

2012-10-03

Towards the Development of an Expectations Assessment Instrument for Caregivers of People with Alzheimer's Disease and Related Dementias: A Pilot Study

Leung, Karen

Leung, K. (2012). Towards the Development of an Expectations Assessment Instrument for Caregivers of People with Alzheimer's Disease and Related Dementias: A Pilot Study (Master's thesis, University of Calgary, Calgary, Canada). Retrieved from <https://prism.ucalgary.ca>. doi:10.11575/PRISM/28489
<http://hdl.handle.net/11023/267>

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UNIVERSITY OF CALGARY

Towards the Development of an Expectations Assessment Instrument for Caregivers of
People with Alzheimer's Disease and Related Dementias: A Pilot Study

by

Karen Leung

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE
DEGREE OF MASTER OF SCIENCE

DEPARTMENT OF COMMUNITY HEALTH SCIENCES

CALGARY, ALBERTA

SEPTEMBER, 2012

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Abstract

Health expectations are probability-driven beliefs regarding the likelihood of certain outcomes occurring, and are associated with health behaviours including adherence with treatment and satisfaction with medical care. Currently, little is known about the expectations that caregivers of individuals with dementia have concerning the illness trajectory and health care. Furthermore, few psychometrically-validated measures are available to assess these beliefs. A two-phase methodology was adopted to explore the diversity of caregiver expectations, and to develop a comprehensive item bank for measuring caregiver expectations. In the first phase, 17 caregivers participated in semi-structured interviews. Using an inductive thematic approach to analysis, five themes were identified including expectations of the diagnosis, memory declines, driving cessation, changes in basic activities of daily living, and end of life. In the second phase, a step-wise item review procedure was developed to derive individual items from the qualitative data, and to further refine the item bank.

Acknowledgements

I would like to thank my supervisor, Dr. Neil Drummond, for his mentorship and guidance over the course of my undergraduate research studentships, my work in the Department of Family Medicine, and now my thesis. I am grateful for his encouragement, openness to allowing me to explore my research interests, and unfailing support in all of my academic endeavours. Thank you for these opportunities as well as your kind words of advice and encouragement. I would also like to thank my committee members, Drs. Misha Eliasziw, Candace Konnert, and James Silvius, for their support and thoughtful insights in my thesis.

Thank you to all of my research participants and the Alzheimer's Society of Calgary for their time and assistance. This research would not be possible without their contributions and willingness to share their narratives, thoughts and feelings with me.

I would also like to acknowledge the generous research support provided by the Departments of Family Medicine and Community Health Sciences, the Canadian Institutes of Health Research Canada Graduate Scholarship, Queen Elizabeth II Graduate Scholarship, Nat Christie Foundation Medical Entrance Scholarship, and the University of Calgary Program for Undergraduate Research Experience. Furthermore, I would like to thank my colleagues and friends in the Department of Family Medicine and in medical school for their support, encouragement, beautiful thesis coffee mugs, and seemingly endless supplies of chocolate and miscellaneous baked goods.

I would like to thank my parents, Steven and Anissa Leung, as well as my grandparents, Fee Ngoo and Siu Hing Luk, for their support throughout my academic studies in research and medicine. Last but not least, I would like to thank my sister and best friend, Dr. Bonnie Leung, for believing in me, always being there to support me, and keeping me grounded.

Dedication

To my biggest supporter and the best sister I could ever ask for, Dr. Bonnie Leung.

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CHAPTER 1: INTRODUCTION

With patient-centered care emerging as a key paradigm for guiding healthcare practices, medical care increasingly involves shared decision-making between the physician and the individual (Stewart et al., 2003). To facilitate effective health care, understanding and managing people's expectations regarding diagnosis, treatment, and prognosis is of major importance. Health expectations may be defined as a person's probability-driven beliefs regarding the likelihood that future health care-related events or states will occur (Janzen et al., 2006). Evidence suggests that eliciting patient expectations and establishing agreement on medical problems are associated with improved health outcomes as perceived by both the patient and the physician (Starfield et al., 1981). Furthermore, unmet patient expectations regarding care are associated with a number of concerning issues, including recurrent visits for unresolved symptoms, lower adherence with treatment, and lower satisfaction with care (Kling, 1993; Rao et al., 2000). Thus, well-managed expectations can have a significant impact on the quality of clinical care.

The year 2011 represents a major demographic milestone (Chertkow, 2008), as the first members of the 'baby boom' generation turn 65 years of age (Rice & Fineman, 2004). As the prevalence of Alzheimer's disease in Canada continues to increase in proportion to the aging population (Lindsay et al., 2004), research is advocating for the better management of Alzheimer-related expectations in clinical care (Gauthier, 1999; Samuels, 2004). Alzheimer's disease is an irreversible neurodegenerative disorder that is characterized by progressive declines in memory and cognition as well as significant impairments in social and daily functioning (American Psychiatric Association, 2000).

What begins in the early stages with atypical memory loss and difficulties managing instrumental activities of daily living such as grocery shopping and banking, subsequently progresses to more severe deficits in basic activities such as bathing and dressing (Perrault et al., 2002). Eventually, the disease advances to a state of total dependence and death (Reisberg & Franssen, 1999).

Currently, little research has examined the expectations held by important stakeholders in dementia care, such as caregivers of individuals with dementia. As these progressive declines in cognition and function occur, caregivers eventually bear much of the responsibility for providing daily care, negotiating for health services, and making medical decisions on behalf of the care recipient (Hirschman et al., 2002). In addition, caregivers must manage the behavioural and psychological symptoms associated with dementia, such as agitation, aggression, wandering, and depression (Lawlor, 2002). These symptoms are related to increased caregiver burden and distress. Moreover, nearly half of all caregivers have reported experiencing at least one episode of depression or an adverse health event as the result of personal strain (Gallagher et al., 1989; Lu & Wykle, 2007).

The few studies conducted to date have mainly investigated expectations from the perspective of socially-endorsed norms and perceived obligations rather than from the predictive orientation that is characteristic of expectations theory. For instance, Smyth and Milidonis (1999) found that the caregivers' normative beliefs about receiving help were significantly related to caregiver burden, role captivity and overload, independent of the actual amount of help received and perceived health severity of the care recipient. Similarly, Kosloski and colleagues (1999) reported that the caregivers' perceptions of societal expectations regarding the provision of care were associated with depression.

Brashares and Catazaro (1994) conducted one of the few studies on caregiver expectations from a predictive perspective. Using the Negative Mood Regulation Scale, which measures generalized beliefs about the types of behaviours and cognitions that will alleviate a negative mood, the researchers found that caregivers who expected to cope with stress and burden with high levels of self-efficacy were less likely to experience severe depression even after controlling for baseline levels of stress and coping responses (Brashares & Catanzaro, 1994). However, this study did not explore other expectations relating to the dementia care-giving experience such as beliefs about the disease trajectory or health and support services, which are also key factors that affect caregiver wellbeing.

As a corollary, there are few instruments available with established psychometric properties for measuring caregiver expectations. With the publication of the United States Food and Drug Administration's (FDA) guidelines for developing patient reported outcome measures, marked interest in measuring subjective beliefs and experiences has emerged (US FDA, 2009). Thus, developing a measurement tool for assessing caregiver expectations about the disease trajectory and health services is a topical area of research and may produce two key benefits. First, from a theoretical perspective, a number of hypotheses regarding the influence of expectations on health behaviours and attitudes have been postulated, but to date, the lack of a validated instrument poses a significant obstacle. For instance, it is possible that expectations of a bleak and pessimistic future or worries about receiving the appropriate support services may be predictive of caregiver maladjustment, such as depression and anxiety. Therefore, by developing an expectations questionnaire, the relationships between cognitions and subjective well-being may be

investigated quantitatively, and in turn, the current theoretical models may be further refined.

Second, from a health services perspective, measuring these expectations may possess some clinical utility as well. By measuring these expectations, unrealistic expectations regarding the disease trajectory and service provision may be identified (e.g., “My loved one will soon be forced to move to a nursing home against their wishes,” adapted from Scholey and Woods, 2003). By making these beliefs explicit, health professionals can ameliorate anxiety by providing accurate information about the disease progression, their care, and strategies to optimize functioning (Keady & Nolan, 1995). In addition, by promoting realistic expectations, health professionals can negotiate feasible treatment goals, initiate the proper support services, and encourage advanced directives regarding future care (Wilkinson & Milne, 2003).

Administering questionnaires is an appealing technique because they require only a modest investment in materials and personnel, and are often acceptable to both patients and health care professionals (Detmar et al., 2002). Because time constraints frequently limit the thoroughness of assessments (van Hout et al., 2000), concise questionnaires may serve as an efficient means for surveying a diverse range of expectations (Sarkisian et al., 2002), and highlighting the most concerning expectations for discussion during the clinical encounter. Moreover, studies examining the utility of expectations assessment tools for psychiatric disorders have found that physicians were more likely to satisfy their patients’ expectations, and were less likely to perceive them as being difficult (Jackson et al., 1999).

A better understanding of caregiver-related expectations may lead to

improvement in person-centered care. Thus, this thesis adopts a two-phase approach, which begins to examine and develop an expectations questionnaire for caregivers of people with dementia, and which might form the basis for future work in validating a clinical tool for quantifying caregiver expectations. In the first phase, this study qualitatively explored the breadth and diversity of expectations held by caregivers of individuals with Alzheimer's disease and related dementias. These results not only provided an increased understanding of caregiver expectations regarding the disease trajectory and health services, but also informed the contents and development of a new measure for assessing expectations. In the second phase, the creation of an item bank for measuring caregiver expectations, as well as the implications of the methods used to generate individual items are further examined.

CHAPTER 2: LITERATURE REVIEW

This chapter presents a review of the relevant literature, consisting of five components. The first major section presents an introductory overview of Alzheimer's disease and related dementias, including the epidemiological trends and the normative disease trajectory. Because informal caregivers tend to provide the majority of the daily care to individuals with dementia, the second section explores the activities, experiences and health consequences of dementia caregiving. Following these discussions on the dementia experience, a review of the theory on health expectations is given. Although the concept of expectations have been investigated extensively in psychology, a number of issues are evident in the health literature including the conflation of expectations with other future-oriented constructs, and the current paucity of research that has examined dementia-related expectations of caregivers. Next, issues regarding the measurement of expectations are discussed. Finally, the proposed study and the research objectives of this thesis are further described.

Alzheimer's Disease & Related Dementias

Dementia is a clinical syndrome that is characterized by acquired impairments in multiple behavioural and neuropsychological domains (American Psychiatric Association, 2000; Ross & Bowen, 2002). According to the Canadian Study of Health and Aging (1994), an estimated eight percent of Canadians aged 65 and older have dementia. This prevalence rate varies across age-specific strata, and has been found to double approximately every five years after age 65, from 2.4% to 34.5% among individuals age 85 and older (McDowell et al., 2004; O'Brien et al., 1999). As the first wave of baby boomers enter their senior years in 2011, it is estimated that the number of

Canadians living with dementia will more than double to 1,125,000 by 2038, and will present a cumulative economic burden in excess of \$153 billion (Alzheimer Society of Canada, 2008). These demographic changes will have significant implications on the provision and configuration of dementia care and health services in general (Keehan et al., 2008).

Nearly two-thirds of individuals with dementia are diagnosed with Alzheimer's disease, thus rendering this the most prevalent subtype (McDowell et al., 2004). Alzheimer's disease is an irreversible neurodegenerative disorder that is characterized by progressive declines in memory and cognition as well as significant impairments in social and daily functioning (American Psychiatric Association, 2000). Although the rate of decline differs between individuals, consistent patterns of cognitive and functional deficits manifest over time (Farlow, 2005; Feldman & Woodward, 2005). In the early stage, atypical memory loss and difficulties managing instrumental activities of daily living such as grocery shopping and banking begin to emerge and subsequently progress to more severe deficits in basic activities such as bathing and dressing during the middle stage (Perrault et al., 2002). At the end stages, the disease advances to a state of total dependence, and eventually, death (Reisberg & Franssen, 1999). This overall rate of decline tends to reflect a quadratic pattern, with more rapid declines occurring in the early and late stages compared to the middle stage (Stern et al., 1994; Wattmo et al., 2008).

Vascular dementia is the second most prevalent form (Erkinjuntt et al., 2003), and shares many overlapping symptoms and neuropsychological features with Alzheimer's disease (Langa et al., 2004). Research estimates that as many as 60-90% of people with

Alzheimer's disease have concurrent cerebrovascular pathology such as small vessel disease, white matter lesions and cerebral infarcts, while one-third of people with vascular dementia also have Alzheimer-related pathology (Kalaria & Ballard, 1999). Furthermore, unlike other forms of dementia such as frontotemporal dementia and Lewy-body dementia, which are respectively characterized by behavioral disturbances (Ratnavalli et al., 2002), hallucinations and extrapyramidal signs (Gnanalingham et al., 1997), both vascular dementia and Alzheimer's disease are characterized primarily by cognitive decline and functional deterioration (Kalaria, 2002). This has led some researchers to postulate that a continuum of pathologies exists, with Alzheimer's disease and vascular dementia representing the two extremes, and a 'mixed' dementia representing the more common condition (Chertkow, 2008; Kalaria, 2002). As a result, a number of studies examining dementia-related phenomena have allowed the inclusion of individuals with Alzheimer's disease alongside those with vascular and mixed dementia (Aminzadeh et al., 2007; Sands et al., 2004).

The Caregiving Experience

The Caregiving Career

The caregiving role develops in response to the emergent dementia-related symptoms and progressive functional declines. The concept of the caregiving career reflects the changes in the types of care or 'work' provided to the individuals with dementia as they experience and navigate the different stages of dementia, and the transitions that bracket those moments of relative stability (Chiriboga, 1994; Hasselkus & Murray, 2007). Sociologists Pearlin and Aneshensel (1994) further described this role as the "unexpected career." Just as it is difficult to anticipate whether a family member will

develop dementia in later life, Pearlin & Aneshensel (1994) suggested that it is difficult to anticipate the immensity of activities and responsibilities encompassed in the role of a caregiver, which lie beyond the generalized social bonds to take care of one's elders in their old age, or one's spouse in sickness and in health (Russell, 2001). These authors suggest that "one does not plan on it, prepare for it, or easily settle into it. It is from this perspective, then, that we can think of caregiving as an *"unexpected career"* (p. 376). Therefore, 'learning on the job' is an integral facet of caregiving, which in turn, necessitates that the role will evolve over time.

Broadly speaking, caregiving activities may be clustered into three domains that reflect the sequelae of dementia-related impairment (Dunkin & Anderson-Hanley, 1998). In the early stages, caregiving activities might include providing support for instrumental activities of daily living (ADL), such as transportation, housekeeping, and personal finances (Alzheimer's Association, 2011). As the disease progresses, increasing functional impairments might require greater support for basic ADL, such as feeding, grooming and toileting (Sclan & Reisberg, 1992). Finally, Dunkin and Anderson-Hanley (1998) identified a third domain of managing the behavioural and psychological symptoms of dementia (BPSD), such as agitation, aggression, depression and wandering behaviours. Although not every individual with dementia will exhibit these symptoms, studies estimate that nearly 20% of individuals with dementia in the community and as many as 80% of those in long-term care will exhibit clinically significant levels of behavioural and psychiatric symptoms (Lawlor, 2002). While BPSD are not a set of diagnostic criteria for Alzheimer's disease, these symptoms are related to increased

caregiver distress and pose a significant challenge for medical management and care (Lyketsos et al., 2000).

As Alzheimer's disease progresses, caregivers not only bear much of the responsibility for providing daily care, but are also key stakeholders in determining access and use of formal healthcare services (Hirschman et al., 2002). These interactions with the health care system may include advocating for assistance from service providers and government agencies (Schulz et al., 2004), negotiating and arranging for in-home services, and making medical decisions on behalf of the care recipient (Alzheimer's Association, 2011; Hirschman et al., 2006). Furthermore, caregivers have an important role in communicating with health professionals, and may contribute valuable observations about neuropsychiatric symptoms and responses to treatment, particularly in the later stage of the disease when insight and awareness among individuals with dementia tend to decline (Kaufer et al., 2000).

The Consequences of Caregiving

Considerable research using both quantitative and qualitative methods has explored the experiences, subjective meanings, and health outcomes associated with caregiving activities. Quantitative studies have found that caregiving can affect subjective evaluations of quality of life. Compared to matched-controls, dementia caregivers report spending significantly more hours per week providing care, and that caregiving negatively impacts their occupation, leisure time, and family dynamics, even after controlling for the intensity of caregiving and sociodemographic factors (Ory et al., 1999). Caregivers also describe experiencing periods of anticipatory grief as they observe their care recipients decline over time, and acknowledge the changing dynamics of their

relationships (Meuser & Marwit, 2001). Grief manifests intellectually, affectively, and existentially, and reflects their current care demands as well as expectations regarding continued changes in the future. Despite these challenges, qualitative findings have also suggested that individuals may derive a sense of meaning from caregiving. These experiences include finding enjoyment in the time spent with their care recipients, reaffirming the intrinsic value of familial relationships, and acknowledging the appreciation shown by their care recipients (Farran et al., 1991; Motenko, 1989).

From a health services perspective, caregiving has clear consequences on physical health and wellbeing. Schulz and Beach (1999) reported that the emotional or mental strain experienced by older caregivers in general was independently associated with an increased risk of mortality. Nearly half of all caregivers have reported experiencing at least one episode of depression or an adverse health event as the result of personal strain (Gallagher et al., 1989; Lu & Wykle, 2007). These findings are further supported by numerous systematic reviews and meta-analyses which have found increased rates of anxiety (Cooper et al., 2007), depression (Pinquart & Sorensen, 2003), and markers of inflammatory and cardiovascular disease (Vitaliano et al., 2003) among those with higher levels of burden. Moreover, increased levels of BPSD and lower amounts of informal social support are risk factors for adverse psychiatric outcomes (Black & Almeida, 2004; Clyburn et al., 2000). These vulnerabilities tend to accumulate during states of disruption, such as transitions from one stage of decline to another (Pearlin & Aneshensel, 1994). Therefore, understanding sources of strain for caregivers and addressing their needs, particularly during moments of transition, is a significant priority for clinical care.

In summary, Alzheimer's disease and related dementias are irreversible

neurodegenerative disorders marked by declines in cognition and function. This disease has wide-ranging neuropsychiatric and functional consequences for individuals with dementia and their informal caregivers who provide considerable support and care throughout the disease trajectory. Most research examining the phenomenology of caregiving as well as the health and psychosocial implications have focused primarily on previous experiences and current challenges. Less research has examined the impact of expectations and beliefs about the future. As hinted by researchers such as Pearlin and Aneshensel (1994) and Meuser and Marwit (2001), unexpected experiences and uncertainties especially during moments of transition are commonly experienced in caregiving. Interpretations of current experiences are influenced by beliefs about the future, such as anticipations regarding upcoming challenges and potential rewards.

Health Expectations

A Predictive Definition of Expectations

Health care professionals are increasingly aware of the value in understanding patient expectations, concerns, and preferences regarding medical care (Barry et al, 2000; Bensing, 2000). With greater emphasis being placed on integrating person-centered principles with evidence-based practices (Gray, 2005; Hasnain-Wynia, 2006; Wagner et al., 2005), eliciting expectations is an apparently simple, yet effective, means of encouraging medical partnership. Health expectations may be defined as a person's probability-driven beliefs regarding the likelihood that future health care-related events or states will occur (Janzen et al., 2006). Research suggests that patient-physician agreement on health issues and treatment goals is associated with reduced polypharmacy (Straand & Sandvik, 2001), improved emotional health, and positive assessments of chronic disease

self-management (Heisler et al., 2003). Communicating expectations may contribute to improved health outcomes (McKinley & Middleton, 1999), and enhance negotiation of valued resources and services (Like & Zyzanski, 1986).

Expectations have been investigated extensively in the psychological literature (Kirsch, 1985; Maddux, 1999). As a complex theoretical construct, expectations embody aspects of being both a subconscious cognitive process and a conscious set of beliefs about the future (Maddux, 1999; Janzen et al., 2006). First, when viewed as a subconscious process, expectancy theory describes how past experiences, knowledge, and causal attributions shape an individual's predictions of future outcomes (Bandura, 1982; Olson et al., 1996). As context-specific applications of expectancy theory, *expectations* are defined as an individual's probability-driven, conscious beliefs regarding the likelihood that a particular future event or experience will occur (Olson et al., 1996; Burgoon, 1993). The final articulation of a conscious expectation is influenced by a number of variables, including cultural and societal norms, situational factors, and personality traits such as optimism, which is a tendency to form expectancies of positive outcomes (Scheier & Carver, 1994; Montgomery et al., 2003).

Janzen and colleagues (2006) provide a useful conceptual model for understanding the formation of an expectation. The expectation development process consists of a number of phases that are encountered in a cyclical and longitudinal sequence, with each phase containing one or more aspects (Janzen et al., 2006). This sequence includes six phases: a *precipitating phenomenon* or the critical experience that initiates reflection and thinking about a specific expectation; a *prior understanding*, which includes previous experiences, knowledge, and beliefs; *cognitive processing*,

which describes how a sense of probability, sense of time, sense of self-efficacy, and perceived expected subjective utility contribute to the emergence of a specific expectation; *expectation formulation*, which is the product of the previous phases; *outcome*, which includes the behaviors, attitudes and motivations that are influenced by a person's expectations; and *cognitive processing after the outcome*, or the post-outcome reflection and thoughts regarding what has occurred.

Conflation of Related Constructs

Within the health literature, however, the lack of a clear, mutually-agreed upon conceptual definition of an expectation has posed a significant challenge for research. Thompson and Sunol (1995) identified the four primary meanings that expectations have subsumed: predicted, ideal, normative and unformed. Uhlmann and colleagues (1984), and recently Janzen and colleagues (2006), suggested there is a clear semantic difference between an expectation and other future-oriented constructs such as desires and hopes. Predictive expectations are defined as probability-driven beliefs regarding the likelihood of future outcomes occurring, which is consistent with the classical, psychological definition of this construct. In contrast, ideal expectations such as hopes represent preference-driven beliefs regarding the *possibility* of valued outcomes occurring, which may or may not have any probability of being realized (Leung et al., 2009b). For instance, patients and certain health professionals have argued that given the numerous anecdotal accounts of people making remarkable recoveries or exceeding life expectancies, maintaining hope is reasonable even in situations with seemingly low probabilities (Little & Sayers, 2004; Snyder, 2002). While hopes and expectations are

closely related, being both future-oriented cognitions, these constructs are distinct and should be investigated independently in their own right (Leung et al., 2009b).

Normative expectations represent what should or ought to happen based on socially-endorsed standards or perceptions of duties and obligations. However, like ideal expectations, these normative beliefs may have no bearing on an individual's beliefs regarding what will imminently happen in his or her own future (Janzen et al., 2006). Pragmatically speaking, a caregiver may perceive that in order to be a "good daughter", she ought to provide attentive care 24 hours a day, but she might more reasonably expect to have difficulties caring her father with dementia at night when he has a tendency to wander (Leung et al., 2009a). Finally, unformed expectations represent a null category in which individuals are unable or unwilling to articulate their probabilistic assessments of future experiences (Thompson & Sunol, 1995). These differing definitions may be a critical confounding factor in the current research.

Drawing on the classical, probability-based definition of expectations, there are four subtypes of expectancies commonly encountered in the literature: stimulus-outcome, behavioral-outcome, self-efficacy, and response expectancies (Maddux, 1999; Kirsch, 1999). Discussions of how these expectancies are theoretically interrelated are presented by Leung and colleagues (2009b) and Rosenstock and colleagues (1988). Stimulus-outcome expectancies are beliefs that certain events will result in particular outcomes (Maddux, 1999). For instance, a caregiver might expect that her mother with advanced dementia will soon need to be placed in a nursing home. Behaviour-outcome expectancies are beliefs that engaging in a certain action will lead to a given outcome (Maddux, 1999), while self-efficacy expectancies are a person's assessment of how

successful one will be in carrying-out a behaviour for achieving that outcome (Bandura, 1989). The aforementioned caregiver might further expect that she will need to speak with her mother's family physician before being able to find placement in long-term care. She expects that she will be successful in having a frank and honest discussion with the family physician about her concerns and needs. Lastly, response expectancies are a person's predicted non-volitional or unconscious responses to situations, including emotional reactions and pain (Kirsch, 1999; Montgomery et al., 2003). She might further expect to experience sadness about placing her mother in nursing home, but ultimately she expects to feel a sense of relief as caregiving at home is becoming less manageable. Overall, a person's expectations are informed by knowledge, cultural norms, and situational factors (Olson et al., 1996).

Caregiver-Related Health Expectations

Despite the importance of expectations in shaping the clinical encounter, to date, few studies have examined caregiver expectations. The available research conducted to date has mainly investigated expectations from the perspective of socially-endorsed norms rather than from the predictive orientation that is characteristic of expectations theory. For instance, Smyth and Milidonis (1999) found that the caregivers' normative beliefs about receiving help (e.g., "I believe that families should care for their own and not ask for outside help") were significantly related to caregiver burden, role captivity and overload, independent of the actual amount of help received and perceived health severity of the care recipient. Similarly, Kosloski and colleagues (1999) examined the relationship between depression and caregivers' endorsement of societal expectations regarding the provision of care (e.g., "I wouldn't be a very good daughter if I didn't care

for my mother”), and they reported a significant and positive association.

To the researcher’s knowledge, only three studies have examined caregiver expectations from a predictive perspective. Using a qualitative design, Andersen and colleagues (2008) examined the expectations of caregivers, patients, and health care professionals regarding cholinesterase inhibitor therapy for Alzheimer’s disease. The researchers reported that some patients and caregivers had relatively optimistic expectations regarding drug benefits, including stabilizing current symptoms and even potentially restoring memory. In comparison, health care professionals had more tempered expectations regarding possible benefits, with most suggesting little foreseeable benefit in terms of delaying the inevitable decline in cognition and daily functioning in the short term (Andersen et al., 2008).

Mitchell and colleagues (2009) conducted a prospective cohort study on the clinical course of advanced dementia and the quality of end-of-life care. These researchers found that among caregivers who understood that the resident with dementia had less than six months to live, and understood the clinical complications expected in advanced dementia, were less likely to pursue burdensome interventions such as parenteral therapy, gastric tube feedings, and hospitalizations. Although this outcome was largely a secondary research finding, this nonetheless highlights the importance of understanding predictive expectations, and how beliefs about the future outcome shape current behaviours and decisions regarding care.

The third study examined the influence of self-efficacy expectations on caregiver depression. Using the Negative Mood Regulation Scale, which measures generalized beliefs about the likelihood that one’s behaviours and cognitions will alleviate a negative

mood, Brashares and Catazaro (1994) found that caregivers who expected to cope with stress and burden with high levels of self-efficacy were less likely to experience severe depression even after controlling for stress levels and coping responses (Brashares & Catanzaro, 1994). However, this study did not explore other expectations related to the dementia care-giving experience such as the disease trajectory or health and support services, which are also key factors that affect caregiver wellbeing.

Because dementia-related expectations among caregivers have remained largely unexplored in the literature, the current study seeks to examine and describe these cognitions. In particular, understanding expectations regarding the disease progression as well as the types and amount of health services that caregivers anticipate will be needed at each dementia stage and transition is important. These beliefs shape the clinical encounter, and addressing these perceptions may foster greater trust and satisfaction in the medical relationship (Bell et al., 2002). Therefore, using a qualitative approach to exploring and documenting caregiver expectations and perspective is suitable and topical area for further research.

Issues of Measurement

The lack of psychometrically-validated questionnaires for measuring caregiver expectations poses a significant challenge. From a research perspective, developing an expectations measure may produce two benefits. First, a number of hypotheses regarding the role of expectations in determining health behaviours and outcomes have been proposed (Janzen et al., 2006; Leung et al., 2009b; Rosenstock et al., 1988), and the development of a validated measure would enable quantitative assessment of these relationships and further refinement of the current conceptual models. Second, given the

current emphasis on evidence-based medicine, conducting research using robust measures would provide more definitive evidence on how to improve person-centered communication, which traditionally includes exploring the patient's current level of function, ideas about health, feelings, and expectations (Silverman et al., 2005; Stewart et al., 2003).

Developing a measure for assessing caregiver expectations may be useful clinically as well. Considerable research has demonstrated that managing expectations can be challenging, as individuals often do not verbalize their expectations, and physician assessments of their perspectives tend to be unsystematic (Bell et al., 2002; Peck et al., 2004). Research has found that in ambiguous situations, the physician's assumptions about the client's expectations are robust predictors of subsequent medical actions (Cockburn & Pit, 1997), and may result in undesirable and even unnecessary medical care (Britten, 2004). Therefore, by asking caregivers to complete a self-report on their expectations, these beliefs are made explicit, and in turn, can be discussed during the clinical interview. Furthermore, unrealistic caregiver expectations may be identified and ameliorated by providing accurate information about the disease progression (Keady & Nolan, 1995). By promoting realistic expectations, health professionals can negotiate feasible treatment goals, initiate the proper support services, and encourage advanced directives regarding future care (Wilkinson & Milne, 2003).

While most physicians traditionally do not use questionnaires for clinical assessments, there is increasing interest in developing and using quantitative instruments for indexing important health-related phenomena including quality of life and expectations (Detmar et al., 2002; Sarkisian et al., 2002). Administering a set of

questionnaire items is an appealing technique because they require only a modest investment in materials and personnel, and are often acceptable to both patients and staff (Detmar et al., 2002). Moreover, studies examining the utility of expectations assessment tools for psychological disorders have found that physicians were more likely to satisfy their patients' expectations, and were less likely to perceive them as being difficult (Jackson et al., 1999). Finally, because time constraints frequently limit the thoroughness of assessments (van Hout et al., 2000), concise measures may serve as an efficient means for surveying a diverse range of expectations (Sarkisian et al., 2002), and highlighting the most concerning expectations for discussion.

Questionnaire Development: Methodological Issues

With the publication of the Food and Drug Administration's (FDA) guidelines for developing patient-reported outcome measures (US FDA, 2009), interest in creating questionnaires for measuring patient experiences and beliefs has increased exponentially (DeWalt et al., 2007). Traditionally, the use of qualitative research to inform questionnaire development is considered a means of strengthening claims of content validity (Fleury, 1993). Content validity is a subjective evaluation of whether an instrument measures what it purports to measure (Cronbach & Meehl, 1951). Thus, a number of methodologists have suggested that questionnaires should be grounded in a clear conceptual model of the construct of interest (Rothman et al., 2007). Furthermore, to adequately capture the meanings and perspectives of the participants, items should be developed inductively using the verbatim words and phrases drawn from the qualitative results (Arranz et al., 2004; Marquis et al., 2005; Niero et al., 2002).

However, there is surprisingly little methodological guidance regarding how to transform the qualitative data into individual questionnaire items (Fleury, 1993). In a structured review conducted of 46 articles published in the last two years that described the development of a variety of novel questionnaires using mixed methods, few insights are offered on how to derive items from the qualitative findings. For instance, Spiegel and colleagues (2010) only briefly stated their approach using a single sentence: “Based on the results of the focus groups, a set of candidate items was generated, which formed the basis for the draft instrument” (p. 592). Granted, given the constraints of publication word limits, the reporting of psychometrics and other quantitative components has often taken precedence over the qualitative components. However, the underreporting of the methods used for item development limits the replicability of these methods.

In reviewing the aforementioned literature, there appeared to be two general approaches to item development, which reflects the qualitative methods used. The first approach was termed “researcher-led,” and it entailed either identifying the core themes of a construct or generating a conceptual model from the qualitative data. Often, these studies used grounded theory to inform the conceptual framework of the construct; using this inductive framework, items were drafted by the developers to represent and populate each thematic category (Egede & Ellis, 2009; Kassam et al., 2010; Lam et al., 2010). Alternatively, the second method was termed “participant-led,” and it also required identifying the key themes from the qualitative data using a variety of methods including content analysis and interpretative phenomenological analysis. This method attempted to stay closer to the words of the participants by drafting items based on verbatim articulations drawn from each theme (Meads et al., 2010; Varas-Diaz et al., 2009;

Wessels et al., 2009). However, in most studies, the specific procedures used to derive items from the data have not been explicitly described. Furthermore, the challenges and implications of using these approaches have largely been unexplored.

The Proposed Study

This thesis begins to examine the measurement of Alzheimer-related expectations using a two-phase approach. Given the paucity of research on health expectations, this study first seeks to explore caregiver expectations regarding the disease progression and the types and amounts of health services they expect to need in the future. Furthermore, because expectations are complex constructs and are often hard to recognize, being both conscious beliefs and a subconscious cognitive process that influences behaviors and attitudes (Janzen et al., 2006), using qualitative methods enable the researcher to capture caregiver perceptions and their expectations using their own words and on their own terms (Patton, 2002). Second, on the basis of these qualitative findings, the researcher will inductively develop a preliminary item bank suitable for assessing caregiver expectations. However, because of the current lack of clear methodological guidance for inductively developing questionnaire items, the latter aspect of this thesis is largely exploratory, and attempts to explicate the rationale used to develop and implement the item development procedures.

Research Objectives

Therefore, this study seeks to explore the diversity of expectations that dementia caregivers have regarding the disease progression and health services. It then seeks to describe a set of procedures for inductively developing a pool of questionnaire items for measuring expectations. In the subsequent chapters, the methods used in this two-phase

qualitative study are described, the qualitative findings and the core domains of caregiver expectations are presented, and a description of the qualitative approach used to develop the preliminary item bank is given. Finally, the implications of this work for the future development and psychometric validation of an instrument are discussed.

CHAPTER 3: METHODS

This chapter presents the research design and methods used in two research phases, which first explore the expectations of dementia caregivers, and second develop and revise a pool of candidate items for inclusion in a questionnaire item bank. The methods used in the first phase are described in four components, including the rationale for adopting a qualitative research design to explore caregiver expectations, the sampling and recruitment strategies, the data collection procedures, and the data analysis approach. The methods used in the second phase of the study are also described in four components including the iterative process of identifying, drafting, and revising the questionnaire items, the sampling and recruitment strategies for conducting an initial review of the items, the data collection procedures, and the data analysis approach. Finally, the processes used to promote rigor and trustworthiness in both studies are discussed.

Phase I: Qualitative Exploration of Caregiver Expectations

Research Design

This phase adopted a qualitative research design. According to Denzin and Lincoln (2003), qualitative research is a set of naturalistic practices that seek to understand, “make sense of, and interpret phenomena in terms of the meanings people bring to them” (p. 5). This approach is suitable for exploring domains such as health expectations, which have not been thoroughly investigated nor easily examined using current quantitative surveys and techniques (Pope & Mays, 1995). A qualitative design is appropriate in this study for two reasons. First, its interactive, open-ended questioning enables the researcher to capture caregiver perceptions and their expectations using their own words and on their own terms (Patton, 2002). This approach may also reveal

emergent participant expectations which could not anticipated a priori by the researcher. Second, its interpretive stance, and assertion that experience and meaning are socially constructed, allows the researcher to further consider and explore expectations “in action” as a subconscious cognitive process (Denzin & Lincoln, 2003).

Qualitative Description

The principles of qualitative description guided this study (Sandelowski, 2000). Qualitative description is a “rediscovered” method, and is viewed as a “back to basics” approach to qualitative study (Sandelowski, 2000). This method grew in response to the perceived increase in the number of studies claiming to use specific methods (e.g., grounded theory or discourse analysis) as a means of gaining methodological legitimacy, but which often lacked full adherence to the theoretical commitments of those methods (Braun & Clarke, 2006; Sandelowski, 2000). Sandelowski (2000) suggested that “a confusing state of affairs exists whereby studies are called narrative, even though they may include nothing more than minimally structured, open-ended interviews, [or] phenomenologic, even though they may include nothing more than reports of the “subjective” experiences of participants” (p. 334). While such approaches may still provide valuable insights into health-related phenomena, these issues nonetheless raise concerns regarding their rigor and trustworthiness, which detract from the findings (Sandelowski, 2000).

As an alternative, qualitative description seeks to comprehensively describe and summarize the events and meanings that people attribute to their experiences (Sandelowski, 2000). This method typically adopts a factist perspective, which views talk as being more or less reflective of the participants’ interpretations of their beliefs,

experiences, and reality at that moment in time (Sandelowski, 2010). Thus, qualitative description is an appropriate method for this study, which seeks to identify a broad set of expectations held by dementia caregivers. In comparison, this objective is less compatible with the aims of other methods such as grounded theory, which seeks to construct models of emergent theoretical relationships (Creswell et al., 2007).

Sampling & Recruitment

Sampling

Because this phase of the study was interested in investigating the detailed and nuanced expectations of caregivers, a smaller target sample size of 15 caregivers was selected to enable a thorough, but manageable, comparative analysis (Patton, 2002). In order to identify a comprehensive set of caregiver expectations, a mixed sampling approach was adopted. This study used a purposive and maximum-variation sampling strategy. The former seeks to identify specific participants that can provide in depth information about a given experience, while the latter attempts to find individuals from a variety of contexts to produce a holistic understanding of the experience of interest (Lincoln & Guba, 1985; Patton, 2002). Snowball sampling and word-of-mouth recruitment were also used to maximize both the diversity in participants and the likelihood of locating those who are “resistant to identification” (Egdell et al., 2010), that is, individuals who do not use the services of community agencies commonly involved in participant recruitment.

In keeping with this study’s exploratory nature, the eligibility criteria were broad. The researcher attempted to sample English-speaking caregivers of people with either a primary or secondary diagnosis of Alzheimer’s disease, vascular dementia or mixed

dementia. These three types of dementia are commonly examined together in research for a number of reasons (Zekry et al., 2002). First, they account for over eighty percent of the prevalent cases of dementia (Skoog et al., 1993). Second, they share many overlapping neurophysiological features and symptoms of cognitive and functional deterioration (Kalaria, 2002; Langa et al., 2004). Third, these dementias are often viewed as distinct from other forms of dementia, such as frontotemporal dementia and Lewy-body dementia, which are respectively characterized by behavioral disturbances (Ratnavallia et al., 2002), hallucinations, and extrapyramidal signs (Gnanalingham et al., 1997). As a result, caregivers of people with frontotemporal dementia or Lewy-body dementia were excluded, as their experiences and concerns are likely sufficiently different to warrant a separate study of their expectations.

The researcher sought to sample caregivers from across the dementia continuum, from people caring for the recently diagnosed to people caring for those with late stage dementia. This range was later broadened to include recently bereaved caregivers who expressed an interest in sharing their experiences and expectations, including about end-of-life care. Both primary and secondary informal caregivers were eligible for inclusion in this study. Dementia care is frequently embedded in complex social relationships, and primary and secondary caregivers may perform different tasks to assist the person with dementia (Gaugler et al., 2003). Furthermore, these caregivers may have divergent expectations about the types and intensity of care and emotional support to be provided. Documenting these beliefs is important, as these expectations can influence caregiving conflict, psychosocial wellbeing, and the course of dementia care (Bourgeois et al., 1996).

Recruitment

The researcher approached a number of health and community services involved in geriatric and dementia care over a period of two and a half years. In 2007, as part of an undergraduate summer research studentship, the researcher and thesis supervisor approached a hospital-affiliated geriatric assessment clinic for assistance in recruitment. Meetings were held with the clinic manager and social workers to address ethical considerations about this study, including the time commitment required of the clinicians and the potential for burdening distressed caregivers. To mitigate concerns, posters describing the study were sent to the clinicians with an active caseload in counseling dementia caregivers. Then, the clinicians distributed the posters only to the caregivers who expressed an interest in participating in research. To protect privacy, the clinicians further asked caregivers whether they were comfortable having their contact information given to the researcher. One participant was identified through this process.

Between September 2009 and January 2010, the researcher met with key stakeholders at the Kerby Centre and their ethics committee to obtain approval for this study. Posters with a description of the study and the researcher's contact information were distributed throughout the public areas, although no participants were identified from this organization. During this time, the researcher was also introduced to staff members at Intercare, which oversees four long-term care facilities for seniors and individuals requiring specialized care. An Intercare coordinator contacted caregivers of residents who met the inclusion criteria, and determined whether these caregivers were comfortable with having the researcher contact them about the study. One recently bereaved caregiver expressed interest in participating, but only after a grieving period. To

respect her wishes, the researcher waited three months before contacting the caregiver and obtaining verbal confirmation that she was still interested in participating.

In addition, the researcher contacted the Alzheimer's Society of Calgary for assistance with recruitment. The researcher, who was a volunteer with this organization, obtained permission from the volunteer manager, communications officer, and the family support coordinators to briefly introduce the study at the beginning of six consecutive Caring with Confidence sessions. Caring with Confidence is a three-part education series for caregivers, and consists of three-hour sessions on what is dementia, strategies for coping with and managing dementia, and end-of-life care. Recognizing the potential for a conflict of interest between the roles of researcher and volunteer (Fontana & Frey, 2003), the researcher deemed that transparency about these roles was necessary. As a result, the researcher introduced herself during these sessions as a student, fellow caregiver, as well as the volunteer assistant to the facilitators. In her volunteer capacity, the researcher stayed for the entire duration of sessions. However, to minimize any negative impacts on group dynamics, the researcher did not mention the study again during the sessions unless prompted by the facilitator or asked by the attendees during the breaks.

From the Caring with Confidence sessions, twelve primary and secondary caregivers from six families expressed interest in participating. To ensure that no one family was overrepresented in the data, the researcher stipulated a priori that a maximum of three caregivers per family were eligible for inclusion in the study, although this ceiling was never exceeded. Three individuals later declined participation. One individual declined because his care recipient was upset about his participation, while one individual declined because she became too busy. Another individual declined because her care

recipient had recently passed away. However, she encouraged her relative, who was a co-caregiver, to participate.

Finally, the researcher recruited six participants through snowballing and word-of-mouth. These participants were either referred to the study by other participants or self-referred, after having casual conversations with the researcher about the Master's program or learning about the study through departmental seminars. In total, seventeen caregivers agreed to participate in this study.

Data Collection

Approach to Data Collection

The qualitative research process is often emergent rather than preordinate in design, and refining the data collection procedures in response to developing issues and insights is frequently both expected and necessary (Creswell, 2009; Lincoln & Guba, 1985). Initially, the researcher intended to explore the caregivers' expectations using a focus group strategy. According to Fontana and Frey (2003), focus groups are "a qualitative data gathering technique that relies upon systematic questioning of several individuals simultaneously" (pp. 70-71). There are many benefits to using informal focus groups. Besides being an economical and convenient data collection method, interactive discussions can stimulate and enhance the participants' recall, understanding, and descriptions of complex constructs such as expectations. Moreover, they produce rich, elaborative data that is predominantly participant-driven (Fontana & Frey, 2003).

However, after attempting to organize three focus groups over a two month period, all of which were subsequently cancelled, the researcher re-evaluated this data collection strategy. Feedback from the participants revealed a number of issues which

hindered their participation. Scheduling a convenient time for groups of participants to meet proved difficult. Among the participants who were working, their availability was largely restricted to evenings. However, for elderly participants, evening sessions were an unattractive option especially when compounded by poor weather and icy road conditions, which posed realistic driving hazards and heightened personal falls risk. Furthermore, for participants who had young families or who lived alone with the person with dementia, finding alternative care was particularly challenging.

The researcher decided to use individual, semi-structured interviews in lieu of focus groups, which provided greater flexibility and reduced the aforementioned burden on participants. This protocol change was approved by University of Calgary's Conjoint Health Research Ethics Board. As a result, the researcher travelled to and met with participants at the time and location of their preference, including at their homes, their place of work, and local cafes. Participants were interviewed separately, except for two dyads who requested to be interviewed together. All participants provided informed consent and agreed to have their interviews audio-recorded.

The Semi-Structured Interview

First, the researcher collected basic demographic data about the participants and their care recipients' age, sex, ethnicity, as well as their relationship to each other. The care recipient's diagnosis and current place of residence was also obtained. Then, to describe the person with dementia's current level of functioning, the researcher administered the Functional Assessment Staging Test (FAST) to caregivers (Reisberg, 1988). The FAST scale is a 16-item brief questionnaire that has been psychometrically-validated for describing the stage of dementia using caregivers as proxy informants

(Reisberg, 1988). This instrument has demonstrated convergent validity with other clinical dementia staging instruments (Pearson's r coefficient ranging from 0.83 to 0.94), and inter-rater reliability ranging from 0.76 to 0.83 among allied health professionals and psychiatrists, respectively (Reisberg, 1988).

A semi-structured interview guide was used to explore participant expectations (Appendix A). As Patton (2002) suggests, interview guides are not prescriptive in nature, but rather serve as an organizational tool that identifies the key domains for the researcher and participant to navigate together. These domains are formative, often undergo modification, and broaden with the addition of new categories as the interview unfolds (Patton, 2002). This interview guide explored three general themes, including the caregivers' beliefs about the likely disease progression, their expectations about coping and the types of care that they will provide to the person with dementia, and finally, the types and intensity of health services that will be needed by, and provided to, the person with dementia and themselves. Potential probe questions were also generated, which explored expectations about key dementia-related transitions including the diagnosis, medications for treating dementia symptoms, driving cessation, use of formal health services, and long-term care placement (Drummond, 2007).

To build rapport and help participants become comfortable with the interview process, caregivers were asked introductory, "grand tour" questions about salient experiences (Lincoln & Guba, 1985), such as how they obtained a dementia diagnosis, and how the person with dementia is currently functioning. These questions not only help to situate the participant, but also provide valuable contextual information (Lincoln & Guba, 1985). In order to obtain rich, detailed information, the questions from the

interview guide were modified when appropriate, and explored in the order most consistent with the participant's narrative (Kaufman, 1994). Because expectations are not always at the forefront of the participant's thoughts, the researcher also used phrases to probe this construct along its probability-based dimension (e.g., "What do you think will likely happen?" or "Were you surprised when that happened?"). In addition, during moments when the participants appeared distressed or upset by the line of questioning, the researcher reminded them that they may stop and resume the interview at any time.

Consistent with the recommendations of Lincoln and Guba (1985), the researcher maintained a field journal in order to build trustworthiness into the *implementation* phase of the naturalist inquiry. First, a log of the day-to-day activities was kept, which consisted of entries detailing the times and dates spent in the field either establishing community connections or collecting data. The researcher also wrote reflexive and introspective memos about personal feelings regarding these experiences, recurrent motifs in the data, any concerns about participant-researcher interactions, and how the data was developing. Lastly, log entries documented the major methodological decisions. All field notes and memos were compiled, which served as both an audit trail (Rodgers & Cowles, 1993) as well as a reminder for the researcher regarding key decisions and rationale for various codes used during the analysis (Burnard, 1991).

Data Analysis

The researcher transcribed the interviews verbatim. However, as numerous methodologists have suggested, the transcription process is intrinsically selective and interpretive, and the transcription conventions adopted will influence the level of detail captured in the text and emergent understandings of the data (Braun & Clarke, 2006;

Lapadat & Lindsay, 1999). Thus, the researcher attempted to transcribe the dialogue as closely as possible, including non-lexical utterances, pauses, and prominent gestures and facial expressions such as weeping and laughter. Because the intent of this study was not to perform a conversation or discourse analysis, the level of detail remained close to the “surface” rather than in-depth to the level of phonetics and timed representations of pauses (Potter & Wetherell, 1994).

A thematic analysis was undertaken using a qualitative descriptive approach (Sandelowski, 2000). This approach seeks to comprehensively describe events and experiences by staying close to the manifest content and words of respondents (Boyatzis, 1998; Sandelowski, 2000), and to organize findings into themes based on a recursive process of comparison, corroboration, and refutation (Braun & Clarke, 2006). First, each transcript and related memos were read and reread to gain an overall sense of the data. Then, using Atlas.ti 4.2 software for data management, initial codes were generated by assigning category labels to sections of text that described the contextual factors, properties and dimensions of expectations (Braun & Clarke, 2006). Although a predominantly inductive coding process was used, deductive coding based on theoretical conceptualizations of expectations (e.g., ideal, normative, probability, and unformed) and expectancies (e.g., stimulus, behavioural, self-efficacy, and response) was also implemented. Throughout this process, the researcher developed a codebook detailing the operational definitions for each code, and created memos to document the process of refining, renaming, collapsing, and splitting codes (Braun & Clarke, 2006).

Themes were developed by iteratively comparing the coded contents across interviews. In keeping with the principles of analytic induction, disconfirming cases were

accounted for by modifying preliminary understandings until interpretations of caregiver expectancies were considered comprehensive and inclusive (Ritchie & Spencer, 1994). Using the criteria proposed by Patton (2002), the researcher paid close attention to thematic internal homogeneity and external heterogeneity. Internal homogeneity suggests that data within themes should cohere meaningfully together, while external heterogeneity suggests that there should be identifiable distinctions between themes (Patton, 2002).

Phase II: Refinement and Development of Questionnaire Items

A step-wise qualitative item review was performed in order to develop a comprehensive item bank for measuring caregiver expectations. Based on the approach described by DeWalt and colleagues (2007), this process consisted of four iterative steps including the development of the extant items, item classification, item revision, and finally, conducting cognitive interviews with health professionals to review the appropriateness of items.

Item Development Process

Identifying & Drafting Items

Using qualitative research to inform questionnaire development is considered both a quality standard and a key strategy for ensuring content validity (Leidy & Vernon, 2008). However, there is surprisingly sparse methodological literature to guide the process of transforming qualitative findings into individual questionnaire items. Furthermore, published studies that used mixed methods to develop and validate novel questionnaires often treat this process as assumed and unproblematic. However, one methodological work by Brod and colleagues (2009) suggested that there is an intricate

relationship between the analytic coding process and item development. Drawing from grounded theory, these authors postulated that open-coded data (i.e., where conceptual labels are assigned to the smallest units of events, actions, and interactions) would produce the specific items in a measure, while axial-coded data (i.e., where categories are grouped together into themes) would become the dimensions or subsections of the measure (Brod et al., 2009).

Although grounded theory was not used in this study, the researcher adopted a parallel strategy by treating the initial codes generated through thematic analysis as analogous to open codes. The researcher returned to the coded data, codebooks, and related memos; using the ‘code editor’ function in Atlas.Ti 4.2, the researcher generated a complete list of the codes with all their linked pieces of transcribed text and memos. As Brod and colleagues (2009) recommended, “to support the assertion that items have high content validity, items generated should use the language of the subjects interviewed and directly reflect the content of qualitative statements made by [participants]” (p. 1271). Thus, the researcher developed a single-sentence item for each coded instance of an expectation using two methods. For short segments of text describing a single expectation, the researcher extracted the key phrases near-verbatim to create one statement item. In contrast, for codes attached to longer, rich and descriptive text which could not be as easily condensed, the researcher used an interpretative approach to assist in developing the statement.

Item Classification

This process produced a large collection of candidate items with considerable redundancy in content, which were often due to minute variations in phrasing. However,

as suggested by DeWalt and colleagues (2007), judgments about the quality and repetitiveness of items were not made at this point. Rather, the items generated were imported into a standardized item library, and the key dimensions, or sources of variation, associated with each item were identified. The goal of this process was to identify idiosyncratic sources of variation between related items, to bracket those sources, and then to revise each item to reflect its simplest and most elementary meaning.

This analysis involved a progression from description, where the data are organized to show patterns in semantic content and summarized, to greater interpretation where the underlying ideas, assumptions, and conceptualizations are examined at the latent level (Braun & Clarke, 2006). The process of identifying and categorizing items was informed by expectations theory (Janzen et al., 2006; Schutz, 1932), as well as iterative and recursive comparisons between related items. First, each candidate item was categorized according to the domains of expectations identified in the previous qualitative study (e.g., disease progression, health services, and caregiving duties). Next, two temporal dimensions were noted including the relevant stage of dementia, and the proximal vs. distal timescale of the expectation (e.g., the expected experience will occur in two hours vs. two years). The items were further assessed based on the tenets of expectancy theory, and were categorized according to the type of expectation (i.e., ideal, normative, or predictive). Items that were misclassified as an expectation, such as general statements about caregiving that lacked a future-oriented component, were further noted. Then, among predictive expectations only, the types of expectancies were classified (e.g., stimulus, behavioural, self-efficacy or response). Throughout this process, memos were created to document the evolving meanings and parameters of the dimensions.

Item Reduction

The purpose of the qualitative item reduction was to iteratively revise or exclude poorly-constructed or redundant items while ensuring sufficient item diversity to capture the construct of caregiver expectations. Given that there are no established criteria for assessing the quality of items and guiding their exclusion, the researcher adopted a similar approach to that developed by DeWalt and colleagues (2007). Because this study was interested in developing an item bank for measuring probability-based expectations, the researcher sequentially excluded items that did not assess expectations from a predictive orientation, semantically redundant items, vague items that were not specific to caregivers, idiosyncratic items that were only mentioned by one participant, and items that were inconsistent with their domain definitions. A constant comparative approach was employed to identify ineligible items within each domain and by each dementia stage.

Item Review Using Cognitive Interviews

Sampling & Recruitment

After developing and refining the pool of candidate items, conducting cognitive interviews to assess the appropriateness, clarity, and readability of the items with potential users is essential (Oremus et al., 2005). Two groups of potential users are caregivers and health professionals. Although it would be desirable to have both groups review the initial items, the researcher decided to recruit health professionals for this preliminary item review process instead of caregivers for two reasons. First, the researcher was concerned about further burdening already busy caregivers for this review process. Second, because these items may become part of a questionnaire for use in

clinical settings, it was also important to ascertain if health professionals could identify any expectations that were of clinical interest but were not identified by the caregivers.

Using a purposive sampling approach, four physicians and three allied health professionals were recruited to participate in the item review. Health professionals were eligible for inclusion if they had been in practice providing dementia care for at least one year, and were familiar with expectations research as evidenced through publications, presentations, or collaborations on studies of this construct. Using the publically-available directories of the Alzheimer's Society of Calgary and the Dementia-NET research group (a pan-Canadian team of researchers and clinicians investigating care and outcomes during dementia-related transitions), health professionals who met these criteria were e-mailed an introductory description of the study and asked for their participation.

Data Collection

The list of questionnaire items and the semi-structured interview schedule (Appendix B) were sent to the participants at least one week in advance of a telephone interview for them to review at their convenience. Telephone interviews were conducted with the participants and all agreed to have the interview audio-recorded. After obtaining informed consent, the participants were asked for their global opinions of the items as well as whether any specific items needed to be modified to improve the clarity or to reduce redundancy. In addition, the researcher also asked the participants about the appropriateness of the items based on the resonating themes and issues identified by the caregivers during the first qualitative study. This included brief discussions about obtaining a specific dementia diagnosis, managing caregiver stress, delirium, anti-

psychotic use, and accessing health services. Memos and field notes were taken to document the thoughts, feelings and reflections of the researcher throughout this process.

Data Analysis

The data analysis consisted of two parts. First, rather than producing verbatim transcriptions of the participants' global recommendations or specific items that required revision, the researcher created a data summary table for each problematic item that was flagged by the participants. The researcher documented the suggestions made by each participant for each of the problematic items, and then made revisions accordingly. In addition, the researcher also documented any broad categories of expectations that were of interest to the health professionals, but were not included as an item. The researcher then returned to the original data collected with caregivers, and reexamined whether there were any such expectations described.

For the latter portion of interview regarding the appropriateness of items, the researcher transcribed the interviews verbatim. A thematic analysis was undertaken using a qualitative descriptive approach (Sandelowski, 2000). Each of the transcripts and related memos were read and reread to gain an overall sense of the data. Using Atlas.ti 4.2 software for data management, initial codes were generated by assigning category labels to sections of text in order to describe the contextual factors, properties and dimensions of the participants' perspective on these expectations (Braun & Clarke, 2006). Themes were developed by iteratively comparing the coded contents across interviews. In keeping with the principles of analytic induction, disconfirming cases were accounted for by modifying preliminary understandings until the interpretations were considered comprehensive and inclusive (Ritchie & Spencer, 1994). Throughout this

process, the researcher developed a codebook detailing the operational definitions for each code, and created memos to document the process of refining, renaming, collapsing, and splitting codes (Braun & Clarke, 2006).

Rigor and Trustworthiness

To promote rigor and trustworthiness, the researcher implemented a number of strategies (Creswell, 2009). First, to ensure that the research findings adequately reflect the perspectives and beliefs of the participants, the researcher explicitly examined negative cases and accounted for them using an analytic inductive approach. Furthermore, participant quotations were used to provide evidence and thick descriptions of the phenomena using the participant's own words (Lincoln & Guba, 1985). Second, to make certain of the accuracy and transparency of the findings, the transcripts were compared against the audio-recordings to eliminate transcription errors. Audit trails were developed using reflexive memos to document the researcher's perceptions on the emergent findings and the methodological decisions made. In addition, comprehensive codebooks were maintained to minimize drift in code definitions and to encourage transparency in the analytic process.

CHAPTER 4: THEMATIC ANALYSIS RESULTS

This chapter describes the results of a thematic analysis based on the interviews with 17 caregivers. First, the basic demographic characteristics of the caregivers and their care recipients are described. Second, the five major themes related to caregiver expectations are presented. These themes, which spanned the caregiving career and reflected participant beliefs about the probable illness trajectory, included expectations about the diagnosis, cognitive decline, driving cessation, basic activities of daily living, as well as delirium and the end of life. Subthemes such as the dynamic interactions between expectations of the disease progression and the types of health services that would be needed were further considered. The analysis sought to both identify the breadth of expectations as conscious beliefs and explore expectations development as a subconscious cognitive process that links interpretations of past experiences with beliefs about possible future outcomes.

Sample Characteristics

Table 1 presents the demographic characteristics of the caregivers and their care recipients, and reflects the purposive sampling strategy used. Caregivers were recruited from the Alzheimer's Society of Calgary (n = 9), Rockyview General Hospital Senior's Health Clinic (n = 1), Intercare (n = 1), as well as through snow-ball and word of mouth (n = 6). The majority of caregivers were female (64.7%) with a mean age of 51.2 years (SD = 20.0 years). Furthermore, fourteen caregivers were Caucasian (82.4%), while three caregivers were Chinese (17.6%). More than half of the participants were caring for parents or parent-in-laws (58.8.7%) while the rest of the sample were caring for spouses (17.6%), siblings (11.8%), or grandparents (11.8%). In addition, the majority of the

caregivers (64.7%) identified themselves as the primary caregiver, that is, the individual responsible for providing the majority of the daily care and assistance to the care recipients. Interviews ranged from 30 minutes to 2 hours 45 minutes. All names were replaced with pseudonyms.

Two dyads and one triad of caregivers from the same families were interviewed to explore the dynamics of familial expectations and norms. Thus, there were a total of seventeen participants caring for thirteen care recipients. The majority of care recipients were female (84.6%) with a mean age of 79.8 years ($SD = 6.8$ years). Furthermore, eleven care recipients were Caucasian (82.4%), while two care recipients were Chinese (17.6%). Their median FAST score was 6c (range = 4 to 7d), suggesting that care recipients, on average, were at a functional stage where they had difficulties managing basic activities of daily living, such as handling the mechanics of toileting. At the time of the interview, seven care recipients resided in the community, four care recipients resided in a nursing home, and two care recipients were deceased.

Table 1. General respondent characteristics.

Family	Respondents	Gender	Caring For	Status	Diagnosis
1	Alice	Female	Mother-in-Law	Primary	Dementia
2	Bob	Male	Mother	Secondary	Dementia
	Carol	Female	Mother-in-Law	Secondary	Dementia
3	Danielle	Female	Grandfather	Secondary	Vascular dementia
3 & 4	Elaine	Female	Father &	Primary	Vascular dementia
			Mother-in-Law	Secondary	Dementia

Table 1. Continuation of general respondent characteristics.

Family	Respondents	Gender	Caring For	Status	Diagnosis
4	Frank	Male	Mother	Primary	Dementia
5	Grace	Female	Sister	Primary	Alzheimer's disease
6	Holly	Female	Mother	Secondary	Dementia
7	Ivan	Male	Wife	Primary	Alzheimer's disease
8	June	Female	Mother	Secondary	Dementia
9	Kathleen	Female	Sister	Primary	Alzheimer's disease
10	Lisa	Female	Grandmother	Primary	Dementia
11	Mitch	Male	Wife	Primary	Alzheimer's disease
12	Nora	Female	Husband	Primary	Vascular dementia
13	Olivia	Female	Father	Secondary	Dementia
	Pearl	Female	Father-in-Law	Secondary	Dementia
	Quinn	Male	Father	Primary	Dementia

Themes

To accustom the participants to the interview process, and to situate them within their personal narratives, the interviewer first asked the caregivers introductory, “grand tour” questions about their experiences thus far (Lincoln & Guba, 1985). For this sample of caregivers, the diagnosis was a concrete and salient event that marked the beginning of the caregiving journey, and thus, served as an appropriate springboard for exploring abstract and complex beliefs such as expectations. To capture the diversity of caregiver

expectations, the interviewer sequentially explored their future-oriented beliefs related to the disease progression, management, and prognosis, with particular attention paid to the dynamic interactions between their perceptions and expectations regarding health services. Furthermore, the researcher sought to explore and understand expectations as a process that linked past experiences with future possible outcomes. Each theme and its respective subthemes are summarized in Table 2.

Table 2. Overview of the Themes.

Themes
Diagnosis
- Pre-diagnosis: Observing Unexpected Changes
- Post-diagnosis: Obtaining a Specific Diagnosis
Memory & Cognitive Declines
- Heterogeneous Expectations According to Time and Stage
- Treatment & Management
Driving Cessation
- Health Services & Drivers' Licenses
Basic Activities of Daily Living
- Acceptability of Care
Delirium & End of Life Care
- Life Expectancy

Diagnosis

Expectations of the diagnosis experience were clustered into two subthemes

regarding the pre-diagnosis and peri-diagnosis period. Discussions of these experiences revealed the complex character of expectations as both a cognitive process, which may have sensitized caregivers to the presence a health problem during the pre-diagnosis period, and as a set of future-oriented beliefs including about peri-diagnostic outcomes. Before exploring each subtheme, however, it is important to note that because the care recipients had received their diagnosis between four months to eight years prior, discussions of these expectations are in essence recollections of historical beliefs. They represent what Shutz (1932) termed “a double mode of expression,” that is, these beliefs consist of a backwards reference in time to previously-held expectations about future-oriented events and outcomes. Hence, these expectations have been filtered and interpreted through the lens of current experiences (Leung et al., 2009b), and may qualitatively differ from the subjective beliefs of other caregivers currently undergoing the process of obtaining a diagnosis. Within the current sample, however, one participant had an extensive personal diary which documented their concerns and thoughts dating back to the pre-diagnosis period, which provided some support for the accuracy and reliability of these recollected expectations. And even without such corroboration, their articulation by respondents as historical expectations is still indicative of their potentiality in terms of being contemporary ones. While the ontological distinction between historical and non-historical expectations is noted, to simplify the present analysis both forms were pooled together as types of future-oriented beliefs regardless of when they were first conceptualized.

Pre-Diagnosis Period: Observing Unexpected Changes

In this sample, caregivers described recognizing the presence of a health problem

after detecting unexpected changes in their care recipients' usual behaviours and cognitive capacity. As all of the caregivers had long-term relationships with their care recipients, even slight changes were personally significant as they contrasted with their expectations drawn from beliefs of how the care recipients "used to be like." For example, June noticed subtle declines in her mother's housekeeping and attention to detail as an early sign. "Her house wasn't clean, and she was meticulous... By anybody's standards, that house was clean. By her standards, it wasn't."

These perceived deviations from "what was normal" may reflect interplays between caregiver observations and expectations. Because expectations are derived from personal experiences and knowledge, these beliefs enable individuals to anticipate certain social interactions and outcomes based on predictable patterns of behaviours and events (Janzen et al., 2006). Thus, discrepancies between their current experiences and expectations regarding their care recipients' personality, roles, and day-to-day routines frequently prompted caregivers to take pause, as these changes were viewed as somewhat peculiar and unexpected. For example, the majority of caregivers noted gradual differences in their family members' homemaking abilities, preferences such as changes in their favourite television programs, and habits. As Kathleen explained, "[My sister] progressed and started doing things that were totally off the wall... She told me that she slept in the nude. In the nude! She's really prissy. That's when we knew it wasn't just the memory loss."

While isolated changes in preferences and personal habits were unexpected, and thus rather surprising, caregivers viewed these changes as being relatively benign. However, caregivers became increasingly concerned when these changes occurred

alongside more severe memory and cognitive declines, such as “the attention span shrunk,” or they were “losing interest in a lot of things.” Particularly among the caregivers who did not reside with their care recipients, they reported being surprised by the rapid deterioration in cognition, personal hygiene, and living conditions. Many had both assumed and expected that their care recipients were functioning well at home, as they had been doing so for many years prior.

“[My grandmother] called us frantically saying that she had lost her car... A few days later, ‘Oh, I got into an accident, and the car’s gone.’ So kind of in and out memory of what had happened. We knew something was wrong when she was responding in that way... We weren’t expecting that, or hadn’t known that it had gone to that point, because she’s just been forgetting things on the phone.” (Lisa)

“[My mother-in-law’s] memory was not good... And there was no personal hygiene. Her toe nails were so long that they had grown around the back and around... The hot water tank had burst. So there was water all over the basement, and there was mould growing up the stairs... Just appalled to find another human being was living in *that* for so long.” (Alice)

For caregivers like Alice and Lisa, these changes were unexpected as neither their care recipients nor other family members had mentioned the living situation, nor had they requested help during regular phone conversations. Prior to these crises, a number of caregivers expected that their family members were simply getting “older... and repeating things and telling the same stories” (Lisa). However, the seriousness and unexpected nature of these accidents, and their care recipients’ inability to respond appropriately to these crises, were viewed as being beyond the expected range of normal aging and the accepted “vagaries of old age” (Cahill et al., 2008). From Lisa’s perspective, for example, the accident itself was unprecedented and unexpected because

her grandmother had been a safe driver with “no record at all of accidents.” Moreover, her grandmother’s confusion over “losing” her car, compounded by the unusual fluctuations and inconsistencies in her memories, were seen as indications of a medical problem.

Peri-Diagnostic Period: Obtaining a Specific Diagnosis

Expectations regarding the peri-diagnostic period consisted primarily of explicitly articulated beliefs, especially regarding the medical care sought and provided in response to the developing symptoms. The retrospective approach used to explore these expectations revealed a number of unmet expectations, or discrepancies between the outcomes that participants thought were likely to occur compared to the outcomes that actually transpired. Nearly half had experienced some challenges with the diagnostic process and were frustrated by the process. For example, Lisa recounted having difficulties obtaining a diagnosis for her grandmother.

Lisa: “She was brought to the [emergency room] after [overdosing] on some meds, and then was released... We said to them, ‘She’s having major issues adjusting, she’s leaving the stove on and all these things.’ And they said, ‘There’s nothing we can do. Sorry.’”

I: “Were you expecting to hear that?”

Lisa: “No. And [we’re] frustrated because what else do you do? We need to have some kind of diagnosis... to do like *anything* with her. They said, ‘It will have to get worse first...’ Does she have to set fire to like the building? Does she have to harm herself? I was mad because it was very much what degree does she have to get to?”

Obtaining a dementia diagnosis was critically important for caregivers because many expected that a formal diagnosis was necessary to access health and social services in the community. Furthermore, discrepancies between caregiver expectations and

experiences may have influenced satisfaction with the diagnostic process. For instance, Lisa had gone to the emergency department anticipating that the staff would provide a diagnosis and assistance for her grandmother, but she was surprised and disappointed when her grandmother was discharged home despite concerns regarding safety. Based on the information provided by emergency room staff, Lisa expected that her grandmother would not receive a diagnosis until the symptoms became worse. However, uncertainty regarding what types of future negative events and their severity constituted “getting worse” was especially frustrating because she expected proactive and preventative intervention.

A proportion of caregivers also expected to receive a diagnosis of a specific dementia subtype. As demonstrated in Table 1, six caregivers recalled receiving a specific diagnosis of Alzheimer’s disease or vascular dementia, while the majority of caregivers were provided with only a general diagnosis of memory problems or dementia.

“[The specialist] preferred to call it memory problems... I thought it was important to know what the progress of the disease would be, so we needed to know whether it was vascular or Alzheimer’s... We needed to know what to expect and then, you know, as difficult as it is, how quickly to expect it. It varies from person to person, but we wanted to make plans especially with the waiting lists that we have in Alberta... You have to plan well in advance... So, we wanted to know, if her memory was progressing this quickly to this point, how quickly before she’s in a long-term care.” (Bob)

Hence, Bob expected that because each dementia subtype can have a different progression, a specific diagnosis was needed in order to know what symptoms to expect and when to expect those changes to occur. Although there is inherent uncertainty in predicting how quickly the symptoms will ultimately progress, caregivers believed that understanding the general clinical course was vital for future care-planning, such as

determining the optimal time to seek long-term care placement given the long waiting lists.

Memory & Cognitive Decline

Memory and cognitive declines were consistently reported to be the earliest symptoms, but certain differences were evident regarding when caregivers expected further declines to occur. According to Zimbardo and Boyd (1999), individuals interpret experiences with reference to time, which provides order, coherence and meaning to events that have happened or projected to happen in the near and distant future. Drawing from the data, a sense of temporality may have been an important factor that shaped the diversity of caregiver expectations. Thus, memory and cognitive declines were explored through the two subthemes of heterogeneous expectations according to perceptions of time, and expectations regarding treatment and management in response to symptoms.

Heterogeneous Expectations According to Perceptions of Time

Caregiver expectations tended to vary with respect to perceptions of time. Of note, caregivers had relatively homogenous expectations of the immediate and distant future. When asked to reflect on their expectations of the immediate future, nearly all caregivers believed that the care recipients would be “stable for now.” As Carol described, “We expect that the next month or two will be pretty much status quo... We will just do our best.” These “status quo” expectations are perhaps unsurprising given that the interviews were conducted during periods of stability. Nearly a third of caregivers had rescheduled their initial interviews, citing that they were too overwhelmed or busy with caregiving or managing deteriorations in their care recipients’ health. Likewise, all of the caregivers expected that continued memory declines were inevitable in the long term, and

that these changes were expected to be an emotionally-difficult experience. “At least he still recognizes you when you see him. You know, when the stage comes when he doesn’t recognize us anymore, well that’s gonna be killer” (Olivia).

Greater diversity was evident in more moderate-term expectations. The majority of caregivers expected further memory declines to occur slowly over the course of the next year or two, and that the memories which were already lost would not return. Many had come to expect certain repetitious behaviours and formulaic conversations, and based on these experiences, caregivers anticipated that these predictable patterns of behaviours would persist.

“His memory will probably slowly... get worse in the next two years. But not right now. Pretty sure, yeah. It won’t be dramatic. He sort of misplaces money... Today he will keep the money inside the Bible or books. But probably next time he will keep it somewhere different... When he suddenly wants the money, he can’t remember. Then he will search again” (Elaine).

In terms of her probability-driven expectations, Elaine felt “pretty sure” that her father’s memory problems would continue to slowly worsen with time. These beliefs were informed by repetitive episodes of misplacing objects and hiding money, she expected that her father would probably continue to do so in the future. In contrast, a handful of caregivers expected stability and even mild improvements in memory. These were mainly secondary caregivers and those caring for individuals with early dementia.

“My expectations for the next year, I believe that my grandfather is now stabilizing, and recovering slightly. I think that his memory will continue to improve. He started reading from the Bible, and giving sermons again... He tries to stay current by listening to the radio and watching news” (Danielle).

Furthermore, the stages of dementia are inherently linked with these perceptions

of time. Especially among caregivers of individuals with early-stage dementia, there was less certainty in their expectations about the rate of cognitive decline and whether changes would affect different cognitive domains equally. For example, Grace tentatively described her expectations, “I don’t know. I think I’ll see a really big change in her. She can do crossword puzzles like you can’t believe. And yet she couldn’t find her scarf sitting right there on her chair. It’s kind of mind-boggling.” Similarly, Holly was surprised when her mother had unexpectedly improved her cognitive assessment score even though there was increased confusion and emergent behavioural issues. She further described how the geriatrician attempted to modify her family’s expectations by cautioning that the declines would continue despite the improved test scores, and that some domains would be affected more than others.

“She went up three points actually... [The specialist] did indicate that just because she could do the test, um, doesn’t mean that the other social and behavioural symptoms are not going to increase. Because that was one of the things we asked, ‘How could she score so well, and yet her whole behaviour had decreased... and she’s more confused in the last year?’”

Treatment and Management

Dynamic interactions may exist between health services and caregiver expectations regarding the management of early cognitive symptoms. Although many caregivers believed that they were “dealing with the symptoms” on their own, and did not expect to need community services at this point, some did express expectations of pharmacological treatment. However, divergent expectations regarding the potential risks and benefits were evident among caregivers with family members who had received drugs compared to those who had not.

Families that received cholinesterase inhibitors held fairly conservative expectations regarding treatment benefits. Most caregivers believed that cholinesterase inhibitors would temporarily “help in slowing down the memory declines” (Mitch). At most, they expected benefits to last for approximately one to two years. For example, Ivan described his expectations and hopes, “The only thing that we can do is use... the medication that slows it down. It works for about two years, and then it collapses and hopefully you can get some other medication.” Expectations that the drugs would inevitably “stop working” or the “effects will taper off” were largely based on the information provided by physicians or gathered through support groups and their own reading. After which, the majority expected that the drugs would be discontinued. “She can get [Donepezil] for two more years. [The doctors] set a limit. I don’t know why that is, but it’s very expensive drug” (Kathleen). Thus, considerations of the costs and eventual lack of treatment benefits were frequently cited reasons for these expectations.

In contrast, the expectations of families who did not receive these drugs were influenced by their awareness of available medications, whether their physicians believed that the drugs were medically appropriate, and concerns about risks and side effects. The knowledge provided by health professionals regarding the availability and appropriateness of the drugs were integral in shaping caregiver expectations and influencing their satisfaction with care. Some families who were not told about the drugs were angered by the lack of information, and thus, the lack of choice about initiating drug therapy. However, among those who received explanations regarding why drug therapy was not indicated, there was greater acceptance of the decision.

“After attending the Alzheimer’s Society meeting, Mom right away

said, ‘How come they didn’t put Dad on some meds?’ Expect it? We didn’t even know about it! No one ever... said let’s try something for his dementia. I mean if it’s offered to you, you can say, ‘Oh, I can’t afford that.’ Or, ‘It wouldn’t make a difference because of his other illnesses.’ It wasn’t even offered.” (Quinn)

The doctor said, ‘You know, there are drugs for the Alzheimer’s dementia. They’re not going to do anything for him because he has small vessel damage on this left side of his head, not Alzheimer’s dementia. This is only going to put another drug in his body.’ So I didn’t expect to get those drugs.” (Nora)

Furthermore, caregiver perceptions regarding the appropriateness of the medications were influenced by their expectations of the disease progression itself. For instance, among caregivers who expected possible cognitive improvements, they did not expect to pursue aggressive pharmacological treatment. “He’s probably not going to need those medications as his memory is already improving on its own” (Danielle). Caregivers were also concerned about potential risks and side effects of the drugs. Alternative approaches, such as encouraging mental stimulation and promoting quality of life, were expected to be equally effective or better than medications. As Frank explained, “Is that medicine valuable? I mean, any risks? I still believe that if they’re happy and have good activities, they’ll enjoy their lives. That’s better than taking medication.”

Driving Cessation

Driving cessation is a critical transition that is increasingly being addressed in dementia care. Of note, five caregivers did not identify any expectations about driving cessation because their family members had never driven. For caregivers who found this issue to be relevant, the interviewer retrospectively explored their reflections and expectations that were held during the driving cessation experience. A retrospective approach was used as all care recipients had already ceased driving at the time of the

interview. Two care recipients had surrendered their drivers' licences, while eight care recipients voluntarily allowed their licenses to expire.

Caregivers recalled experiencing some trepidation about broaching the subject of driving cessation. In general, the majority of caregivers recalled expecting that driving cessation would be "very, very difficult" and "a massive loss of freedom" for their care recipients. For instance, Lisa initially expected that driving cessation would be "very traumatic [for her grandmother]. She'd always said, 'If I ever lose my license, I just want to die.'" Lisa's family also expected that driving cessation would precipitate "issues of her getting groceries etcetera because she'd [have] no transportation." Therefore, a number of caregivers viewed expectations regarding driving and changes in activities of daily living to be linked.

Furthermore, two-thirds of caregivers expected at least some conflict and resistance from their care recipients. In part, caregivers attributed the burgeoning conflict to discrepancies between their own expectations and their care recipients' beliefs about their capabilities.

"[Dad] started to say, 'I shouldn't be driving anymore.' And then he'd have a good spell where he'd be like, 'I can go and drive. I can do whatever I want!' Right up until a year and a half ago, he was still thinking that he was going to whip into a license bureau and renew his license. I mean, he could barely walk. But he still, still thought he could do it." (Quinn)

Most caregivers recalled having multiple debates with their care recipients about driving cessation. Mismatched expectations were a source of conflict, especially when caregivers believed their family members held unrealistic expectations about driving and renewing their licenses. For caregivers like Quinn, it was "exasperating" trying to

encourage more realistic expectations with his father who “could barely walk, let alone safely operate a car.”

A third of caregivers described becoming adamant about driving cessation, particularly when they noticed that their care recipients failed to adhere to the rules and norms of the road. As Kathleen recalled, “Granted, she looked both ways. There were no cars coming. So, she left [the intersection]. And I said, ‘You can’t go through a red light!’” Similarly, Mitch recounted, “I’d let [my wife] drive back from the grocery store. Not a lot of traffic, some lights. And that’s when I almost had a heart attack. She was not observing the lights or the stop signs. So I knew that she couldn’t drive anymore for sure.” All caregivers described that their care recipients were safe and cautious drivers for many years prior, and thus, they were alarmed by the decreased adherence to the predictable rules that govern traffic, which all motorists are expected to follow. Given these hazardous changes, caregivers expected that driving cessation was imminent.

Health Services & Drivers’ Licenses

Although caregivers and some care recipients recognized the need for driving cessation, health services played a role in the actual relinquishment of the drivers’ licenses. Nearly half of the care recipients voluntarily relinquished their licenses or received graduated learner’s licenses after failing a driver’s test. Most caregivers were unsurprised by these developments and expected that these events to occur. Some caregivers attributed this, in part, to how their family physicians attempted to prepare them by modifying their expectations early on through explanations of the driving cessation process, including eventual refusals to approve their drivers’ medical exams.

“I was a bit concerned early on when the family doctor said, ‘I have

to report this condition to the licensing bureau. They probably won't take any action yet, but as long as you're aware they may ask her to do a test.'" (Mitch)

"We wanted her to stop, but it was difficult. She needed a medical, and the doc wouldn't sign it. He offered her a driving test but she [didn't] pass. She could've retaken it. She voluntarily gave it up with a lot of pushing." (June)

Caregivers wanted their care recipients to stop driving, but many expected at least some conflict regarding driving cessation. Establishing a therapeutic alliance, and a common understanding about the need for driving cessation with their family physicians, was helpful for many caregivers (Mead & Bower, 2002). Because some family physicians had previously explained their obligations to report on driving safety and to provide objective drivers' medical exams, caregivers expected to receive support for driving cessation. In fact, the lack of a therapeutic alliance and divergent expectations about cessation was rather upsetting for families.

Quinn: "He did lose [his license]... about a year. He had some TIAs, and the doctors didn't know like when they could happen. You can't drive 'cause you don't know when they're coming. So they took it away a year or two. If there were no more incidences of the TIAs or any troubles, they can give it back. So his doctor reinstated his license."

I: "Oh! Did he? Were you expecting that?"

Quinn: "No. There was no reason in the world that he should be driving."

Although the doctor explained his expectation that if there were not any more episodes, then he might reinstate the license. However, Quinn was surprised by this decision because he believed that their father's dementia had progressed to the point where he was unsafe to drive, despite having no further TIA episodes. In such circumstances where there was less support from health services, families often took

more aggressive approaches to ensure driving cessation. One-third of caregivers confiscated cars, keys, and as the last resort “installed a club on the car” (Kathleen). They expected that if the “car was out of sight, it would be out of mind” (Quinn).

Basic Activities of Daily Living

Caregivers further expected declines in basic activities of daily living, and many anticipated greater usage of community and health services in response to those changes. Difficulties cooking, bathing and continence were viewed as “milestones,” which would signal the need for Home Care and eventual long-term care placement. Expectations regarding these resources may be influenced by personal assessments of the likely safety risks as well as the amount and types of care that they could realistically provide to their care recipients. For activities that only require intermittent care such as meals and bathing, most expected that community-based services would alleviate some caregiver burden and enable their care recipients to remain at home for longer.

“She will cook a roast three times ‘til it’s charred black. Meals on Wheels is good for that and as a reminder. If it’s in her fridge, she will eat it. Before we had to call her at every mealtime, ‘What did you eat? Are you eating?’” (Lisa)

“As long as Irene is like she is right now, and the cleaning lady comes every week... That’s probably what I would do. I’m retired now. I can look after my wife. Ah, I could help her dress to a certain extent... but some personal things, like if she needed help in the bathtub, I couldn’t handle that. You know. I’d have to get some help from Home Care then.” (Ivan)

In contrast, caregivers described struggling with considering long-term care. Although most caregivers preferred for their care recipients to remain “at home for as long as possible,” they did not always expect this. For example, Mitch described these divergent preferences and expectations. “My original goal was to keep her at home until

the fall. We'll have lots of walks outdoors. Maybe sit in the yard. Thought maybe I can handle that... but I had to have this little talk with myself. 'You know, I couldn't do it before. I was finding it difficult. It won't get any easier.'" Based on their assessments of their own skills and abilities, caregivers also identified a number of issues that would precipitate long-term care. Over half of the caregivers identified incontinence, difficulties regulating their care recipient's medications, and increasing safety risks as reasons for contemplating placement. According to Grace, "If she's in a nursing home, then some of these problems would be controlled and we wouldn't have to worry as much."

"One day he will have a problem with incontinence. If he can't make it to the bathroom washroom right away, and then... at that stage he probably will need to go to a nursing home because physically I cannot help him." (Elaine)

"At night, I would just listen. One winter... I heard her open the [front] door. You could not trust her to stay in bed. And I couldn't lock the bedroom door because she might need to use the bathroom. And she doesn't remember how to turn on the lights. Is she gonna fall down the stairs? No, this is not worth it. I couldn't shut my eyes for any length of time." (Kathleen)

Notably, predominantly caregivers of individuals with moderate to severe dementia described expectations of sleep disturbances. These caregivers often spoke about previous episodes of periodic wandering, which influenced their expectations about exhaustion, worries about safety, and potential strategies for managing wandering. For these caregivers, increasing incidents of sleep disturbances was expected to be a key factor for considering long-term care placement in the near future. Some caregivers did find that strategies such as distracting their family members "by turning on the radio" or gently reassuring them have helped in the past, and thus, were expected to help "coax

them back to bed” in the short term. However, the constant sense of vigilance or never being “off duty” resulted in beliefs that this continued stress would ultimately have negative impacts on their long-term health.

Acceptability

Expectations regarding needed specific health services were intricately linked to concerns about their acceptability to other family members including care recipients. The majority of caregivers expected that resources would only be initiated when other family members also acknowledged a need and believed it was at the appropriate time. For example, Holly explained, “I told Dad, ‘Add Mom to the [Wandering] Registry.’ But he’s not ready for it. I think when something bad happens then we’ll be able to push him.” Similarly, caregivers were concerned about how care recipients would react to services, especially those involving intimate care. Mitch initially expected that his wife would not accept bathing assistance from Home Care because he himself had encountered a great deal of resistance, but he was pleasantly surprised.

“I was quite concerned about how [the Home Care worker] was going to handle Mary. I was having trouble giving her baths already, washing her hair and even dressing sometimes became a struggle. [Mitch chuckles]. So I was a little concerned about that, and kind of hung around to see how it’d go. But she said, ‘Don’t worry, I’ve done this before.’ [Mitch and I laugh]. So, before I knew it, she had Mary in the bathtub, and they were singing and laughing and having a good time. I felt good about that.” (Mitch)

A number of caregivers were also concerned about discussing long-term care with their care recipients because they expected at least some distress and possible conflict. Carol anticipated that “the boys will have to have a big heart-to-heart real soon. I think they will tell Mom that it’s gotten too difficult on the family. But she can get quite

emotional and she's a very proud." Caregivers also felt that it was necessary to explain their expectations, which were often focused on potential benefits and optimistic. "And I said to Mom, 'We're looking at the possibilities. It's going to be somewhere close and we can be with you and the kids, too' (Alice). But discrepancies between different family expectations and the realities of long-term care facilities may have resulted in some disappointment. Some caregivers described challenges travelling to nursing homes across the city under the first available bed policy. Others were disappointed with the resources available and lack of flexibility in personal routines, which they did not expect.

"We kept telling that he was going to a better place at the nursing home. There would be more opportunities for recreation. So he looked around, and he said, 'It's sort of a let down.' [Nora and I laugh.] He didn't complain. When he was in hospital, he'd get in the shower and shave. Well, over at the [nursing home]... there was nowhere where they could shower. The only thing they had once a week was a tub bath." [Nora makes a face]. He wasn't okay with that. I was not okay with it. One of the girls there, bless her heart. There was a shower that was just being used [for] storage. They weren't using it. She said, 'I'll clean this out for you.' We took him down and had showers." (Nora)

For families already placed in the nursing home, many praised the staff's willingness to accommodate their preferences when it was possible. From Nora's perspective, the staff went "above and beyond the call of duty" and exceeded her expectations of "conscientious care."

Delirium & End of Life Care

Among the care recipients who had moderate to severe dementia, almost half had experienced at least one episode of delirium either in hospitals or in long-term care. Although delirium is a treatable condition, Kinoshita (2008) suggested that there may be difficulties differentiating delirium from behavioural and psychological symptoms of

dementia (BPSD) based on clinical presentation alone; both may be characterized by delusions and hallucinations. The presence of delirium superimposed on dementia may be associated with adverse outcomes including accelerated cognitive and functional decline, and increased risks of mortality (Fick et al., 2002).

Caregivers often found deliriums to be both distressing and alarming, which was a strong impetus for them to learn more about delirium either from their health professionals or through their own reading. This information in conjunction with their previous experiences shaped their expectations about the likelihood that the delirium would occur again, and the types of actions that they would take should such symptoms appear. For instance, Kathleen described how the hospital physicians explained that when her sister became dehydrated, it could lead to a delirium due to a sodium imbalance. When her sister was admitted to the hospital again with delirium, Kathleen expected that treating the electrolyte imbalances would resolve the delirium.

“They’ve all said that because the sodium was so low, she could be delirious. Get the sodium to normal and the deliriums will settle down nicely... She was in the Emergency Room, and she said, ‘Can you get the baby out of the tree?’ And again, it’s the delusional thing from the low sodium.” (Kathleen)

“He wouldn’t sleep. He’d sit there and watch freaky things around the room. Every time he gets an infection, he will get a delirium and the dementia will progress when he gets sick. We tell the care centre, as soon as you see any delirium, or any odd behaviour right away it means that he’s got an infection. So get him on meds right way. And do the blood work right way.” (Pearl)

These caregivers identified key causative relationships between electrolytic imbalances, infections and bouts of delirium, which they expected would worsen the dementia. Other caregivers likewise expected that their family members with dementia

would “not bounce back [as well] after each time [of] sickness or a delirium.” Because of these expectations that delirium may lead to a quickening of the dementia symptoms, many caregivers described advocating for prompt intervention whenever they noticed any odd behaviour. Based on their prior experiences, they expected that prompt treatment would reduce the duration of severity of symptoms.

Life Expectancy

Although discussion about end of life was a sensitive topic, a number of caregivers spoke about their expectations, perspectives, and concerns. Caregiver expectations regarding end of life may be related to assessments of their care recipients' current health and functioning. “As far as his health goes, I don't expect him to pass away any time soon. So I think that since he's stabilized, the next year will be about the same” (Danielle). While caregivers wanted their family members to have a long and healthy life, they were also uncertain about changes in quality of life as the dementia continues to progress in the future. As Grace described, “[My sister] is healthy. Oh, but my goodness, but that's the sad part too, eh? She could live to be over a hundred... Well if it's going to happen it's going to happen right?” Upon reflecting on the future, many caregivers did describe a sense of satisfaction in that they have attempted to provide the best care possible for their family members. “At the end of the day, I feel good about the time I've put in. You'll always have regrets. When the time comes, I know that we've done our best.” (Pearl)

Two caregivers who participated in this study were bereaved at the time of the interview. Both caregivers described “being shocked at the death” of their family members. For instance, Kathleen described her sister's rapid deterioration, which she did

not expect based on the information that she gathered from physicians and the Alzheimer's Society.

“You know, we didn't expect it. The doctor told us six months. Two weeks later, she was dead. There's quite a bit of difference between six month and two weeks. Really, it was fast. We talked at the Alzheimer's meeting, and they say life expectancy is eight to ten years... But honestly, we are on the same wavelength. We would not like to have seen her live like that for very much longer. It was not a quality to her life. Not, not any of it.” (Kathleen)

CHAPTER 5: ITEM BANK DEVELOPMENT RESULTS

This chapter describes the step-wise, qualitative item development and review used to develop a comprehensive bank of questionnaire items. As other researchers have commented, (Fleury, 1993; Hinkin, 1995), the process of how qualitative data is transformed into questionnaire items is not always transparent and is often assumed to be unproblematic. Therefore, the goal of this chapter is to describe the processes used to generate the items, and in turn, to make explicit the analytic decisions. The results are presented in two parts. First, the item development is presented, which consists of identifying the extant items, and then systematically categorizing them into domains of expectation. Second, the qualitative item reduction is described, which consists of iteratively revising and removing redundant items, and conducting an initial review of the draft items using cognitive interviews with health service providers.

Item Development Process

Identifying and Drafting Items

The purpose of this first process was to identify and draft a comprehensive set of items using the qualitative data. To ensure an acceptable level of content validity, researchers argue that items should use the language of the participants in order to reflect their understandings (Brod et al., 2009; Fleury, 1993). Moreover, using a comparative and recursive approach to drafting, the candidate items should either demonstrate fidelity to the themes of caregiver expectations identified previously, or stimulate further refinement until the themes are considered comprehensive (Stevens, 2009). Therefore, the researcher returned to the qualitative data and examined the data at the level of the codes, which provided the conceptual linkages between the participant articulations and

higher-order, theoretical domains of expectations. Approaching the data at the code level offers a structure for organizing the extensive data, identifying statements of future-oriented beliefs, and subsequently extracting the key words or phrases that represented an expectation (Bradley et al., 2007).

Table 3 at the end of this chapter presents a sample of the draft items derived from participant quotations and their respective domains of caregiver expectations. Although the researcher attempted to develop items by staying close to the words of participants as advocated in the literature, an examination of the utterances revealed two practical issues. First, uninterrupted segments of participant verbalizations frequently contained multiple expectations, and a one-articulation to one-item correlation rarely occurred. Second, a near-verbatim extraction of some expectations was not possible, particularly if the statements made references to prior aspects of the interview, or if the expectation was conveyed through a conversational interchange between the participant and interviewer (Clark & Wilkes-Gibbs, 1986). Therefore, both a descriptive approach to extracting near-verbatim statements and an interpretive approach to developing representations of caregiver expectations were adopted.

Descriptive approach

The following quotation regarding delirium illustrates the presence of multiple expectations in a single articulation:

“Every time he gets an infection, he will get a delirium and the dementia will progress when he gets sick. We tell the [nurses], as soon as you see any delirium or any odd behavior, right away it means that he’s got an infection. So get him on meds right way. And do the blood work right way.” (Pearl)

The first expectation item developed from this utterance was “every time the

person with dementia gets an infection, he/she will get a delirium.” This stimulus-outcome expectation describes the causal association between an infection (i.e., stimulus) and delirium (i.e., outcome), and was a near-verbatim extraction except for the gender-neutral modification. Similarly, the second item extracted was “the dementia will progress when the person with dementia gets sick,” which also reflects a stimulus-outcome expectation. A third expectation was “when there are signs of a delirium or any odd behaviours, I will tell the nurses to get tests and medications right away for the person with dementia” This stimulus-outcome expectation illustrates how symptoms of delirium in the patient (i.e., stimulus) were expected to result in help-seeking behaviours by the caregiver (i.e., outcome). The one intervening segment of speech, “it means that he’s got an infection,” was excluded from the last item because it reflected an attribution about the *cause* of the delirium rather than an expectation about possible consequences or outcomes.

Interpretive Approach

In contrast, other expectations were embedded in referential statements, which could not be extracted verbatim. For example, Lisa stated in her interview:

“And [we’re] frustrated because we need to have some kind of diagnosis... to do like *anything* with her. They said, ‘It will have to get worst first...’ Does she have to set fire to like the building? Does she have to harm herself? I was mad because it was very much what degree does she have to get to?”

In such circumstances, the analysis progressed from basic description to greater interpretation, which required the researcher to explore the latent ideas and assumptions underlying the references to prior discussions and distinctive expressions such as the use of hyperbole (Braun & Clarke, 2006). For example, the term “*anything*” referred to Lisa’s

earlier conversations with the interviewer about the lack of services and feelings that the “bar is set too high to even like get services or even into programs.” Hence, the first expectation derived from this excerpt was, “The person with dementia will need a formal diagnosis in order to get services and into programs.” This item is consistent with her narratives about the difficulties obtaining a diagnosis for her grandmother, and beliefs that a formal diagnosis is needed to access services.

Similarly, a second item generated based on Lisa’s latter dialogue was, “I don’t know how much worse the dementia will have to get before the person with dementia will receive medical help.” This general item reflects Lisa’s exasperation and the uncertainty in her expectations regarding what events would finally result in her grandmother receiving help. Although it might be argued that in this context of speculating about when a person might receive medical assistance, phrases such as, “Does she have to set fire to like a building?” are theoretically stimulus-outcome expectations (i.e., the person with dementia’s dangerous behaviours will result in help). However, pragmatically-speaking, these questions posed by Lisa are rhetorical and interpretation of the underlying beliefs rather than accepting their literal meanings was needed in order to transform them into cogent items. Thus, verbatim extractions of the text were not always possible nor a practical approach to item generation, contrary to current methodological theory.

Item Classification

The drafting process produced a total of 634 candidate items. Given the notable repetition among items, which was often due to minute variations in phrasing, the analysis proceeded to the next phase of item classification. The goal of this process was

to manage the extensive pool of items in such a manner that would enable the researcher to identify closely related items, determine the sources of variation which would inform the removal of redundant items, and revise items to reflect their simplest meaning. Therefore, through this process of categorizing conceptually-related items together, the researcher could compare and identify the best items for retention based on their semantic features (DeWalt et al., 2007).

The researcher imported all of the items into a standardized item library, and categorized each along six conceptual dimensions starting from the broadest dimension to the narrowest. These dimensions were selected a priori either because they were theoretical factors that would influence the face validity of an item bank purporting to assess caregiver expectations, or because they were factors that would influence the final structure and wording of the questionnaire. First, to capture the qualities and nuances related to *dementia caregiving*, each item was categorized into the domains or sub-domains of caregiver expectations that were identified in the previous chapter. Within each domain, items were further categorized according to the stage of dementia. For some items that were generalized expectations and could be applicable for any stage, a code of “Any” was applied.

Next, the items were assessed based on the tenets of *expectancy theory*. The researcher categorized each item according to the type of expectation (i.e., ideal, normative, predictive, or general beliefs), and then only among the predictive expectations, by the type of expectancies (i.e., stimulus-outcome, behavioural-outcome, response, or self-efficacy). Finally, wherever possible, how the participants conveyed their sense of probability and the perceived temporal proximity of the expected outcomes

or experiences were documented. Inductive codes such as, “it’s going to happen, I know it” or “not any time soon,” were initially generated to describe how individuals communicated probability and temporal proximity. As patterns of typical phrases emerged, the researcher applied a more deductive approach.

To illustrate this classification process “in action,” Table 4 at the end of this chapter presents a sample of the items that were categorized using the analytic scheme. For example, one item developed was, “In the next year, the person with dementia’s memory will improve.” In terms of the domain and stage, this item is about expectations of memory and cognitive declines, and reflects an early-stage symptom. With regard to the dimensions of expectancy theory, this item has a predictive orientation and is a form of stimulus-outcome expectancy. That is, the stimulus or memory problem is expected to improve as an outcome. Moreover, the phrases, “in the next year” and “will improve,” respectively suggest a temporally-proximal expectation and sense of certainty in its occurrence.

This classification procedure required the researcher to iteratively compare the emerging families of related items. Attention to the code definition of each domain was necessary, especially among behaviour-outcome expectations. These items tended to consist of two components (i.e., a behaviour as well as an outcome) that involved two different code domains; in order to prevent confounding of the analysis, all items were systematically categorized based on the behaviour. From an analytic standpoint, this approach would also enable the researcher to catalogue, examine, and compare the spectrum of expected outcomes associated with a given experience. For example, “One day when the person with dementia becomes incontinent, then I will probably consider a

nursing home,” was classified as a predictive expectation and a form of behaviour-outcome expectancy. That is, behaviours such as incontinence were expected to precipitate long-term care placement. Although this item involves the two separate domains of activities of daily living and long-term care (which were defined respectively as expectations of the changes in basic daily activities and their consequences vs. expectations of the nursing home experience), the researcher chose to classify this item into the former category. Not only did this approach permit methodical comparisons with other expectations of incontinence, but there was greater congruency between the content of this item and the code definition of the domain. To complete the analysis of the item, the researcher further noted the use of phrases such as, “one day” or “will probably,” which conveys a sense of distal temporality and less certainty in the outcome.

Qualitative Item Reduction

Item Revision and Reduction

The purpose of the qualitative item reduction was to revise or exclude poorly-constructed or redundant questionnaire stems while maintaining sufficient item diversity to fully capture the construct of caregiver expectations from a probability-based perspective. Although there are no established criteria for assessing the quality of items or for guiding their exclusion, the researcher adopted a similar approach to that developed by De Walt and colleagues (2007). Therefore, the researcher sequentially excluded: (1) non-predictive forms of expectations; (2) semantically redundant items; (3) vague items or those that were not specific to caregivers; (4) idiosyncratic items that were mentioned by only one participant; and (5) items that were inconsistent with their domain definitions.

Figure 1 at the end of the chapter presents a flow chart of the item reduction. A broad approach to item exclusion was implemented in order to produce a consistent measure of expectations as a construct. Using the analytic findings from the item classification process, the researcher began by excluding items that did not assess expectations from a predictive orientation ($n = 70$). These included general beliefs that were not expectations (e.g., “Caregiving is exhausting but not stressful”), ideal expectations (e.g., “I hope I die before getting dementia”), and normative expectations (e.g., “Society expects caregivers to have all the answers about dementia”). Such items were removed because they assessed other constructs such as preferences, hopes, and societal norms rather than the caregiver’s probability-driven beliefs about the outcomes or consequences related to dementia and caregiving.

Using a constant comparative approach, semantically redundant items within each domain and stage of dementia were removed. Two main sources of redundancy were evident. First, certain domains contained pairs of items that were the reverse analogues of each other ($n = 15$). For instance, the following self-efficacy expectation, “I can make and store many meals at one time for the person with dementia,” is the opposite of another self-efficacy expectation, “I can’t cook all the meals for the person with dementia.” In such circumstances, the researcher retained the simpler, positively-phrased item. Second, every domain had clusters of items that described near-identical expectations. Ninety-six of these redundant items were excluded while the simplest, positively-phrased items were retained.

However, among a minority of these item clusters, subtle variations in the subtypes of expectancies precluded their removal. For instance, the researcher considered

the following expectations: “I can’t leave the person with dementia alone for more than one hour,” and, “it will be unsafe to leave the person with dementia at home alone for more than one hour.” Although these two items contained virtually identical phrases, both were retained in the item bank because the former is a self-efficacy expectation about the likely level of care that a caregiver could provide, while the latter is a stimulus-outcome expectation that links the anticipated safety concerns with the disease progression. These two items assessed different facets of the expectation construct, and were retained despite their semantic similarities.

Finally, the researcher excluded items that were vague or non-specific to caregivers, idiosyncratic statements, or inconsistent with the domain definition. Among the vague or non-specific items, 36 questionnaire stems were removed because they assessed the caregivers’ *perceptions* of the expectations held by the person with dementia (e.g., “The person with dementia expects that his/her memory will be stable.”). While these items reflect legitimate concerns and experiences, they do not directly assess the expectations of the caregiver, *per se*. In addition, the researcher removed idiosyncratic statements that were mentioned by only one participant (e.g., “When the person with dementia has delirium, he/she will believe that there are bugs crawling on the ceiling.”). These items were highly specific to their experiences, and were unlikely to capture meaningful variation between caregivers in a questionnaire. Lastly, items that were inconsistent with the domain definition were removed to maintain domain homogeneity.

Cognitive Interviews

This section describes the results of the cognitive interviews, which were used to refine problematic items, to develop additional items that were of clinical interest to

health professionals but were not identified so far, and to determine the appropriateness of items. The following presents the basic demographics of participants, the rationale for further excluding items, as well as two themes regarding ethical concerns and the appropriateness of items regarding service access and psychosocial care.

Basic Demographics

Following the item reduction phase, a total of 353 items were presented to health professionals for cognitive interviews. Four physicians and three allied health professionals participated (Table 5, at the end of this chapter). The majority of participants were female (57%), and the mean number of years in practice was 18.1 (SD = 11.3). All participants indicated an interest in the care for the elderly, but three had specialized geriatric training. The duration of interviews ranged from 16 to 53 minutes.

Additional Item Exclusion

An additional 118 items were further excluded based on the feedback of participants (Figure 1, at the end of this chapter). Given the extensive number of items, the researcher first excluded three categories of expectations ($n = 21$) related to obtaining a diagnosis, hospitalizations, and delirium. By doing so, greater homogeneity was achieved by focusing the questionnaire on the expectations of caregivers who already had a dementia diagnosis, were engaged in community-based care, or were contemplating transitioning from the community to long-term care. Moreover, because hospitalizations and delirium are experiences that only affect a subset of caregivers, the majority of health professionals suggested their exclusion as these expectations were highly contingent on personal knowledge and experience. As one social worker stated, “I wonder if you will be asking questions about things that they don’t know about. I mean, a lot of people don’t

know about delirium or perhaps their family member has never had it... If you include these items, you may get a lot of non-responders which will affect your data.”

The researcher then excluded items from across two or more domains that were viewed as being similar ($n = 58$). For example, “The person with dementia will be able to pick the right clothes and dress himself/herself,” semantically encompasses another item, “He/she will leave the house in the wintertime and will not be dressed warmly enough.” The latter item was removed in favor of a more general item. Likewise, the researcher also removed 23 items which the participants found to be too narrow in scope or idiosyncratic (e.g., “Sometimes I will take the person with dementia out to the country and let them drive on an empty road”). Sixteen items that were ambiguous or non-specific were further removed. For instance, “Someone will have to take charge of caring for the person with dementia,” was seen as being too broad, and participants anticipated that most caregivers would endorse such statements, resulting in poor item variability.

In total, the researcher revised 58 items to improve their clarity by (1) removing the use of medical terms from 16 items (e.g., “fractures” was replaced with “breaking a bone”); (2) altering the grammar tense in 30 items to better reflect a future-oriented nature of expectations (e.g., “can” was replaced with “will be able to”); and (3) revising phrases in 12 items that some participants viewed as inflammatory (e.g., “lie” was replaced with “will not be honest with”). The final pool of items is presented in Appendix C. Overall, the Flesch readability grade of the item bank was 69.3%, and the Flesch-Kincaid reading grade level was 7.0, which suggest that these items would be comprehensible by individuals with at least a grade seven education.

Ethical Considerations

Finally, participants were asked to comment on the appropriateness of the items. All participants believed that the items were comprehensive and adequately reflected caregiver concerns and expectations that were commonly encountered in clinical care. However, nearly half discussed the potential ethical implications of an expectations instrument. One nurse commented on the potential psychosocial harm of assessing expectations using a questionnaire.

“There is an ethical implication for listing all these things like forgetting to eat, starting to steal, hitting, becoming argumentative... If you put them in front of a caregiver, these are statements that will just leave them reeling, really upset, and creating a catastrophic reaction in their mind. It’s like you’re opening up their eyes to things they might not know and prefer not to know. Sometimes people grow into this. And that questionnaire can be really traumatic.”

Additionally, participants identified concerns regarding the accuracy of certain statements. For example, “I was wondering if the statements that are not accurate... will be countered in some way? I guess it’s going to happen because people can have sometimes erroneous expectations I guess” (Allied Health Professional). In particular, clusters of items such as, “The person will sometimes start saying inappropriate or offensive things,” or “I worry that he/she will hit someone,” were viewed as being more consistent with other forms of dementia such as frontotemporal dementia than Alzheimer’s disease. Despite the perceived clinical inaccuracies, these items were nonetheless retained because they were near-verbatim extractions of caregiver discourses, and thus, reflected legitimate albeit subjective caregiver expectations and concerns.

Item Appropriateness

Health professionals overall found that the items captured relevant health services

issues, such as difficulties accessing health services and obtaining psychosocial support from family physicians. All of the health professionals acknowledged that navigating community and health services could be challenging for caregivers, in part, because of discontinuities in services and the lack of information about the qualification criteria and the steps required to gain access. As one social worker described, “Yeah, again I would say the expectation seems about right... And then, there are challenges around getting the diagnosis because quite often you need the diagnosis in order to access the services.” One physician further confirmed the importance of assessing expectations about referrals to community services. “For things like the Alzheimer’s Society, the problem with that is doctors don’t refer to, you self-refer. And the same with most support groups, you self-refer. So that’s part of the challenge with this.” Thus, there may be a discrepancy between caregiver expectations that they would receive a referral from physicians for support groups and wider systemic expectations that caregivers would self-refer themselves.

Similarly, in response to items regarding psychosocial care (e.g., “The family doctor will be too busy to monitor or talk to me about caregiving stress,” or “It will not be the family doctor’s job to listen to me complain about caregiving”), the majority of the health professionals agreed that those expectations were likely representative of caregiver experiences.

“Unfortunately, the perception that physicians don’t look after that part of care is probably right. And that is a function of the system and the need to bill is in increments of time and one problem per visit. Because the caregiver’s not the patient, that is what happens here but it’s wrong... I mean, family docs should be responsible for doing this, but they don’t or can’t.” (Physician)

However, one potential concern that participants identified regarding these

expectations was the lack of items that measured the baseline caregiver characteristics, which may act as confounders. For example, whether or not the person with dementia and their caregivers had the same family physician may influence whether the family doctor inquired about psychosocial needs. As one family physician described, “Whenever the families are in, I always... make sure that they’re doing okay. But I think of one of my ladies [with dementia], her kids are not my patients, and I would probably ask them less. Yeah, the ones I ask tend to be my own patients.” Because expectations are context-dependent beliefs, health professionals believed that it was also important to understand the social determinants and context that shaped caregiver perceptions.

Table 3. Sample quotations and their respective draft items.

Sample Quotation	Domain	Sample Draft Item
<p>“We needed to know what to expect and... as difficult as it is, how quickly to expect it. We wanted to make plans especially with the waiting lists that we have... you have to plan well in advance.”</p>	<p>Obtaining a Diagnosis</p>	<ul style="list-style-type: none"> • A specific diagnosis is needed so that I will know what symptoms and changes will occur. • A specific diagnosis is needed so that I will know when symptoms and changes will occur. • We will have to make plans well in advance about nursing homes because of the long wait lists.
<p>“My expectations for the next year, I believe that my grandfather... will continue to improve.”</p>	<p>Memory & Cognitive Decline</p>	<ul style="list-style-type: none"> • In the next year, the person with dementia’s memory will improve.
<p>“One day he will have a problem with incontinence. If he can’t make it to the bathroom washroom right away, and then... at that stage he probably will need to go to a nursing home because physically I cannot help him.”</p>	<p>Basic Activities of Daily Living</p>	<ul style="list-style-type: none"> • One day, the person with dementia will have a problem with incontinence. • One day when he/she has a problem with incontinence, he/she will probably need to go to a nursing home. • I will not be able to manage the person with dementia’s incontinence.

Table 3. Continuation of sample quotations and their respective draft items.

Sample Quotation	Domain	Sample Draft Item
“I was quite concerned about how [the Home Care worker] was going to handle Mary. I was having trouble giving her baths already, washing her hair and even dressing sometimes became a struggle.” (Mitch)	Home Care	<ul style="list-style-type: none"> • Home Care workers will have difficulties managing the person with dementia. • The person with dementia will not accept help with bathing from Home Care.
“Every time he gets an infection, he will get a delirium and the dementia will progress when he gets sick. We tell the nurses, as soon as you see delirium, or any odd behavior... it means that he’s got an infection. Get him on meds. And do the blood work right away.” (Pearl)	Delirium	<ul style="list-style-type: none"> • Every time the person with dementia gets an infection, he/she will get a delirium. • The dementia will progress when he/she gets sick. • When there are signs of a delirium or any odd behaviours, I will tell the nurses to get tests and medications right away.
“But that’s the sad part too, eh? She could live to be over a hundred...” (Grace)	Life Expectancy	<ul style="list-style-type: none"> • I don’t know how long the person will live with their dementia.

Table 4. A sample of the item classification process.

Sample Draft Item	Domain	Stage	Expectation	Expectancy	Probability	Temporality
A specific diagnosis is needed so that I will know what symptoms and changes will occur.	Diagnosis	Early	Probability	Self-efficacy	Will	-
We will have to make plans well in advance about nursing homes because of the long wait lists.	Nursing Home	Any	Probability	Behaviour- outcome	Will	Well in advance
In the next year, the person with dementia's memory will improve.	Memory	Early	Probability	Stimulus- outcome	Will	In the next year
Medication will help slow down the memory declines.	Treatment	Early	Probability	Stimulus- outcome	Will help	-
The person with dementia will be upset about losing his/her driver's license.	Driving Cessation	Early	Probability	Response	Will	-

Table 4. Continuation of a sample of the item classification process.

Sample Draft Item	Domain	Stage	Expectation	Expectancy	Probability	Temporality
The person with dementia will not accept help with bathing from Home Care.	Home Care	Middle	Probability	Behaviour-outcome	Will not	-
Every time the person with dementia gets an infection, he/she will get a delirium.	Delirium	Middle	Probability	Stimulus-outcome	Every time	-
I don't know how long the person will live with their dementia.	Life Expectancy	Late	Probability	Stimulus-outcome	don't know	How long

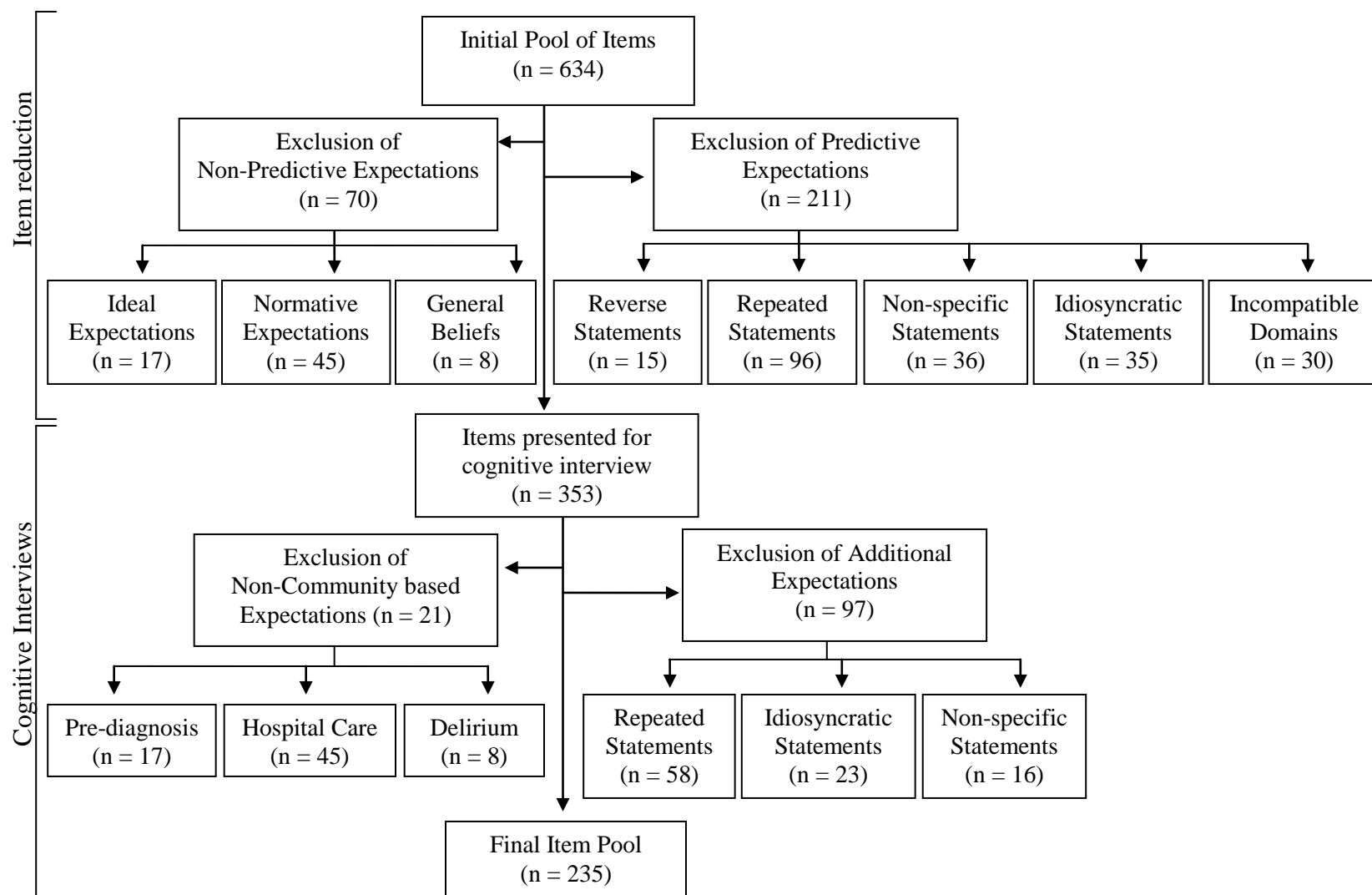


Figure 1. Flow chart of the item exclusion process.

Table 5. Sample characteristics of the health professionals.

Characteristic	N	%
Sex		
Female	4	57.1
Male	3	42.9
Specialty		
Family Medicine	2	28.6
Internal Medicine	2	28.6
Nursing	2	28.6
Social Work	1	14.2
Years in Practice		
Less than 5	1	14.2
5 to 9	1	14.2
10 to 20	2	28.6
21 or more	3	42.9

CHAPTER 6: DISCUSSION & CONCLUDING REMARKS

This chapter explores the main findings and methodological challenges encountered during the development of an item bank for measuring caregiver expectations. First, a discussion of the qualitative content domains is presented, including the implications of the methods used, the comprehensiveness of the domains, and study limitations. Second, a discussion of the approach developed for transforming the qualitative data into individual items is presented, including the congruency between the conceptual and operational definitions of an expectation and study limitations. From a research perspective, the feasibility of developing a set of scales from the item bank, and future directions including evaluating the psychometric properties are considered. Finally, from a clinical perspective, ethical concerns as well as the potential utility of the expectations questionnaires are explored.

Phase I: Qualitative Domains of Caregiver Expectations

Methodological Implications

The purpose of the initial qualitative phase of the study was to explore the diversity of caregiver expectations, which in turn would inform the development of the core domains of the item bank. Drawing from the narratives of 17 caregivers, the researcher identified a number of expectations that spanned the caregiving career from obtaining a dementia diagnosis to providing care at the end of life. These beliefs developed alongside and in response to expectations regarding the projected illness trajectory. Generating the themes was an iterative, recursive process, and refining the data collection and analytic procedures as certain methodological issues and insights

emerged was both anticipated and necessary. Therefore, this section explores the relationship and influence of the methods on the content of expectations.

Expectations as Probability-Driven Beliefs

While conducting the interviews, two challenges associated with exploring an abstract construct like expectations became evident. The first challenge was adequately capturing expectations from a predictive orientation. When posed with direct questions such as, “What are your expectations about long-term care?” participants had some difficulties understanding and responding to a seemingly nebulous concept. Expectations, whether a set of conscious beliefs or a subconscious cognitive process, were not always easily articulated nor recognized by participants (Janzen et al., 2006; Kirsch, 1999). Moreover, given the lack of a unified conceptual definition (Thompson & Sunol, 1995), the term “expectation” may subsume a myriad of colloquial understandings, including probability-driven beliefs, a sense of preference or desirability, and perceived obligations or deservedness of outcomes based on societal norms (Janzen et al., 2006). Thus, at times, there was some ambiguity about whether the participant and the researcher’s definitions of what constituted an expectation were fully synchronous.

Recognizing that unresolved conceptual ambiguity would detract from the validity of the findings, various theory-driven concepts were used in lieu of the term “expectation” to sensitize and focus the discussions on probability-driven beliefs about outcomes. At the broadest level, the four classical theories of stimulus, behavioural, self-efficacy, and response expectancies (Kirsch, 1985; Rosenstock et al., 1988) were explored respectively using lines of questioning to elicit what participants thought would likely happen, how they were planning for the future (Maddux, 2006), whether they could

achieve their plans (Bandura, 1982), and how they would feel about outcomes (Kirsch, 2006). This directive approach helped build conceptual common ground, and brought the participants' probability-based assessments and expectations to the surface of the interviews.

However, as methodologists such as Guba and Lincoln (1994) have argued, “the etic theory brought to... an inquiry by an investigator may have little or no meaning within the emic view of studied individuals” (p. 106). Because classical expectancy theory with its primary emphasis on probability may not be overtly meaningful to participants, the researcher further sought to understand their priorities and concerns about the eventual disease progression and future in general. Aspects of expectancy-value theories were included, which suggest that it is the subjective value of an outcome in addition to assessments of probability that drive the meaningfulness of expectations (Ajzen, 2001; Kravitz, 1996). Thus, concepts containing a subjective value component that were discussed included goals for the future and worry, which is defined as a form of “apprehensive expectation” or belief in the occurrence of aversive outcomes (APA, 2000). While this method introduced greater theoretical complexity, it nonetheless provided opportunities for participants to voice their anticipated concerns and the expectations that were significant to them, all the while maintaining adherence to the probabilistic character of expectations.

Expectations Embedded Within Experiences

The second challenge lay in teasing out instances of articulated expectations, which were often embedded in the rich descriptions of the participant's experiences and not always readily apparent. This issue may, in part, reflect the dual nature of

expectations, which can be both context-dependent beliefs and a subconscious cognitive process that links experiences and behaviours with probable outcomes. However, this intermixing of expectation with experience may also reflect the narrative approach to data collection and the inquiry into historical expectations. Because everyday explanations and discussions of one's beliefs commonly have structures and chronology that are narrative in form (Sandelowski, 1991), it was often natural for participants to first describe their context and experiences before presenting rationales for their beliefs about the future. Concurrently, these discussions of past experiences also provided a window for the researcher to retrospectively explore expectations about key transitions that have already occurred, such as obtaining a diagnosis and driving cessation. In his writings about phenomenology and expectations, Schutz (1932) theorized that this retrospective exploration can be a legitimate approach.

“When we say that the final goal of action always has the temporal character of futurity, this does not mean that it must be literally *in* the future. Suppose that I have just come from a visit to my friend, and you ask me why I went out. Even though my visit to my friend is now literally *in* the past, the time contained within, or expressed by, the phrase “in order to...” is *future*... The interesting feature of this double mode of expression is that... the relational sense of the action... comprises both a backward reference to the past and an orientation toward the future.” (pp 89-90)

By asking participants to recall the expectations that were already formulated, as opposed to asking them to conceptualize nascent expectations, the use of historical expectations may have facilitated discussions and made this abstract concept more tangible to participants. Theory suggests that when making predictions about outcomes, past experiences are critical for informing the contents of outcomes and the degree of certainty in their occurrences (Janzen et al., 2006), particularly if outcomes are attributed

to a stable cause and familiar stimulus (Valle & Frieze, 1976). Therefore, to probe the probability dimension of these historical expectations, participants were asked a variety of questions including whether they were surprised by their experiences so far. According to cognitive theory (Reisenzein et al., 2006), the primary – if not the only – cognitive elicitor of surprise is the occurrence of an unexpected outcome. Of interest, however, was not so much the presence or absence of this feeling but exploring *why* surprise was experienced at all. Surprise contains an implicit evaluative component that compares the expected and actual outcomes. In order to be surprised by any discrepancy, participants must first be aware of, and therefore able to articulate, their initial expectation (Schutzwohl, 1998). Thus, concepts like surprise were largely used as springboards for elucidating caregiver expectations and making these abstract beliefs more explicit.

In summary, the influence of the methods on the emergent data is manifold, especially when examining a highly theoretical construct such as expectation. This data collection approach illustrates the socially-constructed nature of qualitative inquiry (Guba & Lincoln, 1994). Lay participants, though experts of their own experiences, were understandably unaware of the construct's theoretical underpinnings. Hence, these findings in actuality were created via interactions between the researcher and participant, with the theoretical framework supplied by the former and the actual substance of an expectation “in action” supplied by the latter (Guba & Lincoln, 1994). Furthermore, the lines of questioning used to probe the multiple dimensions of expectations also influenced the contents of data. To improve clarity with caregivers, the researcher deconstructed the expectations concept and explicated its key features including probability (e.g., by exploring what would likely occur and experiences of surprise),

temporality (e.g., by focusing on the future orientation in both contemporaneous and historical expectations), and subjective expected value (e.g., by seeking their priorities and concerns regarding the future). All of the strategies employed sought to reduce conceptual ambiguity.

Contents of Expectations

Accepting the interrelationships between the methods and emergent data in principle, this section now explores the main findings. Five domains of expectations were identified, concerning diagnosis, memory, driving, basic activities of daily living as well as delirium and end of life. These expectations reflected the anticipated illness course and caregiving activities; in response to those beliefs, participants further described expectations regarding what health services would be needed and their probable utility. Although the primary goal of this first phase was to describe the spectrum of caregiver expectations, during the analytic phase, it became apparent to the researcher that there were underlying, dynamic mechanisms that influenced the formation, maintenance, and expression of expectations. These modulating factors included cognitive schemas, temporal proximity, the concurrent existence of many expectations, and the perceived utility of expected behaviours and events. Given the close relationship between the core expectation domains and the modulating factors, these findings are discussed together.

Diagnosis

For participants, obtaining the dementia diagnosis was a concrete, salient event that marked the beginning of the caregiving experience, and thus served as a suitable foundation for exploring abstract beliefs like expectations. As all of the care recipients were diagnosed between four months to eight years prior to the interview, these historical

expectations were retrospectively examined. A diversity of expectations as a “subconscious cognitive process” and as “individual beliefs” was evident, which largely clustered into the pre-diagnostic and peri-diagnostic period. Respectively in each cluster, the modulating factors of cognitive schemas and the perceived utility of behaviours and events, such as obtaining a diagnosis and future planning, were seen.

Pre-diagnosis period

In the literature, there is increasing interest in exploring the pre-diagnosis period when a problem has been perceived but no diagnosis of dementia has yet been made. Evidence suggests that a timely diagnosis enables caregivers to find supportive resources (Iliffe et al., 2003), promotes future care planning (Connell et al., 2009) and encourages discussions about observed and expected cognitive changes and safety risks (Byszewski et al., 2007). Hence, understanding the processes whereby individuals determine that symptoms constitute morbidity, and the factors that shape when and how they seek a diagnosis is an important goal. Recent qualitative research has reported that caregivers experience a series of transitions, beginning with a perceived shift from the absence of symptoms to detecting early signs of decline, to normalizing these observations, to experiencing pivotal events that indicate undeniable changes, and which culminate in seeking a diagnosis and possibly help (Krull, 2005; Leung et al., 2011; McCleary et al., in press). However, the interpretive processes that drive the shift from one transitional state into another (e.g., from perceiving the absence of symptoms to detecting the early signs) remain largely unexplored conceptually.

Disconfirming expectations derived from “schemas” may be one such process that influences perceptions of these transitions. Schemas are hypothetical cognitive processes

that store learned causal associations, and serve as “coherent... knowledge-consistent, and expectation-confirming representations of experience” (Alba & Hasher, 1983). These learned patterns of behaviours and events are strengthened with recurrent experiences, and allow a person to extrapolate general information to specific situations and to subsequently form expectations about social interactions and outcomes (Johnson & Magaro, 1987). Drawing from the current results, observing changes that were inconsistent with expectations may have sensitized participants to the presence of early cognitive problems. Because many had decades-long relationships with their care recipients (and had accumulated considerable knowledge of their routines and preferences), even slight changes were meaningful as they contrasted with expectations based on how the care recipients “used to be like.” As such, these changes were viewed as being peculiar and benignly surprising. Thus, discrepancies between expectations and the observed changes in homemaking, personality, and even television show preferences and may have drawn attention to these initial cognitive declines.

Similarly, just as how early changes in personal routines and preferences may have signaled the transition from good health to early decline, the emergence of more severe changes in functional capacities may have alerted the presence of a clear health problem that required medical attention. These “pivotal events” (Krull, 2005) witnessed by participants included car accidents, significant changes in hygiene, and accidental flooding. Many participants had both assumed and expected that their care recipients were functioning well and independently, as they had been doing so for many years prior. However, the severity of these changes lay beyond the expected range of normal aging and schemas of the accepted “vagaries of old age” (Cahill et al., 2008), or as one

caregiver described, “getting older... repeating things and telling the same stories.”

Hence, discrepancies between the observed changes and expectations may be a contributing mechanism that influences problem recognition and the perceived need for medical help seeking. However, the precise nature and postulated role of expectations as a process for stimulating problem recognition and help-seeking requires further investigation.

Peri-diagnostic period

The peri-diagnostic expectations illustrated the dynamic interactions between perceptions of illness and expectations regarding necessary health services. In contrast to the analysis of the pre-diagnosis period, which largely focused on expectations as a subconscious process that shapes interpretations of experience, the peri-diagnostic expectations were primarily individual beliefs about future-oriented outcomes. In particular, participants identified two challenges related to obtaining a dementia diagnosis and described the expected consequences.

First, nearly half of the sample had encountered some challenges obtaining an initial diagnosis, a finding consistent with both quantitative (Boise et al., 1999; Speechly et al., 2008) and qualitative research (Hinton et al., 2004). Participants recalled experiencing frustration because there was often frank cognitive and functional decline by the time medical attention was sought, which they expected would be diagnosed, explained and managed. Discrepancies between expectations and experiences led to both a sense of surprise and dissatisfaction, with the former reflecting unmet probability-driven beliefs that they would receive a diagnosis (Reisenzein et al., 2006), and the latter reflecting unmet values-driven beliefs rooted in the perceived importance of the diagnosis

(Kravitz, 1996). Obtaining a diagnosis was viewed as a necessity by the majority of caregivers because they expected that a formal diagnosis was needed to access health and social services in the community. These expectations are legitimate, and reflect the structure of health services where physician referral and an appropriate diagnosis are often necessary to access scarce interventions and resources (Connell et al., 2009), such as medication, dementia-specific respite care, and day programs (Leung et al., 2011). As a result, caregivers expected that a delayed diagnosis would also delay service access, and thus reduce benefits to care recipients.

Second, among participants who had sought out additional information on dementia, they expected to receive a diagnosis of a specific dementia subtype. Participants recognized that the dementia subtypes could have different rates and patterns of progression (Feldman et al., 2008), and believed that a specific diagnosis was needed in order to know what symptoms to anticipate and when to expect those changes to occur. Furthermore, they expected that there would be advantages to knowing the specific diagnosis, such as for future planning and determining the optimal time for long-term care placement, especially given the present waiting lists. Although little research is available on this issue, studies have found that caregivers tend to prioritize and be particularly satisfied by the quality of information given about the likely disease progression and physician attention to their concerns and expectations (Glasser & Miller, 1998). Obtaining knowledge of the illness trajectory and developing a management plan for the near future further promotes a sense of self-efficacy, and enables caregivers to take an active role in managing illness (Carpenter et al., 2008). Thus, it is perhaps

unsurprising that caregivers expected this information, as it may have provided a greater sense of personal control.

Cognitive Decline & Treatments

The second theme identified was the types of cognitive changes that were expected to develop as the dementia progressed. Individuals interpret their personal experiences with reference to time, which provides coherence and meaning to the events that either have been or will be experienced. Temporal proximity or the time between when outcomes are projected to occur relative to current circumstances may have differentially influenced these expectations (Zimbardo & Boyd, 1999). As suggested by the data, greater homogeneity was evident among expectations regarding the near and distant future (e.g., less than two months and greater than three years, respectively) compared to more moderate-term expectations (e.g., the next six months to a year). These beliefs about cognitive decline were explored through two subthemes regarding the relationship of temporal proximity on the content of expectations, and the types of management caregivers expected to receive for these impending cognitive changes.

Temporal Proximity

Despite recruiting individuals from across the disease continuum, there was notable homogeneity in the distal expectations. All participants reported that continued declines in memory and cognition were inevitable, and a portion also acknowledged that the dementia would likely be a terminal illness. Such expectations may reflect both an understanding of dementia as a progressive neurodegenerative disease and a sense of acceptance of the illness trajectory, as these expectations were often prefaced by statements including, “as difficult as it is to say” or “it’s gonna be [a] killer.” Although

the antecedents of expectations, including prior knowledge and experiences remain largely conceptual, Atance and O'Neill (2001) postulated that "semantic future thinking" may mediate these expectations. Analogous to semantic memory, which is the recollection of learned or rote knowledge (Tulving, 1985), semantic future thinking suggests that expectations about the future (e.g., dementia-related deterioration) do not need to be informed by first-hand experiences, but rather may be conceptualized entirely from learned knowledge (e.g., reading or attending seminars on dementia). Potentially, these homogenous distal expectations may be more strongly driven by knowledge of the disease progression, such that caregivers of early and late-stage people with dementia have similar expectations even without having the same caregiving experiences.

Proximal expectations were likewise homogenous across participants, and the majority anticipated that their care recipients would be stable for the next weeks to come. These beliefs may be shaped by a number of factors including the natural progression of the disease, which is punctuated by periods of relative stability throughout the overall degenerative trajectory (Brooks et al., 1993). From a theoretical perspective, these expectations of stability may be mediated by "episodic future thinking," where individuals' previous experiences inform the likelihood of similar experiences occurring again in the near future (Atance & O'Neill, 2001). Episodic future thinking may be particularly influential on expectations of repetitive questioning, formulaic conversations, and permanent memory deficits because these repeated episodes and conversations were expected to continue, and memories that were already lost were not expected to return. Finally, from a phenomenological perspective, these expectations are perhaps unsurprising given that the interviews were conducted during periods of stability, with

nearly a third of participants having rescheduled their initial interview because they were too overwhelmed by the exigencies of caregiving at the time of first contact with the researcher. Because expectations are filtered and interpreted through the lens of current experiences (Leung et al., 2009b), a sense of stability in the here and now may have primed their expectations and beliefs of stability in the near future (Fraisie, 1984).

In contrast, expectations pertaining to the next six to twelve months were considerably more diverse and were often articulated with less certainty, particularly among participants caring for individuals with early to moderate-stage dementia. Longitudinal studies have found that the early-moderate stage of dementia is marked by considerable transition where most instrumental activities of daily living tended to be lost as scores for the Mini-Mental State Examination approached 18 or less, and major losses in basic activities of daily living tended to occur in the subsequent 12 months (Feldman et al., 2005). Although little research has examined the relationship between the dementia stage and caregiver perceptions of the expected cognitive decline, studies examining caregiver judgments of current functional status have found that accuracy varies by stage. Loewenstein and colleagues (2001) reported that compared to objective measures, caregivers of early-stage patients became less accurate in their judgments as greater functional deficits emerged in the domains under assessment, such as in making change for a purchase and telling the time. Hence, if caregivers had difficulties assessing the functional status in the present, it stands to reason that forming expectations regarding future function would be equally, if not more, challenging.

Overall, the influence of temporal proximity on caregiver expectations may have implications for the development of questionnaire items for a instrument designed to

estimate expectations in individuals. The goal of measurement is to differentiate individuals based on a set of characteristics, such as expectations, in order to understand their relationships with other complex phenomena such as health outcomes, health service usage, and decision making (Pett et al., 2003). If questionnaire items are constructed in such a manner that all individuals response to them in a homogenous fashion, then there would be limited item variance and few practical means of differentiating individuals on that trait (deVellis, 1991). Potentially, in developing the item bank of caregiver expectations, assessing for more moderate-termed expectations would be appropriate given the presence of greater diversity in both content and evaluations of certainty.

Treatment & Management

In response to the current symptoms and proximal expectations regarding continued cognitive decline, participants identified a diversity of treatment-related expectations. Although a variety of pharmacological and non-pharmacological treatments are available, the efficacy of certain interventions is questionable at best (Acevedo & Loewenstein, 2007; Lancot et al., 2003). Hence, understanding caregiver expectations regarding how well a potential treatment works is an important component of care. In terms of pharmacological intervention, one qualitative study by Andersen and colleagues (2008) examined the expectations of key stakeholders regarding cholinesterase therapy for Alzheimer's disease. In contrast to their findings, which reported that some patients and caregivers had relatively optimistic expectations of stabilizing the symptoms and potentially even restoring memory, the majority of caregivers in the current study held more conservative expectations of these drugs. Among those whose care recipients had

received cholinesterase inhibitors, participants expected that the drugs would have a mild stabilization effect that would dissipate after approximate two years, and at which time the drugs would be discontinued. These expectations are consistent with current meta-analyses of the efficacy of cholinesterase inhibitors such as donepezil (Raina et al., 2008), and tended to be influenced by the knowledge and explanations provided by physicians.

However, over a third of participants reported that their care recipients had not received any pharmacological therapy for their dementia. A number of reasons were identified. First, among those providing care to individuals with vascular dementia, many of the caregivers did not expect to receive cholinesterase inhibitors as their physicians explained to them that the drugs were ineffective for the vascular form of dementia. Once again, this finding highlights the important role of healthcare providers in modifying patient and caregiver expectations regarding effective treatments and appropriate care. Second, a number of caregivers were uncertain regarding the benefits of cholinesterase inhibitors and questioned the risk and potential side effects associated with these drugs. Within the context of expectancy theory, the concept of risk – as an estimate of the probability of an adverse outcome occurring – is intriguing (Porta, 2008). To the researcher's knowledge, little research has been conducted on the caregivers' perceptions of risk associated with cholinesterase inhibitors. However, Oremus and colleagues (2007) found that caregivers were willing to accept and continue cholinesterase treatment if their care recipients experienced weight loss or loss of appetite but were unwilling to continue treatment if other symptoms such as headache, nausea, diarrhea, hypotension, or stomach ulcers occurred. Thus the relationship between perceptions of risk and expectations is a

pertinent topic for health services, and further investigation may reveal important determinants of the acceptability of pharmacological agents.

Driving Cessation

The third major theme identified was expectations related to driving cessation. Because all of the care recipients had ceased driving by the time of their interviews, expectations regarding this transition were explored retrospectively. The qualitative interviews revealed a rich diversity of beliefs, and notably within these beliefs was the concurrent existence of multiple stimulus-outcome, behavioural-outcome, self-efficacy and response expectations. These beliefs centered on the necessary actions that were likely needed to ensure driving cessation, and the likely consequences for the care recipient, caregivers, and health professionals.

Caregiver & Care Recipient Expectations

The issue of driving cessation illustrated the complexities of expectations, especially given the concurrent existence and dynamic interactions between their different, theoretical forms. The most frequently described stimulus-outcome expectation was that forfeiting the driver's license would result in a significant loss of freedom for the care recipient. Participants expected a number of consequences. While behaviours such as restricting driving or frank cessation would ensure the safety of the care recipient and the public in general as an outcome, participants were concerned about potential social isolation for both the care recipient and his or her spouse (Adler et al., 2000), as well as concerns about adequately meeting basic needs, such as obtaining groceries. Because driving cessation is a contentious issue, caregivers expected that it would trigger distress and conflict, often because of discrepancies between the caregiver and care recipient's

efficacy expectations. Caregivers recalled that while their care recipients expected that they would still be able to drive safely, caregivers typically believed otherwise especially after witnessing poor adherence to the rules of the road.

Expected Roles of Health Professionals

As an emergent area of research, few studies have examined expectations regarding driving cessation. Drawing from the results of the current study, caregivers both valued and anticipated that the family physician and other health professionals would provide support for driving cessation. Specifically, caregivers appreciated having their family doctors explain the process of driving cessation before serious safety issues developed, including the need for driver's testing and any obligatory reporting of unsafe behaviour to the government. Consistent with the general literature, caregivers also expected that health professionals would establish a therapeutic alliance and present a "united front" on the issue of eventual driving cessation (Mead & Bower, 2002; Parkinson et al., 2005). In fact, when there was a lack of agreement about driving cessation, caregivers reported resorting to more extreme measures to ensure driving cessation such as confiscating car keys or installing a steering wheel lock on vehicles. These behaviours were viewed as a last resort, and were expected to permanently prevent the care recipient from driving.

Basic Activities of Daily Living

The fourth theme that developed from the qualitative data focused on the expected changes in the basic activities of daily living, and the health services that would become necessary in response to these predicted functional declines. These beliefs represented a unique intersection of expectations related to self-efficacy, the disease progression,

locally available health services, and wider health systems issues such as waiting times. From the participants' perspective, the expected emergence of dementia "milestones," such as difficulties with bathing, incontinence, and wandering, would likely signal the need for greater use of community and health services, including Home Care and eventually long-term care placement. These expectations often took into consideration other self-efficacy expectations and assessments about the amount and types of care that they could realistically provide to their care recipients. Therefore, this discussion briefly examines the types of health services that the participants expected to access and their associated expected subjective utility.

Expected Utility of Health Services

Expectations regarding health service usage appeared to cluster into two phases related to the severity of the predicted functional declines. First, for basic activities of daily living that only require intermittent care such as meals and bathing, most participants expected that accessing community-based services would alleviate some of their stress, which in turn would enable care recipients to remain at home for longer. Because caregiver burden is a key predictor of institutionalization (Hebert et al., 2001), considerable research and interventions targeted at providing psychosocial support and Home Care support has been found to increase quality of life (Schoenmakers et al., 2010) and reduce the risk of premature institutionalization among early to moderate-stage individuals with dementia (Mittelman et al., 1996). Moreover, promoting a sense of self-efficacy (Spijker et al., 2008), and obtaining the appropriate level of Home Care may be beneficial for caregivers (Townsend & Kosloski, 2002). These findings are consistent with the results of the current study. Assessments of their own caregiving abilities and

expected level of self-efficacy were key factors in shaping what services participants anticipated would be needed in the future. For example, one caregiver remarked that as his wife's condition progressed, he could assist her with dressing or eating but not with bathing, which would require Home Care.

Second, for activities of daily living that required continual care or for behaviours that were difficult to manage (e.g., wandering and aggression), most participants expected that the development of these symptoms would indicate the need for nursing home placement. Although expectations regarding institutionalization were slightly distressing for participants to discuss, the majority believed that it was important to plan for this transition. Citing concerns regarding the current wait lists for long-term care placement, a number of caregivers expected that "applying sooner rather than" later was probably necessary. Many participants expected that they would have accessed the maximum amount of services before contemplating long-term care, and thus, were concerned about how to bridge the time between applying for long-term care and obtaining a placement. These concerns are legitimate, given that long-term care is a health service that is in relatively short supply relative to demand in an aging society (Harper, 2000). Furthermore, a substantial amount of research has demonstrated that the time preceding obtaining a placement can be markedly difficult for family caregivers (Morin et al., 2007; Strang et al., 2006).

Delirium & End of Life

The final theme explored with participants concerned expectations regarding delirium and end of life. It is important to note that because less than half of the participants had encountered delirium symptoms, inquiries about these expectations were

restricted to those that had knowledge of this condition. Likewise, because discussions of expectations regarding end of life could be a distressing topic for participants, only those who expressed interest in discussing the issue were asked to expand on their thoughts. Currently, little research has examined expectations regarding delirium or end of life. Among the participants whose care recipients have had a delirious episode in the past, they reported that it was a distressing experience. This is a consistent finding in the literature, and caregiver distress is increased particularly if the care recipient experienced hallucinations or marked agitation (Fick et al., 2002). However, these participants also described learning a considerable amount about the signs and symptoms of delirium, such that when the next episode occurred, participants expected to seek immediate help, and to request tests to determine the presence of infections or electrolyte imbalances.

Although the dementia trajectory is relatively well defined, estimating life expectancy is challenging for both health professionals and caregivers (Doberman et al., 2007). Among the bereaved caregivers interviewed, the majority expressed surprise at the seemingly sudden declines in their care recipients even though they were aware that the end of life was near. Although little research has been done on expectations regarding end of life in dementia, Mitchell and colleagues (2009) reported that among caregivers who understood the prognosis and the clinical complications expected in individuals with advanced dementia, their care recipients were significantly less likely to undergo burdensome interventions in the last three months of life, such as parenteral therapy, tube feeding, and hospitalizations. Therefore, a better understanding of expectations and how these cognitions shape end of life decisions may improve end of life and palliative care.

Phase II: Refinement and Development of the Item Bank

Methodological Approach

The purpose of the second phase of this study was to describe the processes used to develop a comprehensive pool of candidate items for measuring expectations, and the step-wise item review conducted to revise the item bank. Because of the paucity of methodological guidance on how to transform qualitative data into questionnaire items, this work is largely exploratory in its attempt to develop a set of methods for generating an item bank. Hence, this section discusses and critically appraises the relationship between the qualitative findings and item development as well as the four-stage approach used to draft the items, systematically categorize them on the basis of their semantic features, revise and reduce the item pool, and conduct cognitive interviews to further refine the item bank.

Qualitative Findings to Item Development

Using qualitative research to inform questionnaire development is considered a quality standard and a key strategy for fostering content validity (Leidy & Vernon, 2008). Methodologists argue that a new questionnaire should further be grounded in a clear conceptual framework that defines the relationships between the domains of the construct being measured (Rothman et al., 2007). Despite these well-meaning imperatives, there is surprisingly little concrete guidance on how to translate qualitative findings into quantifiable items, how to preserve the participants' meanings during this transformation (Fleury, 1993), or how to incorporate a conceptual framework into the interpretation of qualitative data which had been generated inductively. Moreover, the emergence of the thematic framework from the qualitative data essentially results in two separate but

interrelated “blueprints,” and how the conceptual and the thematic come together to shape the construction of items is not well described in the literature (Rothman et al., 2007).

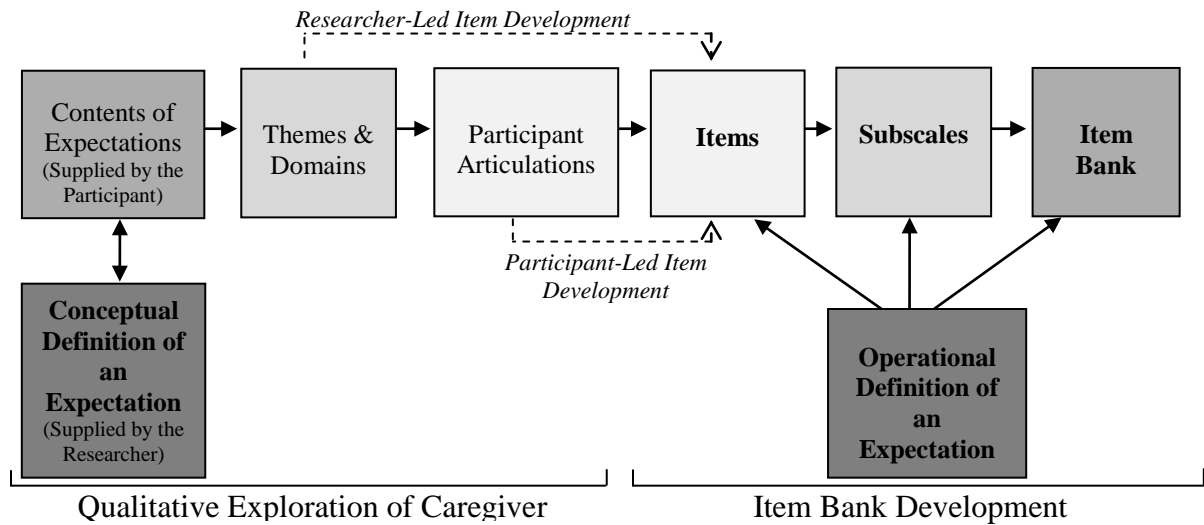


Figure 2: A preliminary model for the development of an item bank

To clarify the relationships between these concepts throughout the course of this study, the researcher developed a simple preliminary model of the process (Figure 2). Working from the premise that exploring an abstract construct like expectations is a socially-constructed enterprise, the conceptual definition and the contents of expectations are contributed interactively by the researcher and the participants from the outset of the data collection. Therefore, the conceptual definition forms the foundation for exploring expectations by way of the interview guide and the lines of questioning used, while the thematic domains arising from the data subsume the totality of articulated caregiver expectations. Mirroring this process, the items derived from the qualitative study form the subscales within the broader item bank. The operational definition of “caregiver expectations” and its measurement should ultimately reflect both the theoretical

properties of expectation and the probability-driven beliefs of caregivers.

Identifying and Drafting Items

The implications of the qualitative approach and the a priori conceptual definition of expectations used to interpret the emergent findings were explored in previous sections of this chapter. Therefore, attention now turns to two issues regarding item development, specifically the theoretical problem of how to draft items while maintaining the conceptual linkage to their thematic domains, and the related practical problem of how to generate the items themselves.

First, the linkage between the qualitative findings and candidate items is largely treated as implicit and unproblematic in the literature. However, I argue that if the purpose of using a qualitative approach is to inductively develop items from the participants' experiences and perspectives as a means of ensuring content validity, then evidence in support of how the items evolved from the thematic findings should be explicitly demonstrated. Nonetheless, in a structured review of 46 articles published in the last two years that described the development of various novel questionnaires using mixed methods, few insights are offered on how to derive items from the qualitative findings. For instance, Spiegel and colleagues (2010) only briefly stated their approach using a single sentence: "Based on the results of the focus groups, a set of candidate items was generated, which formed the basis for the draft instrument" (p. 592). Granted, given the constraints of publication word limits, the reporting of psychometrics and other quantitative components has often taken precedence over the reporting of how items were identified and selected. However, the underreporting of the methods used for item

development not only limits the replicability of the process, but also hinders appraisal and assessment of a questionnaire's content validity.

The second and related issue centers on how to generate the items themselves. In reviewing the aforementioned literature, there appeared to be two general approaches to item development that, in theory at least, enables and preserves the linkages of the items to their thematic roots (Figure 1). The first approach was termed “researcher-led,” and entailed either identifying the core themes of a construct or generating a conceptual model from the qualitative data (e.g., via grounded theory). Informed by this inductive theoretical foundation, the items were drafted by the scale developers to represent and populate each thematic category (Egede & Ellis, 2009; Kassam et al., 2010; Lam et al., 2010). Alternatively, the second method was termed “participant-led.” It also required identifying the key themes from the qualitative data. However, this method attempted to stay closer to the words of the participants by drafting items verbatim using participant articulations drawn from each theme (Meads et al., 2009; Varas-Diaz et al., 2009; Wessels et al., 2009). The current study is more consistent with the latter approach.

For this study, using a participant-led approach to drafting the items was appropriate for three reasons. First, because the concept of an expectation was already well-developed theoretically, using methods such as grounded theory to develop additional conceptual models was viewed as unnecessary. Furthermore, the study sought to identify and measure the subjective beliefs and expectations of caregivers, and generating item stems using the participants' own words would have captured more of their meanings and perspectives. Finally, a participant-led approach appeared to provide a clearer “provenance” regarding the thematic linkages, as the items are developed directly

from participant articulations, which in turn, form the basis of each thematic domain. In retrospect, there was significant appeal to this approach as well as its assertion that items were developed from the participants' own experiences and own words.

However, during the course of the drafting process, it became evident to the researcher that using verbatim extractions was neither always possible nor a practical approach to item generation, contrary to methodological theory (Arranz et al., 2004; Marquis et al., 2005). Uninterrupted segments of participant verbalizations frequently contained multiple expectations, and a one-articulation to one-item correlation rarely occurred. Moreover, interviews are conversation-based. Complex ideas such as expectations were conveyed through a variety of ways, including referentially to earlier aspects of the interview, or more figuratively such as using hyperbole and other rhetorical devices. Therefore, this study required the use of a novel, hybrid approach which combined both a descriptive participant-led approach to glean near-verbatim statements of expectations where possible, with an interpretive researcher-led approach to capture more of the latent or embedded meanings. These challenges highlight the need for more methodological development regarding how to generate questionnaire items from narrative data.

Item Classification, Revision & Reduction

By using a participant-led approach to item development, where every articulated instance of an expectation was transformed into a candidate item, the drafting process produced a large quantity of items with marked repetition. Although other studies have also used verbatim extractions to inform item development, there is sparse guidance on the best practices for evaluating and selecting items for retention in an item bank.

Therefore, an item classification procedure similar to that of DeWalt and colleagues (2007) was developed with the goal of managing the extensive pool in such a manner that would enable the researcher to identify closely related items, determine the sources of variation which would inform the removal of redundant items, and revise the items to reflect their simplest meaning. Based on the classification results, the researcher then eliminated unsuitable or redundant items. Given the close relationship between the item classification and the item revision and reduction, these two phases are discussed together in this section. In particular, issues related to the expectations component of the classification scheme, and the criteria used for removing items, are addressed.

Classification Scheme

To determine the content validity at the item level, a classification scheme was used to assess each item along six dimensions related to dementia caregiving and the tenets of expectancy theory. While classifying the items according to the dementia stage and caregiving domains was relatively uncomplicated, certain nuances in the expectations component of some items made this categorization process more challenging. For example, at the broadest level of *expectations* (i.e., where items were classified as ideal, normative, predictive or general beliefs), items pertaining to worry were more difficult to categorize. By definition, worries are “apprehensive expectations” about experiencing negative future outcomes (Andrews et al., 2010), and at face value, this definition is consistent with a predictive expectation. However, this ‘goodness of fit’ was more problematic when considering worries that were more ‘pathological’ in nature, such as in catastrophic thinking or clinical anxiety disorders (Andrews et al., 2010). In such circumstances, the probability that these adverse events would occur in the future is low,

and yet the beliefs may persist. Thus, pathological worries may be more appropriately categorized as a reverse form of an ideal expectation, that is, a preference-driven belief for the outcome to not occur. These worry items, however, were retained as predictive expectations with the rationale that they could be removed at a later time if their psychometric properties supported their exclusion.

Similarly, at the level of *expectancies* (i.e., where only predictive expectations were further classified as stimulus-outcome, behavioural-outcome, self-efficacy, or response), items containing self-efficacy expectancies were more challenging to identify and classify. Unlike the other types of expectancies where there is a clear future outcome in relation to a specific reference point (e.g., a stimulus or behaviour), self-efficacy expectancies are assessments of one's perceived sense of mastery and the likelihood of achieving specific outcomes based on the individual's current abilities and skill sets (Bandura, 1977). As a result, statements of expected self-efficacy may not necessarily be expressed using a future tense (Shutz, 1932), and often instead employ phrases such as "can" or "will be able to" (Bandura, 2006). Therefore, careful attention was needed not only during the earlier stages of item development, but also during to the classification process to ensure that these candidate items were not excluded because they may have lacked the overt future orientation classically associated with expectations.

Item Revision & Reduction

A broad approach to item exclusion was adopted in order to produce a consistent measure of caregiver expectations. Given the lack of methodological literature for removing poorly-constructed candidate items, the researcher sequentially excluded items using five criteria to ensure construct homogeneity and overall item quality (DeWalt et

al., 2007). Based on the item classification findings, the researcher began by excluding items that did not assess “true” expectations from a predictive orientation, including ideal expectations and normative expectations. In addition, general statements about caregiving that were misclassified as an expectation during the coding process were also excluded. As this study was interested in understanding expectations as probability-driven beliefs regarding future outcomes (Leung et al., 2009b), general statements about caregiving were excluded because they lacked both a future-orientation and probability component. Likewise, ideal expectations which include desires, hopes, and wants (Janzen et al., 2006) were removed as are they based on assessments of preference about future outcomes, which may or *may not* have any probability of their realization (Leung et al., 2009b).

Normative expectations were also excluded, but these beliefs posed an interesting theoretical conundrum. The colloquial use of the term “expectations” often embodies a normative expectations aspect, and the exclusion of these items may reduce the perceived face validity of the item bank. However, normative expectations by definition reflect caregiver perceptions about societal standards and the types of care that ought to be provided rather than what caregivers believe they will probably be able to provide. These normative beliefs were abundantly described in the qualitative data gathered during the first study. For example, Carol described perceiving many normative expectations and experiencing considerable familial pressure to bath her mother-in-law on a daily basis without using Home Care services. This was despite Carol’s reservations regarding the falls risk and her probability-driven expectations that this level of care would be physically difficult for her to manage alone. While these normative beliefs may be important predictors of caregiver wellbeing and depression (Goldsteen et al., 1997), they

ultimately reflect a different construct than predictive expectations and warrant study in their own right.

Cognitive Interviews

Consistent with current methodological theory (DeVillis, 1991; DeWalt et al., 2007), all of the items were subjected to review and revision based on the feedback obtained during interviews with health professionals. These revisions included basic semantic issues such as reducing medical jargon, altering the wording of self-efficacy items from “can” to “will be able to” in order to better capture the nuances of an expectation, and altering language that could have been interpreted as being offensive (e.g., “lie” vs. “dishonesty”).

However, the most substantial revision made to the item bank was the removal of three domains, recognizing that even after the initial item revision and reduction conducted by the researcher, there was still an unfeasibly large pool of candidate items. Based on the suggestions of health professionals, the researcher excluded items related to the diagnostic experience, hospital care, and delirium at this time. Because not every individual with dementia will experience delirium or require hospital care, these items were removed. Furthermore, because only a small subset of caregivers in this sample had experience with delirium and hospital care, additional research using a larger sample of caregivers who were aware of these experiences is needed to further explore and develop items about these topics. In addition, the researcher also removed items related to pre-diagnosis expectations, which enhanced the homogeneity of the item bank by focusing on the beliefs of community-based caregivers with a clear dementia diagnosis. Future research may choose to interview caregivers of people with mild cognitive impairment in

order to fully explore expectations regarding the pre-diagnosis period and risk for dementia in general.

In summary, this section explored the processes used to develop a comprehensive pool of candidate items for measuring expectations of caregivers of people with dementia about the disease and its treatment, and the step-wise item review conducted to revise the item bank. Because of the limited methodological literature on how to develop questionnaire items using qualitative findings, this study sought to discuss the theoretical rationale and implications of the decisions made during the item development process. Thus, the goal of this section was to provide transparency in the methods used to generate the item bank.

Future Directions

Having now developed a preliminary item bank for assessing caregiver expectations, this section discusses possible future research directions and uses for the item bank. First, strategies to further develop the item bank are discussed, such as administering the entire item bank, creating a single computerized adaptive testing bank, or alternatively, generating separate sets of questionnaires to assess each domain of caregiver expectations. Following these discussions on questionnaire development, the ethical and clinical implications of using an expectations questionnaire are considered. Because these items inquire about beliefs regarding the future, there is the potential for certain items to induce thoughts about future events that the caregivers have not yet considered or are not psychosocially ready to contemplate. These items can potentially cause distress, and the ethical considerations are discussed.

Development of the Item Bank

As a multi-dimensional item bank consisting of 235 items, there are a number of options available for further developing the item bank for research or clinical purposes. The first option is to administer the entire item bank to caregivers, which will enable the assessment of the full spectrum of possible expectations. Although this item bank would form a lengthy questionnaire, it would be comparable in size to other well-validated and commonly used tools such as the Child Behavior Checklist (i.e., 118 items) used for assessing pediatric psychopathology (Achenbach et al., 1990), the Revised NEO Personality Inventory (i.e., 240 items) used for measuring personality (Costa & McCrae, 1992) and the Mood and Anxiety Spectrum Scales (i.e., 626 items) used for assessing adult psychopathology (Gibbons et al., 2008). Nonetheless, lengthier questionnaires are associated with increased respondent burden, particularly among elderly respondents (e.g., spousal caregivers) who may require from 21% to 61% more time to complete a lengthy questionnaire compared to younger respondents (Sherbourne & Meredeith, 1992). Furthermore, research has demonstrated that the quality of responses, such as the presence of response sets, and the questionnaire completion rates are negatively correlated with questionnaire length (Galesic & Bosnjak, 2009; Roszkowski & Bean, 1990). Thus, these issues would have implications for establishing the psychometrics and validity of the instrument.

As an alternative, computer adaptive testing bank (CAT) is an increasingly popular method for assessing a diversity of health phenomena using a relatively concise set of questionnaire items. Derived from education testing theory, CAT requires the development of a computer program, which selects items from an item bank that are most

appropriate and relevant for each participant based on their initial responses (Bjorner et al., 2007; Gibbons et al., 2008). Hypothetically, for instance, a caregiver might be asked to input their basic demographic information and the dementia stage of their care recipient. For caregivers of those who have been recently diagnosed with early stage Alzheimer's disease, the relevant items that might be initially presented include expectations about memory declines and instrumental ADLs such as finances and driving cessation. Tentative items related to later stages of Alzheimer's disease, such as expectations related to long-term care, may also be presented to the caregiver. If the caregiver responds as having these expectations then other long-term care items are presented; as a corollary, if caregivers do not hold expectations regarding long-term care, then computer program will "move on" and sample expectations regarding other caregiver domains.

However, CAT is not without limitations as well. First, this process requires considerable expertise in programming the computer software algorithms to respond adaptively to participant responses (Fayers, 2007; Gibbons et al., 2008). In addition, large sample sizes are initially required to establish the psychometrics of the item bank; the domains of the item bank are then divided into parallel forms which require additional validation samples to establish the comparability and reliability of each set (Gibbons et al., 2008). Finally, the psychometric evaluation of item banks frequently uses statistical techniques such as Item Response Theory. In comparison to Classical Test Theory which attempts to quantify the performance of a measure in approximating an individual's *true score* on a specific psychological attribute (e.g., using an Intelligence Quotient [IQ] test to measure an individual's intelligence), Item Response Theory seeks to mathematically

model each item's response as a function of the latent psychological attribute in addition to the parameters representing the item and measurement context (Wilson, 2005). As a result, one limitation to using Item Response Theory is that this technique is most appropriate for assessing unidimensional constructs. Therefore, complex multidimensional concepts such as caregiver expectations might not adequately be modeled statistically (Fayers, 2007).

Finally, another approach is to develop separate questionnaires to assess specific domains of the item bank. For example, one questionnaire might assess expectations regarding driving cessation among caregivers of individuals with early stage dementia, while another independent questionnaire might examine expectations regarding planning for long-term care placement. This parsing out of an item bank is a relatively common procedure, particularly if items are developed inductively using qualitative data as this method tends to produce a large pool of candidate items (Deal et al., 2010; Deal et al., 2011). Moreover, this approach would allow for the use of Classical Test Theory procedures, where the construct validity of the questionnaire could be assessed via exploratory factor analysis using principle components (a premier approach to psychometric evaluation) and standard item analysis procedures (Murphy & Davidshofer, 2003). These procedures will further enable quantitative refinement and estimation of the instrument's reliability and internal consistency (Murphy & Davidshofer, 2003).

Drawing from the findings from the current study, developing a brief questionnaire for assessing expectations regarding long-term care placement, for example, might be a clinically useful tool. First, while most caregivers expect that long-term care may be an inevitable event in the dementia care trajectory, the large majority of

caregivers would prefer to delay placement for as long as possible (Alzheimer's Association, 2011). However, caregivers also acknowledged that with the current shortage of long-term care beds, there would be an expected waiting period between applying for long-term care and finally obtaining placement (Rockwood & Keren, 2010). Moreover, caregivers further expected to experience considerable stress if they wait too long before placement, as they may not be able to adequately care for the individual at home especially if they are already using the maximum available Home Care services and day programs (Morgan et al., 2002). Therefore a dynamic tension exists between these expectations, and a questionnaire may help to identify these beliefs for discussion during a clinical encounter. For example, if the caregiver expects that in the next six months the care recipient will start exhibiting behaviours that often precipitate the need for placement, such wandering and difficulties toileting, then it would be appropriate to initiate discussions about these expectations, and to further assess and advise on these needs.

Ethical Implications

During the interviews with health professionals, a significant ethical issue identified regarding the development of an expectations assessment questionnaire was the potential for causing harm or distress to caregivers. As noted previously, health professionals expressed concerns that because these items would inquire about beliefs regarding the future, potentially, certain items might induce thoughts about future events that the caregivers have not yet considered or are not psychosocially ready to contemplate. These are legitimate concerns, and future research into the psychometric evaluations of these items would need to proceed with caution and due diligence to

participants.

At the fundamental design stage, certain configurations of the item bank or questionnaire might be less likely to cause excess distress; for example, the CAT method of administering questionnaires is sensitive to the response patterns of the participants and only presents items that are relevant to their context and stage of dementia. Similarly, administering a specific questionnaire, such as a measure regarding long-term care expectations to caregivers beginning to contemplate placement may be more appropriate and less likely to cause distress.

Next, at the piloting stage, researchers can determine whether participants find specific questions to be distressing and assess strategies for rephrasing questions to improve clarity and reduce adverse responses. Throughout the research process, participants should be clearly advised that they may stop participating in the research study at anytime and may resume the questionnaire only when and if they feel ready to do so. In the event that they experience emotional discomfort and would like to speak to someone about their feelings, they will be provided with a list of health professionals and the contact information for supportive services through agencies such as the Alzheimer's Society of Calgary.

Limitations of the Study

The first qualitative phase sought to explore the diversity of caregiver expectations regarding the dementia disease progression, the types of health services required throughout the disease trajectory, and the influence of caregiving on health and wellbeing. To our knowledge, this study is one of the first to examine the breadth of dementia-related expectations from the caregivers' perspective. Furthermore,

considerable attention was paid to exploring expectations from a predictive orientation. Because the term “expectations” has colloquially subsumed a variety of meanings including a sense of probability, preference, or perceived deservedness (Thompson & Sunol, 1995), it was important to tease out and clearly define the construct under exploration, as these findings were subsequently used to inform the development of an item bank for measuring predictive expectations only.

However, this study does have limitations. Although the researcher attempted to recruit a participants from a diversity of sources (i.e., community advocacy organization, hospital affiliated geriatrics clinic, and by word of mouth), its data is nonetheless based on a relatively small, volunteer sample of 17 caregivers. As a result, comparisons between different subgroups of caregivers (e.g., ethnicity, primary vs. secondary caregivers, etc) were not feasible. Furthermore, caregivers were recruited from across the disease spectrum, and it might be argued that this approach may have introduced considerable heterogeneity into the results. However, as this work was focused on understanding the scope of caregiver expectations, this sampling strategy helped, rather than hindered, understandings of the diverse beliefs associated with dementia.

Second, to understand the spectrum of expectations from the diagnosis experience to end of life, and to facilitate discussions about an abstract topic like expectations, certain portions of the interview were conducted with participants retrospectively. This process may have introduced some hindsight bias, which is a subconscious tendency for individuals to recollect earlier judgments in such a manner that these beliefs are more consistent with outcomes than would have occurred by chance (Hoffrage et al., 2000). However, the researcher attempted to limit this effect by asking participants whether they

were surprised or had any unmet expectations, which required inducing an active comparison between previous expectations and outcomes. Participants were able to and readily reported any experiences of surprise, which suggested that they were able to identify their earlier expectations, and thus, it appears that the influence of hindsight bias was minimal. Moreover, in qualitative research, it is accepted that while narratives may be shaped by and reinterpreted within the context of each individual's current experiences and understanding of dementia (Denzin & Lincoln, 2003), they can nonetheless provide an understanding of subjective beliefs.

In the second phase of the study, a limitation was that only health professionals participated in the item review process. Although it would have been desirable to have both caregivers and health professionals review the questionnaire items, only health professionals were recruited for the preliminary item review for two reasons. The first was that, as previously mentioned, there was an ethical concern about further burdening already busy caregivers for this review process. Secondly, because these items may become part of a questionnaire for use in clinical settings, it was also important to ascertain whether health professionals could identify additional expectations that were of clinical interest, and worth measuring, but were not identified by the caregivers. While the use of "experts" in lieu of lay reviewers is an accepted methodological practice in instrument development (Brashear et al., 2004; Lonsdale et al., 2008; Sytsma et al., 2001), and was particularly useful for identifying repetitive or ambiguous items and grammatical concerns, this approach may not have identified potential issues from the caregivers' perspectives, such as excessive medical jargon, clarity of items, readability of the item bank, and issues of patient-centric rather than professional concern. The decision

to focus on professional reviewers was largely made in the context of limited time availability for the researcher. However, because the item review process is an iterative procedure which typically requires both qualitative and quantitative assessments (DeWalt et al, 2007), the cognitive interviews conducted with health professionals may be viewed as the first steps to refining and revising the item bank. Future development of this item bank should include lay reviewers alongside the professional ones.

Moreover, a considerable limitation was that judgments regarding the classification of items, and subsequently, the removal of items were decided by the researcher alone. This may have introduced an observer bias and a selection bias in the selection process. A more robust approach would have been to have at least another judge categorize each candidate item using the aforementioned classification scheme, and to rate each item for inclusion or retention. A dual-person assessment of the items would have revealed areas of disagreement, which could have led to revision and improvement of the item classification and exclusion criteria, and could have led to the retention of more suitable items. Furthermore, the level of agreement could be quantified using procedures such as a kappa statistic, which would have provided greater transparency regarding of the level of standardization in the item development procedure.

CONCLUDING REMARKS

This project sought to explore the concept of caregiver expectations, and in turn, to develop an item bank for measuring these beliefs. Based on the narratives of 17 caregivers, the researcher identified a number of expectations that spanned the caregiving career and reflected the anticipated disease progression of dementia. This included obtaining a dementia diagnosis, managing memory and cognitive declines, addressing

concerns regarding driving cessation, managing changes in basic ADLs, and finally contemplating end of life care. A recurrent motif throughout the domains was that specific expectations were held regarding the types and amounts of health services that would become needed as the dementia progresses. In particular, health professionals played an important role in providing information about the diagnosis, treatment options, and the likely disease trajectory of dementia. However, as there are inherent uncertainties in the future, predicting the rates of cognitive change during the early stages of the disease, and the likely life expectancy for individuals at the end of life, was difficult.

Informed by these domains of caregiver expectations, the objective of the second phase of the research was to develop a comprehensive pool of candidate items for measuring expectations. During this process, it became evident to the researcher that the lack of methodological guidance on how to transform the qualitative findings into questionnaire items was a significant limitation. Thus, the second phase attempted to describe a possible set of procedures for drafting candidate items using qualitative data, and a procedure for conducting step-wise item review to revise and refine the item bank. Although this work was largely exploratory, and despite its limitations, the end products of this thesis were a qualitative identification and interpretation of the health expectations of caregivers, as well as a preliminary item bank for assessing these expectations with evidence to support its content validity. These findings add to our current understanding of dementia-related expectations from a person-centered perspective.

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APPENDIX A: SEMI STRUCTURED INTERVIEW FOR CAREGIVERS

Introduction

- Please introduce yourself, and tell us a little about why you have decided to participate in the interview today?

Caregiver Experiences & Health Status Expectations

- What kinds of help do you currently provide to your care recipient?
- Thinking about the next year, what health changes do you expect your care recipient will have?
Potential probe questions:
 - a. How do you expect their memory will change?
 - b. Do you expect any changes in their current abilities to take care of themselves? (e.g., grocery shopping, personal care, basic activities of daily living depending on the patient's stage of dementia)?
- What kinds of additional help will you need to provide to them in the next year?

Health Care Expectations

- What health professionals are your care recipients currently seeing (e.g., family doctor, specialists, nurses, home care, social workers)?
Potential probe questions:
 - a. What do you expect from the doctor when the care recipient goes to see him/her?
 - b. In what ways will the doctor help them in the next year?
 - c. What other health services will they need in the next year?
- Is your care recipient currently taking medication for their memory problem?
Potential probe questions:
 - a. What will these medications do for them?
 - b. If currently taking them: How will these drugs benefit them?
 - c. If currently not taking them: Do you expect that they will take them in the future?
- What health professionals are currently working with you in your role as caregiver (e.g., family doctor, specialists, nurses, social workers, support counselors)?
Potential probe questions:
 - a. What do you expect from these health professionals when you see them?
 - b. In what ways will they help you in the next year?
 - c. What other health services will you might need in the next year?
- Have you experienced any changes to your own health as the result of caregiving?
Potential probe questions:

- a. Do you expect your level of stress to change in the next year?
- b. In your opinion, what are some of the long-term health consequences or benefits of caregiving?
- c. What ways do you use to cope? Will these coping strategies change in the future?

Lifestyle

- How do you think your care recipient's lifestyle change in the next year?
Potential probe questions:
 - a. What are your expectations regarding their driving?
 - b. What are your expectations regarding their work?
 - c. What are your expectations regarding their leisure activity?
 - d. What are your expectations about their social life?
 - e. Do you expect they might need to relocate/move?
 - f. Do you expect their independence will change?
- As a caregiver, how will your own lifestyle change in the next year?
Potential probe questions:
 - a. Has caregiving affected your current relationships in positive or negative ways?
 - b. How will these relationships change in the next year?
 - c. Has caregiving affected your work/leisure/social life?
 - d. Do you think it might affect your work/leisure/social life in the next year?

Caregiving Role

- As a caregiver, what are your expectations for yourself?
Potential probe questions:
 - a. Do you receive enough help from others (e.g., family members and friends)?
 - b. What sort of help will you need from others in the next year?
 - c. Do you receive enough social support from others?
 - d. What sort of support will you need from others in the next year?

Final Comments

- For this discussion, we wanted to learn what people thought about their medical care. Is there anything that we missed?
- Is there anything else that you would like to say but didn't get a chance to?

APPENDIX B: INITIAL ITEM REVIEW QUESTIONS

- Please introduce yourself and tell us a little bit about yourself.
- In terms of the physical presentation of this questionnaire, is it easy to read?
Potential probe question:
 - c. Is the font large enough?
- Are the instructions clearly written? If not, what are some of the issues with the instructions?
Potential probe question:
 - a. Do you have any recommendations for improving the clarity of the instructions?
- Is each question clear? If not, what are the issues with the questions?
Potential probe question:
 - a. Do you have any recommendations for improving the clarity of the questions?
 - b. Is there any terminology that was difficult to understand?
- Do you feel these questions are suitable and appropriate to ask caregivers? If not, which question, and what are some of the issues with that question?
Potential probe question:
 - a. Do you have any recommendations for improving the suitability of the questions?
- Are there any questions that you feel should have been asked, but were not? If so, what are they?
- Overall, did you have any difficulty responding to this questionnaire?
- Is there anything else that you would like to say but didn't get a chance?

APPENDIX C: ITEMS INCLUDED IN THE PRELIMINARY ITEM BANK

I. Expectations of the Disease Progression & Person with Dementia

Expectations about the Disease Progression

1. His/her symptoms will be stable.
2. His/her short-term memory will improve slightly.
3. He/she will feel depressed or anxious about their problems.
4. He/she will come to terms with their diagnosis.
5. He/she will do well on memory tests, but will still have behavior troubles.
6. He/she will forget conversations within minutes.
7. He/she will become more confused.
8. He/she will continue to enjoy his/her life.
9. He/she will be able to pick the proper clothes and dress himself/herself.
10. He/she will forget to write things down on the calendar.
11. He/she will need help with finances.
12. His/her long term memory will continue to be fine.
13. He/she will still be able to make snacks for himself/herself.
14. It will no longer be safe for him/her to use the stove.
15. Sometimes a noisy environment will increase his/her confusion and agitation.
16. As the dementia progresses, the person with dementia will start living in the past.
17. Sometimes it can be positive when the person with dementia forgets about his/her worries and odd beliefs.
18. He/she will become more easygoing.
19. He/she will need more rest as the dementia progresses.
20. He/she will cling to me.
21. He/she will want the family to visit every day.
22. He/she will say or ask the same things over and over again.
23. He/she will be friendly and polite.
24. He/she will get annoyed with me if I stay too long with him/her.
25. He/she will become very possessive of their belongings.
26. He/she will tell different things to different family members.
27. He/she will think that I am bullying him/her.
28. He/she will require constant care and supervision.
29. He/she will sometimes forget to eat.
30. He/she will sometimes start saying inappropriate or offensive things.
31. He/she will behave unpredictably.
32. I worry that he/she will hit someone.
33. He/she will become argumentative.
34. His/her incontinence will come and go.
35. The person with dementia will be completely incontinent.
36. He/she will no longer remember where home is.
37. His/her walking will be affected by dementia.
38. The person with dementia will have trouble sleeping through the night.
39. He/she will start wandering.
40. If the person with dementia gets lost, we will have to call the police.

41. When the person starts wandering at night, I know it will be time to consider a nursing home.
42. As long as the person with dementia is safe, I will let him/her wander the house until they tire.
43. He/she will forget family members.
44. The person with dementia will still be happy.
45. It will no longer be safe for him/her to live at home.
46. He/she will need help with feeding.
47. He/she will need help with bathing.
48. He/she will not be able to chew and swallow food.
49. He/she will lose the ability to talk.
50. He/she will pass away.

Driving Cessation

51. The person with dementia will receive a fair assessment of his/her driving abilities.
52. I worry that the person with dementia will get into a car accident.
53. The doctor will take away his/her driving license.
54. I worry that the person with dementia will not remember that they're not allowed to drive anymore.

Falls Risk

55. I worry about the person with dementia falling and hurting himself/herself.
56. If the person with dementia breaks a bone after falling, they will need to be hospitalized.
57. It will take months for the person with dementia to recover after a fall.
58. If the person with dementia falls, I will want him/her to get as much physiotherapy as possible.

Uncertain Expectations/Miscellaneous Expectations

59. I have come to expect the unexpected with this disease.
60. Because of the fluctuating symptoms, it's hard to predict how the person with dementia will be from day to day.
61. It's hard to say how long the person with dementia will live with the disease.
62. The dementia is progressing quicker than I anticipated.
63. Other chronic problems will affect the health of the person with dementia.
64. The health of the person with dementia can change in an instant.
65. It will be good for the person with dementia to look at photos and remember the good times.

II. Expectations of Health Services

Physicians

66. I can't find a family doctor who is willing to take care of the person with dementia.
67. The family doctor will be too busy to talk to me about caregiving stress.
68. It will not be the family doctor's job to listen to me complain about caregiving.
69. Sometimes the person with dementia will forget what the family doctor's has said.
70. I will attend doctor's appointments with the person with dementia.

71. The doctor will tell me about medications for dementia.
72. My family doctor is patient and will always listen to what the person with dementia has to say.
73. My family doctor will know about the dementia services available in the city.
74. My doctor will try to get both sides of the story from the person with dementia and myself.
75. It will be difficult to get help from doctors until a crisis happens.
76. The person with dementia will need to do worse on tests so that we will qualify for help.
77. Doctors will be compassionate about the challenges that the person with dementia and their caregivers face.
78. When doing assessments, doctors and nurses will take into consideration the day-to-day fluctuations in dementia symptoms.
79. Doctors and nurses will negatively judge me as a caregiver.
80. If doctors and nurses are not patient enough, the person with dementia will become aggressive and agitated.
81. Caring doctors and nurses will make all the difference for people with dementia.
82. I will need to know what kinds of changes will happen to the person with dementia.
83. I will need to know when the symptoms will worsen in the person with dementia.
84. Someone will tell me about the services available to help the person with dementia.
85. I will need a referral to see a counselor or social worker for my stress.
86. I will need some grief counseling when the person with dementia passes away.
87. It will be at least six months before we will get an appointment with a specialist doctor for dementia.
88. It will be difficult to get a hold of the specialist doctor when I have sudden questions about dementia.

Day Program

89. The wait lists will be long for the Day Program.
90. If the person with dementia will attend a Day Program, then I will get some time to myself.
91. The person with dementia will enjoy going to the Day Program.

Home Care

92. We will not need help from Home Care yet.
93. Because of the long wait lists, it will be best to apply early for Home Care.
94. The person with dementia will get an accurate assessment of their need for Home Care.
95. Home care should assess the family's needs too when deciding what services to provide.
96. It will take time for the person with dementia to accept help from Home Care.
97. I feel that Home Care will be less willing to come to low-income neighborhoods to help the person with dementia in their home.
98. It will be hard to get the same Home Care worker to come each time.
99. Having the same Home Care worker will help the person with dementia feel more comfortable.
100. I worry whether the person with dementia will let Home Care bathe him/her.
101. The person with dementia will look forward to visits from Home Care workers.

102. Some Home Care companions do not know how to interact with the person with dementia.
103. Some Home Care workers need more training about dementia.
104. Sometimes the person with dementia will not be honest with Home Care nurse about his/her needs.
105. The Home Care worker will be willing to learn about what strategies work with the person with dementia.
106. The Home Care workers will call me if they have concerns about the person with dementia.

Medications

107. Activities and socializing will be more beneficial to the person with dementia than medications.
108. It will be too late to start the person with dementia on medication for their dementia.
109. As long as the person with dementia is still able to walk and eat on their own, I will continue to give him/her dementia medication.
110. The dementia medication will keep the person with dementia at the same level for a year or two year.
111. The dementia medication will improve the dementia symptoms.
112. The dementia medication will cause side effects.
113. The person with dementia will not get dementia medication because they've had strokes and not Alzheimer's disease.
114. I worry that the person with dementia will take the wrong dose of their medications.
115. The person with dementia will need Home Care to come in and give the medications.
116. Herbal medications and vitamins will help dementia symptoms.
117. I will hide the person with dementia's medication in their food to get him/her to take it.
118. The person with dementia will get a fair evaluation before receiving anti-psychotic medication.
119. Anti-psychotic medication will help manage the person's aggression and emotional outbursts.
120. If the person with dementia is in a calming environment, then he/she will not need so much anti-psychotic medication.
121. If the person with dementia is labeled as aggressive in the nursing home, they may start sedating him/her.
122. Sometimes too much medication will make the person with dementia sluggish and his/her symptoms worse.
123. The nurses and doctors will medicate the person with dementia rather than taking time to find out what's wrong and fix the problems.
124. There will be major breakthroughs in treating dementia in the next ten years.

Assisted Living/Nursing Home

125. There will be a long wait list for the Assisted Living or nursing home facility that I want.
126. I don't know who I will call to learn more about Assisted Living or nursing home options.
127. I will not send the person with dementia to an Assisted Living facility.
128. Assisted Living will be expensive.

129. I will include the person with dementia when looking for an Assisted Living facility.
130. I prefer an Assisted Living facility with many levels of care so that the person with dementia can remain there even when the disease worsens.
131. I will choose an Assisted Living facility that allows the person with dementia and his/her spouse to live together.
132. Because of the long wait lists, I will not be able to choose a nursing home specifically for dementia.
133. Whether we will get into a nursing home is all dependent on the assessment by Home Care.
134. I don't know where to find services to bridge our current needs while we wait for a nursing home spot.
135. The person with dementia will need to be placed in a nursing home soon.
136. It is important to tell that person with dementia that they will need to go to the nursing home.
137. The person with dementia will blame me for putting him/her into a nursing home.
138. The person with dementia will adapt quickly to living in a nursing home.
139. The person with dementia will not like having a roommate at the nursing home.
140. It will be boring for the person with dementia in the nursing home.
141. The person with dementia will enjoy outings from the nursing home.
142. The person with dementia will function better in the nursing home.
143. Sometimes it will be difficult for me to visit the person with dementia in the nursing home.
144. There will be a lot of people who will visit him/her in the nursing home.
145. When it is snowy and cold, I will feel bad about not visiting the nursing home.
146. I want the person with dementia to be transferred to a private room or newer wing of the nursing home.
147. I want the person with dementia to move to our preferred nursing home as soon as there is a bed.
148. If the person with dementia is happy in his/her current nursing home, I will not move him/her to our preferred facility.
149. Caring nurses and aids will help keep the person with dementia calm and content.
150. I worry that other nursing home residents will steal things from the person with dementia.
151. There will not be enough nurses at the nursing home.
152. The nursing home staff will listen to my concerns and act on them.
153. The nursing home staff will have a limited amount of time to feed and dress the person with dementia.
154. The physiotherapists do the best they can, but they will not have enough time to help the person with dementia every day.

III.Expectations of Caregiving, Stress & Coping

Caregiving Tasks

155. I will try to shield the person with dementia from the diagnosis.
156. I will need to learn more about how to take care of the person with dementia.
157. I will sometimes cover-up for the person with dementia.
158. I will value the time that I spend with the person with dementia.

159. The person with dementia expects me to call him/her all the time.
160. I will have to help the person with dementia with shopping.
161. I will have to help the person with dementia with their taxes and finances.
162. I don't know how I will pay for health insurance for things like ambulances.
163. I will cook a lot of the meals for the person with dementia.
164. Having Meals on Wheels will be helpful.
165. Sometimes the person with dementia will not want to eat Meals on Wheels.
166. I will have to change the door locks and the water taps to keep the person with dementia safe.
167. It will be easier to just go along with what the person with dementia thinks rather than correcting him/her all the time.
168. I will try to correct the person with dementia because I don't want him/her to get more confused.
169. If I have been dedicating too much time helping the person with dementia, my other family members will tell me.
170. Taking care of the person with dementia takes away from the time I should be spending with my family and friends.
171. The person with dementia will come and live with me.
172. It will be hard taking over the tasks that the person with dementia used to do.
173. It will be very difficult for me to bathe the person with dementia.
174. I will get an identification bracelet for the person with dementia in case they get lost.
175. It will become hard to trust what the person with dementia says because he/she forgets and makes things up.
176. My family will understand that I have to spend a lot of time helping the person with dementia.
177. Sometimes I will run out of things to do or say with the person with dementia.
178. Distracting the person with dementia sometimes helps.
179. After a difficult day, sometimes putting the person with dementia to bed earlier will help.
180. I will set a good example for my kids so that they will be willing to take care of me when I am older.
181. I can't leave the person with dementia alone because of safety reasons.
182. I will have to take care of the person with dementia at home until there is a bed available at the nursing home.
183. Part of me will feel relieved when the person with dementia passes away.

Caregiver Health/Stress

184. Caregiving will negatively affect my physical health.
185. If things don't change, I will burn out.
186. I will find caregiving stressful.
187. I will say that I will make time for myself, but I rarely do.
188. I will take breaks when I take care of the person with dementia.
189. I don't exercise enough because I am too tired from work/school and caregiving.
190. I will be stressed if the person with dementia gets sick.
191. Even though the person with dementia is in a nursing home, the stress will never really go away.
192. I will not be able to relax when the person with dementia is around.

- 193. At night I will not sleep well because I'm listening for the person with dementia.
- 194. It will bother me when the person with dementia asks me the same things over and over again.
- 195. It will hurt my feelings when the person with dementia doesn't remember that I've visited or brought a gift.
- 196. I will grieve the changes in the person with dementia.
- 197. I will get community services and support resources when I am ready.
- 198. I will not judge myself too harshly.
- 199. Sometimes my family will have arguments about caregiving.
- 200. I know that my family will work out conflicts about caregiving.
- 201. I don't expect my family to put in the same amount of time caregiving as I do.
- 202. I will set reasonable boundaries with my family on how much caregiving that I will do.

Power of Attorney/Advanced Directives

- 203. The person with dementia will get a personal directive and an enduring power of attorney.
- 204. I do not know how to activate a power of attorney.
- 205. I worry that the doctors will declare that the person with dementia lacks capacity when he/she can still make decisions.

Self-Efficacy Expectations

- 206. Because the person with dementia is stable for now, I don't want to think about the future right now.
- 207. I feel controlled by my family's expectations about the things I ought to do for the person with dementia.
- 208. The bar is set too high for my family to access health services and help.
- 209. I have to prepare myself for the challenges that are coming.
- 210. I don't know where to find health services and help for the person with dementia.
- 211. I worry about whether I'm doing the right thing as a caregiver.
- 212. It is hard to know which doctors and resources the person with dementia should see and use.
- 213. Knowing more about how the disease will progress will give me a greater sense of control.
- 214. Sometimes I will question the decisions that I've made as a caregiver.

Social Support Expectations

- 215. Family and friends will not want to visit the person with dementia.
- 216. Friends will not want to hear about my caregiving problems or about dementia.
- 217. I can't ask my friends to look after the person with dementia because I don't know how he/she will behave.
- 218. If I get too stressed then I will tell my family.
- 219. My family and friends will offer to sit with the person with dementia so I can get a few hours off.
- 220. My family and friends will be sympathetic and understanding.
- 221. The neighbors will help me keep an eye on the person with dementia.
- 222. The person with dementia doesn't want to tell anyone about their dementia because he/she is worried about losing friends.

Alzheimer's Society/Support Groups

- 223. The Alzheimer's Society will not be helpful because the person was diagnosed with dementia and not Alzheimer's disease.
- 224. My family will not want to go to the Alzheimer's Society to learn more about dementia.
- 225. My family doctor will refer the person with dementia and my family to the Alzheimer's Society and/or support groups.
- 226. I will go to a support group when I feel ready.
- 227. I will learn new tips on how to manage the person with dementia by going to support groups.
- 228. Only other dementia caregivers will truly understand my concerns and challenges.

Respite/Vacation

- 229. I want to do more travelling but it will be difficult leaving the person with dementia.
- 230. I will find time to meet with friends and relax.
- 231. I will make time to go on vacation and get some rest from caregiving.
- 232. I worry that if I go on vacation, I will have to rush back half-way because of an emergency.
- 233. I worry about how the person with dementia will behave in respite care if I were to go on vacation.
- 234. It takes time to find respite care so that I can go on vacation.
- 235. Once the person with dementia is in the nursing home, then I will go on vacation.

APPENDIX D: CONSENT FORMS



DEPARTMENT OF FAMILY MEDICINE
Primary Care Research & Development Group

#1635, 1632 – 14th Ave. NW
Calgary, AB, Canada T2N 1M7

T 403.210-9246

F 403.270-4329

ndrummon@ucalgary.ca

Consent Form - Caregivers

TITLE: Towards the development of an expectations assessment instrument for caregivers of people with Alzheimer's disease and related dementias: A pilot study

SPONSOR: Canadian Institutes of Health Research (CIHR)

INVESTIGATORS: Neil Drummond, Misha Eliasziw, Candace Konnert, Jim Silvius, Karen Leung

Neil Drummond (Principal Investigator): (403) 210-9246
Karen Leung (Research Coordinator): (403) 210-9259

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND

Caregivers play a critical role in dementia care process. To ensure effective healthcare, understanding and responding to caregiver expectations about the disease progression and health care is necessary. Health expectations are a person's beliefs that certain events are likely to occur during or as the result of medical care. These personal beliefs can influence how a person views and reacts to a diagnosis, treatment, and medical outcomes. As a result, a person's expectations can affect patient-caregiver-doctor relationships.

Despite the importance of assessing caregiver expectations in medical care, no clinical support tool exists that will help doctors identify key expectations for discussion during medical visits. This study seeks to learn what expectations caregivers have, and then to create a clinical support tool for use during medical visits.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to identify a comprehensive list of caregiver expectations regarding the progression of dementia and healthcare. With this list of expectations, we hope to develop an instrument that will help medical personnel better assess these expectations.

WHAT WOULD I HAVE TO DO?

You will be asked to participate in two focus groups, which are informal discussion groups about a particular topic. These focus groups will be audio-taped.

The first focus group will be with four other participants who are also caregivers, and we will ask you to describe your expectations regarding the patient's health and health care in 12 month's time. We will also be inquiring about your own health and health care in relation to your role as a caregiver. This focus group will take approximately 1 hour and 30 minutes to complete.

The second focus group will occur approximately 3 months after the first focus group. We will ask you to discuss whether the questions in our questionnaire are suitable, clear, and appropriate. This focus group will take approximately 45 minutes to complete.

You will also be asked to permit the research coordinator to obtain background information, such as your age, gender, and cultural background.

WHAT ARE THE RISKS?

There is minimal risk to you if you should choose to participate in this study, except the disclosure of your thoughts and feelings, and the time taken for the discussion. This study seeks to learn what expectations caregivers have of the patient's health and health care, their own health and health care in relation to their role as caregiver, and to elicit feedback regarding potential items on our questionnaire. You may experience some emotional discomfort when discussing your expectations; if at any time this happens, you may stop participating and resume only when and if you feel you are ready to do so. In the event that you experience distress and feel you need to talk to anyone about your feelings, you can speak to any of the researchers.

WILL I BENEFIT IF I TAKE PART?

If you agree to participate in this study there may or may not be a direct benefit to you. If you are in the study because you have been identified as having a disease, your condition may be improved during the study but there is no guarantee that this research will help you. The information we get from this study may help us to improve care in the future for individuals with Alzheimer's disease.

DO I HAVE TO PARTICIPATE?

It is important to note that your expression of interest does not obligate you to participate in the current study. Furthermore, should you wish to participate, you may withdraw from the study at anytime by notifying the researchers. Should new information become available that may affect your willingness to participate, the researchers will inform you as soon as possible.

WHAT ELSE DOES MY PARTICIPATION INVOLVE?

No further activities are required beyond what has already been described.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

There are no monetary costs associated with this study. Please note, you will not be paid for your participation.

WILL MY RECORDS BE KEPT PRIVATE?

Only members of the research team will have access to the information. The information we report will be anonymous and consist of responses from groups of people, and not individuals. All interview recordings will be stored in a locked filing cabinet in locked and alarmed accommodation at the Primary Care Research and Development Group offices at the University of Calgary. All transcripts will be stored in a separate locked filing cabinet, and will be destroyed 20 years after publication.

IF I SUFFER A RESEARCH-RELATED INJURY, WILL I BE COMPENSATED?

In the event that you suffer injury as a result of participating in this research, no compensation will be provided to you by CIHR, the University of Calgary, the Calgary Health Region or the Researchers. You still have all your legal rights. Nothing said in this consent form alters your right to seek damages.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Neil Drummond (403) 210-9246

Or

Karen Leung (403) 210-9259

If you have any questions concerning your rights as a possible participant in this research, please contact The Chair of the Conjoint Health Research Ethics Board at the Office of Medical Bioethics, 403-220-7990.

PARTICIPANT'S NAME

SIGNATURE AND DATE

INVESTIGATOR/DELEGATE'S
NAME

SIGNATURE AND DATE

WITNESS' NAME

SIGNATURE AND DATE

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.



FACULTY OF MEDICINE | UNIVERSITY OF CALGARY

DEPARTMENT OF FAMILY MEDICINE
Primary Care Research & Development Group
#1635, 1632 – 14th Ave. NW
Calgary, AB, Canada T2N 1M7
T 403.210-9246
F 403.270-4329
ndrummon@ucalgary.ca

Consent Form – Health Professionals

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SPONSOR: Canadian Institutes of Health Research (CIHR)

INVESTIGATORS: Neil Drummond, Misha Eliasziw, Candace Konnert, Jim Silvius, Karen Leung

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We will ask you to discuss whether the questions in our questionnaire are suitable, clear, and appropriate. This focus group will take approximately 45 minutes to complete.

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WILL I BENEFIT IF I TAKE PART?

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WHAT ELSE DOES MY PARTICIPATION INVOLVE?

No further activities are required beyond what has already been described.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

There are no monetary costs associated with this study. Please note, you will not be paid for your participation.

WILL MY RECORDS BE KEPT PRIVATE?

Only members of the research team will have access to the information. The information we report will be anonymous and consist of responses from groups of people, and not individuals. All interview recordings will be stored in a locked filing cabinet in locked and alarmed accommodation at the Primary Care Research and Development Group offices at the University of Calgary. All transcripts will be stored in a separate locked filing cabinet, and will be destroyed 20 years after publication.

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SIGNATURES

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Dr. Neil Drummond (403) 210-9246

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SIGNATURE AND DATE

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