

**Unique Care Giving Issues for
Family Caregivers of
Chinese and South Asian Older Adults**

by

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Abstract

The purpose of this meta-ethnography was to synthesize qualitative studies on the unique care giving contexts of South Asian and Chinese caregivers and care receivers, and to gain an understanding of the systemic factors that influence their care giving contexts. A broad search of the literature on South Asian and Chinese caregivers and care receivers was conducted and 22 journal articles were selected which met the inclusion criteria for the meta-ethnography. The systematic synthesis of the literature according to the Meta-Ethnography procedures laid out by Noblit and Hare (1988) revealed two dominant themes: (1) The Personal is Political and (2) Becoming an Ally. These interpretations illuminate the care giving contexts under discussion. They are especially beneficial for understanding the challenges and systemic issues which contribute to the care giving contexts of South Asian and Chinese groups.

Keywords: Ethnocultural minority older adults; immigrant; older adult; health; care giving; carers

*To my husband Dave and my daughter
Cyenna...*

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1. Introduction

The older adult demographic in Canada is expected to nearly double in size, reaching 24% of the total population, by the year 2031 (Statistics Canada, 2010a). Interestingly, the ethnocultural minority community represents one quarter of this aging population, which clearly indicates a need for greater understanding of their care giving contexts (Koehn and Kobayashi, 2011). The literature on ethnocultural minority family caregivers and care receivers is limited (Leung and McDonald, 2006). That which is available reports that informal care giving is a common activity in many Canadian families and has been taking place for decades (Henderson, 2002). Informal care is a valuable service provided to older adults by their families and friends, whereas formal care is provided by community organizations and long-term care services (Pyper, 2006). The baby boomers, aged 45-64, represent the largest group of informal caregivers to about 2.3 million older adults with physical or cognitive disabilities.

Not only does care giving benefit the caregiver and care receiver, it also benefits society. The greater community reaps many rewards when citizens take personal responsibility for looking after their loved ones. For example, such caregivers save the Canadian health care system billions of dollars by providing in-home care and they greatly increase the feasibility of care receivers living independently for as long as possible (Sawatsky and Fowler-Kerry, 2003; Research on Aging Policies and Practice, 2010). Likewise, older adults make valuable contributions to society and to their families. Some older immigrants participate in the paid workforce while others provide childcare for their grandchildren, which allows their adult children to work outside the home (McLaren, 2006).

Although there is substantial research that explores patterns of family care giving across the general populace, very little literature exists on care giving in the context of ethnocultural minority populations (Leung and McDonald, 2006). The majority of family care giving research has studied 'Western' cultural habits, making it difficult to generalize

results to ethnic minority cultures (Kim and Lee, 2003; Knight, Longmire, Dave, Kim, and David, 2007). The care giving experiences of ethnocultural minority populations warrants a separate inquiry because minority caregivers face unique issues that are compounded by aging, immigration and settlement factors (Newbold and Filice, 2006).

Newbold and Filice's (2006) study on the health status and health-seeking behaviours of ethnic minority populations in Canada has identified differences between them and Canadian-born individuals. A well-established phenomenon known as the healthy immigrant effect hypothesizes that immigrants who are in good health at the time of their arrival in Canada see their health status decline over time and come to resemble that of their Canadian-born counterparts (Gee, Kobayashi, and Prus, 2004; Newbold and Filice, 2006). At this convergence between the health statuses of the two groups, factors including aging, length of time in Canada, lifestyle choices, help-seeking behaviours, and social and cultural factors may affect overall health and health-seeking behaviours to varying degrees.

The healthy immigrant effect is well established for those aged 64 and under; however, its applicability to the older immigrant group (aged 65 and over) is questionable (Gee, Kobayashi, and Prus, 2004; Newbold and Filice, 2006). Further research is required to examine the healthy immigrant effect in relation to the intersections between socio-demographic, immigration, and health variables (Gee et al., 2004, p.57). For example, Gliberman (1998 as cited in Gee et al., 2004) argues that age is the single most important predictor of health problems. Notably, Gee et al. (2004) and Newbold and Filice (2006) report that the older adult group does not share the same healthy advantage as their younger counterparts when they arrive in Canada; in fact, they report poorer overall health. It should be kept in mind that these older immigrants must also cope with acculturation issues that can limit their ability to access new knowledge and healthcare.

The available literature in Canada concentrates on Chinese and South Asians more than any other ethnocultural group, with approximately 45% of the studies reflecting Chinese populations and one quarter representing South Asian (Khamisa, Koehn & Health of Ethnocultural Minority Older Adults Scoping Review Team, 2010). Regrettably, studies will often bracket many different ethnocultural groups under one

classification—‘Asian’, for example—without categorizing the unique characteristics and experiences that contribute to their heterogeneity (Koehn, Neysmith, Kobayashi, and Khamisa, 2013). Therefore, the Chinese and South Asian populations of older adults considered in this research were selected in order to go beyond what any single study can offer in terms of insight into common factors across studies; this was the reason for the completion of a meta-ethnography.

By focusing on each construct separately, the literature also neglects the interacting effects of aging and ethnicity. Koehn et al. (2013, p.18) argue that there is a need to understand the “intersecting oppressions experienced by visible minority older adults, especially women.” They add that although “multiple variables are often recognized, they are poorly understood in terms of their contribution to inequities in health or health care access...[and]... are rarely situated in the context of systems characterised by power imbalances and discrimination (p.18).” That is to say, perceptions of inequities and discrimination are unique to the intersections of identity experienced by individuals and are shaped by those individuals’ experiences within their social and political environments (Koehn and Kobayashi, 2011). These oppressions can be mitigated, intensified and/or reinforced through public policy.

Given the limited attention paid to considering the interacting effects of multiple variables that shape how individuals situate their experiences and shape their identities, a critical perspective is needed when examining the literature on this topic. The meta-ethnography provides a means by which the unique care giving contexts of South Asian and Chinese caregivers can be illuminated and discussed in the context of power imbalances, class and gender differences, and immigration and settlement factors.

Immigrant caregivers and care receivers face distinct challenges in a new country where their traditional values of caring may not be the same as our own or can easily be misunderstood by the majority of the population. The primary research question to be addressed by this meta-ethnography is thus, In what ways, if any, are care giving contexts unique for Chinese and South Asian care givers and care receivers?

Closely examining the unique care giving contexts of the South Asian and Chinese segment of this demographic will give service providers and policy makers a vital understanding of issues that seriously affect many citizens, and in turn the populace in general. Further, this meta-ethnography might offer support for the creation of new and innovative services that address certain unique, currently unmet, needs. Ideally, it will also illuminate intra-group and inter-group care giving contexts between South Asian and Chinese immigrant groups

2. Methodology

The methodology selected to synthesize the literature on the unique care giving contexts of South Asian and Chinese immigrants is the meta-ethnography. Other approaches to the synthesis of qualitative research include: cross-case analysis, case survey, and multiple exemplar strategies (Britten, Campbell, Pope, Donovan, and Morgan, 2002). The meta-ethnography is considered the most appropriate for reviewing a small sample of papers and it is viewed as the most developed methodology for the synthesis of qualitative research (Dixon-Woods, Cavers, Agarwal, Annandale, Arthur, Harvey, Katbamna, Olsen, Smith, Riley and Sutton, 2006). It goes beyond the customary literature review by extracting key concepts which are then compared and translated across the studies under examination. This method is reflexive and encourages the constant comparison of key concepts and metaphors across the selected literature to form a holistic interpretation of ethnographic accounts. An interpretation of the literature elucidates the underlying meaning of the text and the interconnections among concepts with “the goal of enhancing human discourse” (Noblit and Hare, 1988, p.18).

Meta-ethnography is an interpretive approach to the synthesis of qualitative studies. Interpretive research includes studies that are “ethnographic, interactive, qualitative, naturalistic, or phenomenological” (Noblit and Hare, 1988, p.12). The interpretive paradigm explains social and cultural phenomena through emic accounts, which refer to the participants’ perspectives and stories. The goal is for researchers to take these ethnographic accounts and make sense of them in order to elucidate the meaning of the data across the studies. This is done by reducing individual ethnographic accounts to key metaphors or concepts, which are grouped based on commonalities and interpreted to identify overarching themes. These overarching themes form the synthesis.

Given the interpretive nature of the meta-ethnography, a synthesis is inevitably influenced by the personal and professional bias of the researcher and his or her level of knowledge of the particular area (Noblit and Hare, 1988). A meta-ethnographic synthesis refers to a process that takes individual parts or components of a study and organizes them innovatively to form a holistic representation. Noblit and Hare (1988) assert that any interpretation of the data or selection of metaphors is unique to that synthesis and will differ based on the reviewer's interpretation of the same metaphors. Thus, the synthesis is based on the researcher's perspective and values. Using a meta-ethnographic approach allows the researcher to make inferences from the data, which is considered a strength of interpretive research. Scientifically speaking, quantitative studies are highly valued and respected, but very little is said about the amount of preparation and reflection required by the researcher when examining the quantitative data (Pawson, 2003). This type of methodology demonstrates that all research, whether it is qualitative or quantitative, is interpretive because it involves considerable introspection and interpretation on the part of the researcher.

2.1. A Meta-ethnographic Approach

A meta-ethnography involves a series of dynamic phases. The researcher identifies an area of interest, reads the ethnographic accounts, identifies key concepts and metaphors, determines how the studies are related and groups them accordingly, translates the ethnographies into analogies, synthesizes them, and, finally, yields the synthesis (Noblit and Hare, 1988). Noblit and Hare (1988) argue that to properly conduct a meta-ethnography, one needs to move through seven phases, as follows:

2.1.1. Phase 1: Getting started

The first step in the meta-ethnography was to identify an area of interest that was appealing to me but was also "worthy of the synthesis effort" (Noblit and Hare, 1988, p. 27). With collaboration from my supervisory committee, I came up with a research question, the worthiness of which had already been established in my previous coursework on care giving. The research question is: In what ways, if any, are care giving contexts unique for South Asian and Chinese caregivers and care receivers? As

the qualitative studies are read, however, the initial topic of interest may transform or adjust to reflect the new insights emerging from the literature.

Target population

Manuscripts were included in this meta-ethnography study if they focused on the experiences of immigrant adult child caregivers and/or care receivers of South Asian background, or Chinese background, or both. These two groups were selected because they represent the largest ethnocultural minority communities in Canada according to the 2006 Canadian Census (Statistics Canada, 2010b). Also, the Chinese and South Asian communities represent the largest ethnocultural groups living in extended family systems; fewer than 10% of older Chinese and South Asian adults live alone, compared to about 30% of the rest of the older adult population. These two groups were also selected for this meta-ethnography study because of their significant representation in the literature (Koehn et al., 2013).

It is important to note, however, that Chinese and South Asian populations are extremely heterogeneous and arrive from many different countries and as part of diasporas of various origins. This contributes to their diversity and unique experiences within their cultural group (Koehn et al., 2013). Their experiences are further heightened depending on their respective immigration categories, such as economic or family-class immigrants, and whether they immigrate earlier or later in life.

2.1.2. Phase 2: Deciding what is relevant to the initial interest

The second step of the meta-ethnography is determining its scope and setting appropriate parameters on the inclusion criteria of the literature (Noblit and Hare, 1988). I conducted a literature search using a variety of techniques: searching electronic bibliographic databases (e.g. Ageline, PsycINFO, CINAHL, Medline, and Social Sciences Full TEXT), searching grey literature on Google, hand-searching bibliographies of relevant journal articles, and eliciting recommendations of relevant literature from scholars in the field. After a thorough search, 22 journal articles that met the inclusion criteria were included in the meta-ethnography study (see Appendix A for a list of included manuscripts).

Inclusion criteria

A meta-ethnography is a focused and systematic method of conducting a synthesis of the literature, quite different from a traditional narrative literature review. It features the setting of filters, or inclusion criteria, because too broad an inclusion of the literature will result in an unfocused review and data too cumbersome to organize. Thus, this project included secondary data in the form of qualitative studies and mixed method studies conducted in the past 20 years. Manuscripts were included if they focused on the experiences of immigrant adult child caregivers and/or care receivers of South Asian background, or Chinese background, or both. Studies that included additional populations were considered if one of the main target groups was significantly represented; studies exclusively focusing on spousal caregivers were excluded; relevant journal articles and grey literature were included to contextualize the various themes.

Although this project focused on the Canadian context, studies conducted in the United Kingdom, Australia, New Zealand, and the USA were included since these countries, with the exception of the USA, share somewhat similar health care systems (Koehn et al., 2013). Studies conducted in the USA represent a significant number of published studies given its large population as compared to Canada and the UK, for example. Thus, US studies were reviewed carefully to ascertain that they met the inclusion criteria fully.

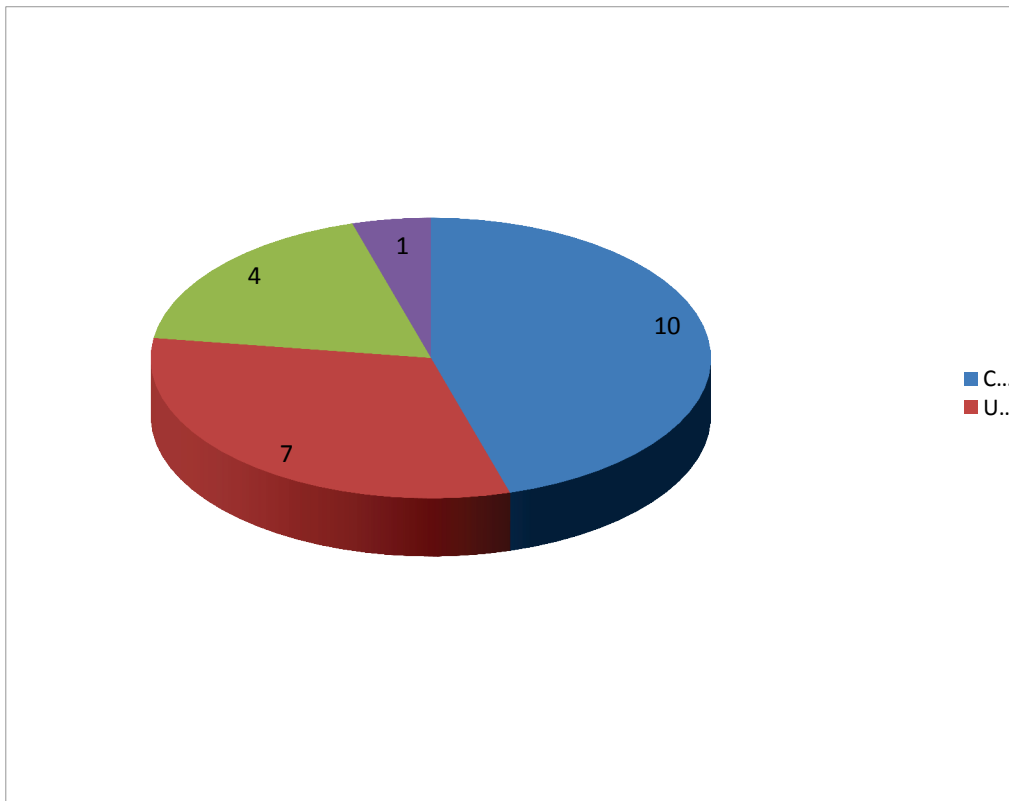


Figure 1. Study locations of research represented in the papers selected for review (N=22)

Figure 1 is a graphic depiction of the countries in which studies were conducted across the 22 papers included in this review. The pie chart shows that ten of the included studies were conducted in Canada, followed by seven in the USA, with four in the UK, and one from Australia. The inclusion of these qualitative papers reflects the study inclusion criteria and the focus for this meta-ethnography. Notably, it is not a representation of the literature on ethnocultural minorities, nor does it comprehensively survey the literature on South Asian or Chinese populations; therefore, this study should not be viewed as exhaustive.

2.1.3. Phase 3: Reading the studies

The third step of the meta-ethnography involved thoroughly reading and making note of the emerging concepts. In addition to these concepts, I noted important study details, including: study title, sample, data collection methods, purpose of the study,

setting, and any methodological issues, in order to identify the study and to contextualize the themes.

2.1.4. Phase 4: Determining how the studies are related

The fourth step involved reviewing the 22 studies for common and recurring concepts. The emerging concepts were: Gendered nature of care giving; filial piety; individual and group decision-making processes; social capital and the role of informal support; health and health-seeking behaviours; access to and utilization of health and social services; gatekeepers; and, overcoming stigma and shame.

Table 1 provides an example of one study to illustrate how the data was organized, with each study listed in columns and the emerging concepts placed in rows. The first six rows pertain to key study details, which include: study title, sample, data collection methods, purpose of the study, setting, and methodological issues. From the seventh row onwards, each cell represents a key concept. This systematic approach helped preserve the individual ethnographic accounts by ensuring these were not lost through the synthesis. It also served to ensure the trustworthiness of the data; in qualitative research, trustworthiness brings rigor into the research process through the use of specific strategies during the data collection and analysis phases (Guba, 1981). A systematic approach calls for the detailed description of the analytic process and results so that readers can assess the strengths and limitations of the study, and have an understanding of the analytical process (Elo and Kyngas, 2007).

Table 1. Sample of tabulated study details and key concepts

Methods and Concepts	Ho, Friedland, Rappolt & Noh (2003)
Key Study Details	
Study Title	Care giving for relatives with Alzheimer's disease:
Sample	12 Chinese Canadian female caregivers
Data Collection	Qualitative in-depth interviews
Purpose	The purpose of this study was to explore Chinese Canadian caregiver's feelings about their experiences of providing care for relatives with Alzheimer's disease.
Setting	Canada
Methodological Issues	Ethnic minority populations are underrepresented in studies (p. 302).

Methods and Concepts	Ho, Friedland, Rappolt & Noh (2003)
Key Concepts	
Filial Piety	Children held strong filial values towards their parents
Help and Health Seeking Behaviors	Selective help and health seeking behaviors
Access and Utilization	
Overcoming Shame and Stigma	
Individual and group decision making processes	Family dynamics can make decision making problematic
Immigrant Status/Migration Experience	
Family Dynamics	Caregivers viewed care giving as positive despite competing demands.
Informal Support and Social Capital	
Gendered Caregiving	Women are usual caregivers, they require specialized knowledge on disease
Second Order Interpretations	Certain features of the Chinese culture, such as strong adherence to filial obligations can help normalize the experience of care giving for women caregivers. These care givers put their elderly family member before their needs and saw this as a natural progression of their life.

2.1.5. Phase 5: Translating the studies into one another

The fifth step in conducting the meta-ethnography involves translating the studies into one another. This was done by comparing the concepts of one paper with concepts of another paper and so forth (Atkins, Lewin, Smith, Engel, Fretheim, and Volmink, 2008). Each paper and its emerging concepts were placed into an excel workbook. Given the amount of data and size of the Excel workbook, only one study with limited data is shown to illustrate this process (see Table 1.). The empty cells represent no data for that particular study. At this point, second order interpretations from each of the studies were included in the Excel workbook (as shown in Table 1.). Second order interpretations are the researcher's interpretation of the ethnographic accounts and are "usually found in the discussion and conclusion section of an article" (Atkins et al., 2008, p.6). Although they were not utilized explicitly in the synthesis, they served as a check to ensure that I had captured the essence of each study, as interpreted by the authors, in the concepts that I had developed (Britten et al., 2002).

2.1.6. Phase 6: Synthesizing translations

The sixth step in the meta-ethnography is synthesising translations. By reading and interpreting the concepts of each of the 22 papers and each author's second order interpretations, I was able to see the commonalities between the studies, from which two main themes developed (Britten et al., 2002). In doing so, I saw that the relationships between the studies "were not refutations of one another even when a particular concept was not identified in the paper" (p. 211); rather, they seemed to be reciprocal translations of one another. Ethnographies which are about similar things or concepts are reciprocal translations of one another because the concepts of one study iteratively convert to a next translated to the next study (Noblit and Hare, 1988). A line of argument was produced based on these third order interpretations of study findings.

2.1.7. Phase 7: Expressing the synthesis

There are different approaches to expressing a synthesis in the meta-ethnography such as: a written paper, "videos, plays, art and music" (Noblit and Hare, 1988, p. 29). The selected approach is based on the audience and what form of synthesis they would appreciate. For the purpose of this academic project, a written paper was selected to synthesize the literature on the care giving contexts of South Asian and Chinese caregivers/care receivers.

2.2. Paradigmatic Position

Given the interpretive nature of a meta-ethnography, it becomes important for the researcher to be transparent about her paradigm because it is essential to the readers' understanding of how the synthesis is contextualized and the biases that emerge from it. My paradigmatic position is based in the Critical Paradigm in which Feminism is subsumed. Critical and Feminist paradigms challenge the status quo to highlight inequities and differences based on class and gender (Bengston, Gans, Putney, and Silverstein et al., 2009; Kincheloe and McLaren, 2011). Notably, some researchers refer to the Critical paradigm as a theory; however, it is much more than this. It extends beyond theory to uncover underlying beliefs of society by recognizing that social

experiences are shaped by power imbalances, and the social and historical context (Kincheloe and McLaren, 2011, p. 139). Thus, it is “concern[ed] with the social construction of experience” (Kincheloe and McLaren, 2011, p.139). These two paradigms influenced how I interpreted the emerging concepts from the studies. Furthermore, they enabled me to understand the broader yet invisible characteristics that influence the care giving contexts of South Asian and Chinese caregivers and care receivers. As Koehn and Kobayashi (2012, p.133) emphasize, there are differences within the older adult population based on their “socially defined characteristics such as gender, race, class, sexuality, immigration status and so on” that place ethnocultural minority older adults in a more vulnerable position. By adopting a critical paradigm, I was able to assess the influence of these intersections on the lives of caregivers and care receivers.

The Critical and Feminist Paradigms allowed me to explore the individual within the context of his/her historical, social, and psychological context. Also, their application to the discussion on the gendered nature of care giving and filial piety was particularly helpful in understanding how family roles are defined and distributed based on hierarchy and gender (Ho, Friedland, Rappolt, and Noh, 2003). As a result, the Feminist theory helps to explain the gendered nature of care giving and what conditions help to maintain it. Furthermore, it examines how patriarchy perpetuates hierarchy, specifically privileging men over women. Moreover, Feminist theory can facilitate understandings of family dynamics; specifically, “relationships between adult children and their aging parents and parents-in-law” (Bengston et al., 2009, p. 524). Familial ties and relationships can be “structured by gender and kinship” (p.524), which aids in explaining how family roles and instrumental activities such as paid work and domestic work are structured by gender.

An important caveat of Feminist theory is that many women have criticized it for “neglecting racial oppression and failing to address the concerns of women of color” (Case, 2012, p. 80). For example, Patricia Hill Collins who wrote extensively about Black feminist thought highlights that women of colour face oppression due to the interacting effects of multiple oppressions, such as race, gender, and class (Collins, 2000). She acknowledges that feminist theory may appear to be all encompassing of women’s struggles at the surface level but in actuality it is based on the struggles of

white middle-class women. Thus, an anti-racist position or black feminist position brings to the forefront the multiple interacting oppressions faced by ethnocultural minority individuals. In response, feminist anti-racist researchers have argued for the “analysis of whiteness, racism, and anti-racism among White women” (p. 81). The anti-racist position will reveal how systemic barriers to help- and health-seeking and access to services prevent many ethnocultural minority caregivers and care receivers from getting the necessary support and care they require.

Anti-racist feminist theory thus maintains that the complex issues facing vulnerable groups require an assessment of the intersecting variables that shape the experiences and identity of the individual (Bengston et al., 2009). The premise behind this is that gender is only one variable that shapes the identity of individuals, but there are many other factors, such as ethnicity, class, age, and immigration history, which contribute to their unique identities and experiences. Thus, a multiple/triple jeopardy theory is incorporated into this analysis to demonstrate how factors such as age, sex, race, and class elevate certain groups over others (King, 1988). These factors are not additive; they are interdependent and compound to shape one’s experience and social position. The analysis of intersecting variables can help to identify whether a group is privileged, oppressed, and/or marginalized based on these intersecting variables (Bengston et al., 2009). Matsuoka et al. (2012) echo these sentiments and emphasize the need to examine interacting effects of micro, mezzo, and macro factors, which are unique to a subset of the immigrant population, specifically those who are sponsored by their adult children.

It is important to state my specific position within these paradigms since it is enmeshed in the analysis of this study. I am a Canadian-born Indian woman, a child of immigrants who were born in India and immigrated to Canada in the late 1970s. I was born and raised in Canada. As I reflect on the course of my pre-teen years to young adulthood today, I am perplexed by the different labels of identity I negotiated between such as: “Indo-Canadian, Canadian, Indian, and South Asian”. I felt I was not fully Canadian or Indian, but somewhere in-between both. It is not until I started university that I started to question my identity and to think more critically about the reasons for feeling divided between two cultures. Learning about theories that question identity and social experience allowed me to critically examine my social identity. I learned that my

identity as a woman of colour influences how I view the world around me, and how I engage in critical reflection about issues. This is evident in my work as a health care social worker. I am aware that my identity and experiences influence my practice. I recognize how my identity as a young, visible minority woman influences my work with clients with respect to interpreting and assessing their psychosocial issues.

2.2.1. *Theoretical framework*

The theoretical framework appropriate for the meta-ethnographic approach is the translation theory of social explanation. In alignment with the 7-phase process outlined above, Turner (1980 as cited in Noblit and Hare, 1988) argues that social explanation is relative and interpretive. Three core features of this theory go hand in hand with a meta-ethnography. The first dimension of the theory emphasizes that all social explanation is relative; secondly, the creation of analogies through translation is critical because it maintains the observed individual account even after it has been interpreted through the synthesizer's paradigm; and lastly, "social explanation must be inductive and framed in terms of comparison of cases" (p. 30), which allows readers to form their own interpretation or understanding while maintaining the gist of the participant's ethnographic accounts. These three steps produce first and second order constructs which in this study will be synthesized to produce third order interpretations that in turn explain the unique care giving contexts of South Asian and Chinese caregivers and care receivers.

3. Findings

After a thorough literature search, followed by the organization and analysis of my data, the final step in my analysis involved listing emerging concepts and their code descriptions on two large poster boards. After carefully reviewing and reflecting on these emerging concepts and descriptions, I was able to see the commonalities between and among the concepts. On one hand, I saw that the concepts were speaking to much broader issues that were political in nature in terms of power imbalances by gender and age between men and women and the young and old. On the other hand, I noticed that many ethnocultural minority care givers and receivers faced structural issues related to incongruent health and social care services and sponsorship policy which prevented many from seeking help and/or gaining access to appropriate services. These structural and systemic issues intensify power inequities and oppressions experienced by older ethnocultural minority adults and limit their opportunities to become independent and productive members of society. This process revealed two overarching themes that help explain the unique care giving contexts of South Asian and Chinese caregivers and care receivers: *The Personal is Political* (Hanisch, 2006) and *Becoming an Ally* (Bishop, 1994). Both of these thematic groupings reflect the legacy of feminist and anti-racist works that have inspired my interpretations.

The first theme, 'The Personal is Political' will discuss the experience of caregivers and care receivers in the context of power imbalances and discrimination as a result of social and political factors (Hanish, 2006; Man Ling Lee, 2007; Cullen, 2000). Several concepts from the literature illuminate some of the inequities faced by South Asian and Chinese caregivers and care receivers. These include: the gendered nature of care giving; filial piety; individual and group decision-making processes, and social capital, and the role of informal support. The theme 'The Personal is Political' will discuss how these concepts influence the personal lives of caregivers and care receivers and shape their personal and social identities within their care giving contexts. The 'Becoming an Ally' theme is a critical interpretation of the challenges ethnocultural

minority caregivers face in a mainstream society that neglects the unique characteristics of a diverse population through systemic barriers that affect help- and health-seeking behaviours and, thus, access to health and social care resources. This overarching theme will cover: help- and health-seeking behaviours; access and utilization of health and social supports; gatekeepers; and, overcoming stigma and shame.

3.1. The Personal Is Political

The slogan ‘the personal is political’ was coined by Carol Hanisch, who was a pioneer of feminism and a leader in the Women’s Liberation Movement in the 1960s (Hanisch, 2006). This phrase captured the essence of existing power differentials between men and women, which positioned women as unequal in society. Women’s Liberation groups drew attention to the limited opportunities for women in the paid work force, for example. Many social justice groups affirmed the need for women to be recognized and afforded equal opportunities, but with some reservation about women’s personal problems being politicized. Women were blamed for their own oppression, and disputes around housework and child care, for example, were considered problems between husband and wife. Taking the onus off women for individually addressing their practical difficulties and recognizing that the issues they faced were a reality of gender and class differences rather than a lack of ability to assert themselves, was the ammunition behind the Women’s Liberation Movement.

Carol Hanisch’s paper “The Personal is Political” was widely distributed across the globe during the Women’s Liberation Movement (Hanisch, 2006). She used the slogan to portray and emphasize “that there were political dimensions to private life, that power relations shaped life in marriage, in the kitchen, the bedroom, the nursery, and at work” (Man Ling Lee, 2007, p.163). It is this politicization of women’s problems that paved the way for future generations of women to have free will and equal opportunities in society. However, Cullen (2000) suggests that to some extent this might not be true at present. Cullen (2000) reflects on her teaching experiences in a Canadian management school during the year 2000. She found stark differences between how she and her students perceived women’s equality. During class discussions, the students revealed that they saw inequalities as resulting from how women defined and

asserted themselves in society rather than stemming from political dimensions (p.3). It is revealing that, although afforded equal opportunities and showcased as independent, intellectual, and as change agents, many women are to this day “constrained by such limits as age, class, ethnicity and so on” (p.5).

Given that women’s personal lives and decisions are rooted in politics, the slogan “the personal is political” is an appropriate interpretation of the qualitative research on care giving specifically relating to several key concepts that emerged from the literature. These concepts include: the gendered nature of care giving; filial piety; individual and group decision-making values and processes; and, social capital and the role of informal support. These concepts will illuminate how the political dimensions discussed here, influence women caregivers and care receivers in terms of how they define their identities in a new country, how they negotiate traditional values with new economic and social realities, and how they try to provide care to their loved ones despite the constraining effects of immigration policy.

3.1.1. *Gendered nature of care giving*

The gendered nature of care giving is not only specific to the Chinese and South Asian cultures, but is a common feature of all cultures (Henz, 2009; Ho et al., 2003; Leung and McDonald, 2006; Neufeld, Harrison, Stewart, Hughes, and Spitzer, 2002; Pyper, 2006;). The majority of caregivers are female adult children and spouses (Ho et al., 2003; Leung and McDonald, 2006). Around the globe, women are seen as the most natural caregivers (Bowes and Wilkinson, 2003; Spitzer, Neufeld, Harrison, Hughes, and Stewart, 2003).

In eastern cultures, it is more common for women than men to be the sole source of care giving within the family framework, as they are expected to look after their spouses, children, and parents and/or parents-in-law after marriage (Ho et al., 2003; Jones, Zhang, Jaceldo-Siegl, and Meleis, 2002; Katbamna, Ahmad, Bhakta, Baker and Parker, 2004; Leung and McDonald, 2006; Spitzer et al., 2003). Katbamna et al. (2004) found, moreover, that women caregivers viewed their caring role as a natural, anticipated duty and responsibility. This duty to provide care not only directly benefited older care recipients, but was an indirect benefit to future generations of caregivers.

Specifically, women were seen as teachers who would instill in their children values of elder care through role modeling and the demonstration of reciprocity in relationships (Spitzer et al., 2003).

Some caregivers felt very strongly about elder care despite situations where they had very little support from their siblings; they wanted to demonstrate the importance of caring for elderly parents so that their children could not question their filial values (Spitzer et al., 2003). This commitment to caring was reinforced in their efforts to maintain a respectful position within the community. For example, some caregivers in Spitzer et al.'s (2003) and Aroian, Wu, and Tran's (2005) studies reported that it was important for them to dedicate themselves to fulfilling their roles as spouse, mother, daughter, and caregiver since they believed their community would not accept them if they were not meeting their obligations.

The global view that women are the most appropriate caregivers is reinforced in some cultures through traditional values around elder care and through women's desire to care for their families. The balancing of multiple roles, and women's demonstrations of a caring attitude towards their families and the community, are political dimensions of care giving that are acquired and learned through societal values, norms, and expectations about women's roles (Spitzer et al., 2003). Thus, women's desire to provide care to their families and aging parents, and the expectation that they will provide care to family members are features of a patriarchal society, and a core element of filial piety which reinforces these gendered roles. It also widens the power imbalances between men and women, and between the older and younger generation within the family framework. The specific focus on hierarchy based on age and gendered roles prevent many women and younger members of the family from expressing their needs or offering their input in a way that would be received as important or equal within the family. It also leads to the unequal distribution of work within the family, with daughters in law having to shoulder the responsibility of care for their family members including, their children, aging parents' in law, and spouses after marriage all the while having to balance competing demands and paid-work.

Balancing the desire to provide care with multiple roles

Chinese and South Asian caregivers and families participating in some studies expressed their hope of providing care to their older family members despite the challenges faced in a new country (see especially Jones et al., 2002; Katbamna et al., 2004; Neufeld et al., 2002). Many South Asian and Chinese women caregivers balanced multiple roles: mother, wife, daughter, employee, and caregiver (Jones et al., 2002; Neufeld et al., 2002). In the countries to which they had immigrated, the women had adopted new roles, but they were also expected to maintain their care giving roles (Leung and McDonald, 2006; Neufeld et al., 2002). Many of the women in the studies, who were caring for their parents or parents-in-law, reported that they did not have enough time for themselves or their spouses and young children; they found it difficult to manage multiple roles and demands (Bowes and Wilkinson, 2002; Jones et al., 2002; Neufeld et al., 2002; Spitzer et al., 2003). Some even suggested that their spousal relationships suffered, while others felt depressed and isolated because their caring duties consumed their days (Spitzer et al., 2003). Others reported feeling stress with competing demands and not having enough time for their own families (Ho et al., 2003). Chinese caregivers reported feeling a loss of self with respect to not knowing who they were anymore since their lives were consumed with caring for their elderly family members. They sacrificed nuclear family life and social life in order to uphold their desire to provide care to their parents and/or parents-in-law.

However, some caregivers carefully planned their days to ensure that their familial obligations and paid work were organized so that they could fulfill all of their duties (Spitzer et al., 2003). For example, one caregiver reported how she got up early in the morning to prepare both breakfast and lunch for her elderly family member before she went to work, and when she returned home she would prepare dinner and complete her evening care (e.g. medications, bath). Some caregivers highlighted the benefits they received from their older family members. For example, one caregiver in Spitzer et al.'s (2003) study felt a sense of happiness and love when she returned home from work to see her older family member waiting by the window for her. Despite the challenges associated with caring and the multiple roles that women negotiate, their desire to fulfill all roles demonstrate their dedication to caring for their families.

Despite balancing care giving duties with their other roles, the women reported that the support of their husbands afforded them the strength to cope (Katbamna et al., 2004; Spitzer et al., 2003). Some women caregivers wanted to feel appreciated by their families for their efforts and desired the support of their families in situations where they were unable to cope and required the assistance of outside help to alleviate the pressures of care giving (Bowes and Wilkinson, 2003; Katbamna et al., 2004; Spitzer et al., 2003; Neufeld et al., 2002)

It is important to consider that although women are seen as the preferred caregivers, there are some idiosyncrasies. For example, Koehn, Spencer, and Hwang (2010) point out the cultural inappropriateness of South Asian elders residing with their married daughters. This can be problematic in situations where a parent's immigration to Canada is sponsored by a son who no longer wishes to have his parents reside with him or in situations where the sponsored older immigrant is being abused, neglected or mistreated. The co-residence with a daughter is viewed as dishonourable because "there's...huge stigma of showing up the son, exposing the family's honour to public shame, and in taking him to court" (p. 35). Similarly, one Chinese participant with dementia felt a great deal of stress knowing that her son did not uphold his filial obligations to her; rather, it was her daughter who was obliged to provide care (Koehn, McCleary, Garcia, Spence, Jarvis, and Drummond, 2012, p. 50). Some elderly parents hoped to be cared for by their sons even if that meant him just being present (Spitzer et al., 2003).

3.1.2. *Filial piety*

Chinese and South Asian caregivers spoke positively about aging and the respect traditionally attributed to the elderly in their countries of origin (Ho et al., 2003; Lawrence et al., 2008). In situations where elderly Chinese family members were invited by their adult children to the host country, some wanted to demonstrate their love and dedication to their parents and repay them for their love, kindness, and nurturing (Ho et al., 2003; Jones et al., 2002). Similarly, South Asian caregivers viewed care giving "as an opportunity to reciprocate past love and support" to their parents (Lawrence et al., 2008). In Lawrence et al.'s (2008) study, some South Asian participants did not have

the opportunity to form strong bonds with their parents, and for this reason they wanted to strengthen their family ties by providing support and care to them.

A growing body of research indicates that cultural values and belief systems about care giving may influence expectations and responsibilities of care giving and how caregivers perceive elder care (Gupta and Pillai, 2002; Ho et al., 2003; Leung and McDonald, 2006; Lo and Russell, 2007). One example of this is filial piety, which is a traditional cultural belief and value system that is common to many eastern cultures (Leung and McDonald, 2006). Filial piety is based on the expectation of reciprocal relationships between children and parents. Adult children are expected to care for their aging parents; a value that is not as evident in non-Asian populations (Bowes and Wilkinson, 2003). Filial piety in the traditional sense dictates who provides care, and the distribution of the care work. For example, within the context of filial piety, gender roles are clearly defined and the responsibility for elder care giving usually falls on the eldest son and his wife (Ho et al., 2003; Hicks and Lam, 1999). The emphasis on gender and age within filial piety are elements of a culture that is patriarchal and hierarchal.

Typically, the daughter-in-law provides the practical aspects of care while the son conducts the non-domestic activities that align with being the breadwinner of the family (Bowes and Wilkinson, 2003). Furthermore, adult children are expected to do whatever they can to meet their filial obligations towards their parents and are expected to exhaust whatever resources are necessary before resorting to formal care (Ho et al., 2003). Many of the adult children and caregivers in the literature were strongly committed to their filial values regarding their parents (Aroian et al., 2005; Hicks and Lam, 1999; Ho et al., 2003; Lawrence, Murray, Samsi, and Banergee, 2008; Spitzer et al., 2003; Leung and McDonald, 2006). The personal love towards their parents and the desire to care for them at all costs is politically motivated through traditional filial values. This caring behaviour and attitude demonstrated the ideal behaviour which defined whether one was a good son or daughter in the eyes of the parent and community (Lawrence et al., 2008).

Living arrangements

Multi-generational families are common across Chinese and South Asian communities (Leung and McDonald, 2006). Fewer than 11% of South Asian and Chinese elders live alone in Canada. However, some older ethnocultural minority

parents prefer to live alone (Lo and Russell, 2007). Some older Chinese persons expressed their desire to live separately from their families in seniors' housing so that they could be self-reliant and "not dependent on their adult children" (Aroian et al., 2005, p. 101). Similarly, in Lo and Russell's (2007) study, one elderly Chinese participant spoke about her desire to live separately from her family, to be self-reliant, and have financial freedom in the event she falls ill. She had few expectations of care from her children and only desired their psychosocial support. Another couple suggested that it is best to live separately from family so that any potential conflicts can be avoided, and they did not wish to be dependent on their children; yet they were happy to receive the financial support from their children that they felt was part of expected filial duty.

Other participants who lived alone received financial and emotional support from their children, which they perceived to be "evidence [of a] good son" (Lo and Russell, 2007, p.34). One elderly parent who resided alone received a monthly allowance from her son. This support demonstrated filial values despite the fact that adult children and parents lived separately for various reasons. Other elderly parents who co-resided with their adult children experienced emotional distress when their filial values were unmet and when they experienced intergenerational conflict with their grand-children (Koehn et al., 2010; Lo and Russell, 2007; Sadavoy, Meier and Ong, 2004). This was echoed in Koehn et al.'s (2010) study where multigenerational living was a source of intergenerational conflict between grandparents who entered a household where grandchildren were acculturated; that is, where they spoke a different language and dressed differently, all of which increased differences between them.

Instrumental support

Older family members received varying levels of support from their adult children as well as formal services. Some spent weekends engaging in social and recreational activities with their children, while others received daily phone calls or daily visits to ensure that their needs were being met (Lo and Russell, 2007). Lo and Russell (2007) emphasized that the level of instrumental support received from adult children was consistent irrespective of whether the elderly parents were co-residing or living separately from them. Interestingly, elderly parents who lived alone received the most help from formal services rather than from their adult children. These older adults knew

they could rely on their family for transportation and accompaniment to appointments, yet they preferred to use formal services for this instead.

Individual and group decision making values and processes

Making daily decisions may appear to be a simple task, but when complex decisions around health care treatment come into play, so do factors that can make simple decision-making quite complicated. When individuals and families adhere to certain familial rules dictated by larger socio cultural norms, then special consideration needs to be given to how individuals perceive and interpret decision-making and how they engage others in this process. As Hicks and Lam (1999), Ho et al. (2003), Koehn et al. (2012) and Braun and Brown (2011) report, decision-making in Chinese families may be based on the philosophy of Confucianism, whereby decision-making is influenced by hierarchy. Typically, the oldest in the family makes the decisions. Everybody in the family is obliged to obey the decision-maker when that person is the parent or the firstborn son (Hicks and Lam, 1999). However, variables that might challenge or disrupt decision-making in a new country are the complexities of a new country and a system that promotes a different style of decision-making. For example, being sponsored in a new country by their adult children tends to reduce and reverse the role of elders who would traditionally hold the power and status in their families in their countries of origin (Koehn et al., 2010).

Decision-making has political dimensions in that filial piety governs who makes decisions based on hierarchy and gender, and this becomes more complicated by acculturation and the challenges encountered in a new country. For example, the family support available in an immigrant's home country is a lot different in the receiving country where kin is fragmented and dispersed. Hicks and Lam (1999), Koehn et al. (2012) and Ho et al. (2003, p.304) emphasize that Chinese people in Canada are residing in a "bicultural context"; in the event that decisions around potential institutionalization of elderly parents come into play, these decisions "may be even more emotionally complex and would be influenced by factors associated with acculturation" (Ho et al., 2003, p. 304).

The concept of free will implies that individuals are free to make decisions based on their own cognisance; however, this may not be the case for individuals who have

limited resources or are facing incongruence around decision-making in the context of health care treatment options (Hicks and Lam, 1999; Sadavoy et al., 2004). For example, Hicks and Lam (1999) point out that the decision-making ideal in western countries focuses on the agency of individuals to “freely make decisions” and select appropriate service or treatment options (p. 417). Yet the elderly patients in their study felt they had very little choice and few options consistent with their values as regarded hospital discharge planning. Furthermore, participants in Koehn et al.’s (2010) study reported that the sponsorship status of Punjabi seniors affected the quality of the relationship between family members because it positioned older adults to be financially dependent which, in turn, reduced their autonomy and free will. Hicks and Lam (1999, p. 417) found that the adult children of Chinese seniors felt they could not make appropriate decisions on behalf of their older family members because of “[limited]...choice of resources especially when services had certain policies that families had to follow.”

While group decision-making is the norm in traditional Chinese and South Asian cultures, these decision-making norms can be challenged when caregivers have limited family support, when family walks away from their filial responsibilities, or when decision-making is a contentious issue (Ho et al., 2003, p. 309). In studies of Chinese and South Asian caregivers, some adult children who held non-traditional beliefs about care giving or decision-making were described as unhelpful, expressing their opinions but offering no practical assistance to the care recipient (Ho et al., 2003; Lawrence et al., 2008, p. 242). Other caregivers felt a sense of guilt at having to make complex decisions about an elderly family member whose care needs were appropriate for higher levels of care or institutionalization (Ho et al., 2003; Bowes and Wilkinson, 2003; Lawrence et al., 2008, p. 242). The caregivers wanted to provide care to their family members but often felt left alone in their decision-making as other family members pressured them to institutionalize their elderly parent. One South Asian caregiver in Lawrence et al.’s (2008, p.242) study recollected how her brother would often say to her “it’s your problem, you took it on.” While the majority of caregivers in this study valued group decision-making, a small number did not.

Overall, families played an important role in decision-making. They could be portrayed as brokers who wore multiple hats to ensure that they could get the necessary

information and support on behalf of a family member (Hicks and Lam, 1999; Ho et al., 2003). They acted as advocates, liaisons between their afflicted family member and community services; they were decision-makers and “navigators of resources” (Hicks and Lam, 1999, p. 427). Notably, this aspect of decision-making and relationships between family members, the elderly, and service providers is under-explored in the literature (p. 428).

3.1.3. Social capital and the role of informal support

Putnam (2000 as cited in Man Ling Lee 2007, p.169) defines social capital as the “connections among individuals...which include social networks and the norms of reciprocity and trustworthiness that arise from them”. This definition of social capital thus emphasizes reciprocity, relationships, and social interactions with others. Having a larger social network means that, through their relationships, individuals may accrue social capital that they can draw on or leverage as the need arises (Lai and Chau, 2010).

With immigration, kin relationships are sometimes left fragmented and dispersed, which can disrupt conventional co-residence patterns because some adult children may not live nearby (Lo and Russell, 2007; Jones et al., 2002; Neufeld et al., 2002, p. 753). Chain migration is the most common way that many older adults immigrate to a new country (Neufeld et al., 2002). Usually a family member immigrates to a new country under economic class, for example, and once they are settled, they will sponsor their family to reunite with them. In such cases, families are left fragmented, with some residing in the host country and others residing in their home country. This can be problematic for caregivers, especially when they would not normally be the usual caregivers for that particular family member or when they experience dual roles and responsibilities which often compete with one another.

Koehn et al. (2010) and Spitzer et al. (2003) report that elderly South Asian and Chinese persons tend to have greater social capital in their home countries where they are more likely to control social and economic resources, navigate services and resources, and have social networks that they can draw upon when needed. For example, one caregiver spoke about the abundance of family support available to her in India and the flexibility she had with respect to taking time off to fulfill her care giving

duties (Spitzer et al., 2003). However, the sponsorship period further diminishes the status of South Asian and Chinese elders hitherto seen as heads of the family, because they must rely on their children as a main source of support and give up all previously-held economic and social power under their dependent status and ineligibility for income resources (Koehn et al., 2010, p.16). This, in turn, reduces their social capital.

Lai and Chau (2010) report on preliminary research findings that explain:

The relationship between social capital and health suggests...that individuals with vast social networks and the perception of access to social support from family...and friends appear to experience better health due to access to resources that provide support in the social, cultural, and economic dimensions. (p. 231)

This is reinforced by Ho et al., (2003) who report that caregivers who had a supportive family coped better with care giving than those who perceived a lack of support. The caregivers in Jones et al.'s (2002) study reported the same, stating that their husbands' support was integral to their ability to continue to provide care to their parents. Caregivers reported that the bulk of their informal support came from their immediate family. Notably, Lawrence et al. (2008) found differences between families who adhered to traditional ideologies versus those who did not, with respect to their level of involvement with the care recipient. Individuals who held traditional values were more likely to participate in family care giving whereas those who held non-traditional beliefs were more likely to disengage from care giving in an effort to preserve their other social roles and identities. In these situations, the caregivers did not have the support they required from their husbands to sustain their caregiver role.

3.2. Becoming an Ally

The literature review speaks volumes to the challenges women caregivers and older ethnocultural adults face when they identify their need for help; when they engage in help- and health-seeking behaviours, and when they negotiate their access to services. The theme, 'Becoming an Ally', was first articulated by Bishop (1994), and encompasses the range of structural and systemic problems that are inherent in the health and social services sector. Bishop created a six-step approach on becoming an

ally that focused on “becoming aware of one’s own oppression and one’s possible roles in being an oppressor of others” (Class Action, 2011, p. 1). She argued for the need to become aware of oppressions, and the conditions that create, maintain, sustain them. She reports that oppressions are not additive or hierarchal, rather they are interdependent, and influence one another. She also notes that ignorance can create conditions of oppression and oppressors which emphasizes the need to learn more about these oppressions or intersecting factors and how they affect individuals. This interpretation of the key concepts thus outlines opportunities where service providers and policy makers can engage in critical self-reflection in order to “understand their privileged position in an unjust system of white supremacy” (Yeung, Spanierman and Landrum-Brown, 2013, p. 17) and where their ignorance may create or reinforce the oppressions experienced by certain groups (Class Action, 2011). Yeung et al. (2013) assert that when we work in a multicultural society, it is important to be aware of the privilege white people have, simply based on skin color, and how this veiled privilege shapes our perceptions of the world.

Deconstructing the privilege and power attached to whiteness can help individuals, service providers, and policy makers to understand structural problems inherent in policies and health and social services, and citizens’ access to and utilization of them. Many safe places or affinity groups have been created across the United States, especially in the context of Universities, to allow places for individuals who are white to raise consciousness about their whiteness, their biases and their experiences, in an effort to highlight the privilege attached to whiteness (Michael and Conger, 2009). Furthermore, these groups allow individuals the opportunity to engage in critical self-reflection as they learn about race and whiteness in order to be anti-racist allies.

The first step in ‘becoming an ally’ is recognizing the privilege attached to whiteness, which is reflected in western health and social services for example. Case (2012) found that the women participants in her study were motivated to combat their privileged position. They did so by interrupting racist thoughts and comments that come from a place of ignorance, and challenging a system that perpetuates oppression. Concepts that emerged from this meta-ethnography that contribute to an understanding of the need to ‘become an ally’ were as follows: Help- and Health-Seeking Behaviours of Caregivers and Ethnocultural Older Adults, Access and Utilization Barriers and the

Important Role of Gatekeepers in Facilitating Access, and Overcoming Shame and Stigma.

3.2.1. *Help- and health-seeking behaviours*

The patterns of help- and health-seeking behaviours are different between ethnocultural minority populations and the ethnocultural majority, with the former group under-utilizing formal services (Sadavoy et al., 2004; Aroian et al., 2005; Stewart, Neufeld, Harrison, Spitzer, Hughes, and Makwarimba , 2006). Given these differences, it is essential that we explore how caregivers and ethnocultural older adults seek help, whether they seek help, and what barriers prevent them from seeking help. The literature reviewed spoke to many factors that influence help- and health-seeking behaviours, such as: the availability of culturally congruent services and previous experiences of health and social care; caregiver's level of awareness of care recipient's disease; cultural and community brokers, and conditions placed on service, stigma, and navigation problems (Aroian et al., 2005; Chan and O'Connor, 2013; Hicks and Lam, 1999; Katbamna et al., 2004; Koehn et al., 2012; Leung and McDonald, 2006; Mackenzie, 2006; Neufeld et al., 2002; Newbold and Filice, 2006; Sadavoy et al., 2004; Stewart et al., 2006; Zhan, 2004).

The first step in gaining access to services is identifying the need for them (Koehn, 2009), and this is based on whether the caregiver or care receiver perceives there is a problem that warrants help (Aroian et al., 2005). The perception of a problem requiring attention is subjective and shaped by the adult's perception and definition of health which may include "a preference for self-care, fear and distrust of Western biomedicine, and a perceived obligation to rely on self or family rather than to use formal services" (Aroian et al., 2005, p.99). The belief that the individual is aware of their body and has control over it prevents many from understanding the value of routine medical care, which can lead to the prevention of many ailments.

The literature reveals that some elderly parents place considerable emphasis on the need for culturally competent service provision. The failure to meet those standards, in their view and that of their caregivers, has shifted the burden of responsibility for their care to families (Braun and Browne, 2011; Stewart et al., 2006). Braun and Browne

(2011, p.8) reported that their Chinese participants emphasized the need to be respectful of cultural rules such as “respecting the hierarchy within families and about eating the correct foods and balancing yin and yang to resolve illness.” They also noted that participants desired service providers who were bicultural and bilingual. Some caregivers sacrificed their responsibilities to other family members, such as to their children, in order to ensure their parents’ needs were met. They felt that the lack of culturally sensitive services would be unacceptable or fail to meet their parent’s’ needs (Spitzer et al., 2003). Some elderly Chinese family members who believed strongly that family provides care reinforced both this belief and the conviction that family is in a position to maintain privacy over personal issues such as health.

3.2.2. *Overcoming stigma and shame*

Certain health conditions such as Alzheimer’s Disease are highly stigmatized in Chinese and South Asian cultures (Bowes and Wilkinson, 2003; Braun and Browne, 2011; Chan and O’Connor, 2013; Hinton et al., 2000; Mackenzie, 2006; Sadavoy et al., 2004; Zhan, 2004). The stigma associated with mental health and dementia prevents many seniors from seeking help. It also inhibits caregivers from seeking help on their behalf (Bowes and Wilkinson, 2003; Braun and Browne, 2011; Chan and O’Connor, 2013;; Zhan, 2004; Hinton et al., 2000; Hinton and Levkoff, 1999; Mackenzie, 2006; Sadavoy et al., 2004).

Many families associated dementia with a mental illness, which is considered highly stigmatic. They were careful to prevent their family member from getting labelled as a person with Alzheimer’s Disease as this would invite stigma on the whole family; this is known as courtesy stigma (Braun and Browne, 2011; Hinton et al., 2000). Furthermore, they were cautious about not speaking of their elder’s condition, as this alone was considered shameful; they attempted to conceal the illness and the person with dementia in order to prevent others from finding out about the diagnosis (Chan and O’Connor, 2013). Such concealment was seen as a strategy to protect the person with dementia “from ridicule.” At the same time caregivers felt embarrassed about the behaviours of the person with dementia in front of others (Mackenzie, 2006, p. 244). However, when the condition worsened, concealment became more difficult, so the afflicted person and their family became isolated from the community. Some caregivers

feared that family and friends would judge them for not taking care of their elderly, while others believed that once associated with the family line, the stigma of Alzheimer's disease would prevent their younger generations from marrying (Chan and O'Connor, 2013). Thus, their fears included loss of face and being seen as a family not fulfilling their filial obligations towards their elders.

Older Chinese people and service providers have a limited understanding of the extent and manifestation of mental illness in this population (Sadavoy et al., 2004). The somaticization of mental health problems in older Chinese people is not uncommon (Braun and Browne, 2011; Sadavoy et al., 2004). It would be typical of older Chinese people to discuss stressful life events in the context of feeling lonely, losing their independence, and having to depend on others. However, in truth, these "life stressors equated to mental health problems" (Sadavoy et al., 2004, p.195).

In studies in which the caregiver was responsible for a person with dementia, help-seeking could be compromised by a lack, or limited knowledge, of Alzheimer's Disease and dementia (Hinton and Levkoff, 1999; Hinton, Guo, Hilly and Levkoff, 2000; Koehn et al., 2012; Zhan 2004). Although the caregivers recognized some early signs of memory loss, most of them dismissed these signs as part of the normal aging process or because the care receiver's early memory loss had not affected their daily functioning (Braun and Browne, 2011; Hinton and Levkoff, 1999; Hinton et al., 2000; Koehn et al., 2012). Some caregivers and care receivers compared the mind and body of older adults to a machine, with an acceptance that over time machines break down (Hinton et al., 2000; Hinton and Levkoff, 1999). This analogy normalized declining health and the challenges of old age.

The normalization of dementia symptoms can thus prevent many from understanding dementia in the elderly, and it is a hindrance to getting the necessary support and treatment required to manage the condition (Bowes and Wilkinson, 2003). Many South Asian caregivers perceived the effects of dementia to be negative and stressful. Their lack of knowledge about the disease prevented them from fully supporting the elderly care recipients for whom they were responsible. In Bowes and Wilkinson's (2003) study, participants expressed views of life phases akin to those expressed by the Chinese in Hinton et al.'s (2000) study. South Asian caregivers

recounted how there was not a name for dementia and that the accepted notion handed down from their parents was that the elderly commonly return to a childlike state.

Recognition and accurate medical assessment of the early signs of dementia are necessary to ensure an appropriate intervention plan that can minimize or slow down any further memory loss and physical function (Hinton and Levkoff, 1999; Koehn et al., 2012). The early detection of Alzheimer's Disease can also lead to the implementation of various support services that could allow caregivers and the afflicted person the opportunity to be connected with resources (Hinton and Levkoff, 1999). For example, one Chinese participant reported that his caregivers sought help only after his physician informed them that his symptoms were abnormal and further medical evaluation of the memory loss was required (Zhan, 2004). Unquestionably, caregivers benefit from having information about Alzheimer's Disease and dementia because they are in a unique position to notice early symptoms (Hinton and Levkoff, 1999; Koehn et al., 2012; Zhan, 2004).

3.2.3. Access to and utilization of social and health care supports

Chinese and South Asian caregivers and care receivers faced challenges with accessing health and community supports (Aroian et al., 2005; Mackenzie, 2006; Marshall, Wong, Haggerty, and Levesque, 2010; Stewart et al., 2006; Neufeld et al., 2002; Spitzer et al., 2003). Some access barriers included: language; transportation; navigating the health and social service sector; and, other service barriers (Marshall et al., 2010; Stewart et al., 2006). These are the same impediments that Canadian-born caregivers of low socioeconomic status experience, but the difficulties of immigrant caregivers were compounded by lack of kin due to migration, adaptation problems, and limited English proficiency (Stewart et al., 2006).

Chinese and South Asian caregivers and care receivers also tend to be selective about which services they will utilize (Aroian et al., 2005, p.95). They are less likely to engage in preventative treatment, such as routine medical care, and are unlikely to use mental health services, all of which can help to explain their "poorer health outcomes" (p. 95). This gap in service use is problematic because older Chinese adults are at risk of developing chronic conditions—both physical and mental—while experiencing social

isolation and loneliness as well (Aroian et al., 2005; Hinton et al., 2000; Koehn et al., 2010; Mackenzie, 2006; Zhan, 2004).

Older Chinese adults preferred to use indirect services that gave them opportunities to be self-reliant, such as transportation, seniors' housing, and adult day programs, as opposed to more personal services like home help and residential care (Aroian et al., 2005). However, Ho et al. (2003) discovered that Chinese caregivers, appreciated informational support and housekeeper services that offset some of their care giving responsibilities. Some participants in these studies used no services because they felt that no amount of help could actually alleviate the strain of care giving.

Conditional service use

Some groups of immigrants, specifically those whose immigration to Canada was sponsored by their adult child, were ineligible for certain social and economic resources for a period of ten years (Neufeld et al., 2002; Koehn et al., 2010; Sadavoy et al., 2004). The lack, or limited availability, of resources for immigrant families can challenge their desire and ability to provide care, and contributes to family stress (Neufeld, 2002; Sadavoy et al., 2004, p. 197). Some caregivers faced a brick wall when they required professional help to supplement their care giving, because sponsorship policy restricted their access to resources (Koehn et al., 2010; Neufeld, 2002). The declaration of sponsorship breakdown would allow older adults access to home care, but this went against the caregiver's desire to provide care and support to their loved ones (Neufeld, 2002). Also, there are detrimental consequences for defaulting on sponsorship obligations (Baker and Benjamin, 2002), including punitive measures to collect funds that the sponsored person may have accessed through income security programs through a cost recovery program called the "Sponsorship Default Program" (Community Coordination, 2006).

Many women caregivers did not access services due to restrictions placed on service use as per immigration and sponsorship policy regulations (Neufeld et al., 2002, Spitzer et al., 2003; Stewart et al., 2006). In Neufeld et al.'s (2002) study, women caregivers reported that they could benefit from services given that their family support systems had diminished due to migration and other care giving demands. Yet many services that could offset these challenges are unavailable. This is the case for adult

children who sponsor their parents' immigration to Canada. Sponsors sign a legally binding sponsorship undertaking by which the sponsor agrees to provide financial support for the duration of ten years (Baker and Benjamin, 2002). Some of the responsibilities of the adult child sponsor include covering costs related to food, shelter, and non-insured medical and dental benefits.

The sponsorship undertaking ensures that the "sponsored immigrant does not become dependent on Canada's social assistance system" (Koehn et al., 2010p. 2). Certain groups of ethnocultural older adults do not have the security of some of Canada's social safety net resources, which consist of social and economic projects that are administered by federal, provincial and joint federal-provincial programs: old age security, guaranteed income supplement, the Canada pension plan, employment insurance, the Canada child tax benefit, and the national child benefit (Baker and Benjamin, 2002; Koehn et al., 2010; Neufeld et al., 2002; Stewart et al., 2006). Given the restrictions placed on access to resources, many sponsored ethnocultural older adults did not use services because they were ineligible for a period of ten years (Koehn et al., 2010).

Cultural/service brokers

Women caregivers spoke of the need for outreach services that could inform them of relevant resources, provide them with information on services, and connect them to services (Koehn et al., 2012; Neufeld et al., 2002, p. 757; Stewart et al., 2006, p.335). The women caregivers discussed the specific need for cultural/service brokers, someone who not only helps to link them to services, but also supports them in their situation (Chan and O'Connor, 2013; Stewart et al., 2006). A cultural broker and advocate of this kind would speak on their behalf to negotiate their access to health and social services. (Stewart et al., 2006, p.335). Some Chinese women caregivers expressed the need for the Chinese community to lobby for resource information in their language. Similarly, service providers point out that these women caregivers have limited self-efficacy to make linkages with community resources and speak for themselves in this regard; most of them entered their host country through the family reunification class, which disrupts their social network and reduces their social capital.

Previous experience of health care

The caregivers' and care receivers' experiences of care giving and health care in their country of origin shaped how they perceive elder care and service use in their host country (Neufeld et al., 2002, p.763; Sadavoy et al., 2004; Spitzer et al., 2003). One participant noted that she was so grateful for the no-cost health services in Canada— unheard of in her country of origin—that she did not want to ask for additional services (Neufeld, 2002, p. 763). Service providers reported that families who were 'managing' on their own did not seek outside help in their host countries. Some health and community services would be unfamiliar if non-existent in the caregiver's country of origin, so they would not be likely to seek out such resources, and elder care is frequently seen as a family affair (Koehn, 2009; Spitzer et al., 2003).

Culturally congruent/incongruent services

Chinese and South Asian caregivers found that their access to assistance was either facilitated or impeded depending on the availability of culturally congruent services (Aroian et al., 2005; Chan and O'Connor, 2013; Leung and McDonald, 2006; Marshall et al., 2010; Sadavoy et al., 2004; Stewart et al., 2006). Taking the step to seek help can be difficult and emotionally laden for caregivers who want to provide all the necessary care and support to their loved ones without formal community help (Leung and McDonald, 2010). Culturally congruent services and service-rich areas could greatly promote help-seeking on the part of caregivers. As an example, Ho et al. (2003) found that all of the 12 Chinese caregivers in their sample had waitlisted an elderly family member for residential care. Most of them had provided care for approximately four years and hoped to continue to do so for as long as possible. Moreover, most of them were "against the idea of institutionalization," which went against their filial values. Ho et al. (2003) propose that the willingness to waitlist despite these beliefs may be attributable to the extensive number of culturally sensitive services for Chinese people in the area.

Language incongruence between service providers and service users is a significant barrier to ethnocultural minority caregivers trying to secure services for their elderly parents (Leung and McDonald, 2006, p.3; Sadavoy et al., 2004). A paucity of ethnocultural, appropriately multi-lingual staff can also prevent people from accessing

services. Without interpreters or staff who can speak the language, many Chinese and South Asian older adults have to rely on their family members for interpretation. This can prevent them from disclosing personal problems to health service providers when they want to maintain their privacy (Sadavoy et al., 2004). Conversely, Leung and McDonald (2006) found that some care receivers wanted their caregivers to interpret when dealing with linguistically incompatible providers, but this was problematic for caregivers because it added yet another responsibility when they were already balancing elder care with other family needs. In Neufeld et al.'s (2002) study, an elderly Chinese woman described how she could not acquire a mobility aid because language barriers prevented her from communicating basic information such as her name and medical card number. These authors also found that the inability to communicate in the same language as medical staff stopped many from understanding a diagnosis, its consequences, and treatment plan; in the case of one participant this led to the deterioration of her diabetic condition.

Caregivers highlighted the important need for culturally responsive service workers who would make an effort to build rapport with them (Chan and O'Connor, 2013). For example, Chan and O'Connor's (2013) found that when non-judgmental and supportive service workers were present, Chinese caregivers were encouraged to discuss their care giving situation and experiences with gaining access to services. Many of the participants who joined the support group said they did so because the sensitive nature of the facilitator made them feel comfortable. Many also commented on how their reservations about speaking about personal problems were linked to their traditional and cultural values. In addition to this, they were circumspect about asking for help and advocating on behalf of themselves and their family members. One participant noted how she felt uncomfortable expressing concerns over her mother's care to management out of fear that the staff would be insulted, and she felt they would not like to hear criticisms. Despite the fact that many of these caregivers bore a heavy load, they did not seek help because, in line with their traditional upbringing, they had learned they were not supposed to challenge authority figures such as health care staff and doctors. Through the family support groups, caregivers acquired the skills and confidence necessary to discuss problems, access resources and question authority figures.

3.2.4. Gatekeepers

The family physician and health care team are usually the first point of contact for ethnocultural minority elders and caregivers (Hinton et al., 2000; Katbamna et al., 2004; Koehn et al., 2012; Marshal et al., 2010). They are also the gatekeepers to the services these people need, playing an integral role in connecting clients to appropriate and relevant services that could offset challenges (Katbamna et al., 2004). In Marshal et al.'s (2010, p. 5) study, participants felt that family physicians should make their new immigrant patients aware of the range of services available so that they could assess their service needs based on the availability of resources. However, if the general practitioner or health care team do not recognize and refer their patients to appropriate services this could lead to "far reaching and potentially costly, consequences" (Hicks and Lam, 1999; Katbamna et al., 2004).

While health care staff and general practitioners are in a position to connect clients to appropriate services, sometimes their own discretion can hinder patients from getting the necessary assessment, treatment and support (Katbamna et al., 2004). A Chinese physician participant in Hicks and Lam's (1999, p.423) study confided how he and his colleagues did not refer older Chinese people with Alzheimer's Disease for diagnostic work-up and treatment when they were aware that the patients' families were supportive and coping. He attributed this decision to the cost attached to these tests and to language barriers. Koehn et al.'s (2012) study found that some physicians dismissed the caregivers' accounts of memory loss and need for further evaluation by normalizing the symptoms as typical of old age. Similarly, Hinton et al. (2000) also found that some Chinese doctors who were aware of the stigmatizing label of dementia and Alzheimer's Disease and were inclined to normalize symptoms of dementia as part of the normal aging process were unlikely to even discuss AD or dementia with the patient. They cited a disinclination for 'burdening' the individual or their family with such a diagnosis to justify their decision. Other physicians highlighted language incongruence as a factor in them not referring a person with dementia for "specialized Alzheimer's Disease services" because the patient did not speak English (Zhan, 2004, p.25).

4. Conclusions

This critical synthesis of the literature on Chinese and South Asian family care giving revealed some interesting interpretations which were influenced by my paradigmatic position. Being a critical social worker and a South Asian women I am familiar with the value of elder care and respect which is learned through role modeling of care and respect. Furthermore, the critical paradigm and feminist lens enabled me to bring to light underlying issues which greatly affect the lives of many immigrant Chinese and South Asian families. Their experiences of care giving are uniquely influenced by the intersections of immigration factors, such as adaptation challenges, acculturation, and government policy which influence their access to resources. Furthermore, power imbalances by age and gender play a significant role in how care giving is perceived and actualized in a new country.

Many similarities between Chinese and South Asian caregivers emerged through this synthesis. Firstly, the gendered nature of care giving, although common across all cultures, was also a feature of care giving in South Asian and Chinese families. Female caregivers across both groups felt a sincere obligation and dedication towards caring for their family members. They balanced multiple roles while being able to fulfil their care giving tasks. This was challenging for them, but as some reported, their adherence to cultural values around elder care afforded them the strength to cope (Ho et al., 2003). Chinese participants who felt strongly about the value of filial piety, for example, reported positive experiences with elder care. Members of the South Asian groups reported similar sensibilities about caring for the elderly. For example, South Asian caregivers generally felt an intrinsic need to care for their parents as a way to give back some of the support and kindness they had received growing up.

Similar beliefs were also held by Chinese and South Asian caregivers and care receivers in regards to the stigma around mental illness and Alzheimer's Disease (Mackenzie, 2006). Both groups felt strongly that the health status of one family

member could reflect badly upon the whole family (Chan and O'Connor, 2013; Braun and Browne, 2011; Hinton et al., 2000; Mackenzie, 2006). As a result, many families try to conceal the afflicted person and their diagnosis or potential diagnosis and do not seek help, which can in turn lead to isolation of the entire family (Braun and Browne, 2011; Mackenzie, 2006). This belief prevented many caregivers and care receivers from getting the support and resources they required to deal with the illness and or with care giving needs. Caregivers and care receivers in both ethnocultural groups also emphasized that there exists a need for culturally congruent services. Language compatibility and a culturally-sensitive response approach were noted as currently lacking, but it was accepted overall that extending services to include these components would facilitate access to programs.

4.1. Overarching Themes

This synthesis gleaned from the literature two overarching themes of the care giving contexts of South Asian and Chinese caregivers and care receivers: 'The Personal is Political' and 'Becoming an Ally'. The first theme, 'The Personal is Political' pertains to the way socio-political factors affect the personal lives of South Asian and Chinese caregivers and care receivers. It highlights the challenges and inequities inherent in policies, cultural rules around care giving, limited social networks, and decision-making processes, all of which influence their daily actions and perceptions of care giving. Furthermore, these inequities particularly affect women as they are most commonly the caregivers in a family and already have many roles to balance. Not only do the external 'politics' of the host country affect how immigrants conduct their personal lives in terms of government regulations and available resources for example, but the immigrants' personal cultural mores also affect how they adapt when family dynamics, or politics, are in upheaval. For example, the concept of filial piety is entrenched in the cultural and social norms in the countries of origin of Chinese and South Asian families. These values do not dissipate after immigration; in fact they are transplanted in the host country and influence family care giving. Although, the literature spoke about the changing face of filial piety, and the varying degrees of adherence to filial piety, such as differing preferences on living arrangements among adult children and their aging parents, it is a value that is patriarchal and hierarchal. Women are expected to carry on

with care giving despite their necessary adoption of new roles. They juggle multiple roles with reduced informal support from kin as a result of a fragmented family network due to migration.

Moreover, filial piety in the traditional sense emphasizes a hierarchal order of decision-making within families, with a specific focus on the dominant role of men. Decision-making is top down, with the eldest male in the family holding the decision making power followed by the eldest son. Again, this prevents many women from engaging in equal discussion about issues that affect their daily lives, including care giving. Thus, these women have limited free will and limited ability to reach their fullest potential in a new country that is based on democratic values and free will. These traditional cultural mores are very important to many Chinese and South Asian families in their new homes, but the limited availability of culturally congruent formal supports contributes to intensifying the difficulties women experience in managing multiple and competing roles.

The second theme, 'Becoming an Ally', is an interpretation of the challenges ethnocultural minority caregivers and care receivers face as a result of a system that is incongruent with their beliefs in its Eurocentric approach to health and community resources. The help- and health-seeking behaviours of South Asian and Chinese caregivers and care receivers have to change greatly as they are bound to be different from accustomed behaviours in the respective countries of origin, and thus require a supportive and sensitive approach by health and community professionals (Braun and Brown, 2011; Spitzer et al., 2003; Stewart et al., 2006; Neufeld, 2002). This theme also illuminates the structural factors, such as sponsorship status which prevent many care givers and receivers from gaining access to resources and from maintaining financial independence through income security programs that are available to Canadians with the exception of sponsored immigrants.

The lack of government assistance with finances and social care services for certain immigrant groups in Canada also pose challenges for caregivers and care recipients. Immigrant groups, such as elderly Chinese and South Asians, must meet a 10-year residency requirement before receiving a government pension (Alternative Planning Group, 2006). Gupta and Pillai (2002) report that economic burdens of care

giving may be stronger for certain immigrant groups because they do not receive government pensions or benefits, such as Medicare to cover costs associated with social care.

Since sponsors are financially responsible for their sponsored parent, they may, as a result, experience financial strain. Lal (2003) notes that financial problems contribute to caregiver stress or burden. All sponsors must meet mandatory minimum income levels to sponsor their parent; however, the sponsorship policy does not consider the changing economic situations of sponsors, for example job loss. Job loss and global economic changes can reduce the sponsor's income, which changes his or her economic situation and possibly the ability to continue to provide for their parent. Providing for all the basic necessities of a parent can be costly especially when the parent is not receiving an income of their own, and is in need of resources to help them live as independently as possible. In this case the sponsor is responsible for covering costs associated with increasing care needs (Baker and Benjamin, 2002).

It has been estimated that less than half of sponsored parents over 60 have no income in Canada (Dempsey and CIC, 2004). Given that their sponsored parent is ineligible for federal benefits such as pensions to cover the cost of their increasing care, financial burden may be more pronounced among adult-child caregivers (Gupta, 1999). As a result of being financially and socially dependant on their adult children, sponsored parents and their children may experience relationship strain despite the quality of their relationship (Koehn, Spencer, and Hwang, 2010).

4.1.1. *Line of argument*

This meta-ethnographic synthesis can be viewed as a reciprocal translation of the studies, given that similar ideas and concepts emerged which translated across the studies. The reciprocal translation resulted in a line of argument: South Asian and Chinese caregivers and receivers face some unique care giving contexts as a result of policy, immigration factors and migration experiences, as well as cultural norms around care giving. Being an immigrant brings out a host of challenges in a new country. Not only must they negotiate their new lives in a culture that is unfamiliar to them, but they must also learn a new language and a new way of living, and adjust their beliefs and

values to reflect those more typical of their new homes and realities. Families and care givers are trying their best to uphold filial values but the economic and structural realities of their new lives are often competing against these values. For example, their care giving patterns have changed in response to fragmented kin relationships, reduced social capital, multiple roles and responsibilities, and changes in filial piety values among adult children and their parents. These factors compound to influence the care giving contexts of South Asian and Chinese care givers and care receivers.

Implications for policy and practice

This meta-ethnography study provides a greater understanding of the care giving contexts of South Asian and Chinese caregivers and receivers. It highlights the need to adopt a critical perspective when designing and delivering programs for ethnocultural populations. An approach which considers individuals within their family, socio-political and historical context can illuminate how these issues compound to influence the care giving contexts of these groups. Also, an understanding of how family care giving is shaped by intersections between migration experiences, gender, age, cultural norms around care giving can shed light on how individuals perceive care giving in a new country. The need to understand diversity among individuals is equally important for service providers who broker and adjudicate access to services. This speaks to the important role of service providers and policy makers in learning more about the diverse needs of ethnocultural populations and challenging beliefs that reinforce familism; this ideology strengthens and reinforces the belief that ethnic minorities take care of their own. In doing so, the government plays a limited role in the creation of healthy public policy and programs that support the needs of immigrant families and women (Matsuoka et al., 2012). Furthermore, it reinforces filial obligations towards family with limited intervention from the government. Matsuoka et al. (2012) argue for change at the government level (macro level) with creation of public policy; changes to immigration programs; and funding for services/programs that support older immigrant women and their independence and access to relevant resources. They also emphasize that these macro level changes will affect individuals directly through the provision of programs that reduce the social isolation of older immigrants and their dependence on family, which can, in turn, reduce care giver burden. Service providers and policy makers can become allies of ethnocultural minorities by recognizing the interplay between multiple

intersections between systemic and political factors which greatly affect the daily lives and caregiving experiences of ethnocultural minorities.

This synthesis was designed with the aim of presenting some interesting interpretations and reflections on the care giving contexts of South Asian and Chinese caregivers and care receivers. The interpretations help to reveal systemic issues that marginalize ethnocultural groups and shed light on some of the invisible privileges certain groups have over others. Clearly, a one size fits all approach does not address the needs of a diverse population, particularly with respect to the delivery of health and community services. Every group is, after all, comprised of individuals; within each individual there lies potential that, when unobstructed, can serve to enhance, enrich, and give back to, the greater community. A healthy, well-adjusted populace is the foundation that upholds a healthy country.

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Appendix.

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South Asian and Chinese

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