Development and Validation of a Scale for Measuring Spousal End-of-Life Communication

by

Nataliya Polchenko

B.A. (Psychology), Simon Fraser University, 2009
M.Eng., National Technical University of Ukraine, 1989

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Name:	**Nataliya Polchenko**
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Title of Thesis:	***Development and Validation of a Scale for Measuring Spousal End-of-Life Communication***
Examining Committee:	**Chair: Dr. Barbara Mitchell** Professor & Graduate Program Chair

Dr. Andrew Wister
Senior Supervisor
Chair and Professor

Dr. Andrew Sixsmith
Supervisor
Professor

Dr. Carole Robinson
Supervisor
Associate Professor
Faculty of Health and
Social Development,
University of British Columbia

Dr. Wendy Thornton
External Examiner
Associate Professor
Department of Psychology

Date Defended: April 16, 2014

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Abstract

Currently there are no instruments measuring communication about end-of-life (EOL) issues in families not involved in palliative care. The purpose of the study was the development and initial validation of a new quantitative instrument, the Marital End-of-Life Communication Scale (MELCS), to measure EOL communication in married/partnered adults. After initial item development and validation in married/partnered adults (age 45 years old and older, N=101), six items, scored by 5-point Likert-type response options, were chosen for the final version of the scale. Factor analyses confirmed the theorized single-factor structure. The MELCS demonstrated excellent reliability (CR=0.892) as well as good content, convergent (AVE=0.587), discriminant, construct, and criterion-related validity. In addition, the scale was invariant across age, gender, and level of death anxiety. Analyses of the nomological network showed that marital EOL communication positively related with general marital communication (R=0.53), and negatively related with death anxiety (R=–0.47) and self-rated health status (R=–0.44).

- **Keywords**: marital communication; end-of-life communication; scale development and validation; older adults; willingness to communicate about end of life; advance care planning

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Chapter 1.   Introduction

All human communication takes place within several contexts. The focus of this thesis is end-of-life communication in several intertwined contexts: marital relationships, aging, and life transitions such as illness and caregiving. The goal of the thesis was the development and validation of a quantitative tool for measuring end-of-life spousal communication in older adults. We define marital end-of-life (EOL) communication as discussions between spouses about death and dying. Marital EOL communication might include any or all aspects of death and dying—health-related (including advance care planning), legal, practical, or spiritual.

1.1.   Why study communication in a context of aging?

Aging and communication are reciprocally linked. On the one hand, aging can negatively or positively affect communication. For example, age-related sensory loss can lead to a decrease in social interaction, poor psychosocial functioning and, as a result, to lower quality of life (Dalton et al., 2003; Heine & Browning, 2004; Heine, Erber, Osborn, & Browning, 2002), while, age-linked *wisdom* is a trait that can enhance interpersonal communication (Baltes & Staudinger, 2000; Huntley & Helfer, 1995). On the other hand, communication can negatively or positively affect aging. The ability to age successfully requires one to competently communicate with, motivate, manage, and manipulate others (Nussbaum, 2007, p. 2). Successful communication has been linked to life satisfaction (Nussbaum, 1983, 1985), as well as the well-being of older people, their family relationships, and their quality of life (H. Edwards & Noller, 2002).

There is a considerable body of literature dedicated to age-related communication disorders. Mostly medical or technical in nature, these works seek to inform clinicians or the hearing-aid industry. Some of them link specific communication difficulties in older adults (usually in a health-care context) to different outcomes.

However, there is little research elucidating relationships between normative age-related changes and communication in healthy older adults. Can older adults successfully adapt to these changes? If yes, how do they do it? Little is known about successful communication strategies at older ages and/or their outcomes. Considering the rapid aging of the population, it would be beneficial to study successful communication in older adults and its relationship with successful aging, in particular, end-of-life communication among older spouses.

1.2. Why study marital communication within the context of aging?

There are several reasons that make the study of communication in older marriages important. First, the attention is warranted by the sheer number of older adults who live as a couple. Marriage is the norm among older adults. According to the recent (2011) Canadian census, the majority (56.4%) of Canadians aged 65 and over lived as part of a couple in 2011. Due to higher mortality rates at the oldest ages, the prevalence of living in a couple declined with age. Thus, 70% of seniors aged 65 to 69 lived as a part of a couple in 2011. Although there were fewer older adults aged 85 years and over who lived with a married or common-law spouse, it was a significant proportion (22.9%, Statistics Canada, 2012).

Second, marriage is a naturally occurring and arguably the most important social support network for older adults, since other social networks decline due to decreased mobility, illness, and the death of friends (Sillars & Wilmot, 1989). Consequentially, the crucial role social networks play in a wide array of positive outcomes—both health and psychosocial (Cohen, 2004)—warrants more attention by social scientists to this institution in general, and to marital communication as the means to maintaining the relationship, in particular.

And third, this area of the otherwise burgeoning communication and marriage fields is considerably understudied. The main focus of the marital relationship literature is overwhelmingly on younger couples (Fincham & Beach, 2010; Gottman & Notarius, 2000) and their marital problems—conflict resolution, parenting, sexual relations, or

managing career and family (Fincham & Beach, 2010). But older couples' needs, challenges, and values are different from those of younger couples. They experience reduced marital stress and conflict (Zietlow & Sillars, 1988), but increased vulnerability to social isolation and physical disability (Sillars & Wilmot, 1989). Therefore, the findings of the literature on younger marriage are not generalizable to the older population. In addition, we know little about the dynamics of marital communication in older spouses. How does communication change when spousal roles change due to illness or caregiving? Do physiological age-related communication difficulties affect marital communication? If yes, what is their impact? Answering these questions is important for providing empirical support for existing life-course theories of communication and for development of evidence-based interventions for older couples.

1.3. Why study communication in older couples in an illness/caregiving context?

Many older adults become primary caregivers of their ill spouses. Over one in 12 Canadian seniors reports being an informal caregiver for at least one of their contemporaries. Twenty-five percent of them provide care to a spouse (Stobert & Cranswick, 2004). This number is probably underestimated, as many older adults would not report themselves as caregivers. Indeed, many do not consider looking after their ill spouse as "caregiving"—rather, they consider it to be a normal part of the marital relationship (Carpenter & Mak, 2007). Even when outsiders view a couple as caregiving, the partners may not see themselves that way (Gaugler, Wackerbarth, Mendiondo, Schmitt, & Smith, 2003). The current high number of older spousal caregivers will rise due to recent demographic trends—rapid population aging and increase in life expectancy.

There is a growing body of research on relationships between caregiver and care receiver. It is reported that affection, attachment, intimacy, conflict, reciprocity, and communication are important for the well-being of older people, their family relationships, and quality of life (Braithwaite, 1998; Carruth, Tate, Moffett, & Hill, 1997; H. Edwards & Noller, 2002; Neufeld & Harrison, 1998; Whitbeck, Hoyt, & Huck, 1994). The studies dedicated to illness/caregiving family transitions are usually disease-specific (e.g.,

cancer [most often breast cancer] or Alzheimer's disease). More often they focus on disease-related communicational problems only. These types of studies report on content, patterns, or frequency of illness-related communication and their relation to health outcomes, caregiver burden, or marital satisfaction and quality of life. These will be reviewed later in the next chapter. Fewer studies examine non-illness-related communication in caregiving couples. For example, the author was able to locate only two studies (by the same group of authors, Badr & Acitelli, 2005; and Badr, Acitelli, & Carmack Taylor, 2008) investigating *relationship talk* and its correlates in couples affected by chronic illness. There are still many important areas of marital communication that have not been systematically studied in an illness/caregiving context but that warrant additional attention from researchers, such as mutual reminiscence, mortality awareness, or end-of-life communication.

1.4. Why study end-of-life communication?

Death is an integral and unavoidable part of life. Proactively preparing for it can help one to have a *good death*—one in which a person dies being in control, being comfortable, having a sense of closure, having recognition of impending death, with beliefs and values honored, burden minimized, and relationships optimized, among other attributes (Kehl, 2006). Achieving these goals is unlikely without effective end-of-life communication in families. However, end-of-life communication in families is arguably the least studied area of relational communication. When it is studied, this typically happens within the context of terminal illness and usually concerns advance care planning (e.g., the Advance Care Planning Evaluation in Hospitalized Elderly Patients [ACCEPT] study, Heyland et al., 2013). Advance care planning (ACP) is concerned with communicating and formalizing personal beliefs, values and wishes regarding possible future health care treatment in case a person becomes incapable of expressing their own decisions ("Advance Care Planning: Making Future Health Care Decisions"). Despite recent efforts in promoting ACP with healthy individuals (e.g., the Respecting Choices program in the US, or My Voice ACP program in British Columbia), it is reported that often advance care planning is done when a patient is admitted to a health care facility (Malcomson & Bisbee, 2009). According to a 2012 Ipsos-Reid national poll, only 19 percent of Canadians have an Advance Care Plan written down (G. Fernie, personal

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communication, March 20, 2014). Considering that ACP was shown to improve EOL care, patient and family satisfaction, and reduce stress, anxiety, and depression in surviving relatives (Detering, Hancock, Reade, & Silvester, 2010) , and that Canadians think that ACP is important (Polchenko, 2012), it is unknown why so few of them have completed advance care plans. However, the same 2012 Ipsos-Reid survey (G. Fernie, personal communication, March 20, 2014) shows that in the provinces where more people discussed healthcare-related decisions with family or friends (e.g., 56% in Alberta, 54% in Saskatchewan/Manitoba versus 36% in Atlantic provinces), more of them have an Advance Care Plan written down (24% in Alberta, 25% in Saskatchewan/Manitoba versus 7% in Atlantic provinces). To explain these differences, more research is needed.

Not all families put off talking about their end-of-life wishes until someone nears death. Many discuss their end-of-life wishes and concerns when they are still healthy and active (Polchenko, 2012). But how, how often, and in what detail is unknown. Or, do they review or change their wishes together once they communicated them? If yes, how? What can be considered as successful end-of-life communication? Does end-of-life communication vary in different cultures? If yes, how? Answering these questions could help in the development of educational programs and therapeutic interventions aimed at reducing death anxiety and promoting open dialogue about end of life, including advance care planning, in families. To answer these questions, end-of-life communication in families needs to be systematically studied. Some of these questions comprised the focus of this thesis. In particular, the study examined attitudes toward talking about end-of-life preferences and concerns in spouses, incidence of EOL discussions and level of satisfaction withe these discussions between spouses, as well as relations between these attitudes and incidences. Also, the relations between spousal EOL communication and general marital communication, death anxiety, and overall health were studied.

1.5. Why a new measure?

It is unclear what accounts for the dearth of research in marital communication in older adults—lack of interest or lack of appropriate psychometric instruments. The

majority of studies in marital communication are based on observations of communicating couples in a laboratory; many are qualitative, while some utilize mixed methods. However, more quantitative studies are needed for testing hypotheses. For this to happen, reliable and valid quantitative tools are required. There are very few existing measures that can be applied to marital communication research in general, and in older populations in particular (those that there are will be reviewed later). Some of these have been developed for clinical practice, not research. Others have been informed by clinical practices, not theories. Yet others are applicable to special cases only. Most of them have been developed for and validated with younger couples   As a result, most of the researchers of published literature on marital communication in older couples and/or in an illness/caregiving context have had to create their own customized measures to be able to investigate their research questions. Many such *ad hoc* questionnaires have not been published. Instead, they were merely mentioned in the respective studies (e.g., Gotcher, 1993; Newton-John & Williams, 2006). As for end-of-life communication measures, the author was not able to locate any. Thus, a new quantitative instrument is needed for studying end-of-life communication that is suitable for older couples. At the same time, it should be able to capture changes in end-of-life communication related to health transitions, illness and caregiving. Development of such an instrument was the goal of the current thesis.

1.6. The scope of the new measure

The new measure was developed to assist in investigating beliefs, comfort level, and willingness to communicate about end-of-life wishes and preferences in middle-aged (45 to 64 years of age) and older (65 years of age and older) couples.

Chapter 2.   Literature review.

The literature on relational communication in the context of aging consists of several separate and distinct small bodies of literature. Among the most developed in the context of aging are the studies of pre-existing or acquired communication disabilities; communication in health care settings, including nursing homes and long-term care facilities; and intergenerational communication. The somewhat less studied areas are communication changes associated with normal aging, communication as a means to maintaining social networks, and illness-related family and marital communication.

Marital communication is usually studied in relation to marital problems and/or marital satisfaction. However, some conversational topics—for example, talking about the future or remembering the past—are often omitted by researchers. Considering that, when studied (Chapter 2.3), end-of-life conversations were correlated with psychosocial benefits, it would be natural to study these among older couples.

Because end-of-life communication between spouses likely occurs across different contexts, related or unrelated to illness, and because the new instrument measures end-of-life communication across all these contexts, we will review the communication literature in these special areas of interest. The purpose of this review is to integrate and generalize the findings, to identify central issues and detect problems.

2.1.   Communication and older couples

What do we know about communication in older couples? The existing knowledge can be summarized just in three sentences: 1) Older couples tend to have a low-risk, low-disclosure style of interaction (Zietlow & Sillars, 1988) that is more positive than in younger couples (Carstensen, Gottman, & Levenson, 1995), predicts marital satisfaction (Schmitt, Kliegel, & Shapiro, 2007) and tends to become more verbally affectionate after a diagnosis of a terminal illness (Badr & Acitelli, 2005; Badr et al., 2008); 2) Topics of their conversations, in addition to sharing thoughts and feelings, include religion, home repairs, and health (Sillars & Wilmot, 1989); and, 3) Happy

couples have more positive interactions than unhappy ones (Szinovacz & Schaffer, 2000). The aforementioned comparative observational studies concluded that some communicational patterns are similar in younger and older couples (Carstensen et al., 1995; Szinovacz & Schaffer, 2000; Zietlow & Sillars, 1988). However, this conclusion, without quantitative validation within an older population, does not justify simple generalization of the rich literature on younger marriages to older marriages. Therefore, considering the lack of such validation studies and the different challenges facing younger and older couples, more research is warranted to see how older couples communicate and how, if at all, these communication processes vary from those in younger couples.

Several books reviewing the literature on marital communication and communication across the life-span dedicate no more than a page or two to this segment of research. For example, *Marital Communication* (Kelley, 2012), a recent book that "synthesizes a large, interdisciplinary body of research that specifically focuses on communication in marriage" (p. vii), has a two-page summary of literature on couples in later life in a chapter on communication across the life cycle. However, these two pages, instead of elucidating communication processes in older couples, only report on unique challenges of older marriages such as relationship loss through illness, death, or relocation; difficulties establishing new relationships; or a need to shift from a child-focused relationship to one that is partner-focused (without mentioning childless couples) (Kelley, 2012, pp. 150-151). In addition, while Kelley (2012, p.152) referenced a few studies reporting higher marital satisfaction in older couples, no studies describing and/or analyzing communication processes in older couples were mentioned in this book.

Another recent book, *Family Communication* (Segrin & Flora, 2005), that "examines state-of-the-art research and theories of family communication," does not cover older couples at all. There are a few pages dedicated to relational processes in three other books, specifically written to examine life-span communication: *Life-span Communication: Normative Processes* (Nussbaum, 1989), *Life-span Communication* (Pecchioni, Wright, & Nussbaum, 2005), and the *Handbook of Communication and Aging Research* (Nussbaum & Coupland, 2004). But what is significant is that, again, most of the referenced material reports on studies about general relational processes

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and/or marital satisfaction, but not about communication processes. In a chapter titled "Family Communication in Later Life," Pecchioni and colleagues (2005) explored "launching" children and the related role shifts and family reorganization (that reflect developmental stages of middle-aged marriages, not older marriages); taking care of elderly parents; divorce, separation, and remarriage in families with young children (it is not clear why this material was covered in a chapter on later-life families); and communication between siblings in later life as well as intergenerational communication (older parent-adult child, and grandparent-grandchild). There was no coverage of older couples' communication l in this chapter or elsewhere in the book.

2.2. Communication in a health care context

Most of the research on communication in a health care context is dedicated to communication with patients/families affected by cancer, Alzheimer's disease, or in palliative care. A vast majority of this literature addresses clinician–patient communication and the importance of creating therapeutic relationships (De Haes & Teunissen, 2005; Harris et al., 2009; Street Jr, Makoul, Arora, & Epstein, 2009). However, while a trusting therapeutic relationship with health care providers is important and beneficial, healthy and supportive family relationships are arguably equally, if not more, important. The family is the most important social context within which illness occurs and is resolved (Litman, 1974). Social support in general, and family support in particular, at the time of diagnosis and during the course of the disease has been associated with better outcomes—higher levels of adjustment, improved prognosis, positive rehabilitation outcomes, improved recovery and increased longevity (Arora, Finney Rutten, Gustafson, Moser, & Hawkins, 2007; Beach & Anderson, 2003; Gotcher, 1993; Kroenke, Kubzansky, Schernhammer, Holmes, & Kawachi, 2006). This reflects the salience of good communication for complex health relationship contexts, such as caregiving to older adults.

2.2.1.   Informal caregiving and communication

Review of communication in caregiving context is important for the development of the new measure, as discussions about end-of-life preferences and concerns often

happen within this context. Informal care of frail elderly within the family far exceeds the formal care provided to older adults by nursing homes, hospices, adult day-care facilities, or social workers (Williams & Nussbaum, 2000, p. 156). It was estimated that over 78% of frail seniors had kin-only care networks (Fast, Keating, Derksen, & Otfinowski, 2004). From 25% (Canadian data, Stobert & Cranswick, 2004) to 38.4% (US data, Wolff & Kasper, 2006) of these kin-only care networks were comprised of elderly caregivers looking after their spouses, which is probably an underestimated proportion.

More attention should be given to communication processes during family care giving for older people, given how these processes affect both caregivers and carereceivers. Studies examining the relationship between caregiver and carereceiver have found that affection, attachment, intimacy, conflict, reciprocity, and communication are important for the well-being of older people, their family relationships, and quality of life (Braithwaite, 1998; Carruth et al., 1997; H. Edwards & Noller, 2002; Neufeld & Harrison, 1998; Whitbeck et al., 1994). Communication in a context of spousal caregiving and other types of informal caregiving may vary significantly due to the nature of the relationship.

There are two areas of research highlighting the importance of communication to the well-being of older carereceivers: overly protective care and patronizing communication. Often, contrary to the intent of caregivers, the communication of overprotection (for example, offering extensive and unnecessary help) has been shown to negatively affect the physical and psychological health of carereceivers (Thompson & Sobolew-Shubin, 1993). Research has shown that overly directive and patronizing communication by informal caregivers is likely to negatively affect the quality of the relationship and the emotional well-being of carereceivers. Moreover, the negative effect of patronizing is likely to be stronger than the positive effect of supportive communication. A small mixed-methods study examining communication between community-dwelling frail older people and their caregiving spouses demonstrated that overly protective, well-intentioned communication addressed toward older adults can be perceived by them as patronizing, and was likely to be interpreted as nonsupportive and disrespectful (H. Edwards & Noller, 1998). A more patronizing and overly directive communication tone in caregivers was associated with low levels of life satisfaction in caregivers themselves. That is, caregivers with low life satisfaction were more likely to

use patronizing communication than caregivers with high life satisfaction. At the same time, patronizing communication from caregivers had a negative effect on the well-being of carereceivers and their perception of the relationship (i.e., high conflict) (H. Edwards & Noller, 1998). These findings suggest that overly directive and patronizing communication is detrimental for both caregivers and carereceivers.

Research has linked communication problems with increased caregiver burden (Savundranayagam, Hummert, & Montgomery, 2005). The more serious was the illness, the higher the burden was, with terminal illness posing the biggest challenge for caregiver. For example, a recent study of family caregivers of terminally ill adults found that all caregivers in the sample reported medical, practical, psychosocial, and religious/spiritual uncertainty, regardless of life experiences or medical sophistication (Hebert, Schulz, Copeland, & Arnold, 2009). Communication was the primary mechanism to manage uncertainty: inconsistent or ambiguous communication contributed to increased uncertainty, while clear and reliable communication between all parties was beneficial for reducing psychological morbidity (Hebert et al., 2009). It is possible that miscommunication in the caregiver–carereceiver relationship can also negatively affect the caregiver after the death of the ill loved one. In a recent study with caregivers whose family member died in a health-care facility, it was discovered that the caregivers lived with guilt for breaking a promise of a home-death they thought they gave to their loved ones (Topf, Robinson, & Bottorff, 2013). It was not clear if caregivers had explicit discussions about place of death with their family members. It is possible that they assumed that caring at home till death was expected from them and, as a result, carried guilt for the broken promise long after their loved one was gone. Had they discussed the possible care demands and place of death with the carereceiver openly, thus removing uncertainty in this regard, the outcome could have been different.

Below is a brief review of the literature on family communication in relation to a serious illness—cancer. Cancer-related communication between spouses is a special case of health-care related marital communication. Often cancer-related communication involves discussing end-of-life issues. In addition, cancer-related communication and end-of-life communication have certain similarities, as they involve hightened sense of mortality and discussions of difficult topics. Compared with other illnesses, communication in the context of cancer is better researched. Therefore, review of the

cancer-related communication literature is useful for the development of the new measure.

There are three main areas of research on cancer-related family communication: how illness and treatment is discussed, what is discussed about illness and treatment, and non-illness-related discussions. The first and the most developed is the study of styles of illness-related communication, examining how couples discuss illness and treatment. Very few works examine the content of illness-related communication, investigating what illness-related topics spouses discuss. Also, very few studies examine non-illness-related communication in families affected by cancer—e.g., how often they discuss their relationship. It is safe to assume that most of the findings can be generalized to other life-threatening illnesses often afflicting older adults, except for Alzheimer's disease, which is beyond the scope of the current research due to its unique challenges to communication.

2.2.2.   Communication and caregiving of individuals with cancer

Cancer creates a stressful situation for the patient and the family; therefore, communication satisfaction could be critical to the development of effective coping strategies (Pearlin & Schooler, 1978). It has been found that families that were able to act openly and express feelings directly had lower levels of depression. Furthermore, direct communication of information within the family affected by cancer was associated with lower levels of anxiety (B. Edwards & Clarke, 2004). Therefore, it is essential to understand the complex processes of how and why information is communicated within families during and after a cancer diagnosis (Harris et al., 2009).

Planning for future care and possible bad outcomes, including death, might be necessitated by a cancer diagnosis. Because the new instrument should be able to measure end-of-life communication in families regardless of health status, including families affected by cancer, review of this literature is relevant for development of the new measure. In addition, it might help to understand whether and how a serious illness such as cancer affects marital communication, and whether it heightens or impedes end-of-life communication.

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Spousal communication in relation to cancer in the general population.

The majority of the work on family communication in the context of cancer has involved breast and prostate cancer and has focused on married partners, rather than more diverse relationships (Harris et al., 2009). Population-based studies of cancer survivors and their family caregivers justify such a focus on marital relationships: the majority of primary family caregivers—65%—were identified as spouses, while 10% were siblings, 35% were children, and 12% were significant others (Mellon, Northouse, & Weiss, 2006). In addition, the strongest links between chronic illness and family relationships were often found in the marital relationship (Kiecolt-Glaser & Newton, 2001). Frequently, spouses, in contrast to patients, had less confidence in their ability to manage the illness and perceived less support across all phases of illness (Northouse et al., 2007), and reported significantly lower quality of life compared to cancer survivors (Mellon et al., 2006). It is possible that such problematic coping can be partially attributed to ineffective communication between spouses.

Unfortunately, more often than not, cancer patients complain about communication problems with their spouses. For example, Jamison, Wellich, and Pasnua (1978) found that 89% of mastectomy patients in their study reported having had little or no communication with their spouses prior to surgery, 87% had little or no communication while hospitalized, and 50% reported little or no communication about the illness after returning home. Another study found that over 86% of the surveyed cancer patients reported communication problems with relational partners (Heinrich, Schag, & Ganz, 1984). More recent studies continue to report this negative trend. For example, Kornblith and colleagues (2006) found that almost 40% of breast cancer patients did not disclose key cancer issues to their partners. It is reasonable to infer that end-of-life issues were not discussed in these couples as well as key cancer issues. Such avoidance of difficult topics in couples' communication can be partially explained by their communication styles.

Buunk and colleagues (1996) constructed a questionnaire to measure three *ways of giving support* in couples where one of the partners is ill—protective buffering, overprotection, and active engagement. This Dutch-language measure was used in the Netherlands in several studies of couples affected by a serious illness (e.g., de Ridder,

Schreurs, & Kuijer, 2005; Hagedoorn et al., 2000; Kuijer et al., 2000). After the measure (B. Buunk, personal communication, February 6, 2013) was translated and compared with English-language communication literature, it became apparent that the *ways of support* reflected illness-related communication styles. For the purpose of the current study *the ways of support* will be further referred to as communication styles.

Protective buffering, a negative pattern of spousal cancer-related communication, is a tendency to hide one's concerns from a spouse and to deny worries in order to "protect" the spouse from negative information (Coyne & Smith, 1994). This communication style, in addition to *overprotecting*, described earlier, often had detrimental effects—it reduced feelings of control and caused more distress (Kuijer et al., 2000; Manne et al., 2007), especially among partners rating their relationship as satisfactory (Manne et al., 2007). It follows that couples whose communication style falls into these two categories do not openly discuss difficult topics such as end of life or possible bad outcomes of cancer.

Another communication style, *active engagement*, refers to involving the partner in discussions, inquiring how the partner feels and engaging in other constructive methods of problem solving (Coyne & Smith, 1994). Active engagement by spouses was positively related to the partners' perceptions of relationship quality and self-efficacy in most studies concerning cancer or heart disease patients (Hagedoorn et al., 2000; Kuijer et al., 2000). Not surprisingly, communication style by a healthy spouse was moderated by characteristics of the cancer in their partner. For example, partners who thought the patient was coping better with the cancer showed more active engagement and less overprotection (Kuijer et al., 2000). Conversely, the more ill the partner was, the more they benefited from active engagement. Also, the sicker patients experienced more negative feelings toward spouses who engaged in overprotection and protective buffering (Hagedoorn et al., 2000). On the other hand, characteristics of communication styles and their impacts on patients' well-being, self-efficacy and physical and mental health were different in studies examining spousal support styles with couples affected by chronic diseases other than cancer, such as asthma or diabetes (e.g., de Ridder et al., 2005). For example, asthma patients or diabetic patients did not seem to benefit from the engaging behaviour of their spouses, or they did not seem to be bothered by spousal attempts to overprotect them; also, the levels of spousal overprotection were

lower in comparison to the cancer couples (de Ridder et al., 2005). This shows that illness trajectory, illness characteristics and, possibly, the level of adjustment to cancer should be taken into consideration when studying illness-related and/or end-of-life communication.

Gotcher (1993, 1995) examined the role patient–family communication played in the adjustment process for cancer patients. His research illustrated both importance of open discussions in families of unpleasant topics such as pain, fear, or death; and need for new quantitative instruments tapping into these topics of family communication. Patient communication interactions in Gotcher's research were measured by an instrument designed *ad hoc* (the author noted that he had to develop the instrument because "no communication instrument tapping patient–family communication interactions concerning cancer was available" (1995, p. 25). Four aspects of communication were assessed: frequency, honesty, encouragement, and discussion of unpleasant topics; along with their relationship with psychosocial adjustment to cancer (measured by a Psychosocial Adjustment to Illness Scale (PAIS)). The results revealed that well-adjusted and maladjusted patients differed in the frequency of communication, level of honesty, amount of encouragement received from relational partners, and the way unpleasant topics were discussed. The well-adjusted partners talked more frequently about illness, reported a more encouraging environment to talk about the illness, had more honest conversations, and discussed unpleasant topics more often. These findings are similar to those of the Dutch group of researchers who reported the benefits of an active engagement style, as well as to several recent studies by Manne and colleagues, who also reported benefits of what they called relationship-enhancing communication (self-disclosure, mutual constructive communication) for the psychological adjustment of cancer patients and their partners (Manne & Badr, 2008; Manne, Badr, Zaider, Nelson, & Kissane, 2010; Manne et al., 2007; Manne et al., 2004). However, Gotcher also made a unique contribution to the body of knowledge by reporting the topics of discussion between spouses.

Gothcher (1995), after examining a series of open-ended questions, reported that both well-adjusted and maladjusted couples discussed a variety of unpleasant topics including pain, fear, cancer recurrence, financial concerns, treatment side-effects, and death. Interestingly, both groups also wished to discuss more thoroughly the topics of

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fear, cancer recurrence, and death. Even well-adjusted partners who indicated they had no problems discussing these topics with their spouses felt the need to have more discussions. Unfortunately, the author did not report if age of the subjects was a factor in any of his findings (his sample consisted of 102 subjects ranging from 25 to 90 years of age). These results suggest these so-called "unpleasant" topics should be included when studying spousal caregiver–carereceiver couples. It would also be interesting to figure out if couples not affected by serious illness discuss them, how often, and if they are satisfied with the content and frequency of these discussions. It appears that the more open couple communication is, regardless of illness status, the better the psychosocial correlates of such communication.

Another seldom-studied theme of marital communication in the context of a serious illness is non-illness interactions. Badr and colleagues examined how talking about their relationship affected couples' marital and psychological adjustment to lung cancer (Badr & Acitelli, 2005; Badr et al., 2008). To assess talking with a partner about the relationship (they termed it *relationship talk*), they developed a brief measure based on the findings from their previous qualitative study. The four main themes assessed by the measure were quality of the relationship, relationship memories, planning for the future, and problem solving. One of the themes, planning for the future, was relevant for the current research, because *planning for the future* often includes discussing possible bad outcomes as well as death and dying in the couples affected by cancer. The measure itself, not published yet in full, was kindly provided by their authors for analysis (H. Badr, personal communication, February 28, 2013), and will be reviewed later. Besides the novelty of its content, the measure is also interesting because it allows the frequency and satisfaction of discussing a particular topic to be assessed concurrently. The researchers found that relationship-talk frequency and satisfaction were only modestly correlated. Among the expected findings that were confirmed were: 1) positive association between both frequency and satisfaction of relationship talk with marital adjustment and their negative association with psychological distress, and 2) negative association between wanting more relationship talk and marital adjustment, and its positive association with psychological distress. These findings supported a mediational model of relationship communication, intimacy, and distress (Manne et al., 2010, reviewed in Chapter 2.4.3), which formed the basis of the framework for the current

research (Chapter 2.4.4). Longitudinal analysis also showed that, over time, greater communication was related to less distress in the partner than in cancer patient (Badr et al., 2008). Among the important contributions of the authors was inclusion of two very important themes previously not studied in dyadic communication within a context of illness—relationship memories and planning for the future. These two communication themes—reminiscence and planning for the future—are especially relevant to older couples.

Cancer, communication, and older adults.

Older adults constitute the majority of cancer patients: 60% of all cancers occur in the 12% of the population older than 65 (Nussbaum, Baringer, & Kundrat, 2003). However, the research literature is disproportionately small on cancer-related communication by older adults. There are several challenges explicitly attributed to "older" cancer. About 85% or more of older adults with cancer in population studies reported at least one comorbid condition (approximately the same percentage is true for cancer-free older adults), with the majority of these 85% having two comorbid conditions (A. Smith et al., 2008). Comorbidities could explain the paucity of cancer communication research with this population, as multiple illnesses usually make people inadmissible for participation in studies. However, it would be reasonable to extrapolate findings in younger populations to older adults: families experience more distress if a patient is more sick (Northouse et al., 2007). This means that more comorbidity would lead to more distress that, in turn, would negatively affect communication. Caregiver burden, which is often higher when caring for sicker older adults, also impedes communication (Harris et al., 2009). These challenges that are unique to "older" cancer add up (Singer, Martin, & Kelner, 1999; K. B. Wright & Frey, 2008) to a list of justifications for the need to study illness-related communication with older populations. Overall, these findings suggest that older couples affected by cancer and comorbid illnesses might have more challenges for communication than their healthier or younger counterparts. It is unclear though whether these challenges translate into more problematic illness-related or end-of-life-related communication due to the lack of instruments capable of measuring such communication. It follows that any study of end-of-life communication in older adults should take into account health status of the participants to control for its possible effect on such communication.

2.3. End-of-life communication

Death anxiety is one of the major factors affecting end-of-life communication (Malcomson & Bisbee, 2009). Among the main barriers to end-of-life communication identified in patients and families were fears of death and dying, as well as feeling threatened by such discussions, and a fear of causing pain (Larson & Tobin, 2000; Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998; Zhang & Siminoff, 2003). However, research has linked more successful communication on end-of-life issues to lesser death anxiety (Feifel & Branscomb, 1973), improved quality of life, and higher ego integrity (Fortner & Neimeyer, 1999; Fortner, Neimeyer, & Rybarczyk, 2000b). In addition, research suggests that older people have less death anxiety and are more willing to talk about death and dying than are middle-aged adults (Gesser, Wong, & Reker, 1987). Also, older persons are more open toward ACP: they are not only willing to talk about end-of-life planning but actually welcome the opportunity (Kastenbaum, 2000; Malcomson & Bisbee, 2009; Wass & Myers, 1982).

Where there was effective communication among the patient, health care providers and the family, the end-of-life experience was improved, benefits for patients and their caregivers were found and fewer aggressive medical treatments were used for terminal patients (A. Wright et al., 2008). In a recent prospective randomized controlled trial (RCT), Detering and colleagues (2010) examined the impact of advance care planning on end-of-life care in elderly patients. They reported that, among patients who received facilitated advance care planning, not only were the end-of-life wishes known and followed better (86% versus 30% in the control group), but several beneficial psychosocial outcomes were noted. In particular, patient and family satisfaction was higher in the intervention group, and surviving family members had significantly less stress, anxiety, and depression than the families of the control patients (Detering et al., 2010).

For end-of-life wishes to be known and followed, they have to be communicated to families and clinicians. However, currently, for many seniors, the first discussion of advance care planning occurs during an acute hospitalization (Reisfield & Wilson, 2004); overall, advance care planning still occurs infrequently, and typically in the context of an acute illness or event (Malcomson & Bisbee, 2009). In addition, it might be too difficult

to talk about end of life when the patients are often ill, fragile, or confused (Feifel & Branscomb, 1973). For directives to be truly *advanced*, they have to be documented in advance; or, at least, communicated to a loved one in advance. As analyses of data from the Canadian Study of Health and Aging (CSHA-3) showed, over 83% of older adults have thought about who would make health decisions for them if they were not able to do it for themselves. However, only 58% of older adults have discussed their preferences for end-of-life care with someone, and 66.3% of those who discussed their preferences have formalized their wishes in a legal document (Garrett, Tuokko, Stajduhar, Lindsay, & Buehler, 2008). Another study reported that 90.5% of community-dwelling older adults thought that advance care planning was a good idea and 84.1% believed that it is better made in advance, while one is healthy and active. However, only 62.8% of the participants acted on their beliefs and discussed their end-of-life wishes with someone, usually a family member (Polchenko, 2012). A smaller proportion of Canadians who ever discussed their healthcare-related decisions with the family—49%, and even fewer who had an Advance Care Plan written down—19%, was reported by the March 2012 Ipsos-Reid National poll (G. Fernie, personal communication, March 20, 2014). The smaller number in the Ipsos-Reid survey can be explained by difference in the sample's age characteristics: it appears that older adults discussed EOL care preferences more often than the general population. To answer why so few have discussed their EOL wishes with their families, more research is needed.

Too few studies research end-of-life communication in families, and almost all of these examined communication when one of the family members is already affected by serious illness. But no research can be found that investigated how healthy families communicate about their members' end-of-life wishes. To reveal how both healthy couples and couples affected by a life-threatening illness talk about end of life in families, items tapping into such conversations should be included in marital communication measures and specific end-of-life-communication instruments should be developed.

In summary, end-of-life discussions in couples are just a part of general relational communication that happens across different contexts. These conversations happen

within a social context—marriage in our case. Due to the lack of evidence, it is unknown if marital satisfaction or general marital communication style are related to quality, substance, or frequency of end-of-life communication. Often necessarily end-of-life communication happens within a context of serious illness and caregiving. Illness-related communication can both impede or enhance adjustment to a disease and increase or reduce spousal caregiver's strain. In addition, illness trajectory and characteristics also affect adjustment and communication. Older people tend to become ill more often, especially with serious illnesses, compared to younger people. These points underscore the importance of studying illness-related communication in older couples. But, ill or not, older adults discuss topics other than illness—their relationships, their past memories and plans for the future. These conversations affect and reflect psychological well-being in both spouses. It follows that, to have a complete picture of relational processes in older couples, all of these contexts need to be included in research on end-of-life communication.

2.4. Theoretical framework

The development of a new end-of-life communication measure was informed by family systems theory (Bavelas & Segal, 1982), the socio-emotional selectivity theory (Carstensen, 1995), and a mediational model of relationship communication, intimacy, and distress (Manne et al., 2010) briefly reviewed below. These theories are relevant for studying communication in older couples within different contexts, including end of life. Due to the inclusive nature of the family systems theory, both theories and the mediational model can be applied concurrently.

2.4.1. Family systems theory

The family systems theory, which treats the entire family as a unit, is a useful theory to inform research on family communication. This model accounts for the reciprocal nature of family relationships, the broader social context in which families exist, and the multiple dimensions that comprise family functioning (Peterson, 2005). According to Peterson, family communication is one of the three main dimensions defining family functioning (organization/structure, health-related cognitions and beliefs, and family communication). Thus, a family response to a crisis—e.g., cancer diagnosis, treatment, survivorship, or bereavement—will be influenced by each of these familial dimensions (Peterson, 2005). Another strength of this theory for research and development of family interventions is that it permits a more inclusive definition of what constitutes a family (Harris et al., 2009). For the purpose of the current research a couple (married or common-law) was treated as a family system.

The family, as a unique social system, is theorized as an "example of an open, ongoing, goal-seeking, self-regulating, social system" (Broderick, 1993, p. 37). Family systems theory posits that an individual does not exist without context. Persons (spouses, in our case) are considered as parts of overall patterns; in turn, these patterns are reflected in spousal interactions (Galvin, Dickson, & Marrow, 2006). Seven properties are thought to characterize a social system such as the couple: 1) Interdependence: 2) Wholeness; 3) Patterns/regularities; 4) Interactive complexity; 5) Openness; 6) Complex relationships; and 7) Equifinality (reflecting a notion of family as a goal-oriented entity).

There is a recent notable example of successful employment of family systems theory in informing communication research. Harris and colleagues (2010) investigated cancer risk communication within families with a member who has melanoma. The authors analyzed the association between family functioning and family communication among first-degree relatives. The results illustrate the interplay between familial characteristics and family communication and demonstrated that familial adaptation, cohesion, coping, and health beliefs are strongly associated with an open style of risk communication within families. The authors concluded that communication is a multi-faceted and complex concept: simply measuring frequency or style may not capture the actual communication tendencies within a family. Examining only one of these facets may provide merely a crude snapshot of the actual communication patterns occurring within families (Harris et al., 2010).

Within the family systems theory marital communication is an essential property of the system. However, this property also carries characteristics of the whole system, for example, *interdependence*, *interactive complexity*, or *openness*. Each for these characteristics has implications for measurement of communication. *Interdependence* implies that a change in one part of the system affects the entire system: changes in one spouse (e.g., illness) impacts the whole system (Galvin et al., 2006). For the purpose of this thesis, assessment of one spouse would be sufficient to provide feedback on the whole couple. *Interactive complexity*, from a systems perspective, means that usually there could not be a simple cause/effect relationship within a system (Galvin et al., 2006). The system is so complex and dynamic that many multidirectional influences interact simultaneously. This property also affects measurement method and interpretations of data: there cannot be one dependent and one independent variable, they usually interact dynamically. A classic pattern, as Galvin et al. (2006, p.313) explain, is the nag/withdraw cycle ("He withdraws because she nags; she nags because he withdraws"), which demonstrates the impossibility of finding the "first cause." For assessment of communication, this property allows us to conclude that communication both affects and reflects a marital relationship at the same time. In other words, this property allows us to theorize that end-of-life communication in couples would correlate with marital relationship. Another characteristic, *openness*, means that a marital dyad, as a system, is open to external/environmental influences. Spouses may communicate

with individuals outside the boundaries of their marriage (e.g., medics, friends, or extended family) and are influenced by the larger ecosystem that includes health, educational, political, and economic institutions (Galvin et al., 2006). This property would emphasize the importance of including different contexts—internal as well as the relevant external ones—for the assessment of marital communication in general and end-of-life communication in particular. Because personal beliefs reflect external influences, inclusion of items tapping into personal beliefs about marital end-of-life communication in the new measure would satisfy the *openness* property of a marital dyad.

2.4.2.   Socioemotional selectivity theory

Socioemotional selectivity theory was helpful for building the content of the new communication measure. According to socioemotional selectivity theory (SST, Carstensen, 1995), people have at least two broad motives for engaging in social interactions: emotion regulation and information gain. Emotion regulation is related to present and present-oriented goals, while information gain is about future-related goals. SST, a lifespan theory of motivation, proposes that as people age and realize that their time is limited, they become more selective in spending their resources: they invest their energy and attention in the relationships and activities that are emotionally more meaningful. This means that focusing more on a known to be rewarding relationship and activities here and now rather than expanding their horizons for some future gains. Accumulating evidence provides support for the theory. For example, when reminiscing, older adults are more likely to recall positive rather than negative stimuli (Charles, Mather, & Carstensen, 2003). After a diagnosis of cancer, older adults tend to focus more on relationships than before diagnosis, often reporting loving each other even more than before (Badr & Acitelli, 2005). The increase in marital satisfaction with age, reported in numerous studies (Fowers & Olson, 1993; Gagnon, Hersen, Kabacoff, & Van Hasselt, 1999; Henry, Berg, Smith, & Florsheim, 2007; Herzog & Rodgers, 1981; Orbuch, House, Mero, & Webster, 1996; T. Smith et al., 2009), is another confirmation for SST.

The relevance of this theory for the current research is in highlighting the extent to which emotional gratification lies behind older adults' relationships and

communication. Awareness of this motivation was useful in developing the content of the new instrument.

2.4.3. Proposed framework for study of marital end-of-life communication

The proposed framework for the instrument development is informed by a mediational model of relationship communication, intimacy, and distress (Fig.1, Manne et al., 2010).

Figure 1. Mediational model of relationship communication, intimacy, and distress
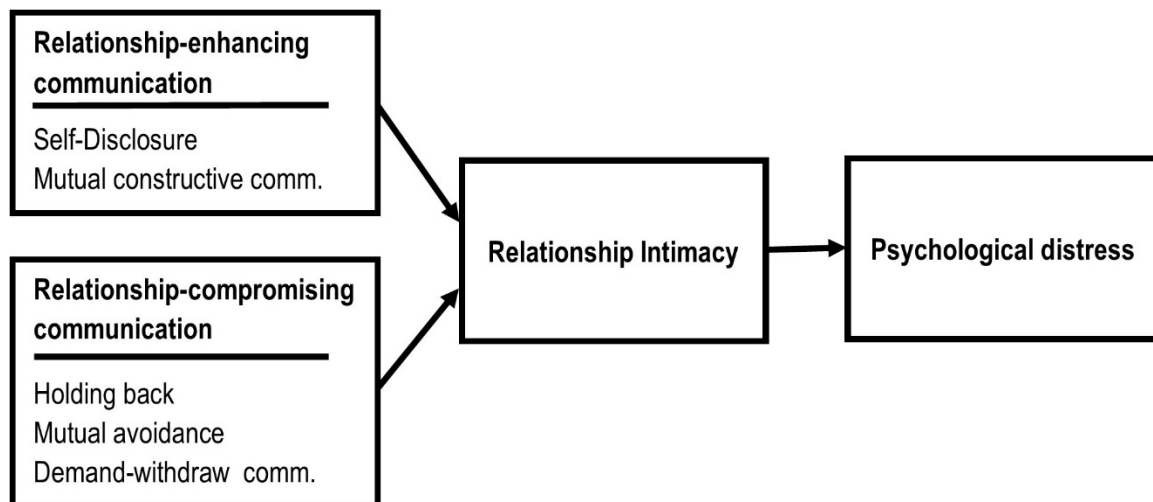
Note. Manne et al., 2010; displayed with the permission from Springer Science and Business Media, license #3113231286883

This model was developed as a result of study of cancer-related communication, relationship intimacy, and psychological distress among couples coping with prostate cancer. The model proposes that the way in which couples talk about, and the degree to which one or both partners avoid talking about illness-related concerns, can either facilitate or reduce relationship intimacy. And, largely through this process these communication strategies impact psychological distress (Manne et al., 2010). The authors noted that the conclusions about the directionality of effects in the model were limited by the cross-sectional design of the study. Although they controlled for the effects of global marital satisfaction on the model, pre-existing distress may have influenced the

communication strategies that both partners used as well as relationship intimacy
(Manne et al., 2010).

As mentioned before, cancer-related communication or end-of-life
communication can be considered a special case of marital communication. Both topics
are difficult to discuss and involve hightened sense of mortality. It seems reasonable to
apply a model of cancer-related communication to end-of-life communication.
Nonetheless, there is a difference between these two communication themes. In couples
already affected by cancer, there is an apparent need to discuss disease-related
concerns, such as treatment strategies. However, talking about end-of-life issues has no
apparent immediacy, especially in healthy couples. Therefore, talking about end of life is
predicated by willingness to communicate about it, not a necessity. The new instrument
assesses willingness to communicate and communication preferences about end-of-life
issues in couples. The schematic representation of the framework, tailored for the
current study, is shown in Fig.2.

Figure 2. Proposed framework for study of marital end-of-life communication
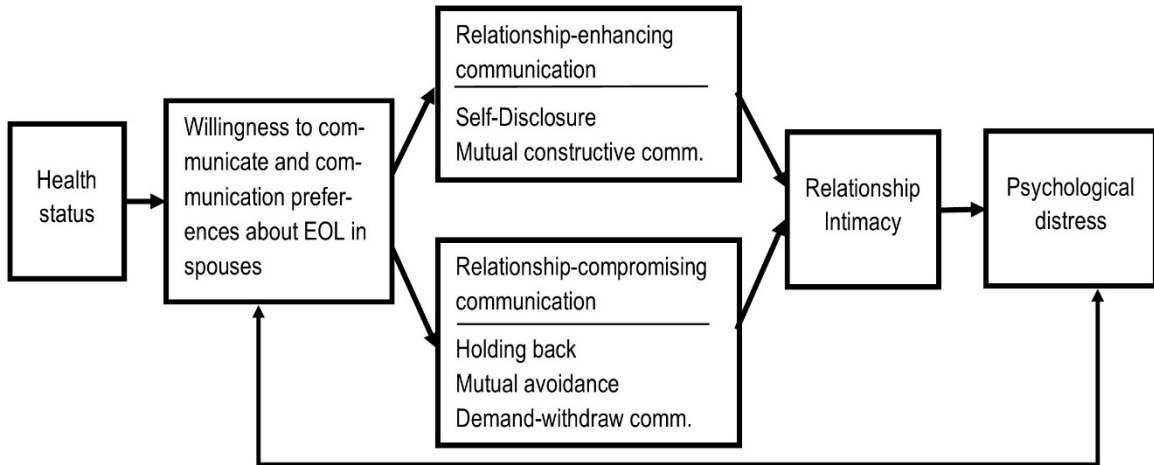
It is unknown if and how general marital communication patterns relate to
patterns of discussions about end of life. It is possible that in some couples who
otherwise have successful interaction, this topic could be compartmentalized and
avoided. How well or how poorly the end-of-life issues are discussed should depend on
the couple's attitudes and communication preferences about death and dying and their

general style of marital communication. At the same time, the model suggests that the manner of these discussions affects relationship intimacy and, in turn, psychological distress.

In addition, we added health status as a possible moderator for marital EOL communication to the proposed framework due to conclusions drawn from the literature on illness-related communication.

2.5. Review of existing measures for communication research

Below is a review of existing quantitative measures potentially relevant to developing a scale of end-of-life communication in older couples. The measures capable of assessing aspects of marital communication in different contexts were searched for in online databases (Google Scholar) and in several sourcebooks: *Communication research measures: A sourcebook* (Rubin, Palmgreen, Sypher, & Beatty, 1994); *Communication research measures II: A sourcebook* (Rubin, Rubin, Graham, Perse, & Seibold, 2009); *Measures for clinical practice and Research: A sourcebook* (Fischer & Corcoran, 2007a); *Handbook of measurements for marriage and family therapy* (Fredman & Sherman, 1987); and *Handbook of family measurement techniques* (Touliatos, Perlmutter, & Strauss, 1990). In addition, several relevant measures were requested directly from the authors when the measures were not published in their entirety in the respective studies. The criteria for choosing the instruments to review were their utility in assessing marital/couples communication of end of life. All of the instruments assessed illness-related communication, were applicable to illness-affected couples only, but nevertheless were useful as a reference for developing a pool of items for the new measure. The main psychometric properties, if provided, are displayed in Table 1 below, followed by a more detailed review of the instruments.

Table 1. Measures for communication research

Scale	Author, year	Items	Reliability	Validity	Sample
The Couples' Illness Communication Scale (CICS)	Arden-Close et al. 2010	4	Patients: 0.84 Partners: 0.80 Test-retest	Content Convergent Construct Criterion	Patients N=187 Partners N=101
Cancer-Related Communication Problems within Couples Scale (CRCP)	Kornblith et al. 2006.	15	0.87 (female patients) 0.81 (male partners)	Content Convergent	189 females 135 males
Relationship Talk measure	Badr et al. 2008	11	0.91 for patients 0.92 for spouses	N/A	169 patients 167 partners
The Cancer Communication Assessment Tool for Patients and Families (CCAT-PF)	Siminoff et al. 2008	18	0.49 Test-retest 0.35	Construct Concurrent:	190 patient-caregiver pairs

2.5.1.   The Couples' Illness Communication Scale (CICS)

The Couples' Illness Communication Scale (CICS, Arden-Close, Moss-Morris, Dennison, Bayne, & Gidron, 2010), is a brief 4-item self-report measure of illness-related couple communication. The CICS demonstrated good reliability (Cronbach's alpha was 0.84 for patients and 0.80 for their partners), inter-item correlations (correlations between items on the CICS ranged from r = 0.49 to 0.64 for patients and from r = 0.33 to 0.59 for partners), and test-retest reliability (0.71 for patients and 0.75 for partners over 3 months); as well as face, content, convergent (highly correlated with the above reviewed ENRICH couple scales communication subscale: r = 0.78, p < 0.001 for patients, and r = 0.69, p < 0.001 for partners), construct, predictive, and criterion validity. The scale was validated for populations affected by a life-threatening illness (cancer) and a chronic progressive disease (multiple sclerosis).

The patient's version of the scale is displayed here in full due to its brevity (the partner's version is basically the same with replaced possessive pronouns):

1) It is hard for me to express feelings about my illness to my partner.
2) I feel comfortable discussing issues related to my illness with my partner.
3) My partner is reluctant to talk about my illness.
4) My partner is willing to share his/her feelings about my illness with me.

<div align="right">(Arden-Close et al., 2010)</div>

The items are scored with a Likert-type scale ranging from 1 (disagree strongly) to 5 (agree strongly). Although brief, simple, and psychometrically sound, the scale was not completely fitting for the current research. In essence, it asks only two questions: 1) How easy/hard it is for me to talk to a partner about illness?; and 2) How easy/hard it is for my partner to talk to about illness with me (the first two and the last two questions are the same questions asked differently)? It seems that the scale could be a quick and effective screening tool flagging those unsatisfied with the illness-related communication exchange. But, unfortunately, it does not provide more information for in-depth investigation of spousal communication in an illness context or for study of end-of-life communication. At the same time, the scale was used as a reference for developing items addressing willingness to discuss difficult topics between spouses for the new measure.

2.5.2.   Cancer-Related Communication Problems within Couples Scale (CRCP)

The Cancer-Related Communication Problems within Couples Scale (CRCP, Kornblith et al., 2006) is a 15-item self-report scale assessing whether patients and their partners have difficulty talking about cancer with each other. Kornblith and colleagues (2006) reported good reliability for both patients and partners (alpha coefficient = 0.87, 0.81, respectively) as well as content and convergent validity (when validated with female cancer patients and male partners).

The premise of the CRCP was that "open-ended communication was the healthiest form of communication of cancer-related communication concerns, serving as

an indicator of better psychological state and marital relationship" (Kornblith et al., 2006, p. 783). Several areas of cancer-related communication problems within couples were assessed by the scale: open communication/emotional support (e.g., "I can tell my spouse anything that is on my mind about my having cancer."), self-protection (e.g., "I can talk about cancer with my spouse because I get too upset."), protective buffering of the other (e.g., "I don't talk about my cancer problems with my spouse because he/she gets upset when I do."), and communication about treatment-related issues (e.g., "My spouse and I talk about our worries about whether my cancer treatment worked."). These areas were theorised to comprise four factors; however, testing did not confirm this factor structure (Kornblith et al., 2006). Therefore, a total score, obtained by summing the number of cancer-related problems, was suggested for use in assessment instead of the four factors.

The CRCP does not directly address topics of end of life. At the same time, talking about cancer usually involves certain level of mortality awareness and might involve direct or indirect discussions of different aspects of end of life. Therefore, the CRCP was a useful measure to inform development of the new scale.

2.5.3. Relationship Talk measure

The Relationship Talk measure (Badr et al., 2008) is a 12-item self-report measure of relationship talk (talking about the nature and state of one's relationship) in the context of cancer. This is the only non-illness communication-related measure located. It was developed on the basis of previous qualitative studies (Badr & Acitelli, 2005) to quantify assessment of spousal communication beyond patient cancer-related disclosures. Examples of relationship talk were identified and synthesized into 11 items addressing the overall quality of the relationship, specific aspects of the relationship (including intimacy), relationship expectations/needs, relational memories (mutual reminiscence), plans for the future of the relationships (end-of-life discussions), and problem solving about the relationship. Here are examples of the items:

1) Did you talk together about your feelings for each one?
2) Did you plan together for the future?
3) Did you talk together about your shared memories and experiences?

4) Did you talk together about the effect the cancer has on your relationship?

<div align="center">(H. Badr, personal communication, February 28, 2013).</div>

The items were scored twice by scales corresponding to two different questions. The first question was, "How often in the past month…." It was scored by a Likert-type scale ranging from 1 "not in the past month" to 5 "all the time in the past month". The second question assessed satisfaction with the frequency of discussion: "Are you satisfied with this?" with the response options (1) "Yes, I am satisfied"; (2) "No, I would like more"; and (3) "No, I would like less". A relationship talk frequency was calculated by averaging scores across items. A relationship talk satisfaction score was calculated by assigning a 1 to each item for which respondents indicated they wanted more or less talk. A total score was calculated by summing the number of endorsed items. Summary scores reflecting desire for more or less frequent talk were calculated similarly (Badr et al., 2008). The scale was not formally validated. Alpha coefficients were calculated to test internal consistency (in a study with cancer patients). For patients, alpha was 0.91 and for spouses—0.92.

The method of measuring communication both by the frequency of discussions and level of satisfaction was used in the criterion-related validation study of the new instrument.

2.5.4. The Cancer Communication Assessment Tool for Patients and Families (CCAT-PF)

The Cancer Communication Assessment Tool for Patients and Families (CCAT-PF, Siminoff, Zyzanski, Rose, & Zhang, 2008) is a 18-item self-report questionnaire designed to assess cancer patient–family communication congruence about treatment and care decisions. Although the authors reported the instrument as reliable and valid, its psychometric properties are questionable. Thus, in a validation study, the reported Cronbach's alpha coefficient was 0.49, which is quite low. The authors explained that this value was "to be expected, as the CCAT-PF does not represent a typical summed scale of moderately correlated items, but the sum of mostly independent items" (Siminoff et al., 2008, p. 219). As such, they should not have 1) summed mostly independent

items, and 2) reported the instrument as reliable. Instead, they could have proposed an alternative scoring system (if they were satisfied with the overall model).

The measure claimed to assess eight areas of communication, including general communication and interaction style, reluctance to report side effects, treatment and care goals, and family communication. Here are examples of the items:

1) I hesitate to mention treatment side effects to my doctors or nurses.
2) I avoid talking about cancer to my family because I don't want to upset them.
3) Medical science may find a cure for cancer so I am willing to take any treatment now to stay alive.
4) I would feel uncomfortable if the doctor began to talk to me about hospice care.

(Siminoff et al., 2008)

It is unclear why this measure was called a *communication assessment tool for patients and families*, as the majority of items don't assess patient-family communication at all. For example, among the above four sample items, only the second one addresses family cancer communication.

It appears that, although possibly useful for clinical assessment, the usefulness of the CCAT-PF in research is questionable due to its problematic psychometric properties. The instrument is reviewed here because it is one of very few measures that assess cancer-related communication in families and therefore it is valuable as a reference for development and wording of items in the new instrument.

In summary, no instruments capable of measuring EOL communication in couples—affected or not affected by a serious illness—were found. The reviewed measures were designed to study illness-related communication in couples affected by cancer, a special case of marital communication. They were useful to the development of the new measure as a reference due to a certain similarity of EOL and illness-related communication, described in Chapter 2.4.3. The new instrument is different from the reviewed ones in two aspects—a subject matter (EOL communication) and a population under study (couples regardless of their health status).

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Chapter 3.   Methods

A new instrument called the Marital End-of-Life Communication Scale (MELCS) was developed to measure end-of-life communication in couples. For the purpose of the current study, end-of-life communication was operationalized as a combination of beliefs, comfort level, and willingness to talk about end-of-life wishes and preferences. The reporting of the development and validation of the new instrument was informed by the guidelines developed by the *STARD* initiative (Meyer, 2003), the *Standards for Educational and Psychological Testing* (AERA/APA/NCME, 1999), recommendations by Streiner and Norman (2008), Gaskin (2012b), and the Modern Sequential Test Analysis framework (Maraun, 2010; Slaney & Maraun, 2008).

The development and validation of the new measure consisted of several steps: 1) selection of candidate items and development of a preliminary version of the MELCS; 2) content validation of the questionnaire; 3) selection of additional measures; 4) defining theoretical and quantitative characterization of the test according to Sequential Test Analysis; 5) data collection and screening; 6) exploratory factor analysis (EFA); 7) assessing the measurement model fit; 8) assessing construct validity and reliability by performing confirmatory factor analysis (CFA); and 9) evaluating criterion-related validity. The analyses were undertaken using IBM SPSS18 (EFA), LISREL8.8 (CFA), and AMOS18 (CFA and SEM). Here is the detailed breakdown of the procedure for the development of the MELCS.

3.1. Selection of candidate items and development of a preliminary version of the MELCS

A pool of 14 prospective items (Appendix A) was constructed based on theories and previous research. Some prospective items were modified from the available scales measuring dyadic communication, interaction, relationship, and adjustment.

3.2. Content validation of the questionnaire

Three experts in the areas of communication and thanatology, recruited at the 3rd Annual Public Health and Palliative Care Conference (Limerick, 2013), examined all items for content validity. The experts were: a professor of palliative care and community health at Middlesex University, a professor of death studies at the University of Bath, and a research fellow in health promoting palliative care at La Trobe University. In case of consensus among two out of the three experts that an item did not meet content validity criteria, the item was eliminated from the pool. Thus, three items were eliminated from the pool, and the rest were deemed to meet content validity criteria. Overall, the experts agreed that the items provided sufficient content coverage and depth; and were relevant to measurement of EOL communication in older couples. The pool of the remaining 11 items (Appendix B) constituted a preliminary questionnaire.

A focus group consisting of nine older adults was gathered to further evaluate the remaining items' content validity. The goal of the focus groups was to receive feedback from married older adults about the relevance of the items to their marital end-of-life communication. The group consisted of four males and five females, aged 65 years and older, married and living independently in the community. The focus group was recruited at a seniors' community centre in Vernon, B.C. by placing a recruitment poster in places of public gatherings. The community centre also provided a room for the focus group facilitation. Before the start of the focus group, the participants were asked to read and sign an informed consent form. After filling out the preliminary questionnaire, the participants were asked broad questions about the questionnaire: i.e., were there confusing questions; would you add or remove anything from the questionnaire; did you like/dislike parts of the questionnaire; etc. The results of group discussions were analyzed and relevant changes made to the questionnaire. The consensus of the focus group participants was that the questionnaire was clear, relevant to their marital end-of-life communication, and sufficiently covered all aspects of marital end-of-life communication. One of the items from the preliminary questionnaire was eliminated after several of the focus group participants found it somewhat confusing. The remaining ten items comprised the finalized version of the MELCS.

3.3. Additional measures

Three established scales, six ad-hoc variables, and a set of demographic and health-related questions were used to assess criterion-related, construct (nomological), convergent and discriminant validity, as well as invariance of the new instrument.

3.3.1. Construct (nomological) validity assessment

As was indicated in the literature, spousal communication predicts marital satisfaction and psychological distress. Therefore, to assess construct validity of the MELCS, measures of marital communication, marital satisfaction and psychological distress were administered together with the MELCS. Here are the brief descriptions of the instruments:

Marital communication: ENRICH Communication Subscale

For the assessment of construct validity of the MELCS, the ENRICH Communication Subscale (Fournier et al., 1983) was employed as a measure of general marital communication. It was theorized that the MELCS and the ENRICH would correlate, thus providing evidence for construct validity of the MELCS.

The PREPARE/ENRICH Inventory (Fournier et al., 1983), available commercially, was designed for both clinical use and research. It contains over 100 scales. The ENRICH Communication Subscale, a 10-item self-assessment instrument, evaluates an individual's feelings, beliefs, and attitudes about the communication in his/her relationship. The subscale was recently validated in a large survey of 50,000 couples (US national sample of married couples). Reported reliability was high (alpha at 0.89). However, the sample contained only a very small number of older adults: only 18 in the 80–and–older range; 17 in the 75–79 range; 67 in the 70–74 range; 136 in the 65–69 range; 276 in the 60–64 range; 607 in the 55–59 range; and 1300 in the 50–54 range (D. Olson, personal communication, February 2013). Despite its lack of validation with older couples, the ENRICH Communication Subscale was chosen for the current study. Psychometric tests were performed with our sample to ensure the subscale's validity in the population under study.

A copy of the instrument including permission to use it in the current research was purchased. The scale is represented in Appendix E, Section D, items 35-44.

Marital satisfaction: Kansas Marital Satisfaction Scale

To assess whether marital end-of-life communication predicts marital satisfaction, the Kansas Marital Satisfaction Scale (KMS, Schumm et al., 1986) was employed. This brief 3-item measure assesses marital satisfaction from the "individual feelings" perspective that differentiates marital quality from other dimensions of a marital relationship, such as marital communication.

The KMS has excellent internal consistency, with an alpha at 0.93, in addition to excellent concurrent and acceptable discriminant validity (Schumm et al., 1986). The individual items are scored on a Likert-type scale ranging from 1 (extremely dissatisfied) to 7 (extremely satisfied). The scale is represented in Appendix E, Section D, Items 45–47. The overall score is obtained by summing individual items.

Psychological distress: Templer Death Anxiety Scale

To assess psychological distress, for the purpose of the current study, a measure of death anxiety was utilized. Death anxiety is negatively correlated with ego integrity and positively correlated with psychological problems (Fortner, Neimeyer, & Rybarczyk, 2000a). High levels of death anxiety would signal high levels of psychological distress. In addition, it would be reasonable to assume that high levels of death anxiety would affect one's end-of-life communication preferences.

The measure used is the Templer Death Anxiety Scale (TDAS, Lonetto & Templer, 1983), a 15-item instrument assessing respondents' anxiety about death. The TDAS includes a broad range of items and concerns about death; has been extensively studied with different populations; and has good internal consistency (alpha at 0.74), temporal stability (a three-week test-retest correlation of 0.83) and validity (Fischer & Corcoran, 2007b). Norms for some populations were reported, including older adults. The scale is represented in Appendix D, Section C. Regression analysis was performed to find whether MELCS and TDAS scores were correlated, thus providing evidence for construct validity.

3.3.2. Ad-hoc variables for criterion-related validity assessment

To assess if marital end-of-life communication attitudes and preferences predict whether end-of-life wishes are formalized or overtly discussed, six additional questions were added to the battery of tests. These ad-hoc variables assessed whether end-of-life wishes of each spouse were discussed and to what level of satisfaction, and whether each spouse had a will and advance directive in place (Appendix E, Section B).

3.3.3. Demographic and health-related covariates

Additional variables were collected with the rest of the instruments (Appendix E, Section E). Age and marital status were assessed to ensure conformity to inclusion criteria (married/partnered adults aged 45 years or older). In addition, age was used to see if it moderated other variables and whether the new measure was invariant across age.

Information about gender, cultural/ethnic background, health status (self-rated), and education were collected to probe if they affect marital end-of-life communication. Self-rating was used for assessment of health for reasons of brevity and because there is no perceived benefit to using objective metrics for these variables in the context of the current study.

In addition, information about possible recent health crises of each spouse was collected. If a recent health crisis was reported, the follow-up question asked about the general diagnosis (a type of disease) to be able to discern whether different illness contexts predict the quality of marital end-of-life communication. For example, if a participant's spouse had a serious illness, the participant could be considered a spousal caregiver. Therefore, collecting these data allowed us to examine whether a caregiving status had impact on marital end-of-life communication.

3.4. Sequential test analysis

Data and statistical analyses were performed following the Modern Sequential Test Analysis framework (Maraun, 2010; Slaney & Maraun, 2008). To maintain

consistency of terms coined by different authors, we will use the terms *test* and *measure* interchangeably as applied to the MELCS.

The sequence consists of several steps:

1. Deduction of the theoretical structure of the test.
2. Generating a quantitative characterization of the theoretical structure.
3. Test of dimensionality: testing the conformity of the empirical behaviour of the test to its quantitative representation. In other words, we assess whether the measure is unidimensional.
4. Reliability estimation: in case of unidimensionality, the test items may be composited and an optimal lower bound to the reliability of this composite can be derived.
5. Nomological validity testing: entering the composite into external validation studies.

Below is a breakdown of these steps, beginning with operational definitions and assumptions.

3.4.1. Operational definitions and assumptions

1. A construct C under investigation is marital EOL communication.
2. We developed a test T comprised of 10 items (*n*=10) to measure the construct C.
3. Population P under investigation is a population of older married adults living in the British Columbia interior.
4. For any individual $i \in P$ the application of the measure results in a set of 10 numbers (test data) that comprise a score vector $\underline{X}_i$.
5. There is an infinity of $i \in P$, and we represent this infinity of $\underline{X}_i$ by the random vector $\underline{X}$. $\underline{X}$ has a 10-dimensional distribution $f_{\underline{X}}$.
6. Test analysis: the adjudication of the performance of T in P as a measure of C, through a consideration of the quantitative properties of $f_{\underline{X}}$.
7. As we don't have access to $f_{\underline{X}}$, nor its parameters, we will draw a sample of size N ($N = 101$) from P, producing a 101 by 10 matrix of numbers. Based on this matrix of test data, we will make inferential decisions about $f_{\underline{X}}$.

3.4.2. Theoretical structure (TS) of the test

The theoretical stricture (TS) of T describes how the items of the test should behave.

1. Theoretical distribution. We theorize that the construct of marital EOL communication that the test (MELCS) was designed to measure is continuously distributed.
2. Response format of items. The response format of items is 5-point ordered categorical, Likert-type. For the purpose of simplified analysis we will consider the response format as quasi-continuous.
3. Number of attributes. The items were designed to measure in common only one construct.
4. Theoretical form of regressions. The theoretical form of regressions of items on construct is linear increasing (LI): items values are higher when EOL communication is of higher level (quality).
5. Theoretical error characteristics. The theoretical error characteristics of each item in measuring C are error laden. It means that an item does not reflect the construct perfectly: if participants have the same level (quality) of EOL communication, their scores are not necessarily the same.

3.4.3. Quantitative characterization of the TS

Quantitative characterization (QC) of the TS, a mathematical paraphrase of the TS, will play the role of a test theory model. It provides quantitative, empirical requirements for $f_{\underline{X}}$ that are in keeping with the TS (Maraun, 2010). If the test's behaviour meets these requirements, it can be deemed as conforming to its TS, and is psychometrically sound.

Quantitative characterization of the MELCS theoretical structure is a unidimensional linear factor model, which is represented below.

1. $C \to \theta, \ \mathrm{E}(\theta) = 0, \ \mathrm{V}(\theta = 1)$, where θ is a continuously distributed latent variable.
2. $LI \to E(\underline{X} \mid \theta) = \underline{\Lambda}\theta, \ \underline{\Lambda} > 0$, where $\underline{\Lambda}$ is a vector of factor loadings.
3. [*Unidimensionality in a linear factor analytic (LFA) sense*]
    $\to c(\underline{X} \mid \theta) = \Psi$,
    where Ψ is a diagonal *n*x*n* (10x10) matrix of residual variances. The

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items are conditionally uncorrelated: when θ is held constant, they are uncorrelated. In other words, the only reason the items correlate is because of their joint dependency on the construct they were designed to measure.

4. [*Items are error-laden indicators of C*] $\rightarrow \Psi$ is positive definite (all conditional variances are positive). In other words, while θ explains all covariance, it does not account for all variance in items.

5. Overall, the classical decomposition of unidimensional linear factor analysis can be represented as below:

$$c(\underline{X}) = \Sigma = c\big(E(\underline{X}\,|\,\theta)\big) + c\big(c(\underline{X}\,|\,\theta)\big)$$

$$= c\big(\underline{\Lambda}\theta\big) + E\big(\Psi\big) = \underline{\Lambda}\underline{\Lambda}'\,\mathrm{V}(\theta) + \Psi$$

$$= \underline{\Lambda}\underline{\Lambda}' + \Psi$$

3.5. Data collection and screening

3.5.1. Data collection

Data collection was performed using a paper-and-pencil questionnaire format. The MELCS measure was complemented with a battery of additional measures (reviewed later) to assess its construct and criterion validity.

As the population if interest consisted mainly of older adults, the questionnaire booklet was formatted accordingly: it employed large-sized fonts and a contrasting background colour for easy reading (Appendix E).

The recruitment posters were placed in community gathering places. The participants were recruited at public events, such as community pancake breakfasts or flea markets. Packages containing a questionnaire booklet, a consent form, and a stamped self-addressed envelope were distributed among those willing to participate in the study. As a token of appreciation for taking part in the study, all participants were handed an advance care planning guide, *My Voice: Expressing My Wishes for Future Health Care Treatment* (BC Ministry of Health, 2013). Completed questionnaires were mailed to the researcher's address and then processed. To protect privacy of the participants, self-addressed envelopes had an SFU logo and the study's title printed in

place of a sender's address to prevent participants from writing their names and addresses on the envelopes.

3.5.2.   Study participants and sample characteristics

The participants for the MELCS administration were recruited in Vernon, B.C.. The recruitment criteria for participants were age 45 years or older (to include middle-aged, 45 to 64 years of age, and older adults, 65 of age and older) and living in a married or common-law relationship. The middle-aged participants were included to examine the new measure across age groups.

One hundred and one questionnaires were completed and returned. The demographic characteristics of the sample are represented in the Table 2 below.

Table 2. Socio-demographic characteristics of study participants

Socio-demographic variable	Frequencies
Gender	
Male	45 (44.6%)
Female	56 (55.4%)
Age group	
45-54	10 (9.9%)
55-64	35 (34.7%)
65-74	36 (35.6%)
75-84	15 (14.9%)
85+	5 (5%)
Ethnicity	
White	99 (98%)
Aboriginal	2 (2%)
Education	
Some school	4 (4%)
High school	21 (20.8%)
College	31 (30.7%)
University	29 (28.7%)
Post-graduate	16 (15.8%)

Socio-demographic variable	Frequencies
Self-rated health status	
Excellent	11 (10.9%)
Very good	39 (38.6%)
Good	38 (37.6%)
Fair	13 (12.9%)
Had a recent health crisis	
Yes	22 (21.8%)
No	79 (78.2%)
Spouse had a recent health crisis	
Yes	22 (21.8%)
No	79 (78.2%)

3.5.3. Normality

Factor analytic methods are considered robust enough to be used with non-normal data (Finney & DiStefano, 2006). Since all MELCS variables are based on a 5-point Likert-type scale, it is reasonable not to expect data to be normally distributed. Therefore, a test for normality has limited value for factor analyzing non-scale data. However, items with no variance provide little information and should be dropped from the scale. Kurtosis analysis can flag such items. Kurtosis greater than |+/-1.00| indicates potentially problematic kurtosis (Muthen & Kaplan, 1985).

3.5.4. Sample size assessment

There is no universal rule for choosing a sample size for scale development. There are two schools of thought: the first offer suggestions of an absolute number of participants as the recommended (arbitrary) sample size and the second proposes a different (also arbitrary) subjects-to-variables (STV) ratio. There are rules of 100 (MacCallum, Widaman, Zhang, & Hong, 1999), 150 (Guadagnoli & Velicer, 1988; Hinkin, 1995), or 500 to 1000 (Comrey & Lee, 1992; in MacCallum et al., 1999); or subjects-to-variables ratios from 5:1 (MacCallum et al., 1999) to 20:1 (Hogarty, Hines, Kromrey, Ferron, & Mumford, 2005). However, MacCallum and colleagues (1999) demonstrated

that common rules of thumb regarding sample size in factor analysis are not valid or useful. In particular, they showed that, if the communalities of variables are consistently high (above the 0.6 level) and factors are well determined, the impact of sample size is greatly reduced; and a sample size "well below 100" can be adequate for factor analytic studies (MacCallum et al., 1999, p. 96). Therefore, given the new measure has good psychometric properties (such as high communalities of variables and good factor's determination), the sample of 101 participants can be considered sufficient for factor analysis.

3.6. Exploratory Factor Analysis

Exploratory Factor Analysis was conducted using Maximum Likelihood Estimation to determine whether the observed variables loaded together as expected, were adequately correlated, and met criteria of reliability and validity. First, to assess whether data collected with the sample size N=101 and 9 variables were sufficient for factor analyzing the MELCS, the Kaiser-Meyer-Olkin Measure of Sampling Adequacy and Bartlett's Test of Sphericity were performed.

3.6.1. Kaiser-Meyer-Olkin Measure of Sampling Adequacy

The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO, Kaiser, 1974) is used to compare the magnitudes of the observed correlation coefficients in relation to the magnitudes of the partial correlation coefficients. KMO's value indicates the extent to which a correlation matrix contains potential factors rather than chance correlations. A value of 6.0 is considered minimally acceptable and a value above 0.8 is considered good for factor analysis (Kaiser, 1974).

3.6.2. Bartlett's Test of Sphericity

The Bartlett's' Test of Sphericity (Bartlett, 1950) is used to test the hypothesis that the correlation matrix is an identity matrix. If the test is significant, it means that our variables are correlated with each other, thus suggesting that they are part of the same factor.

3.6.3. Factor extraction

To test whether the items form a one-dimensional instrument measuring our latent construct, marital end-of-life communication, we ran factor analysis. The chosen extraction method was Maximum Likelihood in order to determine unique variance among variables, and also remain consistent with our subsequent CFA. The factor rotation method of choice was oblique rotation, as in case our factor structure was not unidimensional, we expected the potential factors to be correlated.

In order to decide on the number of factors to retain, we analyzed scree plot, initial communalities, total variance explained (with extraction sums of squared loadings), and factor matrix. In case of extracting more than one factor, a pattern matrix could be the most informative tool of interpretation. Items with the lowest communalities and factor loadings might be dropped to achieve better psychometric properties.

3.7. Confirmatory Factor Analysis

3.7.1. Model fit

To test unidimensionality in a LFA sense, we needed to test a hypothesis $H_0 : \Sigma = \underline{\Lambda}\underline{\Lambda}' + \Psi$ (where Ψ is positive definite) vs. $H_1 : \Sigma$ is any gramian matrix. To do so we employed LISREL8.8 software and maximum likelihood method. The software estimated a model-implied matrix, the closest to the input sample covariance matrix; fitted a decomposition $\Sigma = \underline{\Lambda}\underline{\Lambda}' + \Psi$ (where Ψ is positive definite) to this estimate; and tested this fit. If $\Sigma = \underline{\Lambda}\underline{\Lambda}' + \Psi$, the test is unidimensional in LFA sense in P. To decide if the fit is good enough, we looked in this sequence at following statistics:

1. Variance estimates—all should be positive.
2. Standardized residuals—all should be small, between -4 and 4.
3. Goodness of fit statistics:

   a. The Root Mean Square Error of Approximation (RMSEA)—should be small, between 0 to 0.08 (Browne & Cudeck, 1989). According to Kline (2011) "RMSEA ≤ .05 indicates close approximate fit, values between .05 and .08 suggest reasonable error of approximation, and RMSEA ≥ .10 suggests poor fit" (p.139).

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b. Chi squared statistic, also called the discrepancy function (a formal test of H_0 on $dF = \frac{1}{2}n(n+1) - 2n$), should be not significant (*p*-value for the model .0.05). In case of a large sample it usually is significant; in this case, Chi-square should not exceed two degrees of freedom (Kline, 2011), or up to 5, according to Schumacker and Lomax (2004).

c. The Comparative Fit Index (CFI) compares the fit of target model to the fit of an independent model. For an acceptable fit, it should be above 0.93 (Byrne, 1994).

3.7.2.   Composite reliability, convergent and discriminant validity estimation

Measures useful for establishing convergent and discriminant validity are Composite Reliability (CR), Average Variance Extracted (AVE), Maximum Shared Variance (MSV), and Average Shared Variance (ASV).

Convergent validity

Convergent validity is the extent to which indicators of a specific construct "converge," or share a proportion of variance in common (Hair, Black, Babin, & Anderson, 2010). To assess convergent validity we will examine factor loadings, variance extracted (AVE), and composite reliability (CR).

Factor loadings

Factor loadings (Standardized Regression Weights in AMOS) must be statistically significant and should be 0.5 or higher, and ideally 0.7 or higher (Hair et al., 2010).

Composite Reliability (CR)

Composite reliability for a scale is a measure of reliability and internal consistency based on the square of the total of factor loadings for a construct and can be calculated as below (Hair et al., 2010)

$$CR = \frac{\left(\sum\limits_{i=1}^{n} \lambda_i\right)^2}{\left(\sum\limits_{i=1}^{n} \lambda_i\right)^2 + \left(\sum\limits_{i=1}^{n} \delta_i\right)} \quad ,$$

where λ_i are factor loadings and δ_i are error variance terms for a construct.

CR should be higher than 0.7 to indicate adequate convergence or internal consistency.

Variance extracted

Variance Extracted is a summary measure of convergence among a set of items representing a construct (Hair et al., 2010). It is the average percent of variation explained among the items. Below is the formula for Variance Extracted (AVE):

$$VE = \frac{\sum\limits_{i=1}^{n} \lambda_i^2}{n} \quad ,$$

where λ is the standardized factor loading and i is the item's number. So, for n items, AVE is computed as the sum of the squared standardized factor loadings divided by the number of items.

To indicate adequate convergent validity, AVE should be 0.5 or higher. An AVE of less than 0.5 would show that on average there is more error remaining in the items than there is variance explained by the latent factor structure we imposed on the measure. In addition, the AVE estimate should not be greater than CR.

Invariance tests

It is important for a scale to be generalizable across groups, which is possible if observed scores depend only on latent construct scores, and not on group membership. Measurement invariance is a precursor to any group comparison. Therefore, for the new instrument to be useful for any future studies involving group comparisons, it is important to test it for measurement invariance.

Configural invariance is concerned with how the latent factors are distributed and related in discrete populations. It is tested by analyzing whether the factor structure represented in our CFA achieved adequate fit when both groups are tested together without any cross-group constraints. If the resultant model achieved good fit, we can assume configural invariance (Gaskin, 2012b). In other words, configural invariance would mean that the groups have the same factor structure, which would mean the same conceptual definition of the construct under investigation.

After we passed the test of configural invariance, the next step was testing for metric invariance. Metric invariance addresses whether the groups have the same factor loadings. To achieve metric invariance, the differences between pairs of factor loadings for each variable should not be statistically significant (at least one per factor for partial metric invariance) (Bollen, 1998).

We tested the MELCS for configural and metric invariance in four pairs of groups—younger and older age, men and women, and those with lower and higher levels of death anxiety scores on TDAS. The tests were performed by 1) transforming each ordered variable (age and TDAS) to categorical; 2) splitting every categorical variable in two (age->young and old, death anxiety->TDAS–low and TDAS–high, and gender->men and women); 3) testing the new group pairs' model fit for configural invariance in AMOS; and 4) performing a chi-square difference test on every group pair using Excel's GroupDifferences statistical tool (Gaskin, 2012a).

Internal Consistency Reliability

In case of the acceptable model fit, the test can be composited and its internal consistency reliability can be estimated. The Cronbach's alpha coefficient of internal consistency (a lower bound of reliability of the unit-weighted sum of items) is a function of the number of items and average correlation across the items:

$$\alpha = \frac{k}{k-1}\left(1 - \frac{\sum S_i^2}{S_T^2}\right)$$

where k is the number of items, S_i^2 is the variance of the i th item, and S_T^2 is the variance of the total score obtained by summing all the items (Cronbach, 1951). George and

Mallery (2003) provide the following rules of thumb to interpret alpha: "α > 0.9 –
Excellent, α > 0.8 – Good, α > 0.7 – Acceptable, α > 0.6 – Questionable, α > 0.5 – Poor,
and α < 0.5 – Unacceptable" (p. 231).

We estimated Cronbach's alpha for reference only, as it is currently the most
popular reliability coefficient reported in psychometric studies: it is easy to interpret and
useful in making revisions to scales. However, coefficient alpha tends to underestimate
the reliability (Yang & Green, 2011)—as high as 19% for a six-item test with a relatively
weak general factor and a strong group factor (Green & Yang, 2009). Composite
Reliability is considered to be a less biased estimate of reliability (Green & Yang, 2009;
Raykov, 1997, 2009; Yang & Green, 2011).

Discriminant validity

Discriminant validity is the extent to which a construct is truly distinct from other
constructs. To test for discriminant validity we examined whether the marital EOL
communication (measured by MELCS) was a distinct construct from the constructs of
general marital communication (measured by the ENRICH communication subscale)
and marital satisfaction (measured by KanMS). To do so we built a factor correlation
matrix using ValidityMaster Excel Statistical Tool (Gaskin, 2012c) and compared the
square root of the AVE to all inter-factor correlations. To demonstrate adequate
discriminant validity the square root of the AVE should be larger than the corresponding
inter-factor correlation. This would mean that the indicator variables have more in
common with the construct they are associated with than they do with other constructs
(Hair et al., 2010).

3.8. Construct validity (nomological validity) analysis

The nomological network is a representation of the constructs of interest in a
study, their observable manifestations, and the interrelationships among and between
them (Cronbach & Meehl, 1955). To establish construct validity of the new measure, we
have tested the interrelationships between constructs (and their observable
manifestations, or scores) in the measurement model. According to our theoretical
framework, the constructs of Willingness to Communicate and Communication

Preferences about EOL in Spouses (MELCS), Marital Communication (ENRICH Communication subscale) and Relationship Intimacy (Marital Satisfaction, KanMS) should be positively related, while a construct of Psychological Distress (Death Anxiety, TDAS) should be negatively related. It was also theorized that self-rated health status and marital EOL communication would be related. For convenience, we will use the term *Marital EOL Communication* term instead of the long phrase *Willingness to Communicate and Communication Preferences about EOL in Spouses.*

The proposed measurement model is depicted in Fig 3 below:

Figure 3. Measurement Model
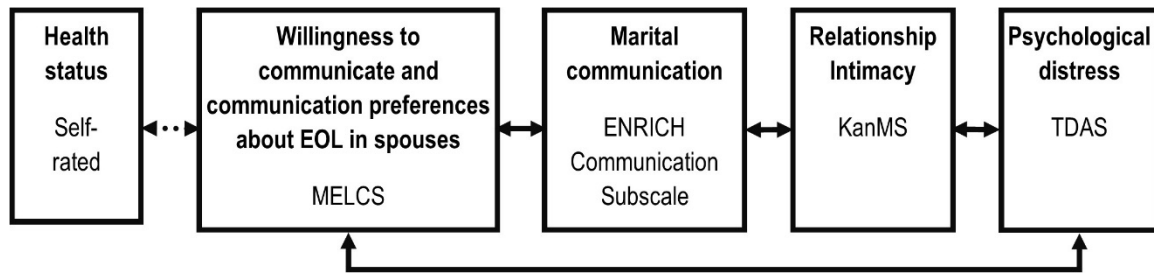
The relationships between constructs were tested using Structural Equation Modeling (SEM) techniques in AMOS 18. The model that included all four latent constructs was built and tested. The interconstruct correlations and their level of significance were analysed and interpreted, and the necessary changes incorporated into the model.

3.9. Criterion-related validity

To claim having criterion-related validity, a scale is required only to have an empirical association with some criterion or accepted "golden standard", without necessarily understanding the theoretical basis for that association (DeVellis, 2012, p. 61).

As no accepted "golden standard" measure of EOL communication exists, we chose as criterion of marital EOL communication four variables that could be considered

objective: having a will, having an advance directive, and incidence of discussions between spouses about EOL preferences and concerns of either spouse (Table 3).

Table 3. Criterion variables

	Variable	Response options
1	I already discussed my EOL preferences with my spouse	1=yes, 2=no
2	I already discussed my spouse's EOL preferences with my spouse	1=yes, 2=no
3	I have a will	1=yes, 2=no
4	I have an advance directive	1=yes, 2=no

These behavioural variables were used as criterion measures for marital EOL communication. The relationships between a score on MELCS and the criterion variables were tested by performing correlation analysis. If there were relationships they would indicate that the MELCS has criterion validity.

Chapter 4.   Results

4.1.1.   Preliminary item analyses

As discussed in Chapter 3, the sample consisted of 101 participants. All items had mean values greater than standard deviations. Responses to most items were reasonably broadly distributed across the five points of the response scale: all five response options were chosen by participants, thus supporting appropriateness of the 5-point Likert-type response format. Analyses of the items are summarized in Table 4 below.

Table 4. Descriptive statistics

	N		Mean	Std. Deviation	Variance	Skewness	Kurtosis
	Valid	Missing					
Best to talk about EOL when healthy	101	0	4.50	.820	.672	-2.514	8.037
EOL is too sensitive a topic	101	0	4.30	.807	.651	-1.295	1.669
I am comfortable to talk about my EOL	101	0	4.53	.641	.411	-1.060	.035
My spouse knows my EOL preferences	101	0	4.43	.622	.387	-.602	-.553
Best to talk about EOL when ill	101	0	3.95	1.220	1.488	-1.287	.792
I am comfortable talking about spousal EOL	101	0	4.43	.683	.467	-.781	-.535
My spouse is comfortable talking about their EOL	101	0	4.33	.709	.502	-.566	-.840
Best to talk about EOL when nearing death	101	0	4.25	.921	.848	-1.143	.482
I know EOL preferences of my spouse	101	0	4.28	.789	.622	-.538	-1.189
Spouses should discuss EOL	101	0	4.57	.606	.367	-1.117	.246

Missing data

MELCS had no missing values. The Kansas Marital Scale had three missing values. To assess whether these values were missing at random, the Little's Missing Completely at Random (MCAR, Little, 1988) test was performed. The results showed that the "missingness," in fact, was random (Chi-square=0.00 DF=0, Sig=.); therefore, we were justified in replacing the missing values with predicted values using the Expectation Maximization algorithm (Laird, 1988) built-in in SPSS. The algorithm estimates the parameters of the data model first, then uses the estimates to create regression equations to predict missing data; and, finally, applies these equations to predict and "fill in" missing data.

Normality check

Responses to all but one item did not demonstrate excessive skewness or kurtosis (>|2.8|). Normality check showed the only problematic item, *Best to talk about EOL when healthy,* had a kurtosis value of 8, which indicated there was insufficient variance in this item to retain it. Looking at the frequency table for this item, we could see that 96.1% of respondents agreed or strongly agreed with this statement. This result is interesting in itself as an indicator of public opinion and is reported as such. However, this item has no discriminatory value and was dropped from the scale and further analyses.

4.1.2.   Exploratory Factor Analysis

We conducted an EFA using Maximum Likelihood to see if the observed variables loaded together on one factor, according to the quantitative characterization of theoretical structure, and met criteria for factor analysis.

The KMO Measure of Sampling Adequacy was 0.873 and Bartlett's Test of Sphericity was significant. The communalities for each variable were all above 0.3 and most were above 0.6. Three items with the communalities below the recommended threshold of 0.5—*Best to talk about EOL when ill* (0.392), *Best to talk about EOL when nearing death* (0.465), and *My spouse knows my EOL preferences* (0.448)—were flagged for removal pending analysis of the factor loadings matrix.

The EFA extracted one factor only. All the factor loadings were well above the recommended minimum threshold of 0.350 thus indicating sufficient convergent validity. However, the same three items that had the lowest communalities also had the lowest factor loadings— *My spouse knows my EOL preferences* (0.406), *Best to talk about EOL when ill* (0.524), and *Best to talk about EOL when nearing death* (0.566). Therefore, they were removed to improve psychometric properties. In the next step, step 2, we again ran EFA using Maximum Likelihood and, indeed, the shortened scale had better properties. The scree plot showed a visibly clearer single factor, and all the factor loadings were above 0.6, thus demonstrating that the chosen 6 items loaded together on a single factor and were appropriate for a factor analysis. The results of both steps are depicted in Figure 4 below.

Figure 4. Factor extraction

EFA Step 1

Scree Plot
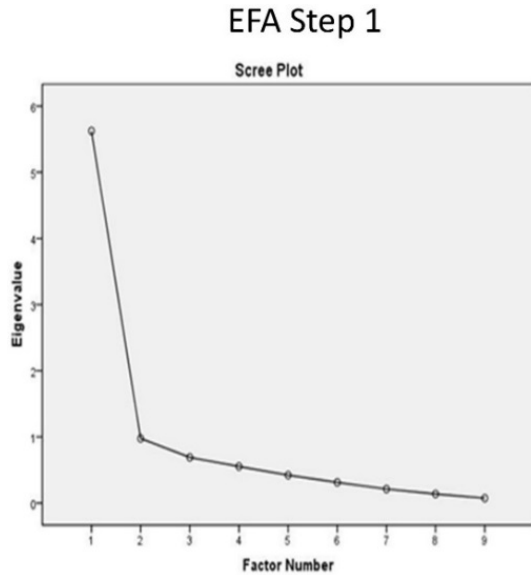
Factor Matrix

	Factor
	1
I am comfortable talking about spousal EOL	.937
I am comfortable to talk about my EOL	.850
Spouses should discuss EOL	.821
EOL is too sensitive a topic	.819
My spouse is comfortable talking about their EOL	.807
I know EOL preferences of my spouse	.735
My spouse knows my EOL preferences	.682
Best to talk about EOL when nearing death	.572
Best to talk about EOL when ill	.529

Extraction Method: Maximum Likelihood.

a. 1 factors extracted. 5 iterations required.

EFA Step 2

Scree Plot
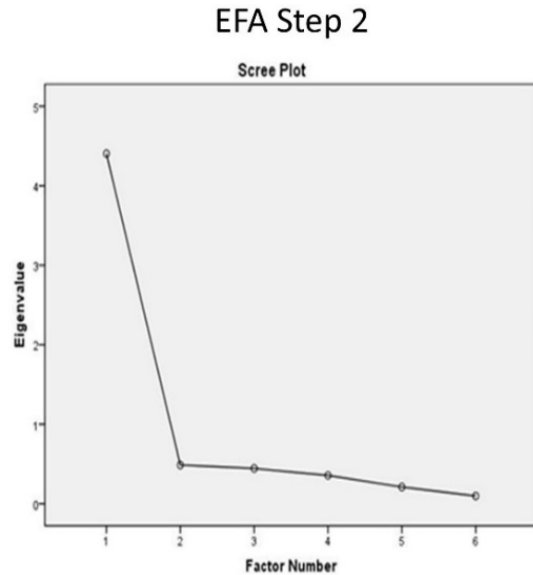
Factor Matrix

	Factor
	1
I am comfortable talking about spousal EOL	.976
My spouse is comfortable talking about their EOL	.848
I am comfortable to talk about my EOL	.809
Spouses should discuss EOL	.808
EOL is too sensitive a topic	.774
I know EOL preferences of my spouse	.718

Extraction Method: Maximum Likelihood.

a. 1 factors extracted. 7 iterations required.

This single-factor model explained 58.44% of the total variance, with the extracted factor having an eigenvalue of 5.625.

4.1.3.   Confirmatory Factor Analysis

Model Fit

The model fit was tested for unidimensionality in LISREL8.8 using the Maximum Likelihood method. The variance estimates were all positive and standardized residuals were small, between -2.03 and 1.99. The RMSEA was 0.0, 90% confidence interval for RMSEA was (0.0; 0.11), and the minimum discrepancy (Chi-square divided by degrees of freedom was) 0.935. The Comparative Fit Index was excellent, CFI=1.000. Overall, the unidimensional model demonstrated a nearly perfect fit and did not require any further modifications. The LISREL output is shown in Appendix H. The summary of the results of model fit analysis are summarized in Table 4 below.

Table 5. Model fit indices

Metric	Observed value	Recommended threshold
CMIN/DF	0.935	<2
CFI	1.000	>0.950, 1.000=perfect fit
RMSEA	0.000	<0.080, 0.000=perfect fit

Composite validity and reliability

To test for convergent validity we calculated the AVE, which was 0.587, above the recommended value of 0.50, and thus signifying good convergent validity.

We also computed the composite reliability for our single factor. The CR was equal 0.892, well above the threshold of 0.70, thus demonstrating excellent reliability of the single factor.

Invariance tests

We tested configural invariance by analysing whether the single factor structure achieved adequate fit when each pair of groups were tested together without any cross-group constraints. Each of three resultant models achieved adequate fit, therefore we assumed configural invariance of the measure across gender, age, and the level of death anxiety. Next, we tested the differences between scores on every variable in each pair. There were two variables out of six that showed significant difference in scores across age and death anxiety level. However, overall results met the criteria for metric

invariance across gender, age, and the level of death anxiety. The results of the invariance tests are represented in the Table 5 below.

Table 6. Metric Invariance tests

		I know EOL preferences of my spouse	Spouses should discuss EOL	I am comfortable talking about spousal EOL	I am comfortable to talk about my EOL	EOL is too sensitive a topic
Men	Estimate	0.380	0.453	0.480	0.480	0.523
	P	0.039	0.013	0.009	0.009	0.011
Women	Estimate	0.700	0.584	0.705	0.516	0.623
	P	0.000	0.000	0.000	0.000	0.000
	z-score	1.481	0.632	1.138	0.187	0.426
AgeYoung	Estimate	0.253	0.321	0.376	0.340	0.513
	P	0.191	0.131	0.062	0.076	0.055
AgeOld	Estimate	0.714	0.701	0.701	0.566	0.573
	P	0.000	0.000	0.000	0.000	0.000
	z-score	2.066**	1.727*	1.548	1.087	0.211
DasHigh	Estimate	0.715	0.808	1.202	1.036	1.010
	P	0.001	0.000	0.000	0.000	0.000
DasLow	Estimate	1.158	1.228	1.362	1.059	1.275
	P	0.000	0.000	0.000	0.000	0.000
	z-score	1.699*	1.816*	0.791	0.121	1.119

Notes: *** p-value < 0.01; ** p-value < 0.05; * p-value < 0.10

4.1.4. Construct (nomological) validity

To examine construct validity of the measure, we tested in AMOS18 its relationship with the other three constructs in our framework—marital communication (Cronbach's alpha in our sample was 0.817), marital satisfaction (Cronbach's alpha at 0.953), and death anxiety. The psychometric properties of the corresponding scales in our sample are summarized in Appendix F. The resulting path diagram, depicted in

Figure 5, shows correlations between the constructs, factor loadings and communalities for each variable.

Figure 5. Path diagram
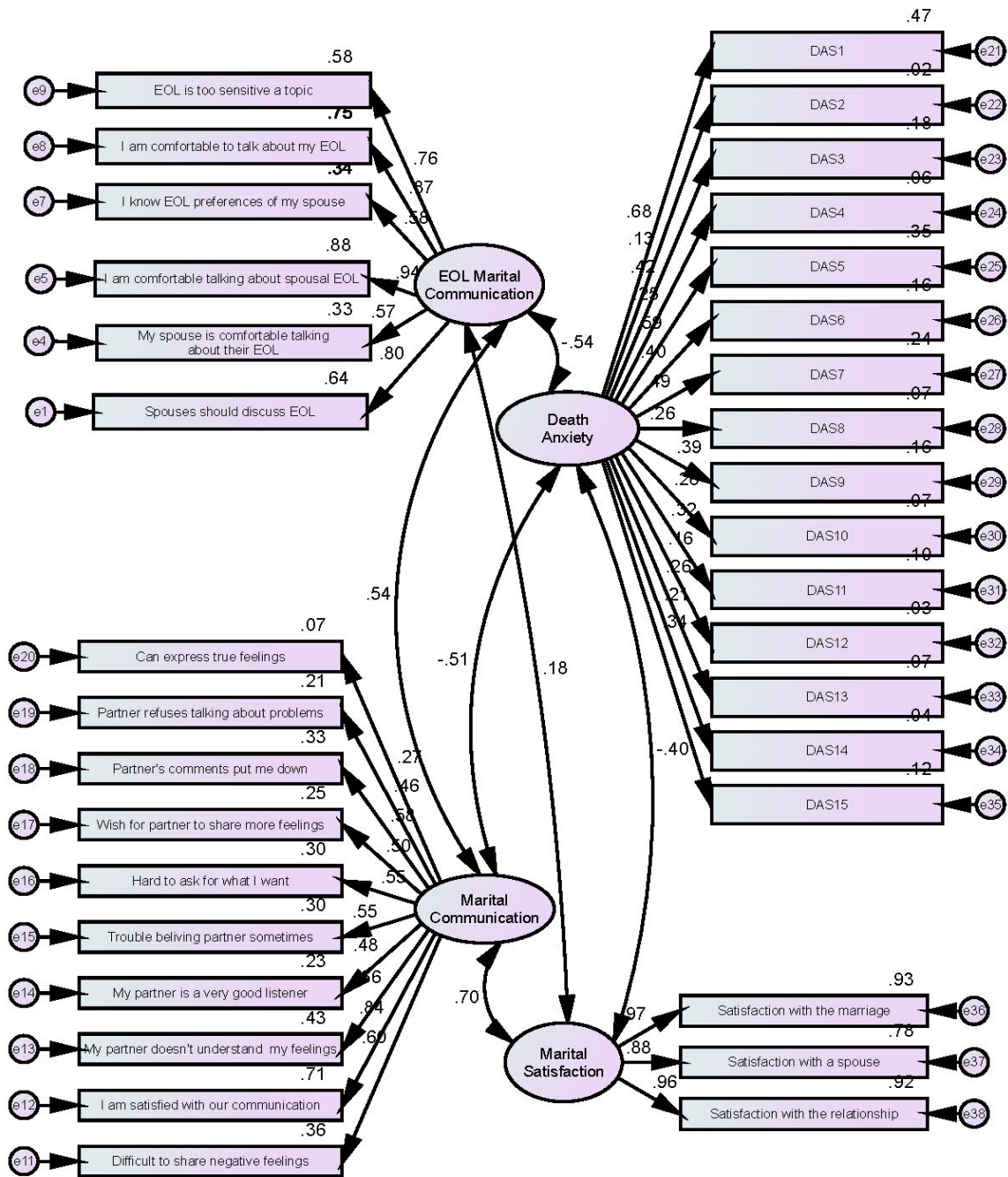
There were several statistically significant correlations in our sample between the constructs, confirming relationship between marital end-of-life and general communication ($r = 0.54$, P< 0.001), marital EOL communication and death anxiety ($r = -0.54$, P< 0.001), as well as between marital communication and marital satisfaction ($r = 0.70$, P< 0.001). These two correlations provide sufficient evidence for construct validity of the new scale. The magnitude of the relationship between MELCS and TDAS had to be revised, as for the purpose of this analysis the un-corrected dataset for TDAS was used (TDAS is an ordinal scale). When all the variables on TDAS were recoded and the composite scores were used according to the scoring rule for correlation analysis of MELCS and TDAS, the correlation coefficient was $r = -0.469$, P<0.001. There was a weak relationship between marital satisfaction and EOL communication ($r = 0.25$, P< 0.01). In addition, there was a relationship between death anxiety and general marital communication ($r = -0.381$, P<0.001) and a weak relationship between death anxiety and marital satisfaction ($r = -0.34$, P<0.001). These findings, not directly relevant to construct validation of the MELCS, nevertheless are interesting in itself.

In addition, negative correlation between marital EOL communication and self-rated health status was detected ($r = -0.44$, P<0.001): the higher the score on MELCS, the lower was the self-rated overall health status. At the same time, no relation between recent health crises in either spouse and a score on MELCS was detected.

Overall, the proposed theoretical framework was principally confirmed. Relevant changes to the original framework path diagram resulted in the path diagram depicted below in Figure 6. We omitted drawing a link between marital EOL and marital satisfaction on the path diagram due to its small effect size (*R Square* = 0.062, P<0.05).

Additional relationships between the MELCS and other variables of interest are shown in Appendix I.

Figure 6. Path diagram for Marital EOL Communication
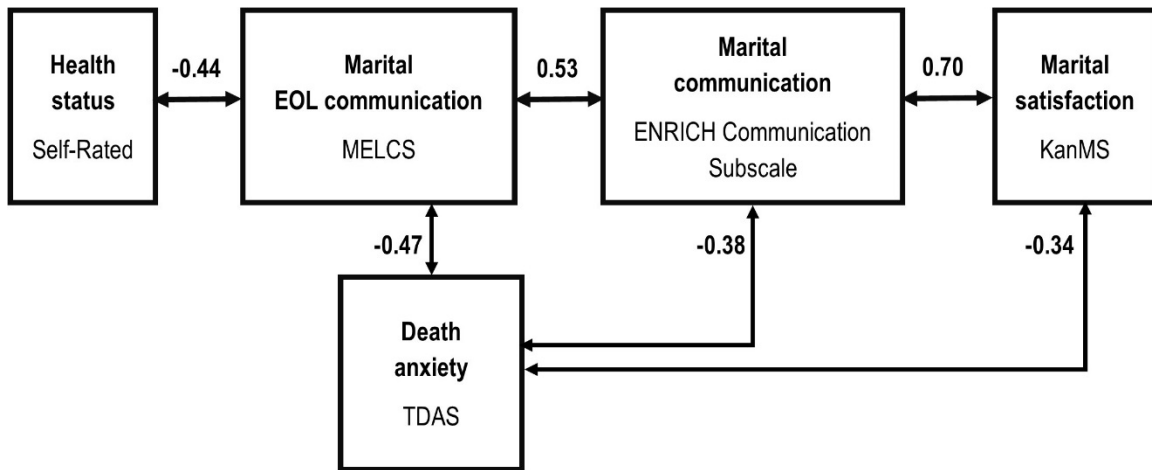
Discriminant validity

A summary table (Table 7) for the discriminant validity test contains a factor correlation matrix for three constructs, with squared AVE displayed on the diagonal.

Table 7. Factor correlation matrix

	CR	AVE	Marital Satisfaction	Marital Communic.	EOL Marital Communic.
Marital Satisfaction	0.955	0.876	0.936*		
Marital Communication	0.815	0.319	0.552	0.565*	
EOL Marital Communication	0.892	0.587	-0.092	0.501	0.766*

*Squared AVE

All the squared AVEs are greater than correlations with other factors, thus meeting requirements for discriminant validity. In other words, Marital EOL Communication is sufficiently distinct from the two other constructs (Marital Communication and Marital Satisfaction), because all indicator variables have more in common with the construct they associated with than with other constructs.

4.1.5. Criterion-related validity

To test for criterion-related validity, associations between MELCS and criterion measures were analysed. Results are represented in Table 8 below.

Table 8. Associations between MELCS and criterion measures

Variable	Correlation with MELCS
Already discussed my EOL preferences with my spouse (1=yes, 2=no)	-0.531**
Already discussed my spouse's EOL preferences with my spouse (1=yes, 2=no)	-0.336**
I have a will (1=yes, 2=no)	-0.240*
I have an advance directive (1=yes, 2=no)	-0.246*

*. Correlation is significant at the 0.05 level (2-tailed).
**Correlation is significant at the 0.001 level (2-tailed).

The associations between the MELCS and criterion measures were significantly correlated, with correlation coefficients of 0.240-0.531. There was moderate correlation between having a will and an advance directive and a score on MELCS: those with higher scores on MELCS were more likely to have a written will and an advance directive. There was a stronger correlation between a score on MELCS and an incidence of discussions about EOL preferences and concerns of either spouse. Those with higher scores on MELCS were more likely to have discussed their own than their spouse's EOL preferences and concerns between each other. Thus, there is medium criterion-related validity between the MELCS and having a will and advance directive, and higher criterion-related validity between the MELCS and incidence of having EOL discussions between spouses about their EOL wishes.

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4.2. Summary of findings

Responses to the MELCS scale with a sample of 101 participants underwent confirmatory factor analysis (CFA). CFA confirmed the appropriateness of modeling MELCS as a unidimensional instrument in a linear factor analytic sense. The measure demonstrated excellent reliability as well as good content, convergent, discriminant, construct, and criterion-related validity. In addition, the scale was invariant across age, gender, and level of death anxiety. Analyses of the nomological network showed that marital EOL communication positively related with general marital communication and marital satisfaction, and negatively related with death anxiety and self-rated health status, confirming our proposed theoretical framework.

Chapter 5.   Discussion

Search for literature on EOL communication leads to a conclusion that little attention is paid to the systematic study of EOL communication in healthy and active people by social or communication sciences. There is a burgeoning literature on Advance Care Planning, as well as on illness-related communication, especially in palliative care. However, this literature is predominantly concerned with communication between patients or their family members with healthcare professionals. As for a non-clinical population, very few studies are done to find out how death and dying—the most sure thing in life—is discussed in families that are not pressed by a terminal diagnosis.

This situation both contributes to a societal denial of death and dying, and stems from this denial. Currently there are no instruments measuring end-of-life (EOL) communication in families not involved in palliative care. It is unclear whether the absence of psychometric instruments is the result or the cause of the lack of research in the area of EOL communication. What is clear is that no systematic research is possible without psychometrically sound instruments. This realization lead the author to become a student of psychometrics and to develop the instrument first, prior to pursuing any exploratory, comparative, or longitudinal studies in the area of EOL communication.

The purpose of the current study was the development and initial validation of a new quantitative instrument, the Marital End-of-Life Communication Scale (MELCS), to measure EOL communication in married/partnered adults regardless of their health status. After initial item development and validation in married/partnered mature adults (age 45 years old and older, N=101), six items, scored by 5-point Likert-type response options, were chosen for the final version of the scale. Factor analyses confirmed the theorized single-factor structure. The MELCS demonstrated excellent reliability (CR=0.892) as well as good content and convergent (AVE=0.587) validity. To establish nomological validity, we had to show that the construct of EOL communication was linked with other relevant, well-researched constructs.

To build the theoretical framework and a measurement model for the new instrument, we had to make several theoretical assumptions. Because of the lack of relevant research, most of these assumptions are conjectures. First was that couples'

general communication style could correlate with their communication about their end-of-life preferences and concerns. It seemed reasonable to assume that if a couple communicated openly and positively between each other, they would also openly discuss difficult topics, such as death and dying. At the same time it would be easy to imagine a very happy couple with great communication skills who would not talk about death and dying at all. It seems that there should be something that would make people who are not yet dying to talk about end of life. The second theoretical assumption was about this "something". There could be external triggers, such as someone else's death or terminal illness. Also, there should be an internal motivator (or de-motivator). Without research it is difficult to guess what internal motivator would make a person talk about their future demise. However, it seemed very reasonable to assume that a *personal* death anxiety would be a player in an *interpersonal* EOL communication: the higher the level of death anxiety in a person, the less likely the person would be talking about death and dying.

Thus, the second theoretical assumption was the negative correlation between marital EOL communication and death anxiety. We would not expect a large magnitude of this correlation, because marital EOL communication happens between two people, but can be affected by a higher level of death anxiety in one partner only. Therefore, it would be possible that a study participant with a low score on death anxiety, nonetheless had a low level of EOL communication because of a high level of death anxiety in their spouse. Still, considering that a couple is a family system, it would be reasonable to expect each spouse's attitudes toward death and dying to affect each other over time and become somewhat similar in most couples. It is also possible that marital EOL communication would be related to the age of the spouses. It was previously shown that death anxiety scores get lower with age. So, if the negative relationship between EOL communication and death anxiety could be established, then it would be reasonable to expect a positive relationship between marital EOL communication and age.

The third theoretical assumption was the possibility of a link between health status of either spouse and level of spousal EOL communication. It seemed reasonable to expect serious illness in one or both spouses to challenge their EOL communication. A direction of this relationship was difficult to predict due to the lack of relevant research. The expectation was for a negative relationship between health and EOL

communication: the increased morbidity would increase mortality awareness that, in turn, would increase salience of a need for EOL communication.

We also included in our initial theoretical framework another construct, marital satisfaction, due to literature showing a relationship between marital communication and marital satisfaction. Therefore, it could be possible that marital EOL communication and marital satisfaction were positively related, too. This was our fourth theoretical assumption.

After running tests for nomological validity, we were able to support all four assumptions. Besides supporting construct validity of the new scale, these results also provided some basis for interpretation. We found that marital EOL communication (measured by the MELCS) was positively and quite substantially (R=0.54) correlated with marital communication (ENRICH communication subscale). At the same time, marital EOL communication was negatively correlated (R=–0.47) with level of death anxiety (measured by TDAS). It is not appropriate to make inferences from validation studies. However, if follow-up studies would support these relationship, the new scale could be very useful both in research and therapeutic applications. If, indeed, talking about end of life moderated level of death anxiety, it would lead to development of communicational interventions. That seems plausible because it parallels exposure therapy for anxiety disorders. It has to be noted that, when talking about death anxiety in our study, we don't mean a disorder, but rather "the state in which an individual experiences apprehension, worry, or fear related to death and dying" (Carpenito-Moyet, 2008, p. 39).

Analyses of relationships between health-related variables and the MELCS brought seemingly contradictory results. On one hand, there was a negative correlation between self-rated health and a score on the MELCS. On the other hand, there was no relationship between having a recent health crisis in either spouse (participant and/or their spouse) and a score on the MELCS. Two conclusions can be drawn from these results. First, and the most relevant to the validation of the MELCS, is that increased self-rated morbidity is moderately correlated with marital EOL communication. It seems that a higher score on marital EOL communication in participants with higher morbidity would reflect better coping with morbidity: those with frailer health might cope better by

having open communication about unpleasant topics, which correlates with better general marital communication, higher marital satisfaction, and lower death anxiety. Another interpretation could be that healthier couples talk less about end of life because they have less apparent need to discuss it than those with salient mortality awareness. Most probably, both explanations are true: more research is needed to substantiate them. Second finding that shows no relation between health crisis incidence and marital EOL communication seemingly contradicts the first one. It would be reasonable to expect occurrence of a recent health crisis being a factor in marital EOL communication, as it would be reasonable to expect high correlation between health crisis incidence and self-reported health status. However, in our sample this correlation was quite weak (R=0.323, P<0.001): many participants who admitted having a recent crisis such as hip replacement or even cancer still rated their health as "good". It shows that health is truly a subjective concept. In addition, only 21.8% of participants reported incidence of a recent health crisis, which is too small a sample. A larger sample of adults with weaker health is needed to confirm or invalidate this finding. It is possible that very high morbidity would affect both self-rated health and EOL communication differently.

Strengths and limitations

The scale has good psychometric properties in our sample. It is brief and easy to administer. However, there are several limitations of the study. One of them is related to the chosen response format. Likert-type response format is an ordered categorical scale and has its share of criticism. First of all, it is difficult to prove whether the answers are equidistantly located on a scale representing our construct or whether or not a middle point question (i.e. "undecided") affects the answers. Second, assumptions of normality in Likert-type items are not really applicable. That is why the results of factor analysis (designed to work with interval data) of Likert-type scales should be interpreted with caution despite many studies showing little difference in outcomes using different methods of analysis. To avoid this criticism we could use Graded Response IRT methods of analysis, such as Samejima's model. In addition to its suitability for analysis of polytomous item response scales, the IRT method is not as sensitive to sample size and provides more information about items under analysis compared to factor analysis.

Another limitation is that we did not perform a separate study after shortening the scale's length to 6 items. Ideally, after finalizing the questionnaire, it should have been validated again with a new sample, as it could be argued that the dropped items somehow affected responses to the remaining items. No temporal stability tests were performed due to limited resourses, which can be considered another limitation. On the other hand, a concept of temporal stability is not without critique itself. Communication is a dynamic construct, it changes over time and is context-dependent. It only would be beneficial if we could test for temporal stability while controlling for these changes, which is nearly impossible.

The sample size in the study, N=101, could be considered small for a factor analytical thechniques according to certain suggested rules of thumb (e.g., Guadagnoli & Velicer, 1988; Hinkin, 1995; Hogarty et al., 2005). However, it was shown that, when the communalities of variables are consistently high and factors are well determined, the impact of sample size is greatly reduced (MacCallum et al., 1999), which was the case in our study. Nevertheless, considering that the recommendations for the sample size differ in the psychometric literature, we wanted to list a small sample size as a limitation of the study.

It could be reasoned that the sample is too narrow: the majority of participants were white and were recruited from the same area. However, it is beneficial for a validation study to have a statistically stable sample. We validated our scale in adults 45 years of age and older, living in the interior British Columbia, and will not attempt to generalize it to different populations. Our claim is that the MELCS is psychometrically sound in the population of adults 45 years of age and older, living in the British Columbia interior. In order to generalize it to a different population, the scale has to be validated with the population under study first.

As was noted before, the sample of participants was not very representative of fragile adults: a median value of self-rated health was "very good" (38.6% of respondents), while no participants rated their health as "poor". This means that the MELCS was validated with relatively healthy population. To discern whether it would be as good a measure of marital EOL communication among sicker adults or those who are experiencing a current health crisis the MELCS has to be additionally validated in those

populations. However, considering that the items in the measure are not specific to a health status, it would be reasonable to posit that the health status should not affect psychometric properties of the MELCS.

The new instrument is designed to measure end-of-life communication in spouses. However, due to the lack of relevant theoretical literature, the construct was operationally loosely defined as a sum of variables reflecting willingness to communicate and communication preferences about end-of-life issues in couples. It is possible that with increased research this construct will be re-defined and the measure would need to be reevaluated. Another study limitation related to the lack of relevant research was developing a theoretical and measurement framework for the study. It had to include a significant amount of conjecture. Fortunately, it appears that the theorized framework was quite robust. However, the study would possibly be stronger if it could rely on a developed theory.

Initially the new instrument was planned to target older couples only (65 years old and older). However, during the development, it became apparent that older couples did not require items specific to old age. Therefore, after the initial content validation in older couples, the study sample was extended to include the middle-aged adults (45 to 64 y.o.). What initially could be a limitation of the scale, became one of its strengths. Because the scale was invariant across age groups (45-65 and 65+ y.o.), it is appropriate to measure EOL communication not just in older couples, but in middle-aged ones as well.

Possible future applications and modifications of the Marital End-of-Life Communication Scale.

It is unknown if EOL communication in families is getting better or easier with age, or whether serious illness makes it more difficult. The Marital End-of-Life Communication Scale could be a useful quantitative instrument to answer these questions. It can be employed for longitudinal or cross-sectional studies focused on age- and health-related changes in couples' communication. The instrument can be used in mixed methods studies that include qualitative methods to get in-depth insight into beliefs, attitudes, and motives behind spousal EOL communication. In addition, the questionnaire can be used in dyadic studies of couples to understand whether and how

spouses differ in their willingness to communicate and communication preferences about EOL issues.

The MELCS can be useful for development and validation of communication interventions. It has to be noted that completing the questionnaire can have a therapeutic effect itself. Many study participants wrote that filling out the questionnaire lead them to re-evaluate their beliefs about EOL communication and resulted in opening a dialogue with their loved ones. Completing the questionnaire can be used as a pretext for having an EOL conversation or an advance care planning session in a couple.

We used death anxiety, a special case of psychological distress, for construct validity testing. It is likely that EOL communication is negatively related with psychological distress as well. Future studies could probe this relationship. If confirmed, EOL communication interventions can be developed to reduce psychological distress, as well as death anxiety.

Because some of the scale's items query beliefs that usually reflect cultural and/or religious beliefs, the MELCS can be used to assess differences in end-of-life communication across different cultures.

The scale could be modified for single adults for assessing end-of-life communication with family members other than spouses.

Conclusion

The study aimed to develop a psychometrically sound quantitative measure of marital EOL communication, resulted in success. This instrument was conceived as a tool for measuring end-of-life communication in healthy couples, as well as couples facing serious illness and informal caregiving. The new measure has good psychometric properties and therefore is appropriate for research or therapeutic applications with middle-aged and older couples. Validation study of the MELCS confirmed the theorized relationships of marital end-of-life communication with general marital communication, marital satisfaction, death anxiety, and self-rated health. The most important potential contributions of the new tool would be extending study of EOL communication from the

clinician-patient realm to families, as well as shifting its focus from a palliative to a general population.

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Appendices

Appendix A. The Prospective Items.

1	I think that the best time for a person to make one's end-of-life wishes and concerns known is when one is active and healthy
2	I am uncomfortable talking about my end-of-life wishes with health-care professionals
3	I think my spouse is comfortable talking about his/her end-of-life preferences with me
4	It is not a good idea [time] to talk about end-of-life preferences with a seriously ill person
5	I am comfortable talking about my end-of-life wishes with my spouse
6	I believe that spouses should discuss their end-of-life wishes and preferences with each other
7	I am not sure whether my spouse knows my end-of-life preferences
8	I think that the best time for a person to make one's end-of-life wishes and concerns known is after one is diagnosed with serious illness
9	I am uncomfortable talking with my spouse about his/her end-of-life wishes
10	I am comfortable talking about my end-of-life wishes with my family
11	I think that the best time for a person to make one's end-of-life wishes and concerns known is when one is nearing death
12	I will talk about end-of-life issues only when I have to
13	I know my spouse's end-of-life preferences
14	I think that end of life is too sensitive a topic to talk about

Appendix B. The Preliminary Questionnaire.

		Strongly disagree	Disagree	Undecided	Agree	Strongly agree
1	I think that the best time for a person to make one's end-of-life preferences and concerns known is when one is active and healthy					
2	I think that end of life is too sensitive a topic to talk about					
3	I am comfortable talking about my end-of-life preferences and concerns with my spouse					
4	I will talk about end-of-life issues only when I have to					
5	I believe my spouse knows my end-of-life preferences and concerns					
6	I think that the best time for a person to make one's end-of-life preferences and concerns known is after one is diagnosed with serious illness					
7	I am comfortable talking with my spouse about his/her end-of-life preferences and concerns					
8	I think my spouse is comfortable talking about his/her end-of-life preferences and concerns with me					
9	I think that the best time for a person to make one's end-of-life preferences and concerns known is when one is nearing death					
10	I know my spouse's end-of-life preferences and concerns					
11	I believe that spouses should discuss their end-of-life preferences and concerns with each other					

Items 2, 4, 6, and 9 are reverse-scored

Appendix C. Recruitment Poster for the Focus Group

SFU

DEPARTMENT OF GERONTOLOGY

2800-515 West Hastings Street
Vancouver BC Canada V6B 5K3
T 778.782.5062
F 778.782.5066

EMAIL: gero@sfu.ca
WWW.SFU.CA/GERONTOLOGY

SFU is looking for people to participate in a focus group.

The purpose of the focus group is to gather feedback that will be used to improve a new questionnaire. This questionnaire will help to learn if and how spouses talk between each other about their end-of-life preferences and concerns.

If you are 65 years of age or older and are married or living in common-law relationship, you can help with the development of a new questionnaire!

We are interested in your feedback about the new questionnaire, 'Marital End-of-Life Communication Scale'. Your participation will involve completing the questionnaire and then discussing it in a small group with up to ten people. We will ask broad questions about the questionnaire: for example, were there confusing questions, would you add or remove anything from the questionnaire, did you like or dislike parts of the questionnaire, etc. The focus group will occur in a private setting at a time and location that is convenient for you. The total time commitment for your participation is approximately one hour.

If you would like to participate or if you are interested in learning more about the research please contact Nataliya Polchenko at

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Appendix D. Finalized version of the MELCS

Marital End-Of-Life Communication Scale

		strongly disagree	disagree	undecided	agree	strongly agree
1	I think that the best time for a person to make one's end-of-life preferences and concerns known is when one is active and healthy					
2	I think that end of life is too sensitive a topic to talk about					
3	I am comfortable talking about my end-of-life preferences and concerns with my spouse					
4	I believe my spouse knows my end-of-life preferences and concerns					
5	I think that the best time for a person to make one's end-of-life preferences and concerns known is after one is diagnosed with serious illness					
6	I am comfortable talking with my spouse about his/her end-of-life preferences and concerns					
7	I think my spouse is comfortable talking about his/her end-of-life preferences and concerns with me					
8	I think that the best time for a person to make one's end-of-life preferences and concerns known is when one is nearing death					
9	I know my spouse's end-of-life preferences and concerns					
10	I believe that spouses should discuss their end-of-life preferences and concerns with each other					

Appendix E. Final Proof of the Questionnaire (Scaled to Fit)

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THINKING OF THE WORLD

Department of Gerontology

Should we talk about end-of-life preferences and concerns with our spouses?

By submitting this questionnaire you are consenting to participate in this research study.

The questionnaire will require approximately 10 minutes to complete.
In order to ensure that all information will remain confidential, please do not include your name.

Thank you for your participation!

		Strongly disagree	Disagree	Undecided	Agree	Strongly agree

Section A

Please start here by answering these questions about your attitude toward talking about end-of-life preferences and concerns.

End-of-life preferences and concerns are those related to the final stage of the journey of life, e.g. advance directives, living will, burial arrangements, spiritual care, organ and tissue donation, etc.

Please check ☑ appropriate box

		Strongly disagree	Disagree	Undecided	Agree	Strongly agree
Q1.	I think that the best time for a person to make one's end-of-life preferences and concerns known is when one is active and healthy	☐	☐	☐	☐	☐
Q2.	I think that end of life is too sensitive a topic to talk about	☐	☐	☐	☐	☐
Q3.	I am comfortable talking about **my** end-of-life preferences and concerns with my spouse	☐	☐	☐	☐	☐
Q4.	I believe my spouse knows **my** end-of-life preferences and concerns	☐	☐	☐	☐	☐
Q5.	I think that the best time for a person to make one's end-of-life preferences and concerns known is after one is diagnosed with serious illness	☐	☐	☐	☐	☐
Q6.	I am comfortable talking with my spouse about **his/her** end-of-life preferences and concerns	☐	☐	☐	☐	☐
Q7.	I think my spouse is comfortable talking about **his/her** end-of-life preferences and concerns with me	☐	☐	☐	☐	☐
Q8.	I think that the best time for a person to make one's end-of-life preferences and concerns known is when one is nearing death	☐	☐	☐	☐	☐
Q9.	I know my spouse's end-of-life preferences and concerns	☐	☐	☐	☐	☐
Q10.	I believe that spouses should discuss their end-of-life preferences and concerns with each other	☐	☐	☐	☐	☐

These questions reflect whether you have already shared your end-of-life preferences and concerns with others

Section **B**

I. Please answer YES or NO			II. Are you SATISFIED with this?	
	YES	NO	Yes, I am satisfied	No, I would like more
Q11/12. I have already discussed **my** end-of-life preferences and concerns with my spouse	☐	☐ →	☐	☐
Q13/14. My spouse and I talked together about **his/her** end-of-life preferences and concerns	☐	☐ →	☐	☐

Please answer YES or NO		YES	NO
Q15.	I have a Will	☐	☐
Q16.	I have an Advance Directive	☐	☐

Please answer the questions below if you don't yet have an Advance Directive

Please answer YES or NO		YES	NO
Q17.	I plan to start my advance care planning soon	☐	☐
Q18.	I don't know how to start my advance care planning	☐	☐
Q19.	I am not interested in having an Advance Directive	☐	☐

The next few questions measure death anxiety.

Your answers will help us establish if attitudes toward end-of-life communication and death anxiety are linked.

If a statement is true or mostly true as applied to you, circle T.

If a statement is false or mostly false as applied to you, circle F.

Q20.	I am very much afraid to die.	T	F
Q21.	The thought of death seldom enters my mind.	T	F
Q22.	It doesn't make me nervous when people talk about death.	T	F
Q23.	I dread to think about having to have an operation.	T	F
Q24.	I am not at all afraid to die.	T	F
Q25.	I am not particularly afraid of getting cancer.	T	F
Q26.	The thought of death never bothers me	T	F
Q27.	I am often distressed by the way time flies so very rapidly	T	F
Q28.	I fear of dying a painful death.	T	F
Q29.	The subject of life after death troubles me greatly.	T	F
Q30.	I am really scared of having a heart attack.	T	F
Q31.	I often think about how short life really is.	T	F
Q32.	I shudder when I hear people talking about World War III.	T	F
Q33.	The sight of a dead body is horrifying to me.	T	F
Q34.	I feel the future holds nothing for me to fear.	T	F

This section is about marital satisfaction and communication.

Your answers will help to clarify if end-of-life communication is related to quality of relationship and communication in couples.

Section

D

Please check ☑ *appropriate box*

		Strongly disagree	Disagree	Undecided	Agree	Strongly agree
Q35.	I can express my true feelings to my partner.	☐	☐	☐	☐	☐
Q36.	When we are having a problem, my partner often refuses to talk about it.	☐	☐	☐	☐	☐
Q37.	My partner sometimes makes comments that put me down.	☐	☐	☐	☐	☐
Q38.	I wish my partner were more willing to share his/her feelings with me.	☐	☐	☐	☐	☐
Q39.	Sometimes it is hard for me to ask my partner for what I want.	☐	☐	☐	☐	☐
Q40.	Sometimes I have trouble believing everything my partner tells me.	☐	☐	☐	☐	☐
Q41.	My partner is a very good listener.	☐	☐	☐	☐	☐
Q42.	My partner often doesn't understand how I feel.	☐	☐	☐	☐	☐
Q43.	I am very satisfied with how my partner and I talk with each other	☐	☐	☐	☐	☐
Q44.	It is difficult for me to share negative feelings with my partner	☐	☐	☐	☐	☐

Q.35-44 represent ENRICH Communication Subscale (Fournier, Olson, & Druckman, 1983)
Used with the permission from D.H. Olson, Life Innovations, Inc.

		Extremely Dissatisfied	Very Dissatisfied	Somewhat Dissatisfied	Mixed	Somewhat Satisfied	Very Satisfied	Extremely Satisfied
Q45.	How satisfied are you with your marriage?	1	2	3	4	5	6	7
Q46.	How satisfied are you with your husband (wife) as a spouse?	1	2	3	4	5	6	7
Q47.	How satisfied are you with your relationship with your husband (wife)?	1	2	3	4	5	6	7

Section E

The last few questions are demographical.

Research has shown that there are connections between people's attitudes toward discussing end of life and factors such as age, marital status, health status, education, ethnicity, or religiosity.

Q48. What is your gender?

☐ Male   ☐ Female

Q49. **What is your age?**

☐ 45-54   ☐ 55-64   ☐ 65-74   ☐ 75-84   ☐ 85+

Q50. **What is the highest level of education you have completed?**

☐ Some school   ☐ High school   ☐ College   ☐ University   ☐ Post-graduate

Q51. **What is your ethnicity?**

☐ White   ☐ Asian / Pacific Islander

☐ Hispanic or Latino   ☐ Black

☐ Aboriginal (e.g. First Nations)   ☐ Other _____

Q53. **What are your living arrangements?**

☐ Alone   ☐ With a spouse   ☐ With family   ☐ With friends

Q53. **I consider my overall health to be:**

☐ Excellent   ☐ Very Good   ☐ Good   ☐ Fair   ☐ Poor

Q55. **If you answered YES to the Q54, what kind of health condition did you experience?**

☐ Stroke   ☐ Cancer   ☐ Heart Disease   ☐ Lung Disease   ☐ Other _____

Q57. **If you answered YES to the Q56, what kind of health condition did your spouse experience?**

☐ Stroke   ☐ Cancer   ☐ Heart Disease   ☐ Lung Disease   ☐ Other _____

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Q58. **Do you have comments, ideas, or suggestions about the topic of the survey?**

_____

_____

_____

_____

_____

_____

_____

_____

_____

Thank you for your participation

Appendix F. Reliability analysis of additional measures

ENRICH Communication Subscale

Reliability Statistics

Cronbach's Alpha	N of Items
.833	13

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Can express true feelings	51.653	50.969	.201	.843
Partner refuses talking about problems	52.465	46.531	.464	.823
Partner's comments put me down	52.248	49.748	.266	.839
Wish for partner to share more feelings	52.416	48.165	.380	.829
Hard to ask for what I want	52.287	47.667	.446	.824
Trouble beliving partner sometimes	52.000	47.480	.454	.823
My partner is a very good listener	51.851	48.768	.598	.817
My partner doesn't understand my feelings	52.475	45.252	.648	.808
I am satisfied with our communication	51.891	47.478	.749	.809
Difficult to share negative feelings	52.446	45.810	.619	.811
Satisfaction with the marriage	49.941	46.976	.579	.814
Satisfaction with a spouse	49.762	48.463	.525	.819
Satisfaction with the relationship	49.970	47.189	.557	.816

KanMS

Reliability Statistics

Cronbach's Alpha	N of Items
.958	3

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Satisfaction with the marriage	12.168	2.901	.943	.915
Satisfaction with a spouse	11.990	3.370	.884	.962
Satisfaction with the relationship	12.198	2.940	.917	.936

Appendix G. The final version of MELCS

		strongly disagree	disagree	undecided	agree	strongly agree
1	I think that end of life is too sensitive a topic to talk about					
2	I am comfortable talking about my end-of-life preferences and concerns with my spouse					
3	I am comfortable talking with my spouse about his/her end-of-life preferences and concerns					
4	I think my spouse is comfortable talking about his/her end-of-life preferences and concerns with me					
5	I know my spouse's end-of-life preferences and concerns					
6	I believe that spouses should discuss their end-of-life preferences and concerns with each other					

Item 1 is reverse-scored

The items scores:

Strongly disagree 1

Disagree   2

Undecided   3

Agree   4

Strongly agree   5

The scale is scored by summing the items scores (Item 1 is reverse-scored).

Appendix H. Test of unidimensionality of MELCS. LISREL Output.

```
                          DATE:  2/27/2014
                          TIME: 13:31



                     L I S R E L  8.80

                          BY

              Karl G. Jöreskog and Dag Sörbom



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```

The following lines were read from file **C:\Users\Nata\Documents\Thesis\Thesis draft\lisrel input melcs6_101.txt:**

```
DA NI=6 NO=101 MA=CM NG=1
CM SY
*
.492
.290 .365
.311 .309 .390
.226 .204 .289 .634
.268 .242 .293 .281 .778
.217 .204 .232 .173 .205 .242
MO NX=6 NK=1 PH=ST LX=FU,FR TD=DI,FR
OU ND=6 ME=ML SE TV RS
```

```
                    Number of Input Variables  6
                    Number of Y - Variables    0
                    Number of X - Variables    6
                    Number of ETA - Variables  0
                    Number of KSI - Variables  1
                    Number of Observations   101
```

Test of unidimensionality of MELCS6

Covariance Matrix

	VAR 1	VAR 2	VAR 3	VAR 4	VAR 5	VAR 6
VAR 1	0.492000					
VAR 2	0.290000	0.365000				
VAR 3	0.311000	0.309000	0.390000			
VAR 4	0.226000	0.204000	0.289000	0.634000		
VAR 5	0.268000	0.242000	0.293000	0.281000	0.778000	
VAR 6	0.217000	0.204000	0.232000	0.173000	0.205000	0.242000

Test of unidimensionality of MELCS6

Parameter Specifications

LAMBDA-X

	KSI 1
VAR 1	1
VAR 2	2
VAR 3	3
VAR 4	4
VAR 5	5
VAR 6	6

THETA-DELTA

VAR 1	VAR 2	VAR 3	VAR 4	VAR 5	VAR 6
7	8	9	10	11	12

Test of unidimensionality of MELCS6

```
Number of Iterations =  7
```

LISREL Estimates (Maximum Likelihood)

LAMBDA-X

	KSI 1
VAR 1	0.533016
	(0.060492)
	8.811329
VAR 2	0.518489
	(0.049052)
	10.570180
VAR 3	0.593902
	(0.047361)
	12.539974
VAR 4	0.461966
	(0.074508)
	6.200250
VAR 5	0.496302
	(0.083054)
	5.975681
VAR 6	0.392869
	(0.041485)
	9.470203

Fitted Covariance Matrix

	VAR 1	VAR 2	VAR 3	VAR 4	VAR 5	VAR 6
VAR 1	0.492000					
VAR 2	0.276363	0.365000				
VAR 3	0.316560	0.307932	0.390000			
VAR 4	0.246235	0.239524	0.274363	0.634000		
VAR 5	0.264537	0.257327	0.294755	0.229275	0.778000	
VAR 6	0.209405	0.203698	0.233326	0.181492	0.194982	0.242000

Fitted Residuals

	VAR 1	VAR 2	VAR 3	VAR 4	VAR 5	VAR 6
VAR 1	0.000000					
VAR 2	0.013637	0.000000				
VAR 3	-0.005560	0.001068	0.000000			
VAR 4	-0.020235	-0.035524	0.014637	0.000000		
VAR 5	0.003463	-0.015327	-0.001755	0.051725	0.000000	
VAR 6	0.007595	0.000302	-0.001326	-0.008492	0.010018	0.000000

Summary Statistics for Fitted Residuals

```
 Smallest Fitted Residual =    -0.035524
   Median Fitted Residual =     0.000000
  Largest Fitted Residual =     0.051725
```

Stemleaf Plot

```
 - 2|60
 - 0|586210000000
   0|138045
   2|
   4|2
```

Standardized Residuals

	VAR 1	VAR 2	VAR 3	VAR 4	VAR 5	VAR 6
VAR 1	- -					
VAR 2	1.226741	- -				
VAR 3	-1.317559	0.526272	- -			
VAR 4	-0.734766	-2.034285	1.995313	- -		
VAR 5	0.111564	-0.777218	-0.210790	1.131185	- -	
VAR 6	0.654756	0.044256	-0.535752	-0.483412	0.505756	- -

Summary Statistics for Standardized Residuals
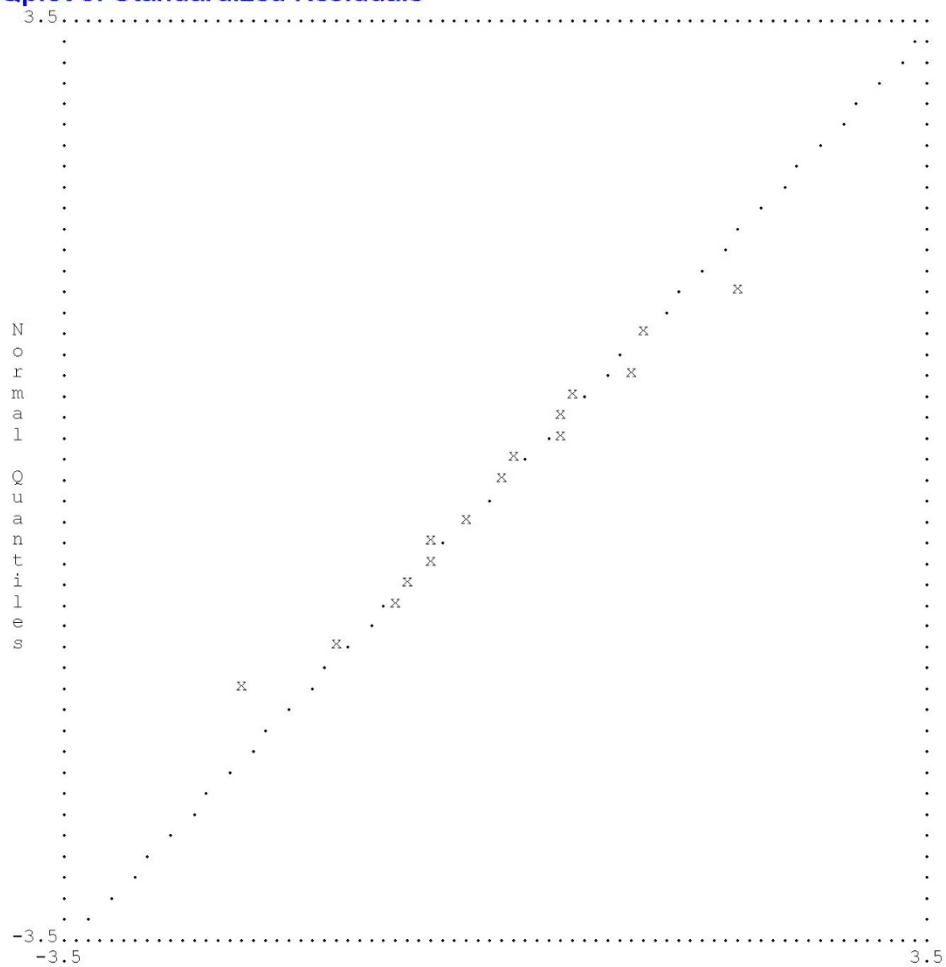
```
 Smallest Standardized Residual =    -2.034285
   Median Standardized Residual =     0.000000
  Largest Standardized Residual =     1.995313
```

Stemleaf Plot

```
 -  2|0
 -  1|3
 -  0|875520000000
    0|1557
    1|12
    2|0
```

Test of unidimensionality of MELCS6

Qplot of Standardized Residuals

Appendix I. Relationships between MELCS and other variables of interest.

Variable	Correlation with MELCS
Already discussed my EOL preferences with my spouse (1=yes, 2=no)	-0.531**
Already discussed my spouse's EOL preferences with my spouse (1=yes, 2=no)	-.336**
I have a will (1=yes, 2=no)	-0.240*
I have an advance directive (1=yes, 2=no)	-0.246*
Gender	0.012
Age	0.031
Religiosity/Spirituality	0.177
Education	0.173
Had a recent health crisis (1=yes, 2=no)	-0.006
Spouse had a recent health crisis (1=yes, 2=no)	0.059

*. Correlation is significant at the 0.05 level (2-tailed).
**Correlation is significant at the 0.001 level (2-tailed).