; Kusano et al., 2012). Staff's own emotional responses, such as a sense of failure and anxiety after a patient's death, fear of deceased family members' strong emotional reactions, or even fear of their own negative emotions are related to their reluctance to offer bereavement care (Chau et al., 2009; Tse et al., 2006). Taken altogether, these barriers hamper health care professionals' ability to provide consistent care to bereaved family members.

With regards to providing bereavement care specifically for ethnic minorities and NESB immigrants, professionals often encounter barriers to cultural competence on multiple levels, including a lack of diversity in the workplace, a lack of training on the ways to work within diverse belief systems, and a lack of resources for developing culturally competent services such as providing culturally appropriate materials, interpreters,



community outreach and public education (Reese & Beckwith, 2015). A deficit in knowledge is not limited to health care recipients; health care providers may also struggle with a lack of knowledge of other cultures and a lack of information on available services for ethnic minorities, contributing to low referral rates (Calanzani et al., 2013). Findings from the current study support the existence of such barriers in the Canadian health care system, as evidenced by bereaved Chinese immigrants' observation of a lack of health care professionals from culturally and linguistically diverse backgrounds, and a lack of informational materials on bereavement care written in Chinese. Some have been erroneously informed by professionals that bereavement care services are offered in English only and no Chinese-speaking services are available, which reflects the professionals' lack of awareness of culturally sensitive and language-specific services available in the community.

Without a working knowledge of the beliefs, values, and practices of other cultures, health care professionals may be oblivious to the unmet needs, barriers to access, and inadequacy of services for ethnic minorities and NESB immigrants. Some may become reluctant to serve diverse groups due to fear and discomfort (Reese & Beckwith, 2015). What is worse, professionals may resort to stereotypes in an attempt to provide "culturally competent care". Previous research, for example, has identified possible gatekeeping behaviours in health care professionals, as they limit patients' and families' access to information on palliative and bereavement care based on their assumptions about ethnic minorities' needs and preferences (i.e., "the attitude that 'they' won't use it anyway"; Frey et al., 2013, p. 523). Calanzani and colleagues (2013) criticized professionals' common assumptions that ethnic minorities would "look after their own", that family support is always readily available, and that family members prefer and are capable of providing support at home, leading to a lack of provision of information and appropriate referrals for minority families. In the current study, it is clear that health care professionals fail to recognize and address the unique cultural and information needs of bereaved Chinese immigrants. They may have overestimated bereaved Chinese immigrants' pre-existing level of knowledge in grief and bereavement care services, and their familiarity with and receptiveness towards seeking professional help. At the same time, practitioners have underestimated the level of effort they need to put in to educate, provide information, and promote health when working with this special population. As a result, professionals

mistakenly assume that their usual or standard procedures for providing bereavement care (e.g., simply telling someone that help is available and handing over a list of resources with little explanation and guidance) are equally appropriate for Chinese immigrants. A brief introduction to bereavement care services may be adequate for native-born Canadians, who tend to be more resourceful and health literate, and are more familiar with palliative and bereavement care. Yet culturally sensitive bereavement care for Chinese immigrants needs to be practitioner-initiated, with a stronger focus on education and health promotion. Merely “informing” them of the existence of bereavement care services is not enough to address their information needs and encourage access.

### ***Initiative to Seek Help and the Model of Self-Referral in Bereavement Care***

In the absence of consistent, staff-initiated delivery of bereavement care, access to professional help then depends on health care users’ own initiative to seek help. In fact, a number of bereavement researchers support the current model of “self-referral” in the delivery of bereavement care (i.e., professional support is provided only if the bereaved requests it). Proponents believe that this model encourages resilience, allows the bereaved to play a more active role in care planning, and promotes individual choices on whether, when, and what services should be provided (Agnew et al., 2010). They advocate for “inreaching interventions” rather than outreach, that is, professional help should be provided only to those who have taken the initiative to ask for help and “opt in” for treatment (Schut & Stroebe, 2005). To them, “initiative to seek help” is a proxy measure of need – those who seek out and ask for help have likely suffered more and have the greatest need for help (Bergman et al., 2011). These recommendations are in line with the bereavement researchers’ consensus that “grief is not a disease”, the fear of “pathologizing grief” and normal reactions to loss, and the need to minimize “false positives” (Schut & Stroebe, 2005). They also reflect the values of the mainstream North American culture, an individualistic culture in which individual autonomy is a priority, and explicit assertion of one’s needs is encouraged and expected. Yet little research has been done to examine whether this “opt-in” approach to provide bereavement care works equally well across cultures.

The current study does find that initiative predicts access to bereavement interventions; consistent with the “opt-in” approach to deliver bereavement care, the

bereaved Chinese immigrants who received professional help tend to be the ones that have taken a more proactive role in requesting help, such as initiating a conversation about grief with their family physicians. A positive relationship between help-seeking behaviours and psychological morbidity is also identified; those who have taken the initiative to seek help have higher mean depression and anxiety scores than those who have not. A significant number of bereaved Chinese immigrants in the current sample, however, never took the initiative to seek help despite scoring above clinical cut-offs on measures of depression and anxiety. The practice of using client initiative to gauge need and inreach strategies in the delivery of bereavement care can lead to the dangerous conclusion of “people are not showing up for services because they do not need services”. In fact, some at-risk or high-distress bereaved individuals may be unwilling or unable to seek help.

The model of self-referral is predicated upon one’s ability to recognize their need for support, level of awareness of the existence of services, knowledge in the routes to take to access support, trust in the effectiveness and appropriateness of the treatment, and the courage and motivation to seek help (Agnew et al., 2010). This health care delivery model, intended to empower those in need to make better health care decisions, may end up putting ethnic minorities and NESB immigrants at a disadvantage in health care access due to their deficit in the skills needed for taking the initiative to seek help. For instance, the need to self-refer for bereavement support is unknown to most bereaved Chinese immigrants in the current study. Due to the culturally encouraged passive and avoidant response style and their experience with a paternalistic health care system in their countries of origin, they expect that it is the health care professionals’ job to initiate services. In fact, many hold the belief that if bereavement support does exist, health care professionals would have taken the initiative to tell them about it. Stigma, fear of negative social consequences, and skepticism towards working with professionals who are ethnically and culturally dissimilar further discourage help-seeking behaviours. More importantly, bereaved Chinese immigrants’ profound lack of knowledge in the existence, nature, and ways to access bereavement care hinders their ability to take initiative. It is simply impossible for someone to ask for something if he or she has no idea that it exists.

Under a model of self-referral, bereaved Chinese immigrants' attempts to request bereavement care highly vary, leading to different outcomes. Most of the participants in the current study never took the initiative to seek help for their grief, and thus never received help. Those who did **and** successfully received treatment are likely more health literate and more resourceful; they either knew that they could approach their family physicians for help, or were already under the care of a mental health professional before their loss. Conversely, for those who took initiative but did not receive professional help, their "initiative" usually consisted of a disorganized, random search for help, such as doing a casual search for services on the internet, or revisiting the hospital with the hope of running into health care professionals that can offer help.

## **Bereaved Chinese Immigrants' Main Concern: Bereavement as a Lonely Journey**

The loss of a family member interacts with Chinese culture, immigration, and the health care system and gives rise to a profound sense of loneliness in bereaved Chinese immigrants. With 1) a heritage culture that advocates the suppression and concealment of personal struggles and stigmatizes negative life experiences, emotions, and violation of social norms, 2) an alienating experience of moving to a foreign land with a culture that is incompatible with one's own, and 3) an unfamiliar health care system that fails to recognize and address their needs and provides little to no support when they need it the most, it is not surprising that bereaved Chinese immigrants unanimously define the core experience of bereavement as a lonely journey, where they feel that they are "*the only soldier fighting this battle*". This is a disconcerting finding as loneliness has been identified as a mediator variable between bereavement and psychological morbidity such as depressive symptoms (Fried et al., 2015).

Loneliness has a physical dimension and an existential dimension. Physical loneliness pertains to the sense of solitude the bereaved feel due to the physical absence of their deceased family members. Those who used to reside with their now-deceased loved ones are acutely aware of the unfillable void in their lives caused by death, akin to a "missing piece" in a puzzle. A profound sense of abandonment is evident. The deceased family members are thought to have had "the easy way out" by dying, while the surviving

family members are left behind to pick up the pieces and continue to survive, waiting for their own demise. On the other hand, existential loneliness reflects what bereaved Chinese immigrants believe to be the essence of human existence and the limit to empathy: the belief that since everyone is a separate entity from others, life by definition is a lonely experience. Bereavement is therefore perceived to be a lonely journey because the bereaved, and only the bereaved, are the ones going through the experience of losing a loved one. The Chinese idiom of “*you never know how much a needle prick hurts unless it is your flesh being poked into*” has been used by bereaved Chinese immigrants to illustrate their belief that others can never truly understand their grief because “*they are not me; they are not the ones experiencing it*”. Since no one can live their lives on their behalf, bereaved Chinese immigrants believe that the responsibility of resolving their grief ultimately resides with themselves. Despite others’ best intention to help, it is still up to them, and only them, to confront, process, and cope with grief alone in the end.

The most prominent dimension of loneliness for bereaved Chinese immigrants, however, is their profound sense of social loneliness. Social loneliness reflects the bereaved Chinese immigrants’ report of a lack of help and social support offered by others – that “*no one helped me*” during the course of bereavement. Contrary to the popular belief that they are well-supported by their social networks, bereaved Chinese immigrants do not receive adequate support from their families and / or friends. Some of them experience a loss of social network for a number of reasons. First, immigration negatively impacts ties with family members due to geographical dispersion. When everyone in the family is living in a different place in the world, geographical distance makes it impossible for them to provide immediate, in-person support to each other. Second, caregiving experiences can lead to social isolation when family caregivers become so devoted to the dying patients that they have no time to socialize and maintain social relationships. After the eventual death of the family member, the bereaved caregiver may suddenly realize that his or her pre-existing social network no longer exists. Third, grief can result in significant social withdrawal. Avoidance of social contact with others only aggravates grief and sense of loneliness among the bereaved.

Even for those with an intact social network, the level of social support received by many bereaved Chinese immigrants remains nonexistent to inferior. The form of social

support most consistently provided to them is nonverbal in nature, consisted of “acts of kindness” such as providing practical help. Yet interestingly, actions do not speak louder than words in this case – bereaved Chinese immigrants still report feeling lonely, unsupported and dissatisfied with the social support they have received, since nonverbal social support cannot compensate for the inadequate or poor verbal communication of grief they have with family and friends. The need to talk to others about the emotions one experiences in response to the loss is termed social sharing in the bereavement literature (Stroebe, Stroebe, Schut, Zech, & van den Bout, 2002).

According to the participants, how much they felt helped and supported socially is defined by how much and how well they could **discuss** their grief with their social network. In general, bereaved Chinese immigrants encounter significant barriers to successful social sharing of grief with others in their social networks. These barriers reflect the conflicts between the bereaved’s personal desire to talk about grief, and the rules governing emotions, communication styles, and relationships in the Chinese culture which forbid them to do so. Verbal discussion of one’s grief inevitably leads to inner emotional arousal, as well as outward displays of distressing emotions. Yet in a culture where emotions are considered “unhealthy”, many feel that they do not have adequate knowledge and skills to respond to their own as well as others’ emotional experiences. The most prominent theme that emerged from the participants’ narratives is the significant fear towards negative emotions among Chinese individuals. Such fear leads to avoidant behaviours in both the bereaved and those in their social networks. The bereaved themselves avoid discussing the loss for fear of experiencing and expressing negative emotions. Family and friends avoid talking as well, for fear of witnessing others’ emotional outbursts and inadvertently aggravating the bereaved due to their lack of knowledge in dealing with emotions.

Ambivalence characterizes bereaved Chinese immigrants’ experience with communicating their grief to other family members. On one hand, they express a preference for discussing grief with family. This preference is likely based on Chinese cultural norms on communication styles and relationships, which stipulate that the death of a family member, being a “private matter”, can only be discussed within one’s family. Family members, being “insiders”, are thought to provide better, more intimate social

support. Yet in reality, an in-depth, open, constructive conversation on grief with family seldom occurs. Most bereaved Chinese immigrants describe their social sharing with family as “*we never really talked about it*”, for various reasons.

Paradoxically, the “insider” status of family members is exactly what makes it so difficult to talk to them about grief. The death of a family member inevitably impacts the entire family due to blood relations or shared kinship, which means that family members may not be able to support each other effectively due to their own grief. Family relationships come with responsibilities, such as the duty to protect other family members from harm, and the duty to support and fulfill each other’s emotional needs. Bereaved Chinese immigrants are therefore reluctant to speak to family about their grief for fear of triggering more grief and perpetuating other family members’ suffering.

Some bereaved Chinese immigrants never talk about their grief with family because they could not identify a suitable “sharee”, or target for disclosure. Death affects different family members to a different extent, and bereaved Chinese immigrants have trouble identifying how others in the family genuinely feel about the loss due to a mismatch between their inner emotional experience and external emotional display. They feel confused as they “*cannot tell from the outside*” what a family member’s true level of grief is. Since they are unsure whether others share the same feelings towards the loss and will be receptive to their disclosure, they are more hesitant to discuss their emotions with others. In addition, some bereaved Chinese immigrants fail to discuss their grief with family because other family members actively avoid the topic. Some bereaved have initiated the conversation, only to receive critical, dismissive, shallow, or cliché responses in return. Bereaved Chinese immigrants who receive avoidant or negative responses from their family members struggle with the fact that kinship does not translate into emotional closeness. Negative responses from family members are particularly hurtful because they violate bereaved Chinese immigrants’ expectation that those closest to them should be the ones that provide the most comfort and support at times of difficulty. In the end, only a minority of bereaved Chinese immigrants successfully have a fruitful, supportive discussion of grief with a highly selected group of family members in one’s nuclear families.

Compared with family, social sharing of grief with friends is more rare and fraught with even more difficulties. This is because the “outsider” status of friends as defined by Chinese culture grammar necessitates both the bereaved and their friends to maintain distance from one another. Honest and open discussion of negative, private matters involving one’s family with an “outsider” is seen as a boundary violation and is associated with a higher risk of negative social consequences. Bereaved Chinese immigrants therefore report feeling more hesitant to initiate a conversation on grief with friends for fear of being seen as “selfish” by burdening others with one’s personal problems, offending others, being negatively judged, or being disliked. Friends are equally hesitant to initiate a conversation on grief because they abide by the same Chinese cultural grammar and see themselves as “outsiders” as well – it is simply socially inappropriate for an outsider to inquire about other people’s family matters. Most of the bereaved individuals who have discussed grief with friends describe it as a “shallow conversation”. By keeping the conversation brief, covert, and superficial, friends can show care and indirectly talk about highly personal topics (such as the death of a friend’s family member) while maintaining a safe personal distance. Recognizing their friends’ lack of intention for more in-depth conversation on their grief, bereaved Chinese immigrants also keep their responses shallow in order to be socially appropriate. In the end, those who managed to have an in-depth, helpful talk about grief with their friends can only do so with a highly selected group of close friends.

Traditional models of grief in Western cultures consider social sharing of grief a necessary step to overcome the loss, as it allows the bereaved to revisit the memories of the death, and confront and “work through” the intense negative emotions associated with grief (Stroebe et al., 2002). Recent research utilizing European samples in the Netherlands or local Chinese residing in Hong Kong, however, fails to find evidence to support the facilitative role of social sharing on adjustment. In Stroebe and colleagues’ (2002) longitudinal study examining psychological distress and disclosure of emotion in bereaved spouses over a course of 2 years, only a main effect of time was found, as the bereaved spouses’ level of distress and frequency of disclosure decreased over time. However, the study failed to find a link between distress and social sharing of emotions. In Chow et al.’s (2007) cross-sectional study of bereaved individuals in Hong Kong, the authors found that, contrary to the Chinese cultural rule prohibiting discussion of negative



emotions and death-related matters, 90% of the participants had shared their bereavement experiences with another person. Interestingly, bereaved individuals in Hong Kong most often shared their grief with friends and professionals (considered to be “outsiders” according to the Chinese culture) in addition to siblings (the “insiders”). When non-sharers (i.e., those participants who never disclosed their grief to anyone) were compared with those who had shared with someone, no significant between-group difference in scores on measures of depression and anxiety was found.

In the current study, combined analysis of quantitative and qualitative data suggests that among the different types of social support described by the participants, social support in the form of social sharing with family emerges as a protective factor for bereaved Chinese immigrants – bereaved Chinese immigrants who are better able to have an in-depth conversation on their grief with a wider number of family members tend to report lower scores on measures of depressive and current anxiety symptoms. Social sharing with family is also negatively associated with the initiative to seek professional help – those who report little to no discussion of grief with family members are more likely to take initiative to seek bereavement support from professionals. Methodological differences between the current study and previous studies on social sharing, such as differences in sample composition and the way “social sharing” is defined and measured, likely contribute to differences in findings. The Stroebe et al. (2002) study defined social sharing in terms of frequency of disclosure without taking into account the quality of such disclosure. Similarly, the Chow et al. (2007) study defined social sharing as a dichotomous variable (the presence versus absence of sharing), which also reflected frequency only. The current study, on the other hand, categorized participants’ experiences with social sharing based on both quality (i.e., how in-depth and supportive the disclosure has been) and the number of sharees with whom the bereaved could talk about grief. It is likely that the impact of social sharing of grief on psychological functioning depends more on the bereaved’s perception on the helpfulness of the conversation rather than the amount of talking (Bonanno & Kaltman, 2002). In addition, half of the sample of the Chow et al. (2007) study consisted of patients recruited from a community-based bereavement counselling centre. It is possible that those who are able to disclose their grief to family members may be less likely to seek professional help, thus accounting for the high frequency of disclosure to professionals rather than family members in their study. It is also likely that

the nature of interpersonal relationships in local Chinese living in their countries of origin is different from that in Chinese immigrants living in a foreign country. Immigration often leads to severance of friendships, and a number of bereaved Chinese immigrants in the current study have noted that the friendships they developed “later in life” (i.e., those they met after emigrating to Canada) are not close enough for an in-depth conversation of grief to occur. Living in a foreign country may have also drawn family members closer as they rely on each other to adjust to a new home. The increased centrality of family members as a source of support for immigrants may have contributed to the facilitative relationship between social sharing with family and psychological functioning found in the current study. Future research needs to expand its definition of social sharing to take into account the multiple dimensions of social support beyond frequency alone, particularly the perceived quality of support and the significance of various interpersonal relationships to bereaved individuals.

## **Coping Strategies in Response to Bereavement**

The current study reveals that bereaved Chinese immigrants receive little support from both their social networks and health care professionals. When bereavement is perceived to be a lonely journey in which the bereaved are the only soldiers fighting the battle, it is not surprising that bereaved Chinese immigrants’ coping strategies of choice tend to be internal and cognitive in nature, consisting of various mental activities to manage grief.

Bereaved Chinese immigrants’ quantitative responses in the Chinese-translated Jalowiec Coping Scale (JCS) reveal that they score the lowest on the Avoidance-Oriented Coping subscale, while scoring the highest on the Problem-Oriented Coping and Isolating Thoughts subscales. Yet qualitative data based on their interview responses suggest that avoidance and suppression of thought and emotions is clearly a frequently used coping strategy. The seemingly inconsistent findings between the two sets of data may have to do with how the subscales are named in the Chinese version of the JCS, as many of the names assigned for the JCS subscales are misnomers. For example, the JCS Avoidance-Oriented Coping subscale consists of unhealthy behaviours such as “eating and smoking more than usual” or “drinking to make yourself feel better”. The majority of the bereaved

Chinese immigrants in the current sample never engaged in these behaviours. Instead, their “avoidance” behaviours consist of cognitive strategies to distract themselves from negative thoughts and feelings. As a result, the JCS Avoidance-Oriented coping subscale does not tap into the same kind of avoidance behaviours displayed by bereaved Chinese immigrants. On the other hand, the JCS Isolating Thoughts subscale captures cognitive avoidance behaviours such as “putting the problem out of your mind and thinking of something else”. Consistent with their reports during the interview, bereaved Chinese immigrants do score high on this subscale.

In addition to thought and emotional suppression, bereaved Chinese immigrants report that they also cope with the death of a family member by taking solace in the fact that their loved ones had a “good death”, diverting their attention onto restoring normal activities, and reframing the loss by confronting and accepting reality, and changing their interpretations of the loss. Some of these strategies clearly reflect elements of the culturally sanctioned coping strategies in the Chinese culture, such as rationalizing death by accepting the immutable reality that the death has occurred, controlling negative thoughts and emotional arousal, or finding comfort if the circumstances surrounding the death of their loved ones meet the criteria of “good death” stipulated in the culture: a pain-free death that puts an end to everyone’s suffering, death at an old age, or having closure on unfinished business before the death. The combined analyses of quantitative and qualitative data examining possible predictors of psychological outcomes reveal that coping with death by taking solace in “good death” and reframing the loss are associated with better psychological functioning such as lower depression and anxiety scores and fewer somatic symptoms. Conversely, emotion-oriented coping as measured on the JCS (which includes behaviours such as blaming the problem on others, resigning oneself to the situation because it is hopeless, or worrying about the problem) has a negative relationship with psychological wellbeing. These findings are consistent with those in previous research. Research on post-loss growth and meaning making has found that coping styles that involve a positive reappraisal of the loss, such as identifying benefits or “silver linings” associated with the death, thinking optimistically, changing interpretation, and maintaining a sense of humour, are consistently associated with shorter, less intense grief and lower levels of depressive symptoms in bereaved individuals (Hibberd, 2013; Lobb et al., 2010; Neimeyer et al., 2006; Shear et al., 2013; Stroebe et al., 2006). It is

postulated that interpreting the loss in positive terms increases positive affect, allows the bereaved to look at the world in a new way, and protects against negative grief outcomes by preventing the development of negative and threatening views on oneself, the future, and the world (Gilles & Neimeyer, 2006; Hibberd, 2013). On the other hand, emotion-oriented coping, which includes behaviours such as venting, anxiety, and self-criticism, predicts poorer adjustment to the loss (Anderson, Marwit, Vandenberg, & Chibnall, 2005; Buckley et al., 2015; Meuser & Marwit, 2000). The ruminative quality of emotion-oriented coping is likely what is detrimental to psychological functioning; immersion and over-concentration in the negative affect associated with the loss means that the bereaved become overly past-oriented, makes it more difficult for them to reorient towards the future, focus on restoration and transition away from negative thoughts and feelings (Anderson et al., 2005).

Surprisingly, the current study fails to identify a relationship between avoidance (i.e., thought and emotion suppression) and psychological functioning, despite the qualitative finding that bereaved Chinese immigrants who engage in this coping strategy unanimously consider it unhelpful. Previous research on the impact of avoidance on grief outcomes in bereaved individuals from the Western cultures has yielded mixed results. While some research has found a strong positive relationship between avoidance and concurrent and prospective levels of grief and depression (e.g., Boelen et al., 2006), others have argued that avoidance may play a facilitative role in adjustment to loss as it helps shield the bereaved from the awareness of painful emotions (e.g., Bonanno, Keltner, Holen, & Horowitz, 1995). Yet similar to the finding in the current study, cross-cultural research on grief avoidance among bereaved spouses and parents residing in Mainland China fails to find any significant relationship between avoidance and distress, a surprising result that the authors of the study were unable to explain (Bonanno et al., 2005). There are two possible reasons for the null finding in the current study. First, as previously discussed, the mean scores in depressive and anxiety symptoms for those with concealed grief (characterized by their use of avoidance, suppression and denial to cover up intense grief) are not elevated. In fact, their scores are more similar to those with minimal or integrated grief than those with intense grief. This suggests that the quantitative measures of psychological functioning may not have accurately captured their level of distress. Second, the sample for this study was recruited via a series of radio shows specifically

devoted to the topic of bereavement. It is likely that people who are highly avoidant of reminders of their loss would have avoided the radio shows and refrained from participating in the current study. The self-selected nature of the current sample may have negatively impacted the strength of relationship between distress and avoidance in the current sample.

## **Limitations of the Current Research**

The current study aimed to study the needs, knowledge, perception, and experiences in bereavement care in a community sample of bereaved Chinese immigrants in Canada. Access to this population for participant recruitment, however, has been fraught with challenges. While the final sample size of the current study is similar to that in previous studies on ethnic minorities' needs in hospice and bereavement care that utilized qualitative methodology (e.g., Enguidanos et al., 2013; Kreling et al, 2010), the small sample size has precluded the use of more sophisticated statistical techniques that offer better control over Type I error without sacrificing power. The current research performed univariate analyses to generate hypothesis on variables (measured by quantitative questionnaires or by quantifying qualitative data) that might predict psychological outcomes and bereavement care utilization, but more research with larger samples is needed to confirm the validity of these preliminary findings. Moreover, the participants in the current sample are predominantly female, making it difficult to explore possible gender differences. It is important for future research to examine how the interface between culture and gender (e.g., cultural beliefs and assumptions on how different genders should express emotions and cope with bereavement) may influence grief experiences, help-seeking behaviours, and the needs for bereavement support services in males versus females.

Some may find the age of the data for the current study concerning, and wonder if findings from the current study are still relevant to the current practice of bereavement care for Chinese immigrants in Canada. A review of recent literature on the delivery of bereavement care in Canada and ethnic disparities in access and utilization, however, suggests that the barriers to access for bereaved Chinese immigrants continue to exist, and may have even worsened due to funding cuts, termination of services and staff in

palliative care, and a push for home death rather than in-hospital support or hospice care (e.g., Lang et al., 2015). The current findings may actually have been an *underestimate* of bereaved Chinese immigrants' current level of suffering and difficulties with health care access.

One of the strengths of the current study is the use of Chinese-translated instruments on psychological functioning with known psychometric properties and validated norms. However, this also implies that the type of constructs that can be studied depends on the availability of instruments in the participants' country of origin. An example is the measurement of grief. At the time of data collection, no well-designed measure of grief in Chinese was available. The only instrument available was brief and measured depressive and anxiety symptomatology rather than grief (Tsui, 2005). The Chinese translated version of Inventory of Complicated Grief, the most widely used instrument in the measurement of grief, was not published until 2016. The current study measured grief by categorizing bereaved Chinese immigrants' grief experiences based on their self-report during the interviews, but the method remained crude. Nevertheless, the current study has suggested possible patterns of grief experiences in bereaved Chinese immigrants that can be verified by quantitative assessment of grief in future research.

Finally, even though the current study reveals that a high number of bereaved Chinese immigrants score above the clinical cut-offs on measures of depressive symptoms and anxiety, the cross-sectional design of the study implies a lack of measurement of baseline functioning prior to loss. It is therefore possible that the mood and anxiety symptoms precede the loss, making it difficult to clarify the relationship between bereavement and psychological functioning in the current sample. The majority of participants did report that their symptoms developed after bereavement, and those who were already under the care of a mental health professional noted that grief exacerbated their pre-existing symptoms. There is however a risk of recall bias. Research using a prospective design is desperately needed in order to better understand the impact of bereavement on psychological wellbeing in this population.

## Clinical Implications and Future Research Directions

*Bereavement care.....to me it is an essential service.*

~ Participant K

A participant of the current study considers bereavement care an “essential service” in health care due to the universality of the experience of losing a loved one, and the suffering this experience can bring to a significant portion of people in the population. Bereaved Chinese immigrants unanimously agree that their ethnic community has an enormous need for bereavement care services. They recognize that the death of one person can have a ripple effect that impacts everyone in his or her social network. By sharing their experiences in the current study, they hope to raise awareness on the lack of support for bereaved ethnic minorities and NESB immigrants, to dispel the myth that their underutilization of bereavement care services reflects a lack of need, and to speak out on behalf of those who are isolated and suffering silently.

The five guiding principles underlying the Canada Health Act form the foundation of the Canadian health care system. One of the principles is the principle of accessibility, which stipulates that access to necessary health services is a right of every Canadian, and must not be impeded by financial or other barriers (*Canada Health Act, 1985*). In reality, however, equity to health care use remains elusive. A number of populations continue to be underserved due to demographic and socioeconomic factors. The access to bereavement care by bereaved Chinese immigrants living in Canada is a prime example that illustrates the multiple barriers many ethnic minority groups and NESB immigrants encounter as they navigate the Canadian health care system.

A multifaceted problem requires a multifaceted solution. Changes on a system level, health care practitioner / researcher level, and health care user level must occur to address the ethnic disparity in access to bereavement care and to facilitate future research on the optimal delivery of bereavement care services to ethnic minorities and immigrants.

## Health Care System Level

It is obvious that a number of problems bereaved Chinese immigrants encounter with bereavement care access have to do with the poor delivery of bereavement care in general. A service that is fragmented, non-standardized, under-funded, and seen as optional rather than essential will not be able to provide quality care to anyone who needs it, regardless of ethnic or cultural backgrounds. Special groups such as ethnic minorities and NESB immigrants, who tend to encounter more barriers due to cultural, immigration-related, and health care system factors, require extra effort, resources and accommodations from the health care system to facilitate their health care access and utilization. Their special needs, however, cannot be effectively met by a system that is already strained. Constraints in the health care system will only lead to even more suboptimal services for this population. Policy changes on a system level are necessary.

The current delivery of bereavement care in Canada suffers from a lack of organization, standardization and coordinated care. Bereavement care practices can range from public education to specialist interventions for those with severe grief and mental health issues. What constitutes bereavement care also differs across programs, health care facilities, health regions, and provinces. There have been recent initiatives to develop guidelines and recommendations on the delivery of bereavement care, but they tend to be disease- or province-specific (e.g., BC Guidelines and Protocol Advisory Committee, 2017; BC Provincial Renal Agency's End-of-Life Working Group, 2009). There is an urgent need to develop national practice standards and models of service suitable for the Canadian environment.

Current research recognizes that different needs exist among bereaved persons, and not everyone requires therapeutic support. Providing blanket bereavement interventions (e.g., grief therapy) to everyone irrespective of needs is ineffective and economically infeasible, and may even cause iatrogenic harm (Schut & Stroebe, 2005; Sealey, Breen, O'Connor, & Aoun, 2015). A tiered public health approach to bereavement support has been proposed in the literature, in which three levels of intervention are provided according to the bereavement needs of family members (Aoun, Breen, O'Connor, Rumbold, & Nordstrom, 2012). The first level of interventions consists of universal, primary prevention efforts that target all bereaved persons, such as education



and the provision of information on grief, loss, and available services. The second level is secondary prevention, which involves selective non-specialist support such as mutual help groups, volunteer support, and peer and community support that can be offered by the voluntary sector and targets individuals at risk of developing complications of bereavement. Processes are also in place for making referrals to appropriate professionals (Costello, 2012). The top tier consists of professional interventions such as grief therapy and mental health services for symptomatic individuals with high level or complex needs (Aoun et al., 2012). This approach to service delivery has been incorporated into the practice guidelines for bereavement care in the United Kingdom and may be adopted for use in the Canadian context (National Institute for Clinical Excellence, 2004).

The public health model to bereavement care is comprehensive, and helps provide an organizational framework for categorizing the large variety of services currently provided across Canada that fall under the umbrella of “bereavement care”. It allows for better standardization of care delivery while retaining flexibility for local needs (Calanzani et al., 2013). Different provinces or health care organizations, for instance, can use the same model of care to guide the development of services at each level of intervention that are specific to their individual needs. The approach is prevention-focused rather than cure-focused; public education, health promotion, and information support are integrated into universal, standard services for all bereaved individuals (BC Centre for Palliative Care, 2015). Providing services that are tailored to the needs of bereaved family members can lead to better quality of care and more efficient use of health care resources (Sealey et al., 2015). This framework also helps guide research examining the various bereavement needs of ethnic minorities and NESB immigrants according to levels of intervention, comparing them across cultures, and evaluating which bereavement practices best match their needs.

Bereavement care has been called the “poor sister to clinical medical care” and a marginal activity in the area of palliative care, because it is often seen as irrelevant to direct patient care (Field et al., 2004, p. 575). Instead of funding services from the overall budget for palliative care, specialized funding needs to be dedicated to bereavement care, so that surviving family members do not need to wait until they become patients

themselves before services can be provided. Dedicated funding helps attract and retain professionals involved or are interested in providing bereavement care by ensuring that they are properly remunerated for their work. It also allows for the establishment of specialized bereavement programs within health care facilities to provide centralized and coordinated bereavement care across different clinical units. The responsibility of providing bereavement care can then be transferred from voluntary, non-profit organizations (which support these services by relying on volunteers and donations) back to the health care system. A portion of the funding for bereavement care should be reserved for education and primary prevention efforts, and the development of programs and resources (e.g., written materials translated to different languages, training of interpreters) at a national level to better accommodate the needs of ethnic and language minorities, immigrants, and other underserved populations. This helps ensure that direct patient care needs not come at the expense of public health initiatives and culturally sensitive practice.

## **Health Care Practitioner Level**

The increasing diversity in the Canadian population implies that cross-cultural bereavement care is the rule rather than the exception. Cultural competence has become an integral part of professional practice in health care. There is a need to increase the ethnocultural and linguistic diversity of health care professionals to reflect the cultural diversity of the community served (Chiarenza, 2012). This is particularly important given bereaved Chinese immigrants' observation of the lack of non-Caucasian health care professionals working in palliative care, and their unmet need to work with "one of us". The availability of a diverse health care staff can encourage access and utilization of bereavement care services by ethnic minorities and immigrants (Reese & Beckwith, 2015).

There is also a need for better training on cultural competence for staff working in end-of-life and bereavement care, with the goal of fostering both specific (i.e., a working knowledge of values, norms and health practices pertaining to a specific cultural group) and general cultural competency (i.e., a set of beliefs, knowledge and skills that enables effective work in any cross-cultural clinical encounter; Fitzgerald, 2000). Cultural-specific knowledge is necessary to guide the day-to-day practice of culturally competent

bereavement care. It informs professionals on how to understand and appropriately respond to a specific patient's behaviour in the context of his or her culture (Sue, 2006). Such knowledge may include understanding the cultural grammar around health, death, emotions, relationships and communication styles, and knowing what culturally appropriate services and resources (e.g., brochures written in the bereaved's preferred language, bereavement services provided in languages other than English) are available in the health care facility or in the community for a specific ethnic group, and ways to facilitate access. On the other hand, general cultural competency enables professionals to develop knowledge and skills for culturally appropriate practices across various cultures, ethnicities, genders, age groups, and linguistic groups, such as improving communication and problem-solving skills, or becoming more self-aware on personal and professional cultural values and biases (Fitzgerald, 2000; Sue, 2006). Professionals possessing both general and specific cultural competency will have the skills to "dynamic size", or knowing when to generalize and when to focus on the individual when working with ethnically diverse patients (Sue, 2006).

## **Researcher Level**

Evidence-based and theory-driven practice of bereavement care for ethnic minority and NESB immigrants is difficult when theories in grief, loss, and bereavement tend to reflect views, beliefs, and values in the Western culture, and when the bulk of research findings come from predominantly Caucasian, English-speaking samples. Even the research methodology (e.g., the variables of interest or modes of inquiry) may reflect the values and practices of an independent and individualistic culture that may not be identified by ethnic minorities and immigrants.

More research on the grief experiences of bereaved ethnic minorities and immigrants is urgently needed, as the current study suggests that previous research findings on bereavement outcomes, factors related to the adjustment to loss, and mediator and moderator variables may not be directly generalizable to ethnic minorities and NESB immigrants. Researchers need to become more aware of the effects of excluding ethnic and language minorities from bereavement research. Future research needs to routinely include ethnicity as a variable in data collection, data analysis, and reporting of results.

New, creative approaches are also needed to overcome the methodological challenges in conducting research with special populations who may not be familiar or receptive to participation in research. For instance, the current study suggests that traditional ways of recruiting participants, such as recruitment posters or letters of invitation, may not work equally well in populations that are unfamiliar with the research process or reluctant to disclose personal information until a relationship is established. The use of “ethnic media” (i.e., media operated by and catering to the cultural and linguistic needs of a particular ethnic group) helps provide access to a population that is typically hard to reach and is underrepresented in research and in treatment settings. It also provides a more personal, intimate approach to participant recruitment. Hearing the researcher’s voice on radio and having the justification, purposes and objectives of a research study clearly explained in the native language of potential participants often help dispel misconceptions and alleviate fear. Advances in medical and psychological research conducted outside North America mean that translated and validated measures of psychological and health care variables are more widely available as well. This helps remove language barriers that previously barred individuals with limited English fluency from participating in bereavement research.

The current study also cautions against the direct generalization of research findings based on local Chinese living in Asia to first-generation Chinese immigrants living in Canada, simply on the basis that both groups share the same racial background. The process of acculturation suggests that while immigrants may continue to retain heritage cultural values on some domains, they can be totally different from the counterparts in their countries of origin in other respects. The current study suggests that certain behaviours, such as social sharing of grief, may hold different meanings for immigrants due to differences in interpersonal relationships, living environments, and types of stressors encountered. Researchers need to recognize immigrants as a unique population rather as an extension of the population “back home”.

Research on ethnic disparities in bereavement care access and utilization needs to move beyond descriptive studies documenting patterns of service use or outcomes, and begin to study whether and how disparities and other predictors of health are associated with different outcomes. The current study, despite being largely descriptive in nature, attempts to identify possible variables that may be important to bereavement

outcomes in Chinese immigrants, such as verbal social support and the use of cognitive reappraisal versus emotion-oriented coping to manage grief. Clearly, more research using larger samples and more sophisticated statistical techniques beyond univariate analyses with corrected alpha values will enable more complex relationships to be tested with adequate statistical power. There is also a need for more research that directly solicits ethnic minorities and immigrants to provide their perspectives on their needs, rather than reporting professionals' perceptions of what these groups need. Utilizing a mixed methods research design allows for the documentation of individual views in a rich narrative, while at the same time provides numerical findings that can be subject to statistical analysis. Finally, cross-cultural bereavement practice will benefit from research examining what therapeutic strategies are considered culturally appropriate, and whether techniques and interventions commonly used in bereavement care, such as provision of written materials or emotion-focused grief therapies, are equally efficacious and well-received in other populations.

### **Addressing Service Needs at the Health Care User Level**

Recognizing their unmet need for information as the biggest barrier preventing them from utilizing bereavement care, bereaved Chinese immigrants consider education as the key to remove barriers in access and improve utilization of bereavement care in their population.

Bereaved Chinese immigrants believe that while not everyone needs therapeutic-focused bereavement interventions, all bereaved individuals should have equal access to information support. This is consistent with the public health approach to bereavement care, which includes provision of information in its first tier of bereavement services that target all bereaved persons. This is also consistent with recommendations from bereavement research and practice guidelines, which suggest that professionals have a duty of care to provide information on the availability of bereavement support in order to ensure that bereavement care services are accessible to all bereaved people (Agnew et al., 2010; Agnew et al., 2011).

Education for bereaved Chinese immigrants likely needs to even be more comprehensive and extensive due to their marked deficit in health-related knowledge. It has to start from the basics and cover a wider variety of topics ranging from the nature of grief, to its impact on physical, psychological, social and occupational functioning, ways to identify, describe and express emotions, ways to cope with loss, ways to detect whether normal grief has taken a turn for the worse, the existence, nature and purpose of bereavement support, types of services available in the community, and the routes to take to seek help.

Education for bereaved Chinese immigrants needs to take the form of both primary and secondary prevention efforts. With regards to primary prevention, the entire local Chinese community (regardless of bereavement status) will benefit from increased public education initiatives on bereavement care that take place outside the walls of health care facilities. Many bereaved Chinese immigrants in the current study highlighted the power of promoting bereavement care through local Chinese media and local immigrant support organizations such as SUCCESS. Combining promotional and educational efforts on bereavement care with other health promotion activities (such as doing a presentation on grief and bereavement care as part of a “health fair” for the Chinese community with speakers talking about other health-related topics) helps normalize and destigmatize grief and death. Learning more about grief and bereavement care services before bereavement occurs allows Chinese immigrants to feel more prepared for the loss, and equips them with the knowledge and skills to recognize symptoms and seek help in a timely way when necessary.

With regards to secondary prevention, bereaved Chinese immigrants urge for more consistent provision of pre-bereavement care that involve assessing needs, detecting those at risk for developing complicated grief and mental health issues, educating them on grief and bereavement care, and providing information on available resources for those facing the impending death of a family member. The best time to catch and provide information to family members is before patient death occurs, when family members or caregivers are still physically present in the health care facilities or have regular interactions with health care professionals. Speaking to them before the actual death occurs means that family members are more likely to retain the information

provided. There is also a need to provide information in the form of something tangible that one can hold onto and take home, such as brochures on grief and available services written in one's native language, or fridge magnets with phone numbers. These serve as important "memory aids" to remind bereaved Chinese immigrants that help exists even after they have left the hospital.

Bereaved Chinese immigrants are dissatisfied with the inconsistent delivery of bereavement follow-up care in the health care system, which ranges from non-existent to random, untimely, and brief follow-up attempts by health care professionals. They need to be educated about the existence and purpose of follow-up support, so that follow-up contact will not seem unexpected or be misinterpreted. They also expressed a desire for more frequent and multiple follow-up contacts that continue for a longer period of time. Due to their delayed realization of grief and the need for support, bereaved Chinese immigrants urge professionals "not to take no for an answer", that is, not to take their initial refusal or lack of interest as a sign that they are adjusting well and do not require professional support. Only if follow-up continues at regular intervals will health care professionals be able to detect those in need.

Bereaved Chinese immigrants have also called for professionals to play a leading role in initiating bereavement services and providing more outreach. Ethnic minorities and NESB immigrants, facing numerous barriers to initiate help seeking, often depend on health care providers to recognize their needs, offer education on available services, or provide referrals (Kimbrough, 2007). As a result, bereaved Chinese immigrants rely on health care professionals to "make the first move". Recent research has called into question whether the "opt-in" approach to provide bereavement care (i.e., care is patient-initiated, and is only provided to those who requested help) adequately meets the needs of surviving family members, as many urge professionals to take a more proactive role in motivating them to seek help (Tabler et al., 2015). Jordan and Neimeyer (2003) observe that there is a group of bereaved persons (whom they called "hermits") who are not improving with the passage of time and informal social support, but are also reluctant or unable to access professional help. Many bereaved Chinese immigrants likely fit their definition of "hermits". For this group of mourners, practitioner-initiated outreach efforts rather than self-referral are necessary to address their needs (Bergman et al., 2011;

Jordan & Neimeyer, 2003). Professionals need to take the lead in reaching out, initiating a conversation about grief, encouraging the bereaved to get help, and providing explicit instructions and guidance on the routes to take to access services.

In addition to information support, bereaved Chinese immigrants report a need for emotional support. While they believe that conversations on death and emotions should be initiated by professionals, at the same time they recognize that it can be difficult to have a dialogue with a population that is aversive to these topics. Experience from professionals offering bereavement care in Hong Kong suggests that they need to access emotions in an indirect manner in order to prevent treatment attrition. Professionals therefore need to be very tactful and implicit in their approach.

One way to provide therapeutic support on emotions without triggering fear and resistance in bereaved Chinese immigrants is by using treatment modalities that are consistent with their needs and cultural values. To bereaved Chinese immigrants, emotional support does not only entail emotional catharsis. A closer examination of their definition for emotional support reveals a strong need for education, as they articulate a desire to learn more about mental health and ways to identify and express emotion. Consistent with the cultural emphasis on practicality, utility, and self-reliance, bereaved Chinese immigrants also express a desire to learn pragmatic strategies they can apply in real life to manage behaviours and emotions. Given their belief that bereavement care is only effective if offered by experts, bereaved Chinese immigrants may be more receptive to a more directive approach in therapy, during which a professional plays a more active role by offering advice, guidance, and / or recommendations. The current study also finds that the use of cognitive reappraisal as a coping strategy is associated with better outcomes for bereaved Chinese immigrants. Taken altogether, cognitive-behavioural approaches, with their emphasis on psychoeducation, practical behavioral strategies and cognitive restructuring (a technique to identify, challenge and modify negative thought patterns and maladaptive interpretation of events), may be particularly appropriate for bereaved Chinese immigrants who need therapeutically focused bereavement interventions.



Finally, bereaved Chinese immigrants appreciate the extra time and patience from professionals when working with them, given the multiple barriers in the Chinese culture that are incompatible with bereavement care delivery. They believe that health literacy and lasting changes in attitudes towards death, palliative care, and bereavement care can be fostered by “slow, silent, unobtrusive and inconspicuous” efforts. This highlights the need for continuity of care and the cultivation of a relationship with family members that begins prior to death. Extended contact allows for the development of trust and familiarity, which are prerequisite conditions for bereaved Chinese to overcome the cultural rules forbidding them from disclosing private matters and emotional difficulties to an outsider, and the shame and stigma associated with negative emotions and help-seeking.

## References

- Abbe, M., Simon, C., Angiolillo, A., Ruccione, K., & Kodish, E. D. (2006). A survey of language barriers from the perspective of pediatric oncologists, interpreters, and parents. *Pediatric Blood & Cancer*, *47*, 819-824.
- Ackroyd, R. (2003). Audit of referrals to a hospital palliative care team: Role of the bilingual health-care worker. *International Journal of Palliative Nursing*, *9*, 352-357.
- Agnew, A., Manktelow, R., Taylor, B. J., & Jones, L. (2010). Bereavement needs assessment in specialist palliative care: A review of the literature. *Palliative Medicine*, *24*, 46-59. doi:10.1177/0269216309107013
- Agnew, A., Manktelow, R., Taylor, B. J., & Jones, L. (2011). Bereavement assessment practice in hospice settings: Challenges for palliative care social workers. *British Journal of Social Work*, *41*, 111-130. doi:10.1093/bjsw/bcq055
- Anderson, M. J., Marwit, S. J., Vandenberg, B., & Chibnall, J. T. (2005). Psychological and religious coping strategies of mothers bereaved by the sudden death of a child. *Death Studies*, *29*, 811-826.
- Aoun, S. M., Breen, L. J., Howting, D. A., Rumbold, B., McNamara, B., & Hegney, D. (2015). Who needs bereavement support? A population based survey of bereavement risk and support need. *PLoS One*, *10*, e0121101. doi: 10.1371/journal.pone.0121101
- Aoun, S. M., Breen, L. J., O'Connor, M., Rumbold, B., & Nordstrom, C. (2012). A public health approach to bereavement support services in palliative care. *Australian and New Zealand Journal of Public Health*, *36*, 14-16.
- Arriaza, P., Martin, S. S., & Csikai, E. L. (2011). An assessment of hospice bereavement programs for Hispanics. *Journal of Social Work in End-of-Life and Palliative Care*, *7*, 121-138. doi:10.1080/15524256.2011.593151
- Ashing-Giwa, K., & Kagawa-Singer, M. (2006). Infusing culture into oncology research on quality of life. *Oncology Nursing Forum*, *33*, 31-36.
- Assareh, A. A., Sharpley, C. F., McFarlane, J. R., & Sachdev, P. S. (2015). Biological determinants of depression following bereavement. *Neuroscience and Biobehavioral Reviews*, *49*, 171-181. doi:10.1016/j.neubiorev.2014.12.013
- Bahl, V. (1996). Cancer and ethnic minorities – The Department of Health's perspective. *The British Journal of Cancer*, *29*, S2-10.

- Barnes, D. M., Davis, A. J., Moran, T., Portillo, C. J., & Koenig, B. A. (1998). Informed consent in a multicultural cancer patient population: Implications for nursing practice. *Nursing Ethics*, 5, 412-423.
- Barrera, M., D'Agostino, N. M., Schneiderman, G., Tallett, S., Spencer, L., & Jovcevska, V. (2007). Patterns of parental bereavement following the loss of a child and related factors. *Omega*, 55, 145-167.
- Barry, C. L., Carlson, M. D., Thompson, J. W., Schlesinger, M., McCorkle, R., Kasl, S. V., & Bradley, E. H. (2012). Caring for grieving family members: Results from a national hospice survey. *Medical Care*, 50, 578-584.  
doi:10.1097/MLR.0b013e318248661d.
- BC Centre for Palliative Care (2015). *The public health approach to palliative care; Principles, models, and international perspectives*. Retrieved from BC Centre for Palliative Care website: <http://www.bc-cpc.ca/cpc/palliative-care-is-a-public-health-issue/>
- BC Guidelines and Protocols Advisory Committee (2017). *Palliative care for the patient with incurable cancer or advanced disease part 3: Grief and bereavement*. Retrieved from the BC Guidelines website: <http://www2.gov.bc.ca/gov/content/health/practitioner-professional-resources/bc-guidelines/palliative-grief-and-bereavement>
- BC Provincial Renal Agency's End-of-Life Working Group (2009). *End-of-life framework: Recommendations for a provincial EOL strategy*. Retrieved from the BC Renal Agency website: [www.health.gov.bc.ca/library/publications/year/2006/framework.pdf](http://www.health.gov.bc.ca/library/publications/year/2006/framework.pdf)
- Beatty, D. D. (2015). Approaches to death and dying: A cultural comparison of Turkey and the United States. *Omega*, 70, 301-316. doi:10.1177/0030222815568962
- Bergman, E. J., Haley, W. E., & Small, B. J. (2011). Who uses bereavement services? An examination of service use by bereaved dementia caregivers. *Aging and Mental Health*, 4, 531-530.
- Berrett-Abebe, J., Levin-Russman, E., Gioiella, M. E., & Adams, J. M. (2017). Parental experiences with a hospital-based bereavement program following the loss of a child to cancer. *Palliative and Supportive Care*, 15, 348-358.  
doi:10.1017/S1478951516000821.
- Billings, J. A., & Kolton, E. (1999). Family satisfaction and bereavement care following death in the hospital. *Journal of Palliative Medicine*, 2, 33-49.  
doi:10.1089/jpm.1999.2.33
- Billups, F. D. (2014). Trustworthiness and the quest for rigor in qualitative research. *The NERA Researcher*, 52, 10-14.

- Blevins, D., & Papadatou, D. (2006). The effects of culture in end-of-life situations. In *Psychosocial issues near the end of life: A resource for professional care providers*. (pp. 27-55). Washington, DC, US: American Psychological Association.
- Boeije, H. (2002). A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Quality and Quantity*, *36*, 391-409.
- Boelen, P. A., de Keijser, J., van den Hout, M. A., & van den Bout, J. Treatment of complicated grief: A comparison between cognitive-behavioural therapy and supportive counselling. *Journal of Consulting and Clinical Psychology*, *75*, 277-284.
- Boelen, P. A., van den Bout, J., & van den Bout, M. A. (2006). Negative cognitions and avoidance in emotional problems after bereavement: A prospective study. *Behaviour Research and Therapy*, *44*, 1657-1672.
- Bonanno, G. A., & Kaltman, S. (1999). Toward an integrative perspective on bereavement. *Psychological Bulletin*, *125*, 760-776.
- Bonanno, G. A., & Kaltman, S. (2001). The varieties of grief experience. *Clinical Psychology Review*, *21*, 705-734.
- Bonanno, G. A., Keltner, D., Holen, A., & Horowitz, M. J. (1995). When avoiding unpleasant emotion might not be such a bad thing: Verbal-autonomic response dissociation and midlife conjugal bereavement. *Journal of Personality and Social Psychology*, *68*, 975-989.
- Bonanno, G. A., Papa, A., Lalande, K., Zhang, N., & Noll, J. G. (2005). Grief processing and deliberate grief avoidance: A prospective comparison of bereaved spouses and parents in the United States and the People's Republic of China. *Journal of Consulting and Clinical Psychology*, *73*, 86-98.
- Bonanno, G. A., Papa, A., & O'Neill, K. (2001). Loss and human resilience. *Applied and Preventive Psychology*, *10*, 193-206.
- Bonanno, G. A., Wortman, C. B., Lehman, D., Tweed, R., Haring, M., Sonnega, J.,...Nesse, R. M. (2002). Resilience to loss, chronic grief, and their pre-bereavement predictors. *Journal of Personality and Social Psychology*, *83*, 1150-1164.
- Boykin, A., Schoenhofer, S., & Valentine, K. (2014). *Health care system transformation for nursing and health care leaders: Implementing a culture of caring*. New York, NY: Springer.
- Braun, K. L., & Nichols, R. (1997). Death and dying in four Asian American cultures: A descriptive study. *Death Studies*, *21*, 327-359.

- Breen, L. J., Aoun, S. M., O'Connor, M., & Rumbold, B. (2014). Bridging the gaps in palliative care bereavement support: An international perspective. *Death Studies*, 38, 54-61. doi:10.1080/07481187.2012.725451
- Bucaro, P. J., Asher, L. M., & Curry, D. M. (2005). Bereavement care: One children's hospital's compassionate plan for parents and families. *Journal of Emergency Nursing*, 31, 305-308.
- Buckley, T., Spinaze, M., Bartrop, R., McKinley, S., Whitfield, V., Havyatt, J.,...Tofler, G. (2015). The nature of death, coping response and intensity of bereavement following death in the critical care environment. *Australian Critical Care*, 28, 64-70.
- Buckley, T., Sunari, D., Marshall, A., Bartrop, R., McKinley, S., & Tofler, G. (2012). Physiological correlates of bereavement and the impact of bereavement interventions. *Dialogues in Clinical Neuroscience*, 14, 129-139.
- Buppert, C. (2015). After a patient dies, should I have contact with family members? *Medscape*. Retrieved from: [http://www.medscape.com/viewarticle/839984\\_3](http://www.medscape.com/viewarticle/839984_3)
- Burton, C. L., Yan, O. H., Pat-Horenczyk, R., Chan, I. S., Ho, S., & Bonanno, G. A. (2012). Coping flexibility and complicated grief: A comparison of American and Chinese samples. *Depression and Anxiety*, 29, 16-22.
- Calanzani, N., Koffman, J., & Higginson, I. J. (2013). *Palliative and end of life care for black, Asian and minority ethnic groups in the UK: Demographic profile and the current state of palliative and end of life care provision*. Retrieved from Marie Curie Cancer Care website: [https://www.mariecurie.org.uk/globalassets/media/documents/who-we-are/diversity-and-inclusion-research/palliative-care-bame\\_full-report.pdf](https://www.mariecurie.org.uk/globalassets/media/documents/who-we-are/diversity-and-inclusion-research/palliative-care-bame_full-report.pdf)
- Canada Health Act (1985, c. C-6). Retrieved from the Justice Laws Website: <http://laws-lois.justice.gc.ca/eng/acts/c-6/FullText.html>
- Canadian Cancer Society (2015). *Right to care: Palliative care for all Canadians*. Retrieved from Canadian Cancer Society's website: <https://www.cancer.ca/~media/cancer.ca/CW/get%20involved/take%20action/Palliative-care-report-2016-EN.pdf>
- Canadian Hospice Palliative Care Association (2013). *A model to guide hospice palliative care: Based on national principles and norms of practice*. Retrieved from Canadian Hospice Palliative Care Association website: <http://www.chpca.net/media/319547/norms-of-practice-eng-web.pdf>
- Canadian Institute for Health Information (2007). *Health care use at the end of life in western Canada*. Ottawa: CIHI.

- Carr, D. (2008). Factors that influence late-life bereavement: Considering data from the Changing Lives of Older Couples study. In M. S. Stroebe, R. O. Hansson, H. Schut, & W. Stroebe (Eds.), *Handbook of bereavement research and practice: Advances in theory and intervention* (pp. 417-440). Washington, DC: American Psychological Association.
- Carr, D., & Jeffreys, J. S. (2011). Spousal bereavement in later life. In R. A. Neimeyer, D. L. Harris, H. R. Winokuer, & G. F. Thornton (Eds.), *Grief and bereavement in contemporary society: Bridging research and practice* (pp. 81-92). New York, NY: Routledge.
- Carstairs, S. (2010). *Raising the bar: A roadmap for the future of palliative care in Canada*. Ottawa, ON: The Senate of Canada. Retrieved from: [http://www.chpca.net/media/7859/Raising\\_the\\_Bar\\_June\\_2010.pdf](http://www.chpca.net/media/7859/Raising_the_Bar_June_2010.pdf)
- Chan, C., Ho, P. S. Y., & Chow, E. (2001). A body-mind-spirit model in health: An Eastern Approach. *Social Work in Health Care, 34*, 261-282.
- Chan, C. L. W. (2005). Bereavement and palliative care in China. *International Journal of Palliative Nursing, 11*, 631-631.
- Chan, C. L. W., & Chow, A. Y. M. (2006). *Death, dying and bereavement: A Hong Kong Chinese experience*. Hong Kong: Hong Kong University Press.
- Chan, C. L. W., Chow, A. Y. M., Ho, S. M. Y., Tsui, Y. K. Y., Tin, A. F., Koo, B. W. K., & Koo, E. W. K. (2005). The experience of Chinese bereaved persons: A preliminary study of meaning making and continuing bonds. *Death Studies, 29*, 923-947.
- Chan, C. W. H., & Chang, A. M. (2000). Experience of palliative home care according to caregivers' and patients' ages in Hong Kong Chinese people. *Oncology Nursing Forum, 27*, 1601-1605.
- Chan, H. Y. L., Lee, L. H., & Chan, C. W. H. (2013). The perceptions and experiences of nurses and bereaved families towards bereavement care in an oncology unit. *Supportive Care in Cancer, 21*, 1551-1556. doi:10.1007/s00520-012-1692-4
- Chan, M. F., Lou, F. L., Arthur, D. G., Cao, F. L., Wu, L. H., Li, P.,...Lui, L. (2008). Investigating factors associate to nurses' attitudes towards perinatal bereavement care. *Journal of Clinical Nursing, 17*, 509-518.
- Chan, W. C. H., & Chan, C. L. W. (2011). Acceptance of spousal death: The factor of time in bereaved older adults' search for meaning. *Death Studies, 35*, 147-162. doi:10.1080/07481187.2010.535387
- Chaplin, D. (2003). A bereavement care service to address multicultural user needs. *Nursing Times, 99*, 26-29.

- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London: Sage.
- Chau, N. G., Zimmerman, C., Ma, C., Taback, N., & Krzyzanowska, M. K. (2009). Bereavement practices of physicians in oncology and palliative care. *Archive of Internal Medicine*, *169*, 963-971.
- Cherlin, E. J., Barry, C. L., Prigerson, H. G., Schulman-Green, D., Johnson-Hurzeler, R., Kasl, S. V., & Bradley, E. H. (2007). Bereavement services for family caregivers: How often used, why, and why not. *Journal of Palliative Medicine*, *10*, 148-158. doi:10.1089/jpm.2006.0108
- Chi, I., & Boey, K. W. (1993). Hong Kong validation of measuring instruments of mental health status of the elderly. *Clinical Gerontologist*, *13*, 35-51.
- Chiarenza, A. (2012). Developments in the concept of "cultural competence". In D. Ingleby, A. Chiarenza, W. Deville, & I. Kotsioni (Eds.), *Inequalities in health care for migrants and ethnic minorities* (pp. 66-81). Antwerp, Belgium: Garant.
- Chiu, C.-Y., & Hong, Y.-Y. (2006). *Social psychology of culture*. New York, NY: Psychology Press.
- Chiu, Y. W., Yin, S. M., Hsieh, H. Y., Wu, W. C., Chuang, H. Y., & Huang, C. T. (2011). Bereaved females are more likely to suffer from mood problems even if they do not meet the criteria for prolonged grief. *Psycho-Oncology*, *20*, 1061-1068. doi:10.1002/pon.1811
- Chow, A. Y. M., Chan, C. L. W., & Ho, S. M. Y. (2007). Social sharing of bereavement experience by Chinese bereaved persons in Hong Kong. *Death Studies*, *31*, 601-618.
- Christ, G.H., Bonanno, G., Malkinson, R. & Rubin, S. (2003). Bereavement experiences after the death of a child. In M. J. Field & R. E. Behrman (Eds.), *When children die: Improving palliative and end-of-life for children and their families*. Washington, DC: The National Academies Press.
- Clements, P. T., Vigil, G. J., Manno, M. S., Henry, G. C., Wilks, J., Das, S.,...Foster, W. (2003). Cultural perspectives of death, grief, and bereavement. *Journal of Psychosocial Nursing and Mental Health Services*, *41*, 18-26.
- Cochran, W. G. (1954). Some methods of strengthening the common chi-square tests. *Biometrics*, *10*, 417-451.
- Cohen, L. L. (2008). Racial/ethnic disparities in hospice care: A systematic review. *Journal of Palliative Medicine*, *11*, 763-768. doi:10.1089/jpm.2007.0216

- Contro, N., Larson, J., Scofield, S., Sourkes, B., & Cohen, H. (2002). Family perspectives on the quality of pediatric palliative care. *Archives of Pediatrics and Adolescent Medicine*, *156*, 14-19.
- Corbin, J., & Strauss, A. (1990). Grounded theory research: Procedures, canons and evaluative criteria. *Zeitschrift für Soziologie*, *19*, 418-427.
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Thousand Oaks, CA: Sage.
- Costello, J. (2012). End of life care and bereavement. In P. Wimpenny & J. Costello (Eds.), *Grief, loss and bereavement: Evidence and practice for health and social care practitioners*. New York, NY: Routledge.
- Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, CA: Sage.
- Creswell, J. W., & Plano Clark, V. L. (2011). *Designing and conducting mixed methods research* (2nd ed.). Thousand Oaks, CA: Sage.
- Crooks, V. (2009). *A timeline of palliative care policy and practice in British Columbia, Canada*. Retrieved from Canadian Virtual Hospice's website: [http://www.portailpalliatif.ca/Assets/Timeline%20of%20Palliative%20Care%20in%20British%20Columbia\\_Report\\_Crooks\\_2009\\_20120709112317.pdf](http://www.portailpalliatif.ca/Assets/Timeline%20of%20Palliative%20Care%20in%20British%20Columbia_Report_Crooks_2009_20120709112317.pdf)
- Currier, J. M., Holland, J. M., & Neimeyer, R. A. (2009). Assumptive worldviews and problematic reactions to bereavement. *Journal of Loss and Trauma*, *14*, 181-195.
- Currier, J. M., Neimeyer, R. A., & Berman, J. S. (2008). The effectiveness of psychotherapeutic interventions for bereaved persons: A comprehensive quantitative review. *Psychological Bulletin*, *134*, 648-661.
- D'Agostino, N. M., Berlin-Romalis, D., Jovcevska, V., & Barrera, M. (2008). Bereaved parents' perspectives on their needs. *Palliative and Supportive Care*, *6*, 33-41.
- Davies, B., Sehring, S. A., Partridge, J. C., Cooper, B. A., Hughes, A., Philp, J. C.,...Kramer, R. F. (2008). Barriers to palliative care for children: Perceptions of pediatric health care providers. *Pediatrics*, *121*, 282-288.
- De Leersyner, J., Boiger, M., & Mesquita, B. (2013). Cultural regulation of emotion: Individual, relational, and structural sources. *Frontiers in Psychology*, *4*, 1-11.
- De Trill, M., & Kovalcik, R. (1997). The child with cancer. Influence of culture on truth-telling and patient care. *Annals of the New York Academy of Sciences*, *809*, 197-210.



- deCinque, N., Monterosso, L., Dadd, G., Sidhu, R., Macpherson, R., & Aoun, S. (2006). Bereavement support for families following the death of a child from cancer: Experience of bereaved parents. *Journal of Psychosocial Oncology*, *24*, 65-83.
- deJong-Berg, M. A., & deVlaming, D. (2005). Bereavement care for families part 1: A review of a paediatric follow-up programme. *International Journal of Palliative Nursing*, *11*, 533-539.
- deJong-Berg, M. A., & Kane, L. (2006). Bereavement care for families part 2: Evaluation of a paediatric follow-up programme. *International Journal of Palliative Nursing*, *12*, 484-494.
- Dere, J., Tang, Q., Zhu, X., Cai, L., Yao, S., & Ryder, A. G. (2013). The cultural shaping of alexithymia: Values and externally oriented thinking in a Chinese clinical sample. *Comprehensive Psychiatry*, *54*, 362-368. doi: 10.1016/j.comppsy.2012.10.013.
- Dijkstra, I. C., & Stroebe, M. S. (1998). The impact of a child's death on parents: A myth (not yet) disproved? *Journal of Family Studies*, *4*, 159-185.
- Donovan, L. A., Wakefield, C. E., Russell, V., & Cohn, R. J. (2015). Hospital-based bereavement services following the death of a child: A mixed study review. *Palliative Medicine*, *29*, 193-210. doi:10.1177/0269216314556851
- Doran, G., & Downing Hansen, N. (2006). Constructions of Mexican American family grief after the death of a child: An exploratory study. *Cultural Diversity and Ethnic Minority Psychology*, *12*, 199-211.
- Dyregrov, K., Dyregrov, A., & Kristensen, P. (2015). Traumatic bereavement and terror: The psychosocial impact on parents and siblings 1.5 years after the July 2011 terror killings in Norway. *Journal of Loss and Trauma*, *20*, 556-576. doi:10.1080/15325024.2014.957603
- Dyregrov, K., Nordanger, D., & Dyregrov, A. (2003). Predictors of psychosocial distress after suicide, SIDS and accidents. *Death Studies*, *27*, 143-165.
- Ekman, P. (1972). Universals and cultural differences in facial expressions of emotion. In J. Cole (Ed.), *Nebraska symposium on motivation*. Lincoln, NE: University of Nebraska Press.
- Ekman, P., & Friesen, W. V. (1969). The repertoire of nonverbal behavior: Categories, origins, usage, and coding. *Semiotica*, *1*, 49-98.
- Eisenbruch, M. (1984). Cross-cultural aspects of bereavement: II. Ethnic and cultural variations in the development of bereavement practices. *Culture, Medicine and Psychiatry*, *8*, 315-347.

- Endo, K., Yonemoto, N., & Yamada, M. (2015). Interventions for bereaved parents following a child's death: A systematic review. *Palliative Medicine*, *29*, 590-604. doi:10.1177/0269216315576674
- Enguidanos, S., Yonashiro-Cho, J., & Cote, S. (2013). Knowledge and perception of hospice care of Chinese older adults. *Journal of the American Geriatric Society*, *61*, 993-998.
- Ettema, E. J., Derksen, L. D., & van Leeuwen, E. (2010). Existential loneliness and end-of-life care: A systematic review. *Theoretical Medicine & Bioethics*, *31*, 141-169.
- Evans, N., Meñaca, A., Andrew, E. V. W., Koffman, J., Harding, R., Higginson, I. J.,...Gysels, M. (2012). Systematic review of the primary research on minority ethnic groups and end-of-life care from the United Kingdom. *Journal of Pain and Symptom Management*, *43*, 261-286. doi:10.1016/j.jpainsymman.2011.04.012
- Fasse, L., Sultan, S., Flahault, C., Mackinnon, C. J., Dolbeault, S., & Brédart, A. (2014). How do researchers conceive of spousal grief after cancer? A systematic review of models used by researchers to study spousal grief in the cancer context. *Psycho-Oncology*, *23*, 131-142. doi:10.1002/pon.3412
- Fauri, D. P., Ettner, B., & Kovacs, P. J. (2000). Bereavement services at acute care settings. *Death Studies*, *24*, 51-64.
- Fausey, C. M., & Boroditsky, L. (2010). Who dunnit? Cross-linguistic differences in eyewitness testimony. *Psychonomic Bulletin & Review*, *18*, 158-164. doi:10.3758/s13423-010-0021-5
- Field, A., Maher, P., & Webb, D. (2002). Cross cultural research in palliative care. *Social Work in Health Care*, *35*, 523-543.
- Field, D., Reid, D., Payne, S., & Relf, M. (2004). Survey of UK hospices and specialist palliative care adult bereavement services. *International Journal of Palliative Nursing*, *10*, 569-576.
- Fielding, R., & Chan, C. L. W. (2000). *Psychosocial oncology and palliative care in Hong Kong: The first decade*. Hong Kong: Hong Kong University Press.
- Fitzgerald, M. H. (2000). Establishing cultural competency for mental health professionals. In V. Skultans, & J. L. Cox (Eds.), *Anthropological approaches to psychological medicine: Crossing bridges* (pp. 184-200). London, England: Jessica Kingsley Publishers.
- Fong, R., & Yeung, A. (2012). Chinese. In S. Loue & S. Sajatovic (Eds.), *Encyclopedia of immigrant health* (Vol. 2) (pp. 422-426). New York: Springer.

- Forte, A. L., Hill, M., Pazder, R., & Feudtner, C. (2004). Bereavement care interventions: a systematic review. *BMC Palliative Care*, 3, 3-3.
- Fram, S. M. (2013). The constant comparative analysis method outside of grounded theory. *The Qualitative Report*, 18, 1-25.
- Frey, R., Gott, M., Raphael, D., Black, S., Teleo-Hope, L., Lee, H., & Wang, Z. (2013). 'Where do I go from here'? A cultural perspective on challenges to the use of hospice services. *Health and Social Care in the Community*, 21, 519-529. doi:10.1111/hsc.12038
- Fried, E. I., Bockting, C., Arjadi, R., Borsboom, D., Amshoff, M., Cramer, A. O. J.,...Stroebe, M. (2015). From loss to loneliness: The relationship between bereavement and depressive symptoms. *Journal of Abnormal Psychology*, 124, 256-265. doi:10.1037/abn0000028
- Friesen, W. V. (1972). *Cultural differences in facial expressions in a social situation: An experimental test of the concept of display rules*. Unpublished doctoral dissertation, San Francisco: University of California.
- Fuhrman, O., McCormick, K., Chen, E., Jiang, H., Shu, D., Mao, S., & Boroditsky, L. (2011). How linguistic and cultural forces shape conceptions of time: English and Mandarin time in 3D. *Cognitive Science*, 35, 1305-1328. doi:10.1111/j.1551-6709.2011.01193.x.
- Galatzer-Levy, I. R., & Bonanno, G. A. (2012). Beyond normality in the study of bereavement: Heterogeneity in depression outcomes following loss in older adults. *Social Science and Medicine*, 74, 1987-1994.
- Gelfand, M. J., Nishii, L. H., & Raver, J. L. (2006). On the nature and importance of culture tightness-looseness. *Journal of Applied Psychology*, 91, 1225-1244.
- Gelfand, M. J., Raver, J. L., Nishii, L., Leslie, L. M., Lun, J., Lim, B. C.,...Yamaguchi, S. (2011). Differences between tight and loose cultures: A 33-nation study. *Science*, 332, 1100-1104.
- Gillies, J., & Neimeyer, R. A. (2006). Loss, grief, and the search for significance: Toward a model of meaning reconstruction in bereavement. *Journal of Constructivist Psychology*, 19, 31-65. doi:10.1080/10720530500311182
- Gudmundsdottir, M., & Chesla, C. A. (2006). Building a new world: Habits and practices of healing following the death of a child. *Journal of Family Nursing*, 12, 143-164.
- Gudykunst, W. B., & Matsumoto, Y. (1996). Cross-cultural variability of communication in personal relationships. In W. B. Gudykunst, S. Ting-Toomey, & T. Nishida (Eds.), *Communication in personal relationships across cultures* (pp. 19-56). Thousand Oaks, CA: Sage.

- Gupta, R., & Yick, A. G. (2001). Preliminary validation of the acculturation scale on Chinese Americans. *Journal of Social Work Research and Evaluation, 2*, 43-56.
- Hall, E. T. (1976). *Beyond culture*. Garden City, NY: Anchor Press.
- Hall, P., Stone, G., & Fiset, V. J. (1998). Palliative care: How can we meet the needs of our multicultural communities? *Journal of Palliative Care, 14*, 46-49.
- Hannover, B. (2009). Culture and social cognition in human interaction. In F. Strack & J. Forster (Eds.), *Social cognition: The basis of human interaction* (pp. 291-310). New York, NY: Psychology Press.
- Hansson, R. O., & Stroebe, M. S. (2007). *Bereavement in late life: Coping, adaptation, and developmental influences*. Washington, DC: American Psychological Association.
- Hardy-Bougere, M. (2008). Cultural manifestations of grief and bereavement: a clinical perspective. *Journal of Cultural Diversity, 15*, 66-69.
- He, L., Tang, S., Yu, W., Xu, W., Xie, Q., & Wang, J. (2014). The prevalence, comorbidity and risks of prolonged grief disorder among bereaved Chinese adults. *Psychiatry Research, 219*, 347-352. doi:10.1016/j.psychres.2014.05.022
- Heine, S. J. (2012). *Cultural psychology* (2nd ed.). New York, NY: W. W. Norton.
- Hibberd, R. (2013). Meaning reconstruction in bereavement: Sense and significance. *Death Studies, 37*, 670-692. doi:10.1080/07481187.2012.692453
- Ho, S. W., & Brotherson, S. E. (2007). Cultural influences on parental bereavement in Chinese families. *Omega, 55*, 1-25.
- Holland, J. M., Keene, J. R., Kirkendall, A., & Luna, N. (2015). Family evaluation of hospice care: Examining direct and indirect associations with overall satisfaction and caregiver confidence. *Palliative and Supportive Care, 13*, 901-908. doi:10.1017/S1478951514000595
- Holmes, T. H., & Rahe, R. H. (1967). The social readjustment rating scale, *Journal of Psychosomatic Research, 11*, 213-221.
- Holton, J. A. (2007). The coding process and its challenges. In A. Bryant, & K. Charmaz (Eds.), *The Sage handbook of grounded theory*. (pp. 265-289). Thousand Oaks, CA: Sage.
- Holtlander, L. F. (2008). Caring for bereaved family caregivers: Analyzing the context of care. *Clinical Journal of Oncology Nursing, 12*, 501-5016. doi: 10.1188/08.CJON.501-506.

- The Hospital for Sick Children (2011). *Report of the bereavement care task force*. Retrieved from: <http://sashabella.com/pdfs/SickKids-Bereavement-Care-Task-Force-Report-2011.pdf>
- Hsu, M. T., Kahn, D. L., Yee, D. H., & Lee, W. L. (2004). Recovery through reconnection: A cultural design for family bereavement in Taiwan. *Death Studies, 28*, 761-786.
- Institute of Medicine (1984). *Bereavement: Reactions, consequences, and care*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/8>.
- Itzhar-Nabarro, Z., & Smoski, M. J. (2012). A review of theoretical and empirical perspectives on marital satisfaction and bereavement outcomes: Implications for working with older adults. *Clinical Gerontologist, 35*, 257-269. doi:10.1080/07317115.2012.657604
- Ivoncavich, D. A., & Wong, P. T. P. (2008). Role of existential and spiritual coping in anticipatory grief. In A. Tomer, G. Eliason, & P. T. P. Wong (Eds.), *Existential and spiritual issues in death attitudes* (pp. 209-233). New York: Lawrence Erlbaum Associates.
- IWK Health Centre (2014). *Bereavement follow-up: Policy / procedures*. Retrieved from IWK Health Centre's website: [http://policy.nshealth.ca/site\\_published/iwk/document\\_render.aspx?documentRender.IdType=6&documentRender.GenericField=&documentRender.Id=50577](http://policy.nshealth.ca/site_published/iwk/document_render.aspx?documentRender.IdType=6&documentRender.GenericField=&documentRender.Id=50577)
- Jacobs, S., Hansen, F., Kasl, S., Ostfeld, A., Berkman, L., & Kim, K. (1990). Anxiety disorders during acute bereavement: Risk and risk factors. *Journal of Clinical Psychiatry, 51*, 269-274.
- Jalowiec, A., & Powers, M. (1981). Stress and coping in hypertensive and emergency room patients. *Nursing Research, 30*, 10-15.
- Jordan, J. R., & Neimeyer, R. A. (2003). Does grief counseling work? *Death Studies, 27*, 765-786. doi:10.1080/713842360
- Kagawa-Singer, M. (1998). The cultural context of death rituals and mourning practices. *Oncology Nursing Forum, 25*, 1752-1756.
- Kagawa-Singer, M., & Blackhall, L. J. (2001). Negotiating cross-cultural issues at the end of life: 'You got to go where he lives'. *Journal of the American Medical Association, 286*, 2993-3001.
- Kagawa-Singer, M., & Kassim-Lakha, S. (2003). A strategy to reduce cross-cultural miscommunication and increase the likelihood of improving health outcomes. *Academic Medicine, 78*, 577-587.

- Kang, T., Hoehn, K. S., Licht, D. J., Mayer, O. H., Santucci, G., Carroll, J. M.,...Feudtner, C. (2005). Pediatric palliative, end-of-life, and bereavement care. *Pediatric Clinics of North America*, *52*, 1029.
- Kaunonen, M., Tarkka, M.-T., Laippala, P., & Paunonen-Ilmonen, M. (2000) Impact of supportive telephone intervention on grief after the death of a family member. *Cancer Nursing*, *23*, 483-491.
- Keesee, N. J., Currier, J. M., & Neimeyer, R. A. (2008). Predictors of grief following the death of one's child: The contribution of finding meaning. *Journal of Clinical Psychology*, *64*, 1145-1163. doi:10.1002/jclp.20502
- Kemp, C. (2005). Cultural issues in palliative care. *Seminars in Oncology Nursing*, *21*, 44-52.
- Kenny, M., & Fourie, R. (2015). Contrasting Classic, Straussian, and Constructivist grounded theory: Methodological and philosophical conflicts. *The Qualitative Report*, *20*, 1270-1289.
- Kersting, A., Braehler, E., Glaesmer, H., & Wagner, B. (2011). Prevalence of complicated grief in a representative population-based sample. *Journal of Affective Disorders*, *131*, 339–343.
- Keyes, K. M., Pratt, C., Galea, S., McLaughlin, K. A., Koenen, K. C., & Shear, M. K. (2014). The burden of loss: Unexpected death of a loved one and psychiatric disorders across the life course in a national study. *American Journal of Psychiatry*, *171*, 864-871. doi:10.1176/appi.ajp.2014.13081132
- Kidd, J., Reid, S., Collins, N., Gibbons, D., Black, S., Blundell, R.,...Ahu, M. H. (2014). *Kia mau te kahu whakamauru: Health literacy in palliative care*. Retrieved from the New Zealand Ministry of Health website: <https://cdn.auckland.ac.nz/assets/fmhs/faculty/ABOUT/newsandevents/docs/Health-literacy-in%20palliative-care-report.pdf>
- Kimbrough, J. B. (2007). Health literacy as a contributor to immigrant health disparities. *Journal of Health Disparities Research and Practice*, *1*, 93-106.
- Kissane, D., Lichtenthal, W. G., & Zaider, T. (2007). Family care before and after bereavement. *Omega*, *56*, 21-32.
- Koenig, B. A., & Davies, B. (2003). Cultural dimensions of care at life's end for children and their families. In M. J. Field & R. E. Behrman (Eds.), *When children die: Improving palliative and end-of-life care for children and their families* (pp. 509-552). Washington, DC: The National Academies Press.

- Kolb, S. M. (2012). Grounded theory and the constant comparative method: Valid research strategies for educators. *Journal of Emerging Trends in Educational Research and Policy Studies*, 3, 83-86.
- Kongnetiman, L., Lai, D., & Berg, B. (2008). *Cultural competency in pediatric palliative care: A literature review*. Retrieved from Alberta Health Services website: <http://fcrc.albertahealthservices.ca/publications/cultural/Cultural-Competency-in-Palliative-Paediatric-Care-Research-Report.pdf>
- Kreicbergs, U., Valdimarsdottir, U., Onelov, E., Henter, J.-I., & Steineck, G. (2004). Anxiety and depression in parents 4-9 years after the loss of a child owing to a malignancy: A population-based follow-up. *Psychological Medicine*, 34, 1431-1441.
- Kreling, B., Selsky, C., Perret-Gentil, M., Huerta, E. E., & Mandelblatt, J. S. (2010). 'The worst thing about hospice is that they talk about death': Contrasting hospice decisions and experience among immigrant Central and South American Latinos with US-born White, non-Latino cancer caregivers. *Palliative Medicine*, 24, 427-434. doi:10.1177/0269216310366605
- Kristensen, P., Weisaeth, L., & Heir, T. (2012). Bereavement and mental health after sudden and violent losses: A review. *Psychiatry*, 75, 76-97. doi:10.1521/psyc.2012.75.1.76
- Kung, W. W., & Lu, P.-C. (2008). How symptom manifestations affect help seeking for mental health problems among Chinese Americans. *Journal of Nervous and Mental Disease*, 196, 46-54.
- Kusano, A. S., Kenworthy-Heinige, T., & Thomas, C. R., Jr. (2012). Survey of bereavement practices of cancer care and palliative care physicians in the Pacific Northwest United States. *Journal of Oncology*, 8, 275-281. doi:10.1200/JOP.2011.000512
- Kwak, J., & Haley, W. E. (2005). Current research findings on end-of-life decision making among racially or ethnically diverse groups. *The Gerontologist*, 45, 634-641.
- Laakso, H., & Paunonen-Ilmonen, M. (2001). Mothers' grief following the death of a child. *Journal of Advanced Nursing*, 36, 69-77.
- Lalande, K. M., & Bonanno, G. A. (2006). Culture and continuing bonds: A prospective comparison of bereavement in the United States and the People's Republic of China. *Death Studies*, 30, 303-324.

- Lannen, P. K., Wolfe, J., Prigerson, H. G., Onelov, E., & Kreicbergs, U. C. (2008). Unresolved grief in a national sample of bereaved parents: Impaired mental and physical health 4 to 9 years later. *Journal of Clinical Oncology*, *26*, 5870-5876. doi:10.1200/JCO.2007.14.6738.
- Lang, A., & Carr, T. (2013). Bereavement in the face of perinatal loss: A hardiness perspective. In D. S. Becvar (Ed.), *Handbook of family resilience* (pp. 299-319). New York, NY: Springer Publishing.
- Lang, A., Fleiszer, A. R., Duhamel, F., Aston, M., Carr, T., & Goodwin, S. (2015). Evidence-informed primary bereavement care: A study protocol of a knowledge-to-action approach for system change. *International Journal of Qualitative Methods*, *14*, 122-145.
- Lee, G. R., & DeMaris, A. (2007). Widowhood, gender, and depression: A longitudinal analysis. *Research on Aging*, *29*, 56-72.
- Li, H. (2004). Barriers to and unmet needs for supportive services: Experiences of Asian-American caregivers. *Journal of Cross-Cultural Gerontology*, *19*, 241-260.
- Li, S. P., Chan, C. W. H., & Lee, D. T. F. (2002). Helpfulness of nursing actions to suddenly bereaved family members in an accident and emergency setting in Hong Kong. *Journal of Advanced Nursing*, *40*, 170-180.
- Li, J., Laursen, T. M., Precht, D. H., Olsen, J., & Mortensen, P. B. (2005). Hospitalization for mental illness among parents after the death of a child. *New England Journal of Medicine*, *352*, 1190-1196.
- Li, J., Precht, D. H., Mortensen, P. B., & Olsen, J. (2003). Mortality in parents after death of a child in Denmark: A nationwide follow-up study. *Lancet*, *361*, 363-367.
- Li, J., & Prigerson, H. G. (2016). Assessment and associated features of prolonged grief disorder among Chinese bereaved individuals. *Comprehensive Psychiatry*, *66*, 9-16. doi:10.1016/j.comppsy.2015.12.001
- Liben, S., Papadatou, D., & Wolfe, J. (2008). Paediatric palliative care: Challenges and emerging ideas. *Lancet*, *371*, 852-864.
- Lichtenthal, W. G., Sweeney, C. R., Roberts, K. E., Corner, G. W., Donovan, L. A., Prigerson, H. G., & Wiener, L. (2015). Bereavement follow-up after the death of a child as a standard of care in pediatric oncology. *Pediatric Blood and Cancer*, *62*, S834-869.
- Littlewood, J. L., Cramer, D., Hoekstra, J., & Humphrey, G. B. (1991). Parental coping with their child's death. *Counselling Psychology Quarterly*, *4*, 135-141.



- Liu, N. C., & Lai, E. Y. L. (2006). Find a way out: Bereavement support in Taiwan hospice. *Supportive Care in Cancer, 14*, 4-10.
- Lobb, E. A., Kristjanson, L. J., Aoun, S. M., Monterosso, L., Halkett, G. K. B., & Davies, A. (2010). Predictors of complicated grief: A systematic review of empirical studies. *Death Studies, 34*, 673-698.
- Long, C. O. (2011). Ten best practices to enhance culturally competent communication in palliative care. *Journal of Pediatric Hematology and Oncology, 33*, S136-139.
- Ludke, R. L., & Smucker, D. R. (2007). Racial differences in the willingness to use hospice services. *Journal of Palliative Medicine, 10*, 1329-1337.
- Ma-Kellams, C. & Blascovich, J. (2012). Enjoying life in the face of death: East-West differences in responses to mortality salience. *Journal of Personality and Social Psychology, 103*, 773-786.
- Macdonald, M. E., Liben, S., Carnevale, F. A., Rennick, J. E., Wolf, S. L., Meloche, D., & Cohen, S. R. (2005). Parental perspectives on hospital staff members' acts of kindness and commemoration after a child's death. *Pediatrics, 116*, 884-890.
- Mack, J. W., Hilden, J. M., Watterson, J., Moore, C., Turner, B., Grier, H. E.,...Wolfe, J. (2005). Parent and physician perspectives on quality of care at the end of life in children with cancer. *Journal of Clinical Oncology, 23*, 9155-9161.
- Mahon, M. M., & Page, M. L. (1995). Childhood bereavement after the death of a sibling. *Holistic Nursing Practice, 9*, 15-26.
- Mak, M. H. J. (2001). Awareness of dying: an experience of Chinese patients with terminal cancer. *Omega, 43*, 259-279.
- Mak, M. H. J. (2002). Accepting the timing of one's death: An experience of Chinese hospice patients. *Omega, 45*, 245-260.
- Marin, G., Sabogal, F., Van Oss Marin, B., Otero-Sabogal, R., & Perez-Stable, E. (1987). Development of a short acculturation scale for Hispanics. *Hispanic Journal of Behavioral Sciences, 9*, 183-205.
- Markus, H. R., & Kitayama, S. (1991). Culture and the self: Implications for cognition, emotion, and motivation. *Psychological Review, 98*, 224-253.
- Matsumoto, D., & Kupperbusch, C. (2001). Idiocentric and allocentric differences in emotional expression, experience, and the coherence between expression and experience. *Asian Journal of Social Psychology, 4*, 113-131.

- Matsumoto, D., Yoo, S. H., Fontaine, J., Anguas-Wong, A. R., Arriola, M., Ataca, B.,...Grossi, E. (2008). Mapping expressive differences around the world: The relationship between emotional display rules and individualism versus collectivism. *Journal of Cross-Cultural Psychology, 39*, 55-74.
- Matsumoto, D., Yoo, S. H., & Nakagawa, S. (2008). Culture, emotional regulation, and adjustment. *Journal of Personality and Social Psychology, 94*, 925-937.
- McGrath, P., Vun, M., & McLeod, L. (2001). Needs and experiences of non-English-speaking hospice patients and families in an English-speaking country. *American Journal of Hospice & Palliative Care, 18*, 305-312.
- McKinley, D., & Blackford, J. (2001). Nurses' experiences of caring for culturally and linguistically diverse families when their child dies. *International Journal of Nursing Practice, 7*, 251-256.
- Meuser, T. M., & Marwit, S. J. (2000). An integrative model of personality, coping and appraisal for the prediction of grief involvement in adults. *Omega, 40*, 375-393.
- Michael, C., & Cooper, M. (2013). Post-traumatic growth following bereavement: A systematic review of the literature. *Counselling Psychology Review, 28*, 18-33.
- Middleton, W., Moylan, A., Raphael, B., Burnett, P., & Martinek, N. (1993). An international perspective on bereavement related concepts. *Australian and New Zealand Journal of Psychiatry, 27*, 457-463.
- Milberg, A., Olsson, E.-C., Jakobsson, M., Olsson, M., & Friedrichsen, M. (2008). Family members' perceived needs for bereavement follow-up. *Journal of Pain and Symptom Management, 35*, 58-69.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd Ed.). Thousand Oaks: Sage.
- Mjelde-Mossey, L. A., & Chan, C. L. W. (2007). Survey on death and dying in Hong Kong: Attitudes, beliefs, and preferred end-of-life care. *Social Work in Health Care, 45*, 49-65.
- Mo, H. N., Shin, D. W., Woo, J. H., Choi, J. Y., Kang, J., Baik, Y. J.,...Cho, S. H. (2012). Is patient autonomy a critical determinant of quality of life in Korea? End-of-life decision making from the perspective of the patient. *Palliative Medicine, 26*, 222-231. doi:10.1177/0269216311405089
- Mok, E., Chan, F., Chan, V., & Yeung, E. (2003). Family experience caring for terminally ill patients with cancer in Hong Kong. *Cancer Nursing, 26*, 267-275.

- Mok, H., Lai, D. W. L., Lin, D., Wong, M. P., & Ganesan, S. (2003). Chinese Canadians in a cross-cultural psychiatry outpatient clinic: Some exploratory findings. *BC Medical Journal*, *45*, 78-81.
- Mok, E., Martinson, I., & Wong, T. K. S. (2004). Individual empowerment among Chinese cancer patients in Hong Kong. *Western Journal of Nursing Research*, *26*, 59.
- Mok, E., & Tam, B. (2001). Stressors and coping methods among chronic haemodialysis patients in Hong Kong. *Journal of Clinical Nursing*, *10*, 503-511.
- Morris, S. E., & Block, S. D. (2015). Adding value to palliative care services: The development of an institutional bereavement program. *Journal of Palliative Medicine*, *18*, 915-922. doi:10.1089/jpm.2015.0080.
- Munet-Vilaro, F. (2004). Delivery of culturally competent care to children with cancer and their families – The Latino experience. *Journal of Pediatric Oncology Nursing*, *21*, 155-159.
- National Consensus Project for Quality Palliative Care (2013). *Clinical practice guidelines for quality palliative care* (3rd ed.). Retrieved from National Consensus Project for Quality Palliative Care website: [http://www.nationalconsensusproject.org/NCP\\_Clinical\\_Practice\\_Guidelines\\_3rd\\_Edition.pdf](http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf)
- National Hospice and Palliative Care Organization (2012). *NHPCO facts and figures: Hospice care in America* (3rd edition). Retrieved from National Hospice and Palliative Care Organization website: [http://www.nhpco.org/sites/default/files/public/Statistics\\_Research/2012\\_Facts\\_Figures.pdf](http://www.nhpco.org/sites/default/files/public/Statistics_Research/2012_Facts_Figures.pdf)
- National Hospice and Palliative Care Organization (2015). *NHPCO facts and figures: Hospice care in America* (2015 edition). Retrieved from National Hospice and Palliative Care Organization website: [http://www.nhpco.org/sites/default/files/public/Statistics\\_Research/2015\\_Facts\\_Figures.pdf](http://www.nhpco.org/sites/default/files/public/Statistics_Research/2015_Facts_Figures.pdf)
- National Institute for Clinical Excellence (2004). *Guidance on improving supportive and palliative care for adults with cancer*. Retrieved from the National Institute for Clinical Excellence website: <https://www.nice.org.uk/guidance/csg4>
- Neimeyer, R. A., Baldwin, S. A., & Gillies, J. (2006). Continuing bonds and reconstructing meaning: Mitigating complications in bereavement. *Death Studies*, *30*, 715-738. doi:10.1080/07481180600848322

- Ng, P., Ho, W.-C., Tsun, A., & Young, D. K. W. (2016). Coping with bereavement of widows in the Chinese cultural context of Hong Kong. *International Social Work, 59*, 115-128. doi:10.1177/0020872813509395
- Ngo-Metzger, Q., Phillips, R. S., & McCarthy, E. P. (2008). Ethnic disparities in hospice use among Asian-American and Pacific Islander patients dying with cancer. *Journal of the American Geriatrics Society, 56*, 139-144.
- Noggle, B. J. (1995). Identifying and meeting needs of ethnic minority patients. *The Hospice Journal, 10*, 85-93.
- North Okanagan Hospice Society (2011). *December 2011 newsletter*. Retrieved from North Okanagan Hospice Society's website: [nohs.ca/uploads/files/1112\\_newsletter.pdf](http://nohs.ca/uploads/files/1112_newsletter.pdf)
- Oliver, L. E. (1999). Effects of a child's death on the marital relationship: A review. *Omega, 39*, 197-227.
- Oxman-Martinez, J., & Hanley, J. (2004) Research on diversity: Contributions to better health policy and practice. In C. Andrews (Ed.), *Our diverse cities* (Vol. 1) (pp. 115-118). Retrieved from the Metropolis and Federation of Canadian Municipalities website: [http://canada.metropolis.net/research-policy/cities/publication/diverse\\_cite\\_magazine\\_e.pdf](http://canada.metropolis.net/research-policy/cities/publication/diverse_cite_magazine_e.pdf)
- Packman, W., Horsley, H., Davies, B., & Kramer, R. (2006). Sibling bereavement and continuing bonds. *Death Studies, 30*, 817-841.
- Palliative Care Australia (2005). *Standards for providing quality palliative care for all Australians*. Retrieved from Palliative Care Australia website: <http://palliativecare.org.au/wp-content/uploads/2015/07/Standards-for-providing-quality-palliative-care-for-all-Australians.pdf>
- Papadatou, D., Martinson, I. M., & Chung, P. M. (2001). Caring for dying children: A comparative study of nurses' experiences in Greece and Hong Kong. *Cancer Nursing, 24*, 402-412.
- Payne, S., Chapman, A., Holloway, M., Seymour, J. E., & Chau, R. (2005). Chinese community views: Promoting cultural competence in palliative care. *Journal of Palliative Care, 21*, 111-116.
- Peng, K. & Nisbett, R. (1999). Culture, dialectics, and reasoning about contradiction. *American Psychologist, 54*, 741-754.
- Ping, S. L., Chan, W. H. C., & Lee, T. F. D. (2002). Use of a bereavement service among suddenly bereaved families in Hong Kong. *Journal of Clinical Nursing, 11*, 289-290.

- Polatinsky, S., & Esprey, Y. (2000). An assessment of gender differences in the perception of benefit resulting from the loss of a child. *Journal of Traumatic Stress, 13*, 709-718.
- Prigerson, H. G., Bierhals, A. J., Kasl, S. V., Reynolds, C. F., Shear, M. K., Day, N.,...Jacobs, S. (1997). Traumatic grief as a risk factor for mental and physical morbidity. *American Journal of Psychiatry, 154*, 616-623.
- Prong, L. L. (1995). Childhood bereavement among Cambodians: Cultural considerations. *The Hospice Journal, 10*, 51-64.
- Radloff, L.S. (1977). The CES-D scale: A self report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385-401.
- Randhawa, G., Owens, A., Fitches, R., & Khan, Z. (2003). Communication in the development of culturally competent palliative care services in the UK: A case study. *International Journal of Palliative Nursing, 9*, 24-31.
- Reese, D. J., & Beckwith, S. K. (2015). Organizational barriers to cultural competence in hospice. *American Journal of Hospice and Palliative Medicine, 32*, 685-694.
- Reid, D., Field, D., Payne, S., & Relf, M. (2006a). Adult bereavement in five English hospices: Participants, organisations and pre-bereavement support. *International Journal of Palliative Nursing, 12*, 320-327.
- Reid, D., Field, D., Payne, S., & Relf, M. (2006b). Adult bereavement in five English hospices: Types of support. *International Journal of Palliative Nursing, 12*, 430-437.
- Ryder, A. G., Yang, J., Zhu, X., Yao, S., Yi, J.,...Bagby, R.M. (2008). The cultural shaping of depression: Somatic symptoms in China, psychological symptoms in North America? *Journal of Abnormal Psychology, 117*, 300-313. doi: 10.1037/0021-843X.117.2.300.
- Saldaña, J. (2013). *The coding manual for qualitative researchers*. Los Angeles: SAGE Publications.
- Sandelowski, M. (2003). Tables or tableaux? The challenges of writing and reading mixed methods studies. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social and behavioral research* (pp. 321-350). Thousand Oaks, CA: Sage.
- Saumure, K., & Given, L. M. (2008). Rigor in qualitative research. In L. M. Given (Ed.), *The SAGE encyclopedia of qualitative research methods* (pp. 796). Thousand Oaks, CA: Sage.

- Sbaraini, A., Carter, S. M., Evans, R. W., & Blinkhorn, A. (2011). How to do a grounded theory study: A worked example of a study of dental practices. *BMC Medical Research Methodology*, *11*, 128. doi:10.1186/1471-2288-11-128.
- Scharlach, A. E., Kellam, R., Ong, N., Baskin, A., Goldstein, C., & Fox, P. J. (2006). Cultural attitudes and caregiver service use: Lessons from focus groups with racially and ethnically diverse family caregivers. *Journal of Gerontological Social Work*, *47*, 133-156.
- Schulz, R., Boerner, K., Shear, K., Zhang, S., & Gitlin, L. N. (2006). Predictors of complicated grief among dementia caregivers: A prospective study of bereavement. *American Journal of Geriatric Psychiatry*, *14*, 650-658.
- Schulz, R., Hebert, R., & Boerner, K. (2008). Bereavement after caregiving. *Geriatrics*, *63*, 20-22.
- Schut, H., & Stroebe, M. S. (2005). Interventions to enhance adaptation to bereavement. *Journal of Palliative Medicine*, *8*, S140-147.
- Scott, K. W. (2004). Relating categories in grounded theory analysis: Using a conditional relationship guide and reflective coding matrix. *The Qualitative Report*, *9*, 113-126.
- Sealey, M., Breen, L. J., O'Connor, M., & Aoun, S. M. (2015). A scoping review of bereavement risk assessment measures: Implications for palliative care. *Palliative Medicine*, *29*, 577-589.
- Select Standing Committee on Health (2016). *Improving end of life care for British Columbians*. Retrieved from the Legislative Assembly of British Columbia's website: <https://www.leg.bc.ca/content/CommitteeDocuments/40th-parliament/5th-session/health/1stReport/SSCHealth-Report-2016-05-10.pdf>
- Seto Nielsen, L. S., Angus, J. E., Howell, D., Husain, A., & Gastaldo, D. (2015). Patient-centered care or cultural competence: Negotiating palliative care at home for Chinese Canadian immigrants. *American Journal of Hospice and Palliative Medicine*, *32*, 372-379. doi:10.1177/1049909114527338
- Shah, S. M., Carey, I. M., Harris, T., Dewilde, S., Victor, C. R., & Cook, D. G. (2013). The effect of unexpected bereavement on mortality in older couples. *American Journal of Public Health*, *103*, 1140-1145. doi:10.2105/AJPH.2012.301050
- Shah, S. N., & Meeks, S. (2012). Late-life bereavement and complicated grief: a proposed comprehensive framework. *Aging and Mental Health*, *16*, 39-56. doi:10.1080/13607863.2011.605054
- Shear, M. K. (2012). Grief and mourning gone awry: Pathway and course of complicated grief. *Dialogues in Clinical Neuroscience*, *14*, 119-128.

- Shear, K., Frank, E., Houck, P. R., & Reynolds, C. F. 3rd (2005). Treatment of complicated grief: A randomized controlled trial. *Journal of the American Medical Association*, *293*, 2601-2608.
- Shear, M. K., Ghesquiere, A., & Glickman, K. (2013). Bereavement and complicated grief. *Current Psychiatry Reports*, *15*, 406-406. doi:10.1007/s11920-013-0406-z
- Shear, M. K., & Skritskaya, N. A. (2012). Bereavement and anxiety. *Current Psychiatry Reports*, *14*, 169-175. doi:10.1007/s11920-012-0270-2
- Shapiro, E. R. (1996). Family bereavement and cultural diversity: A social developmental perspective. *Family Process*, *35*, 313-332.
- Shek, D. T. L. (1988). Reliability and factorial structure of the Chinese version of the State-Trait Anxiety Inventory. *Journal of Psychopathology and Behavioral Assessment*, *10*, 303-317.
- Shek, D. T. L. (1993). The Chinese version of the State-Trait Anxiety Inventory: Its relationship to different measures of psychological well-being. *Journal of Clinical Psychology*, *49*, 349-358.
- Simon, N. M., Shear, K. M., Thompson, E. H., Zalta, A. K., Perlman, C., Reynolds, C. F.,...Silowash, R. (2007). The prevalence and correlates of psychiatric comorbidity in individuals with complicated grief. *Comprehensive Psychiatry*, *48*, 395-399.
- Silverman, G. K., Jacobs, S. C., Kasl, S. V., Shear, M. K., Maciejewski, P. K., Noaghiul, F. S., & Prigerson, H. G. (2000). Quality of life impairments associated with diagnostic criteria for traumatic grief. *Psychological Medicine*, *30*, 857-862.
- Simon, N. M., Shear, K. M., Thompson, E. H., Zalta, A. K., Perlman, C., Reynolds, C. F.,...Silowash, R. (2007). The prevalence and correlates of psychiatric comorbidity in individuals with complicated grief. *Comprehensive Psychiatry*, *48*, 395-399. doi:10.1016/j.comppsy.2007.05.002.
- Soetanto, A. L. F., Chung, J. W. Y., & Wong, T. K. S. (2006). Are there gender differences in pain perception? *Journal of Neuroscience Nursing*, *38*, 172-176.
- Sormanti, M., & August, J. (1997). Parental bereavement: spiritual connections with deceased children. *The American Journal of Orthopsychiatry*, *67*, 460-469.
- Spencer-Rodgers, J., Boucher, H., Mori, S., Wang, L. & Peng, K. (2009). The dialectical self-concept: Contradiction, change, and holism in East Asian cultures. *Personality and Social Psychology Bulletin*, *35*, 29-44.
- Spielberger, C. D., Gorsuch, R. C., & Lushene, R. E. (1970). *Manual for the State Trait Anxiety Inventory*. Palo Alto, CA: Consulting Psychologists Press.

Stahl, S. T., & Schulz, R. (2014). Changes in routine health behaviors following late-life bereavement: A systematic review. *Journal of Behavioral Medicine*, 37, 736-755. doi:10.1007/s10865-013-9524-7

Statistics Canada (2016a). 150 years of immigration in Canada. Retrieved from <http://www.statcan.gc.ca/pub/11-630-x/11-630-x2016006-eng.htm>

Statistics Canada (2016b). 2011 National Household Survey data tables: Citizenship (5), Place of Birth (236), Immigrant Status and Period of Immigration (11), Age Groups (10) and Sex (3) for the Population in Private Households of Canada, Provinces, Territories, Census Metropolitan Areas and Census Agglomerations, 2011 National Household Survey [Catalogue number 99-010-X2011026]. Retrieved from Statistics Canada: <http://www12.statcan.gc.ca/nhs-enm/2011/dp-pd/dt-td/Rp-eng.cfm?TABID=2&LANG=E&APATH=3&DETAIL=0&DIM=0&FL=A&FREE=0&GC=0&GK=0&GRP=1&PID=105411&PRID=0&PTYPE=105277&S=0&SHOWALL=0&SUB=0&Temporal=2013&THEME=95&VID=0&VNAMEE=&VNAMEF=>

Statistics Canada (2016c). 2011 National Household Survey data tables: Ethnic Origin (264), Single and Multiple Ethnic Origin Responses (3), Generation Status (4), Age Groups (10) and Sex (3) for the Population in Private Households of Canada, Provinces, Territories, Census Metropolitan Areas and Census Agglomerations, 2011 National Household Survey [Catalogue number 99-010-X2011028]. Retrieved from Statistics Canada: <http://www12.statcan.gc.ca/nhs-enm/2011/dp-pd/dt-td/Rp-eng.cfm?LANG=E&APATH=3&DETAIL=0&DIM=0&FL=A&FREE=0&GC=0&GID=0&GK=0&GRP=0&PID=105396&PRID=0&PTYPE=105277&S=0&SHOWALL=0&SUB=0&Temporal=2013&THEME=95&VID=0&VNAMEE=&VNAMEF=>

Statistics Canada (2016d). 2011 National Household Survey data tables: Visible Minority (15), Immigrant Status and Period of Immigration (11), Age Groups (10) and Sex (3) for the Population in Private Households of Canada, Provinces, Territories, Census Metropolitan Areas and Census Agglomerations, 2011 National Household Survey [Catalogue number 99-010-X2011030]. Retrieved from Statistics Canada: <http://www12.statcan.gc.ca/nhs-enm/2011/dp-pd/dt-td/Rp-eng.cfm?LANG=E&APATH=3&DETAIL=0&DIM=0&FL=A&FREE=0&GC=0&GID=1118296&GK=0&GRP=1&PID=105392&PRID=0&PTYPE=105277&S=0&SHOWALL=0&SUB=0&Temporal=2013&THEME=95&VID=0&VNAMEE=&VNAMEF=>

Statistics Canada (2016e). Language highlight tables, 2011 Census. Retrieved from Statistics Canada: <http://www12.statcan.gc.ca/census-recensement/2011/dp-pd/hlt-fst/lang/index-eng.cfm?Lang=E>

Stevenson, M., Achille, M., Liben, S., Proulx, M.-C., Humbert, N., Petti, A.,...Cohen, S. R. (2016). Understanding how bereaved parents cope with their grief to inform the services provided to them. *Qualitative Health Research*. Advance online publication. doi:10.1177/1049732315622189



- Strauss, A.L., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.
- Strauss, A.L., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage.
- Stroebe, M., Schut, H., & Stroebe, W. (2007). Health outcomes of bereavement. *Lancet*, *370*, 1960-1973.
- Stroebe, M., Stroebe, W., & Abakoumkin, G. (2005). The broken heart: Suicidal ideation in bereavement. *American Journal of Psychiatry*, *162*, 2178-2180.
- Stroebe, M., Stroebe, W., Schut, H., Zech, E., & van den Bout, J. (2002). Does disclosure of emotions facilitate recovery from bereavement? Evidence from two perspective studies. *Journal of Consulting and Clinical Psychology*, *70*, 169-178.
- Stroebe, M.S., Folkman, S., Hansson, R.O., & Schut, H. (2006). The prediction of bereavement outcome: Development of an integrative risk framework. *Social Science and Medicine*, *63*, 2440–2451.
- Stroebe, M. S., Hansson, R. O., Schut, H., & Stroebe, W. (2008). Bereavement research: Contemporary perspectives. In M. S. Stroebe, R. O. Hansson, H. Schut, & W. Stroebe (Eds.), *Handbook of bereavement research and practice: Advances in theory and intervention* (pp. 3-25). Washington, DC: American Psychological Association.
- Stroebe, W., Stroebe, M., Abakoumkin, G., & Schut, H. (1996). The role of loneliness and social support in adjustment to loss: A test of attachment versus stress theory. *Journal of Personality and Social Psychology*, *70*, 1241-1249.
- Stroebe, W., Zech, E., Stroebe, M. S., & Abakoumkin, G. (2005). Does social support help in bereavement? *Journal of Social and Clinical Psychology*, *24*, 1030-1050. doi:10.1521/jscp.2005.24.7.1030
- Sue, S. (2006). Cultural competency: From philosophy to research and practice. *Journal of Community Psychology*, *34*, 237-245.
- Tabler, J., Utz, R. L., Ellington, L., Reblin, M., Caserta, M., Clayton, M., & Lund, D. (2015). Missed opportunity: Hospice care and the family. *Journal of Social Work in End-of-Life and Palliative Care*, *11*, 224-243. doi: 10.1080/15524256.2015.1108896
- Taylor, C. & Gibbs, G. R. (2010). How and what to code. Retrieved from: [http://onlineqda.hud.ac.uk/Intro\\_QDA/how\\_what\\_to\\_code.php](http://onlineqda.hud.ac.uk/Intro_QDA/how_what_to_code.php)

- Thomas, N. D. (2001). The importance of culture throughout all of life and beyond. *Holistic Nursing Practice, 15*, 40-46.
- Ting-Toomey, S. (1999). *Communicating across cultures*. New York, NY: Guildford Press.
- Triandis, H. C., McCusker, C., & Hui, C. H. (1990). Multimethod probes of individualism and collectivism. *Journal of Personality and Social Psychology, 59*, 1006-1020.
- Tse, D. M., Wu, K. K., Suen, M. H., Ko, F. Y., & Yung, G. L. (2006). Perception of doctors and nurses on the care and bereavement support for relatives of terminally ill patients in an acute setting. *Hong Kong Journal of Psychiatry, 16*, 7-13
- Tsui, T. K. (2005). *The dimensions of grief among Chinese in Hong Kong* (Unpublished master's thesis). University of Hong Kong, Hong Kong.
- van der Houwen, K., Stroebe, M., Schut, H., Stroebe, W., & van den Bout, J. (2010). Mediating processes in bereavement: The role of rumination, threatening grief interpretations, and deliberate grief avoidance. *Social Science & Medicine, 71*, 1669-1676. doi:10.1016/j.socscimed.2010.06.047
- van der Houwen, K., Stroebe, M., Stroebe, W., Schut, H., van den Bout, J., & Wijngaards-De Meij, L. (2010). Risk factors for bereavement outcome: A multivariate approach. *Death Studies, 34*, 195-220. doi:10.1080/07481180903559196
- Wang, C.-W., & Chan, C. L. W. (2015). End-of-life care research in Hong Kong: A systematic review of peer-reviewed publications. *Palliative and Supportive Care, 13*, 1711-1720. doi:10.1017/S1478951515000802
- Wang, R. H., & Martinson, I. M. (1996). Behavioral responses of healthy Chinese siblings to the stress of childhood cancer in the family: A longitudinal study. *Journal of Pediatric Nursing, 11*, 383-391.
- Weiss, R. S. (2008). The nature and causes of grief. In M. S. Stroebe, R. O. Hansson, H. Schut, & W. Stroebe (Eds.), *Handbook of bereavement research and practice: Advances in theory and intervention* (pp. 29-44). Washington, DC: American Psychological Association.
- Whittam, E. H. (1993). Terminal care of the dying child. Psychosocial implications of care. *Cancer, 71*, 3450-3462.
- Widger, K., Davies, D., Drouin, D. J., Beaune, L., Daoust, L., Farran, R. P.,...Bishop, M. (2007). Pediatric patients receiving palliative care in Canada: Results of a multicenter review. *Archives of Pediatrics and Adolescent Medicine, 161*, 597-602.

- Wiener, L., McConnell, D. G., Latella, L., & Ludi, E. (2013). Cultural and religious considerations in pediatric palliative care. *Palliative and Supportive Care*, *11*, 47-67. doi:10.1017/S1478951511001027
- Wijngaards-de Meij, L., Stroebe, M., Schut, H., Stroebe, W., van den Bout, J., van der Heijden, P., & Dijkstra, I. (2007). Neuroticism and attachment insecurity as predictors of bereavement outcome. *Journal of Research in Personality*, *41*, 498-505.
- Wilkinson, S., Croy, P., King, M., & Barnes, J. (2007). Are we getting it right? Parents' perceptions of hospice child bereavement support services. *Palliative Medicine*, *21*, 401-407.
- Williams, J. R., Jr. (2005). Depression as a mediator between spousal bereavement and mortality from cardiovascular disease: Appreciating and managing the adverse health consequences of depression in an elderly surviving spouse. *Southern Medical Journal*, *98*, 90-95.
- Williams, A.-L., & McCorkle, R. (2011). Cancer family caregivers during the palliative, hospice, and bereavement phases: A review of the descriptive psychosocial literature. *Palliative and Supportive Care*, *9*, 315-325. doi:10.1017/S1478951511000265
- Wilson, D. M., Dhanji, N., Playfair, R. Nayak, S. S., Pupilampu, G. L., & Macleod, R. (2016). A scoping review of bereavement service outcomes. *Palliative and Supportive Care*. Advance online publication. doi:10.1017/S147895151600047X
- Wilson, D. M., & Playfair, R. (2016). Bereavement programs and services in the province of Alberta: A mapping report. *Canadian Journal of Aging*, *35*, 273-278.
- Wolff, P., & Holmes, K. J. (2011). Linguistic relativity. *Wiley Interdisciplinary Reviews: Cognitive Science*, *2*, 253-265. doi:10.1002/wcs.104
- Worden, J. W., Davies, B., & McCown, D. (1999). Comparing parent loss with sibling loss. *Death Studies*, *23*, 1-15.
- World Health Organization (2016). WHO definition of palliative care. Retrieved from <http://www.who.int/cancer/palliative/definition/en/>
- Woodgate, R. L. (2006). Living in a world without closure: Reality for parents who have experienced the death of a child. *Journal of Palliative Care*, *22*, 75-82.
- Yang, J. S., & Kagawa-Singer, M. (2007). Increasing access to care for cultural and linguistic minorities: ethnicity-specific health care organizations and infrastructure. *Journal of Health Care for The Poor and Underserved*, *18*, 532-549.

- Yam, B. M., Rossiter, J. C., & Cheung, K. Y. (2001). Caring for dying infants: Experiences of neonatal intensive care nurses in Hong Kong. *Journal of Clinical Nursing, 10*, 651-659.
- Yeh, S.C.J., & Chou, H.C. (2007). Coping strategies and stressors in patients with hemodialysis. *Psychosomatic Medicine, 69*, 182-190.
- Yick, A. G., & Gupta, R. (2002). Chinese cultural dimensions of death, dying, and bereavement: focus group findings. *Journal of Cultural Diversity, 9*, 32-42.
- Zanchetta, M. S., & Poureslami, I. M. (2006). Health literacy within the reality of immigrants' culture and language. *Canadian Journal of Public Health, 97*, S26-30.
- Zisook, S., Iglewicz, A., Avanzino, J., Maglione, J., Glorioso, D., Zetumer, S.,...Shear, M. K. (2014). Bereavement: Course, consequences, and care. *Current Psychiatry Reports, 16*, 482-482. doi:10.1007/s11920-014-0482-8
- Zisook, S., & Kendler, K. S. (2007). Is bereavement-related depression different than non-bereavement-related depression? *Psychological Medicine, 37*, 779-794.
- Zisook, S., & Shear, K. (2009). Grief and bereavement: What psychiatrists need to know. *World Psychiatry, 8*, 67-74.

# Appendix A.

## Interview Guide

### Psychological Functioning and Bereavement Care Needs of Bereaved Chinese Immigrants in Canada

#### INTERVIEW GUIDE

Thank you for meeting with me today. We want to hear your story and learn what your experience has meant to you. We are particularly interested in learning how your cultural heritage influenced your experience. We want to hear about what was helpful, but also about anything that didn't go as you would have liked and your recommendations for how we can better serve Chinese families when their family member passes away.

We will be talking about a difficult and painful time in your life. Please remember you are free to skip any question or stop the interview at any time. If you need to take a break, please don't hesitate to let me know.

The length of the interview will be approximately one hour. Feel free to make your answers as long or short as you wish. With your permission, I'll tape-record our conversation.

Do you have any questions before we begin?

#### I. ABOUT THE FAMILY MEMBER

- 1a. Tell me about [name of family member].
- 1b. Why did [name of family member] pass away? When?

#### II. IMPACT OF BEREAVEMENT ON FAMILY MEMBERS

- 2a. What was it like for you when [name of family member] died? What did you think? How did you feel? What did you do?
- 2b. How has [name of family member]'s death affected you? What has helped you cope since \_\_\_\_\_ died? What was not helpful?
- 2c. How has [name of family member]'s death affected your wife/husband/ partner?
- 2d. How has \_\_\_\_\_'s death affected [children in the family]?
- 2e. How has the death affected your other relatives?

I would like to ask you some questions now about palliative care and bereavement care, and the contact you have had with health care professionals regarding [family member's] death.

III. KNOWLEDGE OF PALLIATIVE AND BEREAVEMENT CARE

3a. Have you ever heard of palliative care?

3b. What do you know about palliative care?

- *beliefs about services*
- *knowledge about services*
- *myths and superstitions*

3c. Have you ever heard of bereavement care?

3d. What do you know about bereavement care?

- *beliefs about services*
- *knowledge about services*
- *myths and superstitions*

IV. NEED FOR SERVICES AND EXPERIENCES WITH SERVICES

4a. What kind of support have you received for dealing with [name of family member]'s death? From where did you receive support? (*Organizations, churches, health clinics, informal social network? Have a list of some suggestions to use as probes to help people know what you are asking about*). Who initiated it?

4b. Before or after [the family member] passed away, did any health care professional involved in the [family member]'s care mention to you about bereavement support? What did they tell you?

4c. What, if any, contact have you had with health care professionals involved in [the family member]'s care since [the family member] died? Have you and / or your family members received support from any health care professionals other than those who were involved in the family member's care? Tell me about them.

- *phone / mail / visits*
- *attendance at funeral / memorial*
- *support groups*
- *counseling*
- *who initiated?*
- *when did that happen?*
- *wished for anything different?*

4d. Who / Which outside organizations offered services? Who initiated? What did they offer? When did that happen?

- 4e. Which service(s) did you use? Why or why not? When and what happened? How did you benefit (or not) from these services?
- 4f. Have you ever sought help yourself? When did that happen? Why / why not? Where did you go? Who did you talk to? What happened?
- 4g. Did you encounter any difficulties when you tried to access services for you and your family? If yes, what are they?
- 4h. Do you think you have a need for bereavement support services from outside organizations? Why / why not?
- 4i. When did you start to realize that you need bereavement support services?
- 4j. How do you think you benefitted / will benefit or NOT benefit from bereavement care?
- 4k. Do you think Chinese families in general have a need for bereavement care? Why / why not?
- 4l. How do you think Chinese families in general would benefit or NOT from bereavement care?

#### V. ASSESSMENT OF SERVICES

- 5a. (IF HE / SHE HAS ACCESSED SERVICES) How do you feel about the bereavement services you have used? What did you feel good about? What about things that made you unhappy?
- *expectations / confidence*
  - *personal / family involvement*
  - *quality of care*
  - *comfort providing care*
  - *staff assistance*
  - *staff gender*
  - *staff language and culture*
  - *barriers to better care*
  - *wished anything was done differently*
- 5b. (IF HE / SHE HAS ACCESSED SERVICES) What was the most helpful bereavement service(s) you received? Can you give me an example – tell me what happened. How about the least helpful? Why? Ask for another example.
- 5c. (IF HE / SHE HAS ACCESSED SERVICES) How did you feel about palliative and bereavement care before receiving services? How about now?
- *cultural beliefs*
  - *expectations*
  - *myths and superstitions*

- 5d. (IF HE / SHE HAS ACCESSED SERVICES) What would you want more or less?
- 5e. Thinking back over your whole experience, who do you think were the people who helped you the most? What did they do that was helpful? Ask for an example. How about those that were the least helpful? Why? Ask for an example.
- *family*
  - *hospital staff*
  - *community*
  - *church*
  - *support groups*
  - *counseling or therapy*
  - *others*
- 5f. What services do you think should be offered to bereaved Chinese families?
- 5g. How can we improve current services to encourage more bereaved Chinese families to use them?
- 5h. (IF HE / SHE HAS ACCESSED SERVICES) Based on your experience with bereavement services, what are the services that you feel are sensitive to bereaved Chinese families' needs? What services, behaviors etc. are inappropriate / foreign / insensitive to typical Chinese families? Ask for examples.
- *hospital staff's attitude, language and cultural competence*
  - *language and cultural barriers*
  - *nature of services*
  - *Western philosophy of bereavement services vs Chinese culture*
- VI. FINAL QUESTIONS
- 6a. What advice/ suggestions/recommendations would you give to other families who face similar circumstances with their family member?
- 6b. Are there any advice/suggestions/recommendations you would give especially to another Chinese family?
- 6c. What advice/ suggestions/recommendations would you give to professionals who care for families under similar circumstances?
- 6d. Is there anything we haven't asked that you would like to add?
- 6e. Do you have any comments about the interview? What was it like to participate?

That concludes all the questions I have for you. What you have shared is extremely valuable and will help us provide better care to other families in the future. Please don't hesitate



to contact us if there is anything else you think of that you would like to tell us, or if you have any questions about this project. Thank you again.