

Running head: PSYCHOSOCIAL NEEDS WITHIN NURSING HOMES

Psychosocial Needs within Nursing Homes: Perspectives of Family Members, Staff, and
Residents

By

Julie Erickson

A Thesis submitted to the Faculty of Graduate Studies of the University of Manitoba in
partial fulfillment of the requirements of the degree of

DOCTOR OF PHILOSOPHY

Department of Psychology

University of Manitoba

Winnipeg

Copyright © 2017 by Julie Erickson

Acknowledgements

This dissertation could not have been completed without the support from numerous individuals and organizations. Thank-you to my coadvisors, Drs. Malcolm Doupe and Corey Mackenzie, for their guidance, mentorship, and support over the past several years. Thank-you to Drs. Dan Bailis, Judith Chipperfield and Genevieve Thompson for their valuable input as members of the internal committee. I also gratefully acknowledge the financial support provided by Research Manitoba (Graduate Studentship), the University of Manitoba (Graduate Fellowship), the Department of Psychology (Direct Aid to Achieve Award), the Centre on Aging (Esther & Samuel Milmot Scholarship and the Barbara Jean Payne Memorial Award in Social Gerontology), and the Translating Research in Elder Care Program (trainee fellowship). Thank-you to Lindsay Berard, Jack Friesen, Melanie Gumbs, Sara Reid, and Alana Kull for their assistance with various aspects of participant recruitment, data collection and analysis. Thank-you to Ms. Candice Letkeman for her copyediting services. Finally, a heartfelt thank-you to my Winnipeg, Edmonton, and Toronto “families” for support that was provided in many in different forms throughout my graduate training. I could not have completed this dissertation without your kindness, encouragement, and steady dose of humour.

Table of Contents

Abstract.....	9-10
General Introduction.....	11-28
Background.....	12-23
Population Aging.....	12-13
Aging Societies and the Demand for Nursing Home Care.....	13-14
Medical Needs of Nursing Home Residents.....	14-15
The Changing Scope of Nursing Home Care.....	15-17
Models of Psychological and Social Need.....	17-22
Psychological Well-Being.....	19-20
Socioemotional Selectivity Theory.....	20-21
Self-Determination Theory.....	21
Social Production Functions.....	22
Psychological and Social Well-Being in Nursing Homes.....	22-24
Gaps in the Literature.....	24-27
Research Objectives.....	27-28
Phase One: List Development and Validation.....	28-38
Introduction.....	28-29
Method.....	29-32
Results.....	32-36
Discussion.....	36-38
Phase Two: Delphi Survey for Residents with Dementia.....	38-74
Introduction.....	38

Method.....	38-46
Results.....	46-70
Discussion.....	70-74
Phase Three: Pilot Survey for Residents without Dementia.....	74-82
Introduction.....	74
Method.....	74-77
Results.....	77-82
Discussion.....	82
Phase Four: Focus Group with Staff.....	83-106
Introduction.....	83
Method.....	83-86
Results.....	86-107
Discussion.....	107-108
General Discussion.....	108-140
Limitations.....	126-133
Implications for Research and Practice.....	133-141
Conclusion.....	141-143
References.....	144-171
Appendices.....	172-212

Tables

Table 1. Initial and Revised Psychosocial Needs Following Phase One.....	35-36
Table 2. Cross Tabulation of Cognitive Performance Scale Scores with DSRS Scores.....	43
Table 3. Phase Two Participant Demographics.....	48-49
Table 4. Round 1 of the Delphi Survey with the Dementia Group: Rated Importance of Psychosocial Needs for Resident Well-Being,,.....	51-53
Table 5. Round 1 of Delphi Survey with the Dementia Group: Rated Impact of Psychosocial Needs for Residents' Stay in Nursing Home.....	55-57
Table 6. Round 2 of the Delphi Survey with the Dementia Group: Rated Importance of Psychosocial Needs for Resident Well-Being.....	59-61
Table 7. Round 2 of the Delphi Survey with the Dementia Group: Rated Impact of Psychosocial Needs for Residents' Stay in Nursing Home.....	63-65
Table 8. Psychosocial Needs for NH Residents with Dementia after First and Second Delphi.....	66-67
Table 9. Phase Three Participant Demographics.....	78-79
Table 10. Final list of Psychosocial Needs for Residents without versus with Dementia.....	81-82
Table 11. Round 1 of Delphi Survey with the No-Dementia Group: Rated Importance of Psychosocial Needs for Resident Well-Being.....	196-198
Table 12. Round 1 of the Delphi Survey with the No-Dementia Group: Rated Impact of Psychosocial Needs for Residents' Stay in Nursing Home.....	201-202

Table 13. Round 2 of the Delphi Survey with the No-Dementia Group: Rated Importance of Psychosocial Needs for Resident Well-Being.....	204-206
Table 14. Round 2 of the Delphi Survey with the No-Dementia Group: Rated Impact of Psychosocial Needs for Residents' Stay in Nursing Home.....	208-210

Figures

Figure 1. Format of Delphi Survey Items.....44

Figure 2. Summary of Psychosocial Needs for Residents with Dementia.....72

Figure 3. Participant Recruitment for Phases Two and Three.....76

Figure 4. Summary of Articulated Data from Staff Focus Group.....86-87

The terror of sickness and old age is not merely the terror of losses one is forced to endure but also the terror of isolation. As people become aware of the finitude of their life, they do not ask for much. They do not seek more riches. They do not seek more power. They ask only to be permitted, insofar as possible, to keep shaping the story of their life in the world--to make choices and sustain connections to others according to their own priorities. In modern society, we have come to assume that debility and dependence rule out such autonomy. What I have learned . . . is that this is very much possible.

-Atul Gawande, "Being Mortal," p. 146-147.

Abstract

Growth in the number of older Canadians (i.e., those age 65 and older) has brought nursing home (NH) care into sharper focus. Although the physical health needs of NH residents are well described, less is known about which psychological and social needs are important to this population. The objectives of this dissertation are to: (a) develop and content validate a list of psychosocial needs relevant to NH residents that is informed by theory and their experiences, (b) use the developed list of needs and the perspectives of family members to determine which psychosocial needs are most important to residents with dementia and to a preliminary extent, residents without dementia, and (c) begin to understand how NH staff are enabled or hindered in meeting NH residents' psychosocial needs. A comprehensive literature review and focus group with NH residents ($n = 5$) informed the development of the initial list of psychosocial needs. A Delphi survey administered through both a mailing and an online format with family members ($n = 34$) was used to establish consensus about which of these psychosocial needs were essential for NH residents with dementia. From the initial list of 25 psychosocial needs, family members of residents identified 16 needs that are highly important for residents with dementia. These needs can be grouped into the categories of choice and control, personal effectiveness, social connection, fun and pleasure, and self-acceptance. Six of these needs were identified by family members as being essential for resident well-being, which were grouped into the categories of choice and control (choice to accept or decline help from others), personal effectiveness (perceiving that staff are responsive to requests, access to devices that increase independence, and opportunities to talk with staff about care), and social connection (opportunities to maintain relationships

with friends and family outside the nursing home, and warm and caring exchanges with staff). There was considerable overlap between the essential psychosocial needs for residents with dementia and a small sample of residents without dementia. Further, these needs are closely aligned with Self Determination Theory (Ryan & Deci, 2000). The results of the Delphi survey informed a follow-up focus group with NH staff ($n = 10$) to better understand the strategies they use to help residents meet their psychosocial needs, as well as the challenges they encounter when trying to do so. Staff perceived that providing person-centred and individualized care, as well as engaging in their own self-care, facilitates residents' psychosocial well-being. Staff perceived that residents' psychosocial needs are met though exercising choice and control wherever possible. Safety concerns, lack of time, and conflict with family members were some of the challenges identified by staff in helping residents to meet their needs. NH facilities are encouraged to explore how to support staff members' efforts to meet these needs and minimize the barriers identified in this research. Smaller staff–resident ratios and additional staff training and education are two of several possible strategies to support staff in meeting residents' psychosocial needs. The results of this study can help advance our knowledge of NH residents' psychosocial needs and the role that staff members play in meeting these needs. Collectively, these findings are consistent with a person-centred philosophy of NH care. They also underscore the importance of future research examining effective interventions to address nursing home residents' psychological and social needs, especially those related to choice and control, personal effectiveness, and social connection. This information will be helpful for optimizing nursing home residents' mental health, well-being, and quality of life.

Psychosocial Needs within Nursing Homes: Perspectives of Family Members, Staff, and
Residents

Population aging has generated significant interest regarding the supply and demand of health care services, including nursing homes (NH). One third of Canadians over the age of 85 currently reside in a NH, with a projected 25% increase in the use of NH beds (or their equivalent) in the next two decades (Chateau et al., 2012; Doupe, Fransoo, Chateau, Dik, Burchill, Soodeen, 2011). Although a considerable amount of literature has identified the complex medical needs of NH residents (Grabowski, Aschbrenner, Rome, & Bartels, 2010; Lee, Chau, Hui, Chan, & Woo, 2009; Morrison, 2009), comparatively little research has examined the psychological and social needs of these individuals.

The purpose of this dissertation is to create and content validate a list of psychosocial needs specific to NH residents with dementia, based on the perspectives of residents and their family members. I also sought to gather preliminary information on the psychosocial needs of residents without dementia¹. These data also informed a follow-up focus group which was designed to help understand the strategies that NH staff use to help residents meet their psychosocial needs, and to identify the challenges they encounter in doing so. Collectively, this evidence is valuable for promoting more effective NH transitions and optimizing residents' quality of life by helping inform care providers about how to best help residents meet their psychosocial needs.

¹ Parallel strategies were used to identify what psychosocial needs are most important to NH residents without dementia, however these analyses are based on a small pilot sample of family member respondents and should be considered as preliminary.

The subsequent literature review will contextualize this dissertation, first with a description of the changing age demographics of the Canadian population and its implications for NH care. Then a summary of the research on the medical aspects of NH care and the physical health difficulties commonly experienced by residents is provided. Subsequently, there is a review of literature documenting how the scope of NH care has broadened to include mental health and well-being. Psychological and social needs according to several prominent theories of psychosocial need are defined in the proceeding section. These theories have been overlooked in the current body of research on NH resident well-being, despite mental health being an increasing focus of NH care. The literature review concludes with a discussion of the significant limitations within this literature and how this study will begin to address some of these limitations.

Background

Population aging. Canada, along with many developed countries, is experiencing unprecedented growth in the number of adults over the age of 65. Aging of the “baby boomer” cohort (people born between 1946 and 64) (United Nations, 2002) and extended life expectancies have contributed to an increasingly “grey” population (United Nations, 2002). The United Nations (2002) reports that the magnitude and speed of population aging will continue to be dramatic, with the number of individuals over the age of 50 tripling within the next 50 years, reaching nearly two billion by 2050. Canada’s population mirrors this worldwide trend. In 2011 approximately five million Canadians were over the age of 65, and this figure is expected to double by 2026 (Belanger & Caron-Malenfant, 2010). The shifting demographics of Canada’s population has the potential to introduce numerous social and economic challenges, including issues

related to labor supply, intergenerational relationships, social and private income security and most notably, health care systems (Certified General Accountants Association of Canada, 2005).

Aging societies and the demand for nursing home care. Accentuated demand on health care resources is a commonly cited concern related to population aging. An increasing incidence of chronic disease and comorbid conditions requiring complex treatment and care is expected to place strain on particular areas of the health care system such as pharmaceuticals, new technologies, home care and nursing homes (Certified General Accountants Association of Canada, 2005). Increased health care utilization during the last year of life, in particular, is often identified as contributing to the rising costs of an aging population (Wister & Speechley, 2015).

When older adults' physical health needs progress beyond what can be provided independently or by family caregivers, NH placement is often required. Although a relatively small proportion of Canada's total population resides in NH facilities, nearly 30% of adults over the age of 85 reside in long-term care (Milan & Bohnert, 2011). NH use patterns have also changed considerably over the past two decades (Menec, MacWilliam, Sooden, & Mitchell, 2002). Between the years 1985 and 1999, admission rates to Manitoba personal care homes² increased by 32%, primarily due to older adult population growth and despite individuals being admitted into NHs later in life and for shorter periods of time in recent years (Menec et al., 2002). In the next two decades over half of the baby boomer generation will be older than 75, which coincides with an anticipated 25% increase in the demand for NH beds or their equivalent (Chateau et al.,

² *Personal care home* is used in Manitoba to refer to *nursing home*. The two terms will be used interchangeably here.

2012; Doupe et al., 2011). Compounding this increasing demand, NH residents today have more complex needs than in previous years and are, on average, older, sicker, and closer to death than NH residents two decades ago (McGregor et al., 2010; Menec et al., 2002). As such, the “typical” NH resident today has considerably more medical challenges than in previous years and requires substantially more care and specialized services.

Medical needs of nursing home residents. NH residents are often admitted with a wide range of physical health problems and are usually cognitively impaired. Residents are typically admitted for long-term, custodial care for chronic conditions (Gill, Gahbauer, Han, & Allore, 2009). A considerable amount of research has described the types of physical health conditions commonly experienced by NH residents in addition to their associated levels of functional impairment (Ang, Au, Yap, & Ee, 2006; Helvik, Engedal, Benth, & Selbæk, 2014; Karakaya, Bilgin, Ekici, Köse, & Otman, 2009; Li, Cai, Mukamel, & Glance, 2010; Lichtenberg, 2012), trajectories of physical health decline (Jones, Dwyer, Bercovitz, & Strahan, 2009; Levy & Wojtusiak, 2015; Van Rensbergen & Nawrot, 2010; Wetzels, Zuidema, de Jonghe, Verhey, & Koopmans, 2010) and predictors of mortality (Ahearn, Jackson, McIlmoyle, & Weatherburn, 2010; Aneshensel, Pearlin, Levy-Storms, & Schuler, 2000; Kiely & Flacker, 2003; Magaziner et al., 2005; Thomas, Cooney, & Fried, 2013; Van Dijk et al., 2005). Although a thorough review of this literature is beyond the scope of this dissertation, the most common conditions and diseases experienced by older adults in nursing homes include hypertension, dementia, depression, arthritis, diabetes mellitus, gastroesophageal reflux disease, atherosclerosis,

congestive heart failure, cerebrovascular disease, and anemia (Moore, Boscardin, Steinman, & Schwartz, 2012).

A considerable amount of literature focuses on the NH care of residents with dementia. Cognitive impairment is one of the strongest predictors of NH admission and the majority of residents have a diagnosis of dementia (Gaugler, Duval, Anderson, & Kane, 2007). Recent Canadian data indicates that 62% of NH residents in Alberta, Manitoba and Saskatchewan have dementia (Estabrooks et al., 2013). Dementia is a syndrome characterized by chronic and progressive disease processes in the brain resulting in cognitive impairment in areas such as memory, language, orientation, learning capacity, comprehension, and judgement (Breitner, 2006). Alzheimer's disease, vascular dementia, and frontotemporal dementia are the most common forms of dementia among NH residents (Hendrie, 1998). In addition to its cognitive effects, dementia can be accompanied by a variety of neuropsychiatric symptoms such as aggression, psychotic symptoms, and depressive or apathetic symptoms (Seitz, Purandare, & Conn, 2010). A diagnosis of dementia tends to be associated with a variety of adverse outcomes in NH settings, including falls (Van Doorn et al., 2003), polypharmacy (Beloosesky, Nenaydenko, Gross Nevo, Adunsky, & Weiss, 2013; Tamura, Bell, Inaba, & Masaki, 2012), hospitalization (Carter & Porell, 2005), and mortality, especially during the first few months following admission (Van Dijk, Van de Sande, Dippel, & Habbema, 1992).

The changing scope of nursing home care. The preceding body of literature has documented that NH residents are typically admitted with a wide variety of significant physical and cognitive concerns that require complex and on-going medical care. For good reason, published research has focused on managing NH residents' complex and

comorbid medical conditions. This mirrors the historical trend for NHs to be seen as extensions of hospitals, with a predominantly biomedical approach to care (Henderson & Vesperi, 1995). Changes to US policy and public health reform in the 1980s heralded the *culture-change movement* in US nursing homes and later, in Canada (Henderson & Vesperi, 1995; Shier, Khodyakov, Cohen, Zimmerman, & Saliba, 2014). This movement signaled a growing recognition that humanistic (i.e., person-centred) approaches to care are essential to improving the quality of life of residents (Henderson & Vesperi, 1995). This movement broadened the continuum of NH care to not only include medical services but also those that addressed the psychological and social welfare of residents. The prevailing biomedical model of care continues to shift to person-centred NH care (Koren, 2010).

As person-centred models of care have proliferated, so has research examining quality of NH care (Havig, Skogstad, Kjekshus, & Romøren, 2011; Rosemond, Hanson, Ennett, Schenck, & Weiner, 2012; Spilsbury, Hewitt, Stirk, & Bowman, 2011; Weech-Maldonado, Meret-Hanke, Neff, & Mor, 2004) and resident quality of life (Doumit & Nasser, 2010; Kane, 2003; Mukamel et al., 2012; Schenk, Meyer, Behr, Kuhlmeier, & Holzhausen, 2013; Shin, 2013; Zimmerman, Sloane, et al., 2005). This body of literature also examines interventions designed to improve the psychological and social well-being of NH residents. These interventions are varied and include, for example, reminiscence therapy, music therapy, scheduled pleasant activities, social interactions, physical exercise, and staff training (Testad et al., 2014).

Testad and colleagues' (2014) systematic review of these interventions demonstrates that varying definitions of psychological and social well-being are being

used within research, not all of which are based on validated theory. There is a considerable amount of published research that provides support for several theories of psychological and social need (Carstensen & Turk-Charles, 1994; Ormel, Lindenberg, Steverink, & Verbrugge, 1999; Ryan & Deci, 2000; Ryff, 1989), and many of these theories have been examined in relation to lifespan development and aging (Ryan & LaGuardia, 1995; Scheibe & Carstensen, 2010; Steverink & Lindenberg, 2006).

Significantly less research has applied these theories to NH settings, however.

Neglecting theory is problematic as it limits our understanding of complex phenomena and limits the application of empirical findings (Green, 2000). The following review summarizes four prominent models of psychological and social needs, as well as literature examining age-related changes in psychological needs.

Models of psychological and social need. Just as meeting the physiological needs of hunger and thirst are essential for maintaining physical well-being, so too are satisfying psychological and social needs necessary for mental health and well-being. It is important to distinguish the concept of psychological and social “need” from other constructs such as “motivation,” “goals,” and “quality of life” although there has historically been varying perspectives on how these constructs are distinct (Deci & Ryan, 2000). According to Deci and Ryan, needs are “innate psychological nutrients that are essential for ongoing psychological growth, integrity, and well-being” (p. 229). They are universal and attainable under optimal circumstances and without deprivation and threat. Motivation has been conceptualized as an energizing force that propels behaviour. Deci and Ryan make the distinction between intrinsic and extrinsic motivation, with the former being behaviours that are engaged in because they are inherently pleasurable or

interesting. Extrinsically motivated behaviours are engaged in for external consequences such as money or other rewards. Satisfied psychosocial needs are thought to enhance intrinsic motivation and some forms of extrinsic motivation, which are beyond the scope of the review here (i.e., internalized extrinsic motivation; Deci & Ryan, 2015).

Conversely, thwarted psychosocial needs can undermine intrinsic motivation and result in a greater dependency on external rewards for behaviour (Ryan & Deci, 2000). Goals are distinguished from motivation and needs in that they are highly valued aspirations that are learned and can vary individually. They are the anticipated outcomes of motivated behavior and can be intrinsic (e.g., personal growth, relationships, community) or extrinsic (e.g., wealth, fame, image). Research has linked psychological need satisfaction with having intrinsic goals more so than extrinsic goals (Deci & Ryan, 2015).

Considering the above, satisfied psychological needs can be seen as facilitating intrinsic motivation and goal orientations and some forms of extrinsic motivation, however, the behaviour stemming from these motivations and goals are likely to further satisfy one's psychosocial needs and facilitate well-being (Deci & Ryan, 2015).

Quality of life is distinct from the concept of a psychological and social need. Quality of life is a multidimensional construct that encompasses both subjective appraisals of an individual's life circumstances and objective indicators such as cognitive functioning and functional ability (Mjorud, Kirkevold, Rosvik, Selbaek, & Engedal, 2014). Lawton's quality of life framework is commonly referred to in the nursing home literature and includes the components of psychological well-being, perceived quality of life, behavioral competence, and the objective environment (1994). Satisfied psychological and social needs can be considered a necessary precondition of a good

quality of life. In contrast with the concept of psychosocial needs, quality of life is not universal and can be influenced by a number of individual and environmental characteristics (Mjorud, Kirkevold, Rosvik, Selbaek, & Engedal, 2014). There is a large body of literature on quality of life in NHs and how resident characteristics such as cognitive impairment, presence of a mental disorder, and functional ability affect quality of life (Banerjee et al., 2009; Beerens et al., 2013; Martin-Cook, Hynan, Rice-Koch, Svetlik, & Weiner, 2005; Shin, Carter, Masterman, Fairbanks, & Cummings, 2005).

Despite the conceptual differences between a psychological need, motivation, goal, and quality of life, there is a lack of agreement on what constitutes a psychological and social need. A number of prominent theories have attempted to define the psychological and social needs that are essential for well-being.

Psychological Well-Being. Ryff's multidimensional theory of Psychological Well-Being posits that six constructs are implicated in mental health and well-being: self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth (Ryff & Singer, 1996; Ryff, 1989). Self-acceptance, broadly defined, refers to holding a positive attitude toward oneself in both the present and past. Positive relationships with others, characterized by warmth, trust, and affection, are also seen as critical in Ryff's model. Autonomy, from this perspective, is seen as being synonymous with self-determination, independence, and regulating one's behavior. Environmental mastery refers to the ability to choose the situations one participates in and take advantage of the opportunities they present. Purpose in life involves a sense of intentionality and being goal oriented. Ryff's model also holds that psychological well-being requires continued growth and personal development, which may be accomplished

through meeting new goals and confronting different challenges. Published cross-sectional data suggests that purpose in life and personal growth tends to decline from midlife to old age but that there is little change across the adult lifespan in environmental mastery, autonomy, positive relations with others and self-acceptance (Ryff & Keyes, 1995; Ryff, 1989). Ryff's model was examined in relation to the process of community relocation in late life (Ryff & Essex, 1992) and found that adaptive psychological adjustment to relocating was related to a greater sense of environmental mastery, purpose in life, and positive relations with others.

Socioemotional Selectivity Theory. Socioemotional selectivity theory (SST) is a developmental theory of motivation and goal selection. SST posits that changes in goal selection and motivation are due to shifts in time perspective (Carstensen, 2006). Individuals who are more future oriented adopt goals centred on acquiring knowledge, new experiences and social connections (Carstensen & Turk-Charles, 1994). Younger adults frequently espouse this time perspective and its associated motivations. Present-focused individuals, however, are increasingly aware of life's finality and become more motivated to maximize life in the present moment. Older adults often espouse this time perspective, which translates into a desire to prioritize emotionally gratifying pursuits and intimate relationships (Carstensen, 2006). Older adults accomplish this by paying more attention to emotional aspects of situations, engaging in emotion-focused coping as opposed to problem-focused coping strategies, and spending time on emotionally close relationships (Carstensen & Mikels, 2005; Carstensen, 2006; Lockenhoff & Carstensen, 2004). These pursuits tend to be associated with higher levels of emotional well-being compared to those of future-focused individuals (Carstensen et al., 2011). Although SST

is not a theory of psychological need per se, it highlights motivations and goals that are highly salient to older adults and implicated in their emotional well-being.

Self-Determination Theory. Self-Determination Theory (SDT) (Ryan & Deci, 2000) specifies that there is a universal and inherent drive to satisfy one's needs for autonomy, competence and relatedness. These needs must be satisfied to achieve a sense of well-being. Autonomy, much like its definition in Ryff's model, refers to a sense of volition over one's behavior (Ryan & Deci, 2000). Competence involves a sense of efficacy in regulating one's internal and external environment and is closely related to Ryff's (1989) construct of environmental mastery. Finally, relatedness is achieved by feeling connected to and cared for by others. Research examining SDT's psychosocial needs in late life has, in fact, often focused on NH settings. Autonomy, competence and relatedness have been related to NH residents' psychological well-being (O'Connor & Vallerand, 1994). Rodin & Langer's (1977) landmark study demonstrated that NH residents who exercised choice and personal responsibility over the care of a houseplant were more socially involved, subjectively happier, and had lower mortality rates than residents assigned a houseplant cared for by staff. Similarly, Kasser and Ryan (1999) demonstrated that the degree to which needs for autonomy and relatedness were met within a NH was correlated with subjective well-being (Kasser & Ryan, 1999). Although there is literature suggesting that meeting needs for autonomy and relatedness, in particular, are instrumental for well-being within a NH setting, less is known about the process of meeting these needs. It is unclear to what extent age, functional decline, and NH residency influence how psychosocial needs are met, if at all.

Social Production Functions. According to the theory of Social Production Functions (SPF), needs for affection, behavioural confirmation, and status are critical for psychosocial well-being (Lindenberg, 1996). Affection stems from relationships that provide a sense of liking or love, acceptance, and trust (Ormel et al., 1999). Satisfying this need leaves the sense of being understood, empathized with, taken care of, and connected to others (Steverink & Lindenberg, 2006). Affection is independent of the need for behavioural confirmation and status. The need for behavioural confirmation is met in relationships that provide a feeling of productivity or usefulness within society, and doing what is moral or “right” (Ormel et al., 1999). It involves feeling productive, useful, and functional, primarily in the eyes of others and independent of the needs for affection or status (Steverink & Lindenberg, 2006). Finally, status is achieved from relationships that instill a sense of autonomy, importance, influence, and respect (Lindenberg, 1996). It also involves a sense of recognition for one’s skills or assets (Steverink & Lindenberg, 2006). Regarding age-related changes in psychosocial need, some research documents that among adults aged 65 to 98, needs for affection, status, and behavioural confirmation remain equally important with advancing age, but the need for behavioural confirmation becomes more difficult to satisfy (Steverink & Lindenberg, 2006).

Psychological and social needs in nursing homes. Although there are other conceptual frameworks which attempt to define psychosocial needs (e.g., Maslow, 1943; Alderfer, 1969; McClelland, 1965), Ryff’s Psychological Well-Being model (1989), SST (Carstensen & Turk-Charles, 1994), SDT (Ryan & Deci, 2000) and SPF theory (Ormel et al., 1999) have been relatively more prominent in published research on aging and mental

health, reflecting their utility in examining psychological and social needs and how they may change with age. As such, this study will be informed by these theories primarily. Research employing Ryff's theory, SDT, SST, and SPF has tended to focus on community-dwelling older adults, which has left some uncertainty about whether psychosocial needs may be different within NHs. Conceivably, NH residents could experience changes in the relative importance of their psychosocial needs, or their available means to meet these needs. Although the preceding models specify that psychological and social needs are universal and relevant to all age groups, they also acknowledge that the ability and opportunity to meet these needs could vary as individuals age and experience physical and functional decline, and environmental changes (Ryan & La Guardia, 2000; Steverink & Lindenberg, 2006). These challenges are apparent in a NH context where challenges imposed by physical disability or cognitive impairment could limit an individual's ability to engage in basic and instrumental activities of daily living, thereby decreasing autonomy. Additionally, the relative importance of particular needs could fluctuate in response to particular stressors or changes in one's environment. NH residents may have a greater need for relatedness as they enter the NH given that it may be more challenging to maintain relationships with friends and family outside the NH. Residents may also experience an increased need for autonomy or competence upon admission if they are being admitted unexpectedly or against their wishes.

It is possible, then, that NH residents' psychosocial needs vary in content and importance relative to individuals who do not reside in nursing homes due to different stressors and changes within their environment which make it more difficult to meet their

psychosocial needs. There is little research, however, that has attempted to define what the psychosocial needs of NH residents are, limiting the ability to examine the relative importance of these needs. Vourlekis, Gelfand and Greene (1992) are among the few researchers who have attempted to identify the psychosocial needs relevant to NH residents. The authors devised a list of 28 psychological and social needs of NH residents that included items such as “emotional support and assistance in coping with the transition to nursing home”, “recognition of status and wholeness of one's life history”, “choice concerning important daily routines”, and “maintaining contact with friends, associates and community ties outside the home.” However, these items were developed through informal questioning of NH social workers and without the input of nursing home residents or their caregivers. As a result, the items and their rated importance reflect social workers’ and NH administrators’ perspectives (Vourlekis, Gelfand, & Greene, 1992). Furthermore, item development was not guided by theories of psychosocial need such as those reviewed in the previous section. Neglecting validated theories limits our understanding of complex phenomena and restricts the ability to apply empirical findings on a broader level. Additionally, the scope of this study was limited in terms of identifying residents’ psychosocial needs and as such, there is little guidance for NH staff for how they can help residents meet these needs.

Gaps in the Literature

From the preceding literature review, our knowledge of the psychosocial needs of NH residents is limited. Previous attempts to define the psychosocial needs of residents have tended not to incorporate theories of psychosocial need or the perspectives of multiple stakeholders such as residents, their family members, and staff. There are other

prominent gaps in our knowledge of the psychosocial needs of NH residents that bear consideration.

First, little is known about the psychosocial needs of residents with dementia. This gap in the literature is particularly concerning given that the majority of individuals within nursing homes are cognitively impaired (Estabrooks et al., 2013) and these individuals, especially those with severe dementia, may encounter challenges communicating their needs and whether they are being met. Frustration or neglect of these needs can lead to functional losses and decreased well-being (Ryan & LaGuardia, 1995). Unmet psychological and social needs among NH residents have often been inferred based on the prevalence of mental disorders such as major depressive disorder or generalized anxiety disorder. Hancock and colleagues (2006) investigated the degree of unmet physical, environmental, psychological, and social needs among NH residents with dementia. Unmet psychological and social needs, as indicated by the presence of mental disorders such as depression and anxiety, were common among individuals with dementia. Although the prevalence of mental disorders, especially untreated disorders, among NH residents with dementia is important to consider, using diagnosable mental disorders as a defining criteria of unmet psychosocial need is problematic. NH residents who meet criteria for a psychiatric disorder such as major depressive disorder or generalized anxiety disorder are in the minority (Seitz et al., 2010). By restricting the examination of psychosocial need satisfaction to clinical populations, many NH residents are excluded and little information is obtained regarding what needs are salient for individuals without a diagnosable mental disorder. Furthermore, NH residents who do not meet criteria for a mental disorder cannot be assumed to possess good mental health

and satisfied psychosocial needs. A considerable body of research supports the assertion that the lack of a mental disorder does not imply mental health (Keyes, 2005, 2007).

There is a clear need for a more comprehensive understanding of the psychosocial needs of residents with dementia.

A second limitation of the literature to date on NH residents' psychosocial needs is that it has generally not sampled individuals who may be more familiar with types of needs important to NH residents. From this perspective, family members of NH residents are a valuable yet underutilized source of information. Involved family members have access to the medical, psychological, and social history of residents, and they have been privy to the process of NH transition, which could conceivably influence the types of psychosocial needs endorsed as important. Family members have frequently been sampled in research examining the experiences and care for NH residents with dementia (Cohen-Mansfield, Parpura-Gill, & Golander, 2006; Liu, Guarino, & Lopez, 2012), and individuals in palliative care (Palan Lopez, 2009; Shield, Wetle, Teno, Miller, & Welch, 2005; Wetle, Shield, Teno, Miller, & Welch, 2005). Family members tend to be heavily involved during transitions to NH care as well as making decisions about care. As such, they offer a valuable and unique perspective about the psychosocial needs of nursing home residents, both those with and without dementia.

The literature on psychosocial needs in NHs to date has also been limited in the types of methods used to establish what needs are most important to NH residents. Vourlekis and colleagues (1992) used a "reiterated process of experiential and intuitive identification of issues on the part of a diverse group of nursing home experts" (p.114) to generate a list of psychosocial needs and subsequently asked social workers to rate the

importance of these needs. This is one of other possible methods by which to examine the relative importance of psychosocial needs. Delphi methods have been used extensively in health care and mental health research (Jorm, 2015) as a means of developing agreement among “experts” (broadly defined) on indicators of health care quality (Boulkedid, Abdoul, Loustau, Sibony, & Alberti, 2011; Burnell et al., 2012; Kröger et al., 2007; Vasse et al., 2012). The Delphi process involves an iterative series of questionnaires to gather information and ultimately agreement among respondents on the content of a particular construct, such as quality of care indicators in nursing homes (Hasson, Keeney, & McKenna, 2000; Keeney, Hasson, & McKenna, 2006). Although this process has not yet been applied to the area of NH residents’ psychosocial well-being, the Delphi technique is well suited to help establish agreement on NH residents’ psychosocial needs.

Given the lack of research on NH residents’ psychosocial needs, there is also a significant gap in our knowledge of the strategies that NH staff can use to help residents meet their psychosocial needs. It is also unclear which specific staff practices and institutional policies enable residents to meet their needs and what challenges are encountered in this regard. This information may be beneficial to facilities in understanding how their practices and policies align with the needs of residents.

Research Objectives

This dissertation will help fill several gaps and address a number of limitations in the literature on NH residents’ psychosocial well-being. Its objectives are fourfold:

1. To develop and validate a list of psychosocial needs important to NH residents based on previous research on this topic, theories of psychosocial need, and feedback from NH residents (Phase One).
2. To establish consensus on a list of the most important psychosocial needs to NH residents with dementia, based on the reports of their family members (Phase Two).
3. To gather preliminary information on the needs of residents without dementia, based on the reports of their family members (Phase Three).
4. To develop a preliminary understanding of how NH staff help residents meet their psychosocial needs and identify significant challenges they encounter in this regard (Phase Four).

Phase One: Psychosocial Need List Development and Validation

Introduction

An important first step in establishing the relative priority of NH residents' psychosocial needs requires generating a list of possible needs and establishing its content validity. Item generation and validation can employ a number of different techniques, some of which can include a literature review of relevant theory and data, and open-ended interviews with a group of perceived experts in the subject matter (Haynes, Richard, & Kubany, 1995). The primary objective of Phase One is to create and content validate a list of psychological and social needs important to all NH residents using prior research on, and theories of, psychosocial need and the perspective of residents. A comprehensive literature review and a modified focus group with NH residents helped achieve this objective. Focus groups are a widely used qualitative research method

designed to obtain individual and group perceptions of a specific area of interest in service of increasing understanding and measurement of constructs such as psychosocial need (Massey, 2011; O'Brien, 1993). This focus group was limited in scope given that its primary purpose was to gather feedback from NH residents to modify the list of psychosocial needs for its use in subsequent phases. Collectively, these methods helped create and validate an initial list of psychosocial needs that would assist in establishing consensus on the most important needs for residents with dementia in Phase Two.

Method

Participants. I approached the director of care at a publicly funded nursing home within the Winnipeg Regional Health Authority to assist in recruiting approximately four to eight cognitively intact residents to participate in one 60-minute focus group. Focus groups of this size have been recommended as they facilitate group discussion but are not excessively large so as to discourage disclosure (Carlsen & Glenton, 2011). I approached this particular facility because of its historical involvement in research studies and continued eagerness to participate in ongoing projects. This facility contains 200 beds and is largely funded by the government of Manitoba. Residents cover a third of their cost of living, as is the case for all NHs in Manitoba. Residents of this facility are primarily members of the Jewish faith. I sent an email describing the nature of the study to the director of care and followed up over the phone. She gave me permission to recruit cognitively intact residents in consultation with the nursing care manager. The nursing care manager approached approximately eight residents to provide written (Appendix A) and verbal information about the focus group. The nursing care manager approached these residents based on their level of cognitive functioning, different degrees of physical

health and mobility, and anticipated interest in participating. Of the individuals approached, five residents expressed an interest in participating in the focus group and indicated when they would be available to meet. I gave each focus group participant \$15 for participating.

Materials.

Psychosocial need list. A thorough literature review provided content for an initial list of psychosocial needs (Appendix B). To develop this list, I used PsycINFO, Google Scholar, and PubMed. I included published articles, books, and theses in my search and used various combinations of the following search terms: psychological need, psychosocial need, psychological well-being, social well-being, subjective well-being, nursing home, long term care, nursing care, older adults, geriatric, dementia, and cognitive impairment. These terms yielded approximately 795 hits. I excluded publications that were not directly relevant to the research questions or the study population. I summarized the remaining literature ($n = 46$ peer reviewed publications) into an initial list of 24 psychosocial needs. I clustered these needs into six categories that are consistent with SDT (Ryan & Deci, 2000), SPF theory (Ormel et al., 1999), and Ryff's model of psychological well-being (Ryff, 1989). I labeled them as autonomy, competence, relatedness, purpose and meaning, pleasure and fun, and self-acceptance. I put the items into each category based on their perceived fit with the theme of the category. I relied heavily on the items developed by Vourlekis and colleagues (1992) and revised several of their items so as to be more reflective of these theories. The initial list of psychosocial needs was intended to be more inclusive to provide participants with a sufficient selection.

Focus group discussion guide. Discussion guides are typically used within focus groups to direct participant conversation to the topics of interest (Massey, 2011).

Discussion guides include a series of questions designed to elicit rich discussion and answers from participants. For the purposes of the present study, the discussion guide consisted of the following questions posed to the group of nursing home residents (accompanied by the initial list of psychosocial needs): (a) Would you add any needs to this list? (b) Would you exclude any needs from this list? (c) Does this list capture the psychosocial needs of residents with dementia? Although participants were cognitively intact, they were residing in a facility consisting primarily of residents with dementia. As such, they would be somewhat familiar with the needs of this population. The discussion group guide with my verbal instructions to participants is provided in Appendix C.

Procedure. Prior to commencing the focus group, I conducted the literature review and compiled the initial list of psychosocial needs. I sought feedback on this initial list from members of the research team (i.e., Drs. Corey Mackenzie and Malcolm Doupe). They perceived the reading level of the items to be too high and suggested simplifying the language. Additionally, one member of the research team (Dr. Mackenzie) recommended that an item be added to address how the NH might help residents accept their strengths and weaknesses, stemming from literature on the Strength and Vulnerability Integration (SAVI) theory (Charles, 2010).

Approximately one month after creating the list of needs, I met with the sample of five nursing home residents in a quiet, private meeting room at their facility. All participants were sufficiently cognitively intact and were able to provide informed consent. I started the focus group meeting by describing the study and summarizing the

risks and benefits of participating. I instructed participants to read the information and complete the consent form if they agreed to participate. I recorded and made notes on the content of the focus group and which speakers spoke when. Before beginning the focus group discussion I distributed a paper copy of the list of psychosocial needs and allowed several minutes for participants to read the list. I allotted approximately 15 minutes for each question within the discussion guide to allow time for participant questions and informed consent. At the end of the focus group, I thanked participants for their participation and gave them each \$15. I gave them the option of leaving their contact information if they wished to receive the results of the study. I used participant responses from the focus group to revise the list of psychosocial needs for its use in Phase Two and Three.

Analyses. Given that the purpose of the first focus group was to refine the list of psychosocial needs for its use in Phase Two, I did not use a formal method of qualitative data analysis. I transcribed the audio recording of the focus group and summarized residents' responses to each of the questions. I used their suggested revisions to revise the list of psychosocial needs before commencing Phase Two.

Results

The initial list of 24 psychosocial needs is displayed in Table 1. Residents provided positive feedback on this list, indicating that the items represented what was important from their perspective. Residents also provided constructive feedback on how to modify certain items and the names of categories. Residents were largely in agreement regarding the importance of each need on the list and spent a large portion of the focus group discussing how particular needs were either being met or identifying challenges

that made it difficult to meet these needs. For example, one resident affirmed the importance of having control over which social, recreational or religious activities are pursued within the facility and when, although he added that sometimes there were limited opportunities for formal and informal social interaction. This often depended on the time of day and availability of staff. A comment from another resident, affirmed the importance of having a sense of community within the NH but felt that his age presented a barrier to that: “I find that being a younger person (...) it’s harder to connect with residents who are a lot older than I am or in different situation. And I’d like to be around people who have similar interests more.” Other comments underscored the need for residents to continue doing as many activities of daily living as they could for as long as they were capable, while recognizing that staff needed to balance residents’ need for independence with maintaining their safety. One resident indicated that he would have liked the facility to accommodate his ability to drive but this was apparently difficult to coordinate. Another resident highlighted the importance of having warm, caring exchanges with staff and perceived that when they weren’t it had a significant impact on her mood. Further, this resident indicated that when she perceived that staff genuinely cared for her well-being she felt more at ease and welcome within the facility. One comment from another resident also highlighted the importance of interactions with staff and their responsiveness and mentioned: “That is so important that when you talk to them...they listen and pay attention and care for us. And don’t make you feel like a burden...or nuisance.” Another resident affirmed the need for opportunities to contribute to the functioning of the nursing home, such as volunteering on resident council or assisting with odd jobs: “you gotta get out of bed. If you don’t it’s a long day of doing the

same things (...) when I moved in I saw a lot of people sleeping all day. Getting involved in different things is important (...) and having some things to look forward to.”

Similarly, the need for pleasure and fun was unanimously agreed upon as being essential to the list of psychosocial needs. Several residents indicated that activities such as outings to restaurants, gambling, cooking or baking, and listening to live music significantly contributed to their quality of life.

Several residents suggested that the language of the list be simplified to make it more readable. One means of accomplishing this was changing the names of the categories to enhance clarity. As such, I renamed the *autonomy* category to *choice and control*, the *competence* category to *personal effectiveness*, and *relatedness* to *social connection*. I also simplified the names of specific items, with “control over what ADLs are performed and when” changed to “control over when personal care is performed, e.g., eating, bathing, dressing.” “Choice to pursue or decline assistance from others” was also changed to “choice to accept or decline help from others.” “Contributing to the functioning of the nursing home” was changed to “contributing to the personal care home” and “opportunities to interact with young people” was changed to “opportunities to pass along knowledge and experience to young people.” “Personal care home provides opportunities to foster self-acceptance of personal strengths and weaknesses” was also revised to “personal care home encourages acceptance of strengths and weaknesses.”

One resident suggested that an item be added that reflect the need to learn new skills. He indicated that he had a lifelong desire to learn how to play the guitar and had

hoped he could arrange guitar lessons within his facility but this was proving to be difficult. I added an item within the purpose and meaning category to address this concern. Table 1 displays the revised list of psychosocial needs beside the initial list.

Table 1

Initial and Revised Psychosocial Needs Following Phase One

Initial Phase One Psychosocial Needs	Revised Phase One Psychosocial Needs
<p>AUTONOMY</p> <ol style="list-style-type: none"> 1. Control over which activities of daily living are performed and when (e.g., eating, bathing, dressing) 2. Choice to pursue or decline assistance from others 3. Control over what social, recreational religious activities are pursued and when 4. Access to activities <i>within</i> the PCH 5. Access to activities <i>outside</i> the PCH 6. Opportunities to be involved in decisions related to one's care 7. Control over room arrangement, inclusion, and placement of personal belongings 	<p>CHOICE AND CONTROL</p> <ol style="list-style-type: none"> 1. Control over when personal care is performed (e.g., eating, bathing, dressing) 2. Choice to accept or decline help from others 3. Control over what social, recreational, and religious activities are pursued and when 4. Access to activities <i>within</i> the PCH 5. Access to activities <i>outside</i> the PCH 6. Opportunities to be involved in decision-making about care 7. Control over room arrangement, inclusion, and placement of personal belongings
<p>COMPETENCE</p> <ol style="list-style-type: none"> 8. Doing activities of daily living (e.g., dressing, feeding) that are appropriate for one's capabilities 9. Access to assistive devices (e.g., walker) which maximize independence 10. Opportunities to talk with PCH staff about care 11. Feeling that staff are responsive to resident feedback or requests 	<p>PERSONAL EFFECTIVENESS</p> <ol style="list-style-type: none"> 8. Doing personal care activities (e.g., dressing, feeding) that are appropriate for one's capabilities 9. Access to devices (e.g., walker) that increase independence 10. Opportunities to talk with staff about care 11. Perceiving that staff are responsive to feedback or requests
<p>RELATEDNESS</p> <ol style="list-style-type: none"> 12. Opportunities to maintain important relationships with friends and family outside the PCH 13. Opportunities to form and 	<p>SOCIAL CONNECTION</p> <ol style="list-style-type: none"> 12. Opportunities to maintain relationships with friends and family outside the PCH 13. Opportunities to create new

maintain new relationships within the PCH

- 14. Access to activities that create a sense of community within the PCH
- 15. Warm and caring exchanges with care staff
- 16. Touch and physical affection
- 17. Opportunities for sexual intimacy or sexual expression

PURPOSE AND MEANING

- 18. Opportunities to express religious, cultural, or ethnic identity
- 19. Opportunities to interact with and contribute to younger people
- 20. Contributing to the functioning of the nursing home (e.g., serving on resident council, performing odd jobs)
- 21. Opportunities to set and achieve goals
- 22. Opportunities to reflect on past accomplishments and contributions

PLEASURE AND FUN

- 23. Opportunities to do activities that are fun or pleasurable

SELF-ACCEPTANCE

- 24. PCH provides opportunities to foster self-acceptance of personal strengths and weaknesses

relationships within the PCH

- 14. Access to activities that create a sense of community within the PCH
- 15. Warm and caring exchanges with care staff
- 16. Touch and physical affection
- 17. Opportunities for sexual intimacy or sexual expression

PURPOSE AND MEANING

- 18. Opportunities to express religious, cultural, or ethnic identity
- 19. Opportunities to pass along knowledge and experiences to younger people
- 20. Contributing to the PCH (e.g., serving on resident council, performing odd jobs)
- 21. Opportunities to set and achieve goals
- 22. Opportunities to reflect on past accomplishments and contributions
- 23. Opportunities to learn new skills

PLEASURE AND FUN

- 24. Opportunities to do activities that are fun or pleasurable

SELF-ACCEPTANCE

- 25. PCH encourages acceptance of personal strengths and weaknesses

Discussion

Phase One resulted in the successful development and preliminary content validation of a list of 25 psychosocial needs across six categories of choice and control, personal effectiveness, social connection, purpose and meaning, pleasure and fun and self-acceptance. These categories and items mirror several prominent theories of

psychosocial need, such as Ryff's model of psychosocial well-being (Ryff, 1989), SST (Carstensen, 1992), SDT (Ryan & Deci, 2000), and SPF (Ormel et al., 1999). The items also build on prior published research on NH resident psychosocial need (Vourlekis et al., 1992). The list differs in that it includes items that were not directly addressed by Vourlekis and colleagues, such as fun and pleasure, sexual expression and intimacy, and self-acceptance. Phase One participants agreed that all items on the list were important and they offered helpful suggestions to revise it. The most significant changes involved simplifying the language of the categories and particular items. An item that reflected one resident's comment regarding the importance of opportunities to learn new skills was also added. The revised list of needs that emerged at the end of Phase One was comprehensive, inclusive, and deemed by NH residents to represent their psychological and social needs. Despite this, Phase One was limited in some respects. The residents who participated in the focus group were not representative of most NH residents. They were sufficiently cognitively intact and physically healthy to participate. As such, their experience of residing in a NH and their perspective on what is most important from a psychological and social perspective may be different from cognitively impaired residents and residents with more significant physical health problems. Nonetheless, this sample provided helpful feedback on the initial list of psychosocial needs that might have been more difficult to obtain with a sample of severely cognitively impaired residents. Their feedback helped to further refine the list of psychosocial needs for Phases Two and Three.

As an additional limitation, the items developed in this phase are not an exhaustive list of the needs pertaining to choice and control, personal effectiveness, social

connection, purpose and meaning, pleasure and fun, and self-acceptance. As such, these items should be considered as examples of need in each domain, with the understanding that many other individual items exist.

Phase Two: Delphi Survey for Residents with Dementia

Introduction

The objective of Phase Two is to obtain consensus on the psychosocial needs that are most important to residents with dementia and to identify those that are essential. This phase used a Delphi survey to reach consensus. This methodology has been frequently utilized in health research in general (Campbell, Braspenning, Hutchinson, & Marshall, 2003; Fleuren, Wiefferink, & Paulussen, 2004; Hasson et al., 2000; Keeney et al., 2006), and research specific to mental health (Jorm, 2015) and nursing home settings (Burnell et al., 2012; Kröger et al., 2007). Given the ethical and logistical difficulties with sampling NH residents with dementia, family members provided their input on the psychosocial needs of these residents. Family members, given the prominent role that they play in decision-making about care, offer a valuable perspective on residents' psychosocial needs. Gathering information about residents' psychosocial needs from multiple stakeholder groups will help generate a more holistic understanding of these needs. Related research on NH resident quality of life indicates that family members' ratings of quality of life domains is significantly correlated with residents' ratings, demonstrating that family members are a reliable and useful source of information about NH residents' well-being (Kane et al., 2005). The inclusion criteria specified that these individuals should be well-informed about the experiences of their family member residing in a NH and what, from a psychosocial perspective, was most important to this person.

Method

Participants. I recruited family members of NH residents to participate in the Delphi procedure. “Family member” is defined in the present study as a spouse, common-law partner, child, or son- or daughter-in-law. Family members who did not meet several inclusion criteria were ineligible to participate. To participate, family members were required to be cognitively intact (based on self-report), visit their family member at least once per month (based on self-report), and perceive themselves to be in an informed position on the psychosocial needs of their family member. I relied on self-report data given that no objective data were available to confirm the frequency of family members’ visits to their NH resident. Family members were also expected to complete all iterations of the Delphi process.

I consulted a recent systematic review on Delphi methods to determine an ideal number of participants to recruit for this study (Boulkedid et al., 2011). I also considered possible attrition and the resources available to conduct three iterations of the Delphi survey. As such, my final goal was to recruit $n = 30$ family members. In preparation for recruiting individuals for Phase Two, I attended a meeting for all nursing home directors of care ($n = 37$) within the Winnipeg Regional Health Authority. At this meeting, I made a brief presentation in which I described the nature of the study and requested assistance with recruiting family members. Following this meeting, directors of care from three facilities expressed an interest in assisting with recruitment and were given the inclusion criteria for the study. These directors of care represented three facilities, the first of which also assisted with recruitment for Phase One. The second was a 147-bed facility and the third was a 100-bed facility. While all three facilities are nonprofit, they differed

in terms of their religious affiliation. One facility catered to individuals of the Jewish faith, the second facility catered to individuals of the Mennonite faith, and the third was secular. Directors of care and nursing care managers assisted in contacting family members of residents to pass along written information about the study (Appendix D) and followed up over the phone or in person to see whether the family member was interested in participating. Family members who expressed interest in participating provided an email address or phone number where they could be contacted. This initial recruitment effort yielded contact information for 56 family members across the three facilities, with 39 individuals eventually consenting to complete the first Delphi survey. Family members each represented one NH resident.

Materials.

Sociodemographic questionnaire. All participants in Phase Two completed a sociodemographic questionnaire (Appendix F) before commencing the first Delphi survey. Participants provided information about their age, sex, self-rated health and levels of stress, relationship to the NH resident, and the frequency and typical duration of their visits. They also provided information about their NH resident (e.g., age, gender, marital status, and physical health). Participants then completed the Dementia Severity Rating Scale to provide an indicator of their resident's cognitive functioning.

Dementia Severity Rating Scale. The DSRS (Appendix G) (Clark & Ewbank, 1996) is an informant-based multiple-choice questionnaire that assesses mild to severe dementia by asking respondents to rate an individual's ability to function in 11 different categories: memory, orientation, judgment, social interaction, home activities, personal care, language, recognition, eating, incontinence, and mobility. In the "judgment"

category, for example, respondents rate whether the individual is “Normal” (0), “Only doubtful impairment in problem-solving ability” (1), “Moderate difficulty in handling complex problems, but social judgment usually maintained” (2), “Severe impairment in handling problems, social judgment usually impaired” (3), or “Unable to exercise judgment in either problem solving or social situations” (4). The DSRS requires approximately 10 minutes to complete. The DSRS displayed a high degree of internal consistency in this sample (Cronbach’s alpha = 0.92). In other published research, it has been documented to have excellent test–retest reliability ($r = 0.90$) in a sample of caregivers of individuals with Alzheimer’s disease (Clark & Ewbank, 1996). DSRS scores are highly correlated with a number of neuropsychological measures commonly used to assess cognitive impairment such as the Mini-Mental Status Examination, the Boston Naming Test, the Clock-Drawing task, and word recall and delayed-recall tasks (Clark & Ewbank, 1996). As such, the instrument demonstrates high concurrent validity when used by lay caregivers and is a useful tool with which to approximate dementia severity. To be consistent with previously published data, I used a cutoff score of 21 or greater to suggest probable dementia (Clark & Ewbank, 1996). To ensure that DSRS scores were aligning with facility-level indicators of cognitive functioning, I also collected Cognitive Performance Scale (CPS) scores for a subset of the residents within this sample. I contacted the staff member who assisted with participant recruitment at each facility and requested the CPS scores for each participant’s corresponding NH resident.

Cognitive Performance Scale. The CPS consists of five items from the interRAI/Minimum Dataset, which are completed by nursing staff based on a semi-

structured clinical interview, clinical observation and chart review (Morris et al., 1994). CPS items are rated based on the resident's level of consciousness (comatose or not) and their performance in the following domains: ability in making decisions regarding tasks of daily life, short term memory, procedural memory, ability to make him or herself understood, and ability to feed oneself (Morris et al., 1994). Scores are created by way of a computer-based algorithm and range from 0 (intact) to 6 (severely impaired). Scores on the CPS show moderate agreement with mini mental status examination scores, with some research documenting 68% agreement in identifying cognitively impaired individuals (Wellens et al., 2013). Scores of two or higher are typically used to suggest a probable dementia diagnosis (Wellens et al., 2013). I requested the CPS scores for NH residents in Phase Two several months after completing the Delphi survey to confirm dementia diagnoses. CPS scores are cross-tabulated with DSRS scores in Table 2. This research categorized DSRS scores into three categories of severity based on suggestions from previous research (Clark & Ewbank, 1996; Xie et al., 2009). The majority of residents who exceeded the cutoff score for dementia on the DSRS (i.e., score > 21) had a CPS score of two or more, suggesting that these two instruments were largely in agreement about classifying cognitive impairment. The Pearson correlation coefficient between DSRS and CPS scores in the sample of Phase Two family members was $r = 0.88, p < 0.001$, suggesting both measures were in sufficient agreement in terms of indicating dementia severity.

Table 2

Cross Tabulation of Cognitive Performance Scale Scores with DSRS¹ Scores

CPS Scores	DSRS Scores		
	< 21 Cognitively Intact	22-39 Mild-Moderate Dementia	40+ Severe Dementia
Intact/Borderline Intact (0-1)	1 (100%)	6 (33.3%)	
Mild (2)		5 (27.7%)	
Moderate (3)		7 (38.8%)	6 (40%)
Moderately Severe (4)			1 (6.6%)
Severe (5)			4 (26.6%)
Very Severe (6)			4 (26.6%)

¹Note: DSRS = Dementia Severity Rating Scale

Delphi surveys. Respondents viewed the list of psychosocial needs in each round of the Delphi survey. In each round, participants rated the importance of each psychosocial need on two dimensions. First, they rated the importance of each need for the resident's mental health as 1 (essential), 2 (important but not essential) 3 (unessential), or 4 (don't know or undecided). Second, respondents rated the impact of each need on the resident's experience in a nursing home as 1 (large impact), 2 (moderate impact), 3 (neutral), 4 (minimal impact), or 5 (no impact). Space was allotted for written comments after each section. An example of the format of the Delphi survey items is in Figure 1 below. The first Delphi survey is displayed in full in Appendix H. The second Delphi survey followed the same format as the first but was revised to only include items in which consensus was reached during the first Delphi survey. The third and final survey for family members displayed the final list of psychosocial needs for this group

and offered respondents the opportunity to provide any additional comments about this list, such as whether it was comprehensive or whether any needs should be added.

<p>How important would you say this need is for the resident’s mental health?</p>	<p>What impact does this have on the resident’s experience of living in a personal care home (PCH)?</p>
<p>1 = Essential 2 = Important but not Essential 3 = Unessential 4 = Don’t know or undecided</p>	<p>1 = Large impact 2 = Moderate impact 3 = Neutral 4 = Minimal impact 5 = No Impact</p>
<p>1 2 3 4</p>	<p>1 2 3 4 5</p>

Figure 1. Format of Delphi Survey Items

Procedure. I contacted all family members who expressed interest in participating in Phase Two and sent their preference of a paper survey, fillable electronic PDF form, or link to complete the first Delphi survey online. The online version of the survey was hosted on Qualtrics. I requested that participants complete the first Delphi survey within two weeks. The content of the paper and electronic versions of the Delphi survey were identical. First, I presented participants with an information sheet about the study and consent form. Second, participants completed the sociodemographic questionnaire and the DSRS for their family member. Then participants rated the importance of each psychosocial need on the list according to the impact it had on the resident’s mental health and overall experience in the NH. They also had space to

provide comments following each section. Participants either mailed or emailed copies of their completed surveys back to me. I computed the rated importance of each item on both dimensions. For an item to be included in subsequent Delphi iterations, at least 70% of participants must have rated it as “essential” or “important but not essential” for resident mental health or as impacting residents’ experience in a NH moderately or largely. Items not achieving this degree of agreement were removed from the list of needs and not included in the next Delphi iteration. Although from a conceptual standpoint, psychological and social needs should be “essential” for well-being, retaining information about items deemed to be “important but not essential” for mental health and well-being is still useful, especially for NH facilities. Distinguishing needs that are critical from those that are desirable (but not a necessity) may help inform how resources are allocated in facilities.

Family members of residents with dementia then received a second iteration of the Delphi survey. As per Delphi procedure (Hasson et al., 2000), each participant viewed how important each psychosocial need was rated in the first iteration. Instructions indicated that participants were to use this information to inform their ratings in the second iteration in order to facilitate consensus. Identical to the first Delphi iteration, participants rated the importance of each need on the same two dimensions (i.e., importance for residents’ mental health and impact on their experience within a NH). I analyzed and revised the items using the same definition of consensus from the first iteration of the Delphi. No items could be eliminated following the second iteration as all items met the criteria for consensus (i.e., 70% of respondents rating the item as “important but not essential” or “essential” for resident mental health or as having a

“moderate” or “large” impact on the residents’ experience within a NH). Therefore, on the third survey, participants provided informal written feedback on the final list of needs, such as whether they would add any needs. After returning the final survey, I mailed participants a thank-you card and a gift certificate.

Analyses. Analysis of Delphi data consists of identifying items that are sufficiently important to respondents based on consensus and accordingly eliminating items which do not obtain a certain degree of consensus. The type of criteria used to determine consensus in Delphi techniques is varied and subject to debate. Consensus on a topic is typically determined based on whether a certain percentage of votes falls within a prescribed range (Hsu & Sandford, 2007). One recommended criterion is that consensus is achieved by having 80% of subjects’ votes fall within two categories on a seven-point scale (Hsu & Sandford, 2007). Green (1982) suggests that at least 70% of Delphi subjects need to rate three or higher on a four-point scale and the median has to be at 3.25 or higher. Delphi rules assert that selection procedures should be consistent in all rounds. I adopted Green’s (1982) recommendation and specified that 70% of participants must have rated items as either “essential” or “important but not essential” for resident mental health. Additionally, at least 70% of participants must have rated needs as having a “large” or “moderate” impact on residents’ experiences in a nursing home.

Concerning respondents’ written feedback on the final list of needs, I did not use a formal qualitative method to analyze these data. I read through the comments several times and subsequently categorized them into different thematic groups.

Results

DSRS scores. The DSRS scores of the residents represented in Phase Two indicated that nearly all respondents ($n = 33$ out of 34) had a probable dementia diagnosis. They had a mean DSRS score of 39.3 (SD = 11.5, range = 21.0-61.0), indicating that most residents exceeded cutoff of 21 for dementia. This sample will be referred to as the “dementia group”. DSRS scores did not significantly predict the ratings of psychosocial need importance on either dimension on the first Delphi survey.

Sociodemographic characteristics. Table 3 summarizes the sociodemographic features of the dementia group who participated in the Delphi surveys. This group was predominantly female (79.4%), between the ages of 55 and 59 (67.6%), the children or stepchildren of residents (85.3%), in “good” (75.5%) to “excellent” (17.6%) health, reporting “moderate” degrees of stress (54.5%), and visited their resident at least once a week (88.2%) for one to three hours at a time (82.4%). The majority of the family members in the dementia group had a female resident (79.4%) who was over the age of 90 (54.5%) and widowed (71.9%). The dementia group’s perception of their resident’s physical health was variable: 43.8% thought their resident was in good health, 31.3% reported fair health, and 25% were deemed in poor health. The majority of family members had residents living in either the Mennonite (50%) or secular facility (38.2%). Of the original sample of $n = 34$ family members, 79.4% participated in the second Delphi iteration and 70.5% participated in the final survey. There were no significant differences between family members who dropped out of the study and those who remained in.

Table 3

Phase Two Participant Demographics

	Family Members of Residents with Dementia (n=34)
Sex	
Male	7 (20.6%)
Female	27 (79.4%)
Age	
40-54	7 (20.6%)
55-59	23 (67.6%)
70-84	4 (11.8%)
Health	
Excellent	6 (17.6%)
Good	26 (76.5%)
Fair	2 (5.9%)
Poor	0 (0%)
Stress	
Mild	13 (39.4%)
Moderate	18 (54.5%)
High	3 (6.1%)
Relationship to Resident	
Child or stepchild	29 (85.3%)
Niece or nephew	1 (2.9%)
Spouse	3 (8.8%)
Other	1 (2.9%)
Frequency of visits	
Less than once a month	0(0%)
Once a month	0 (%)
Twice a month	3 (8.8%)
Once a week	17 (50%)
Daily or nearly every day	13 (38.2%)
Length of Visits	
Less than one hour	3 (8.8%)
1-3 hours	28 (82.4%)
3-5 hours	2 (5.9%)
More than 5 hours	0 (0%)
Age of resident	
<60	0 (0%)
60-69	0 (0%)
70-79	6 (18.2%)

80-89	9 (27.3%)
90+	18 (54.5%)
Resident sex	
Male	6 (17.6%)
Female	27 (79.4%)
Resident marital status	
Married or common-law	5 (15.6%)
Widowed	23 (71.9%)
Separated or Divorced	4 (12.5%)
Single	0 (0%)
Resident physical health	
Excellent	0 (0%)
Good	15 (43.8%)
Fair	10 (31.3%)
Poor	9 (25%)
Nursing Home Religious Affiliation	
Jewish	4 (11.8%)
Mennonite	17 (50%)
Secular	13 (38.2%)
Delphi Response Rate	
Round 2	27 (79.4%)
Round 3	24 (70.5%)

Round 1 of Delphi survey with the dementia group. Table 4 displays the results of the first round of the Delphi survey with the dementia group. Items that exhibited a large degree of agreement from respondents in terms of being “essential” for resident mental health tended to come from the psychosocial categories of personal effectiveness and social connection. These include personal care activities (e.g., dressing, feeding) that are appropriate for one’s capabilities (67.6% of participants rating “essential”), access to devices (e.g., walker) that increase independence (72.7%), perceived staff responsiveness to feedback or requests (81.8%), opportunities to maintain

relationships with friends and family outside the personal care home (79.4%), and warm and caring exchanges with care staff (91.2%). The dementia group was more variable in their ratings of items within the purpose and meaning category and other items such as access to activities outside the PCH, opportunities to be involved in decision-making about care, and opportunities for sexual intimacy or sexual expression. The items that achieved consensus for inclusion are indicated within Table 4. Items within each category are rank ordered by percentage agreement.

Table 4

Round 1 of the Delphi Survey with the Dementia Group: Rated Importance of Psychosocial Needs for Resident Well-Being (n=34)

	Essential	Important but not essential	Unessential	Don't Know	Consensus Y/N
CHOICE AND CONTROL					
Control over which social, recreational, or religious activities are pursued or when	18 (52.9%)	8 (23.5%)	6 (17.6%)	2 (5.9%)	Y
Access to activities within the PCH	18 (52.9%)	12 (35.3%)	2 (5.9%)	2 (5.9%)	Y
Choice to accept or decline help from others	15 (44.1%)	11 (32.4%)	7 (20.6%)	1 (2.9%)	Y
Control over room arrangement, inclusion and placement of personal belongings	13 (40.6%)	10 (31.3%)	8 (25%)	1 (3.1%)	Y
Control over when personal care is performed (e.g., eating, bathing, dressing)	12 (35.3%)	14 (41.2%)	6 (20.6%)	1 (2.9%)	Y
Opportunities to be involved in decision-making about care	11 (32.4%)	13 (38.2%)	9 (26.5%)	1 (2.9%)	N
Access to activities outside the PCH	10 (29.4%)	9 (26.5%)	13 (38.2%)	2 (5.9%)	N
PERSONAL EFFECTIVENESS					
Perceiving that staff are responsive to feedback or requests	27 (81.8%)	1 (3.0%)	5 (15.2%)	0 (0%)	Y
Access to devices (e.g., walker) that increase independence	24 (72.7%)	3 (9.1%)	5 (15.2%)	1 (3.0%)	Y
Doing personal care activities (e.g., dressing, feeding) that are appropriate	23 (67.6%)	4 (11.8%)	7 (20.6%)	0 (0%)	Y

for one's capabilities

Opportunities to talk with staff about care	19 (55.9%)	8 (23.5%)	6 (17.6%)	1 (2.9%)	Y
---	------------	-----------	-----------	----------	---

SOCIAL CONNECTION

Warm and caring exchanges with care staff	31 (91.2%)	3 (8.8%)	0 (0%)	0 (0%)	Y
---	------------	----------	--------	--------	---

Opportunities to maintain relationships with friends and family outside the PCH	27 (79.4%)	3 (8.8%)	2 (5.9%)	2 (5.9%)	Y
---	------------	----------	----------	----------	---

Touch and physical affection	21 (61.8%)	10 (29.4%)	3 (8.8%)	0 (0%)	Y
------------------------------	------------	------------	----------	--------	---

Opportunities to create new relationships within the PCH	14 (41.2%)	14 (41.2%)	6 (17.6%)	0 (0%)	Y
--	------------	------------	-----------	--------	---

Access to activities that create a sense of community within the PCH	14 (41.2%)	14 (41.2%)	5 (14.7%)	1 (2.9%)	Y
--	------------	------------	-----------	----------	---

Opportunities for sexual intimacy and sexual expression	0 (0%)	2 (6.1%)	22 (69.7%)	8 (24.2%)	N
---	--------	----------	------------	-----------	---

PURPOSE AND MEANING

Opportunities to express religious, cultural, and ethnic identity	12 (35.3%)	8 (23.5%)	11 (32.4%)	3 (8.8%)	N
---	------------	-----------	------------	----------	---

Opportunities to reflect on past accomplishments and contributions	9 (26.5%)	13 (38.2%)	11 (32.4%)	1 (2.9%)	N
--	-----------	------------	------------	----------	---

Opportunities to pass along knowledge and experiences to younger people	7 (20.6%)	12 (35.3%)	14 (41.2%)	1 (2.9%)	N
---	-----------	------------	------------	----------	---

Contributing to the PCH (e.g., serving on resident council and performing odd jobs)	3 (8.8%)	7 (20.6%)	21 (61.8%)	3 (8.8%)	N
---	----------	-----------	------------	----------	---

Opportunities to set and achieve goals	2 (5.9%)	10 (30.3%)	13 (39.4%)	8 (24.2%)	N
--	----------	------------	------------	-----------	---

Opportunities to learn new skills	1 (2.9%)	11 (32.4%)	17 (50.0%)	5 (14.7%)	N
-----------------------------------	----------	------------	------------	-----------	---

PLEASURE AND FUN					
Opportunities to do activities that are fun or pleasurable	21 (63.6%)	7 (21.2%)	2 (6.1%)	3 (9.1%)	Y
SELF-ACCEPTANCE					
PCH encourages acceptance of personal strengths and weaknesses	20 (60.6%)	6 (18.2%)	3 (9.1%)	4 (12.1%)	Y

Note. Shaded items did not meet criteria for consensus

Table 5 summarizes how participants rated the importance of each psychosocial need for residents' overall experience within the NH. These ratings are similar to how items were rated on the first dimension (i.e., resident mental health). The following items exhibited a large degree of agreement in terms of having a "large impact" on residents' stay in a NH: personal care activities (e.g., dressing, feeding) that are appropriate for one's capabilities (67.6%), access to devices (e.g., walker) that increase independence (69.7%), perceived staff responsiveness to feedback or requests (72.7%), opportunities to maintain relationships with friends and family outside the PCH (76.5%), warm and caring exchanges with care staff (85.3%), and access to fun or pleasurable activities (66.7%). Items that achieved consensus for inclusion are indicated within Table 5. Items within each category are rank ordered by percentage agreement.

The following items did not achieve a sufficient level of agreement from the dementia group on either of the dimensions of importance and were excluded from the next Delphi iteration: access to activities outside the PCH (choice and control), opportunities to be involved in decision-making about care (choice and control), opportunities for sexual intimacy or sexual expression (social connection), and all items within the purpose and meaning category (i.e., opportunities to express religious, cultural, and ethnic identity; opportunities to pass along knowledge and experiences to younger people; contributing to the PCH; opportunities to set and achieve goals; opportunities to reflect on past accomplishments and contributions; and opportunities to learn new skills).

Table 5

Round 1 of Delphi Survey with the Dementia Group: Rated Impact of Psychosocial Needs for Residents' Stay in Nursing Home (n=34)

	Large Impact	Moderate Impact	Neutral	Minimal	No Impact	Consensus Y/N
CHOICE AND CONTROL						
Access to activities within the PCH	20 (58.8%)	8 (23.5%)	3 (8.8%)	1 (2.9%)	2 (5.9%)	Y
Control over when personal care is performed (e.g., eating, bathing, dressing)	14 (41.2%)	10 (29.4%)	2 (5.9%)	6 (17.6%)	2 (5.9%)	Y
Control over which social, recreational, or religious activities are pursued and when	14 (41.2%)	11 (32.4%)	4 (11.8%)	1 (2.9%)	4 (11.8%)	Y
Control over room arrangement, inclusion and placement of personal belongings	13 (38.2%)	8 (23.5%)	4 (14.7%)	2 (5.9%)	6 (17.6%)	N
Choice to accept or decline help from others	12 (35.3%)	12 (35.3%)	5 (14.7%)	3 (8.8%)	2 (5.9%)	Y
Opportunities to be involved in decision-making about care	11 (32.4%)	12 (35.3%)	6 (17.6%)	0 (0%)	5 (14.7%)	N
Access to activities outside the PCH	9 (27.3%)	8 (24.2%)	6 (18.2%)	1 (3%)	9 (27.3%)	N
PERSONAL EFFECTIVENESS						
Perceiving that staff are responsive to feedback or requests	24 (72.7%)	4 (12.1%)	0 (0%)	1 (3.0%)	4 (12.1%)	Y
Access to devices (e.g., walker) that increase independence	23 (69.7%)	4 (12.1%)	2 (6.1%)	0 (0%)	4 (12.1%)	Y
Doing personal care activities (e.g., dressing, feeding) that are appropriate for one's capabilities	23 (67.6%)	5 (14.7%)	1 (2.9%)	2 (5.9%)	3 (8.8%)	Y

Opportunities to talk with staff about care	17 (50.0%)	9 (26.5%)	3 (8.8%)	2 (5.9%)	3 (8.8%)	Y
SOCIAL CONNECTION						
Warm and caring exchanges with care staff	29 (85.3%)	3 (8.8%)	2 (5.9%)	0 (0%)	0 (0%)	Y
Opportunities to maintain relationships with friends and family outside the PCH	26 (76.5%)	4 (11.8%)	2 (5.9%)	0 (0%)	2 (5.9%)	Y
Touch and physical affection	21 (61.8%)	4 (11.8%)	6 (17.6%)	3 (8.8%)	0 (0%)	Y
Access to activities that create a sense of community within the PCH	15 (44.1%)	12 (35.3%)	3 (8.8%)	0 (0%)	4 (11.8%)	Y
Opportunities to create new relationships within the PCH	14 (41.2%)	11 (32.4%)	4 (11.8%)	2 (5.9%)	3 (8.8%)	Y
Opportunities for sexual intimacy or sexual expression	0 (0%)	2 (6.3%)	8 (25.0%)	3 (9.4%)	19 (59.4%)	N
PURPOSE AND MEANING						
Opportunities to express religious, cultural, or ethnic identity	12 (35.3%)	6 (17.6%)	6 (17.6%)	3 (8.8%)	7 (20.6%)	N
Opportunities to reflect on past accomplishments and contributions	8 (23.5%)	12 (32.4%)	5 (14.7%)	4 (11.8%)	6 (17.6%)	N
Opportunities to pass along knowledge and experiences to younger people	6 (17.6%)	11 (32.4%)	7 (20.6%)	1 (2.9%)	9 (26.5%)	N
Contributing to the PCH (e.g., serving on resident council, performing odd jobs)	4 (12.1%)	4 (12.1%)	5 (15.2%)	2 (6.1%)	18(54.5%)	N
Opportunities to set and achieve goals	2 (6.1%)	4 (12.1%)	10 (30.3%)	6(18.2%)	11(33.3%)	N
Opportunities to learn new skills	2 (5.9%)	6 (17.6%)	12 (35.3%)	3 (8.8%)	11 (32.4%)	N

PLEASURE AND FUN

Opportunities to do activities that are fun or pleasurable	22 (66.7%)	4 (12.1%)	5 (15.2%)	1 (3.0%)	1 (3.0%)	Y
--	------------	-----------	-----------	----------	----------	---

SELF-ACCEPTANCE

PCH encourages acceptance of personal strengths and weaknesses	18 (54.5%)	8 (24.2%)	2 (6.1%)	3 (9.1%)	2 (6.1%)	Y
--	------------	-----------	----------	----------	----------	---

Note. Shaded items did not meet criteria for consensus

Round 2 of Delphi survey with the dementia group. Table 6 displays how important family members rated the importance of each psychosocial need for residents' well-being. Items that exhibited a large degree of agreement in terms of being "essential" for resident well-being in this round were similar to the first round in that they were primarily from the personal effectiveness and social connection categories. These items, rank ordered by the percentage of family members rating them as "essential" include opportunities to maintain relationships with friends and family outside the personal care home (96%), warm and caring exchanges with care staff (92%), perceiving that staff are responsive to feedback or requests (87.5%), choice to accept or decline help from others (76%), access to devices (e.g., walker) that increase independence (75%), and opportunities to talk with staff about care (70.8%). As indicated within Table 6, all items achieved consensus. These essential items are in boldface within Table 6. Items are ordered in each category based on the percentage of individuals who rated it "essential."

Table 6

Round 2 of the Delphi Survey with the Dementia Group: Rated Importance of Psychosocial Needs for Resident Well-Being (n=27)

	Essential	Important but not essential	Unessential	Don't know	Consensus Y/N
CHOICE AND CONTROL					
Choice to accept or decline help from others	19 (76.0%)	4 (16.0%)	1 (4.0%)	1 (4.0%)	Y
Control over which social, recreational, or religious activities are pursued and when	17 (68.0%)	5 (20.0%)	1 (4.0%)	2 (8.0%)	Y
Control over room arrangement, inclusion and placement of personal belongings	15 (60.0%)	5 (20.0%)	5 (20.0%)	0 (0%)	Y
Access to activities within the PCH	13 (52.0%)	11 (44.0%)	1 (4.0%)	0 (0%)	Y
Control over when personal care is performed (e.g., eating, bathing, dressing)	6 (24.0%)	17 (68.0%)	1 (4.0%)	1 (4.0%)	Y
Access to activities outside the PCH					
Opportunities to be involved in decision-making about care					
PERSONAL EFFECTIVENESS					
Perceiving that staff are responsive to feedback or requests	21 (87.5%)	1 (4.2%)	1 (4.2%)	1 (4.2%)	Y
Access to devices (e.g., walker) that increase independence	18 (75.0%)	3 (12.5%)	3 (12.5%)	0 (0%)	Y
Opportunities to talk with staff about care	17 (70.8%)	3 (12.5%)	4 (16.7%)	0 (0%)	Y
Doing personal care activities (e.g.,	16 (64.0%)	7 (28.0%)	2 (8.0%)	0 (0%)	Y

dressing, feeding) that are appropriate for one’s capabilities

SOCIAL CONNECTION

Opportunities to maintain relationships with friends and family outside the PCH	24 (96.0%)	0 (0%)	0 (0%)	1 (4.0%)	Y
Warm and caring exchanges with care staff	23 (92.0%)	2 (8.0%)	0 (0%)	0 (0%)	Y
Opportunities to create new relationships within the PCH	8 (32.0%)	13 (52.0%)	4 (16.0%)	0 (0%)	Y
Access to activities that create a sense of community within the PCH	7 (28.0%)	16 (64.0%)	1 (4.0%)	1 (4.0%)	Y
Touch and physical affection	16 (64.0%)	6 (24.0%)	2 (8.0%)	1 (4.0%)	Y
Opportunities for sexual intimacy or sexual expression					

PURPOSE AND MEANING

Opportunities to express religious, cultural, and ethnic identity
 Opportunities to pass along knowledge and experiences to younger people
 Contributing to the PCH (e.g., serving on resident council, performing odd jobs)
 Opportunities to set and achieve goals
 Opportunities to reflect on past accomplishments, contributions
 Opportunities to learn new skills

PLEASURE AND FUN					
Opportunities to do activities that are fun or pleasurable	17 (68.0%)	7 (28.0%)	1 (4.0%)	0 (0%)	Y
SELF-ACCEPTANCE					
PCH encourages acceptance of personal strengths and weaknesses	16 (64.0%)	4 (16.0%)	1 (4.0%)	4 (16.0%)	Y

Note. Shaded items were excluded following the first Delphi iteration. Items in boldface were rated by at least 70% of participants as “essential.”

Table 7 summarizes the rated impact of each psychosocial need for residents' experience within the NH for this iteration. Items that exhibited a large degree of agreement in terms of having a "large impact" on residents' experience within a nursing home primarily came from the personal effectiveness and social connection categories. These items, ordered by the percentage of family members rating them as "essential," include opportunities to maintain relationships with friends and family outside the personal care home (88%), warm and caring exchanges with care staff (88%), perceiving that staff are responsive to feedback or requests (84%), and access to devices (e.g., walker) that increase independence (72%). Items are ordered in each category based on the percentage of individuals who rated them as having a large impact. The "large impact" items listed above are in boldface.

All items included within the second Delphi iteration round met the consensus criteria, therefore no items were excluded following this round. A summary of the final list of psychosocial needs for this group compared to the initial list within Phase Two is provided in Table 8. Items in boldface are considered to be the essential items on this list.

Table 7

Round 2 of the Delphi Survey with the Dementia Group: Rated Impact of Psychosocial Needs for Residents' Stay in Nursing Home (n=27)

	Large Impact	Moderate Impact	Neutral	Minimal	No Impact	Consensus Y/N
CHOICE AND CONTROL						
Control over which social, recreational, or religious activities are pursued and when	16 (64.0%)	4 (16.0%)	1 (4.0%)	2 (8.0%)	2 (8.0%)	Y
Control over room arrangement, inclusion and placement of personal belongings	15 (60.0%)	5 (20.0%)	1 (4.0%)	2 (8.0%)	2 (8.0%)	Y
Choice to accept or decline help from others	14 (56.0%)	8 (32.0%)	1 (4.0%)	1 (4.0%)	1 (4.0%)	Y
Access to activities within the PCH	14 (56.0%)	10 (40.0%)	1 (4.0%)	0 (0%)	0 (0%)	Y
Control over when personal care is performed (e.g., eating, bathing, dressing)	13 (52.0%)	8 (32.0%)	2 (8.0%)	1 (4.0%)	1 (4.0%)	Y
Access to activities outside the PCH						
Opportunities to be involved in decision-making about care						
PERSONAL EFFECTIVENESS						
Perceiving that staff are responsive to feedback or requests	21 (84.0%)	2 (8.0%)	1 (4.0%)	1 (4.0%)	0 (0%)	Y
Access to devices (e.g., walker) that increase independence	18 (72.0%)	4 (16.0%)	0 (0%)	1 (4.0%)	2 (8.0%)	Y
Doing personal care activities (e.g., dressing, feeding) that are appropriate	17 (68.0%)	6 (24.0%)	0 (0%)	1 (4.0%)	1 (4.0%)	Y

for one's capabilities

Opportunities to talk with staff about care	12 (48.0%)	8 (32.0%)	3 (12.0%)	1 (4.0%)	1 (4.0%)	Y
---	------------	-----------	-----------	----------	----------	---

SOCIAL CONNECTION

Opportunities to maintain relationships with friends and family outside the PCH	22 (88.0%)	3 (12.0%)	0 (0%)	0 (0%)	0 (0%)	Y
--	-------------------	-----------	--------	--------	--------	---

Warm and caring exchanges with care staff	22 (88.0%)	2 (8.0%)	1 (4.0%)	0 (0%)	0 (0%)	Y
--	-------------------	----------	----------	--------	--------	---

Touch and physical affection	15 (60.0%)	6 (24.0%)	2 (8.0%)	2 (8.0%)	0 (0%)	Y
------------------------------	------------	-----------	----------	----------	--------	---

Access to activities that create a sense of community within the PCH	8 (32.0%)	11 (44.0%)	4 (16.0%)	1 (4.0%)	1 (4.0%)	Y
--	-----------	------------	-----------	----------	----------	---

Opportunities to create new relationships within the PCH	7 (28.0%)	9 (36.0%)	6 (24.0%)	1 (4.0%)	2 (8.0%)	N
--	-----------	-----------	-----------	----------	----------	---

Opportunities for sexual intimacy or sexual expression

PURPOSE AND MEANING

- Opportunities to express religious, cultural, or ethnic identity
- Opportunities to pass along knowledge and experiences to younger people
- Contributing to the PCH (e.g., serving on resident council and performing odd jobs)
- Opportunities to set and achieve goals
- Opportunities to reflect on past accomplishments and contributions
- Opportunities to learn new skills

PLEASURE AND FUN						
Opportunities to do activities that are fun or pleasurable	15 (60.0%)	7 (28.0%)	1 (4.0%)	2 (8.0%)	0 (0%)	Y
SELF-ACCEPTANCE						
PCH encourages acceptance of personal strengths and weaknesses	12 (48.0%)	5 (20.0%)	5 (20.0%)	2 (8.0%)	1 (4.0%)	Y

Note. Shaded items were excluded following the first Delphi iteration. Items in boldface items were rated by at least 70% participants as having a “large impact.”

Table 8

Psychosocial Needs for NH Residents with Dementia after First and Second Delphi Round

First Delphi Round (Items ordered by % agreement)	Second Delphi Round (Items ordered by % agreement)
<p>CHOICE AND CONTROL</p> <ol style="list-style-type: none"> 1. Control over which social, recreational, or religious activities are pursued and when 2. Access to activities within the PCH 3. Choice to accept or decline help from others 4. Control over room arrangement, inclusion and placement of personal belongings 5. Control over when personal care is performed (e.g., eating, bathing, dressing) 6. Opportunities to be involved in decision-making about care 7. Access to activities outside the PCH 	<p>CHOICE AND CONTROL</p> <ol style="list-style-type: none"> 1. Choice to accept or decline help from others 2. Control over which social, recreational, or religious activities are pursued and when 3. Control over room arrangement, inclusion and placement of personal belongings 4. Access to activities within the PCH 5. Control over when personal care is performed (e.g., eating, bathing, dressing)
<p>PERSONAL EFFECTIVENESS</p> <ol style="list-style-type: none"> 1. Perceiving that staff are responsive to feedback or requests 2. Access to devices (e.g., walker) that increase independence 3. Doing personal care activities (e.g., dressing, feeding) that are appropriate for one's capabilities 4. Opportunities to talk with staff about care 	<p>PERSONAL EFFECTIVENESS</p> <ol style="list-style-type: none"> 1. Perceiving that staff are responsive to feedback or requests 2. Access to devices (e.g., walker) that increase independence 3. Opportunities to talk with staff about care 4. Doing personal care activities (e.g., dressing, feeding) that are appropriate for one's capabilities
<p>SOCIAL CONNECTION</p> <ol style="list-style-type: none"> 1. Warm and caring exchanges with care staff 2. Opportunities to maintain relationships with friends and family outside the PCH 	<p>SOCIAL CONNECTION</p> <ol style="list-style-type: none"> 1. Opportunities to maintain relationships with friends and family outside the PCH 2. Warm and caring exchanges with care staff

- 3. Touch and physical affection
- 4. Opportunities to create new relationships within the PCH
- 5. Access to activities that create a sense of community within the PCH
- 6. Opportunities for sexual intimacy or sexual expression

- 3. Access to activities that create a sense of community within the PCH
- 4. Touch and physical affection



PLEASURE AND FUN

- 1. Opportunities to do activities that are fun or pleasurable

PLEASURE AND FUN

- 1. Opportunities to do activities that are fun or pleasurable

SELF-ACCEPTANCE

- 1. PCH encourages acceptance of personal strengths and weaknesses

SELF-ACCEPTANCE

- 1. PCH encourages acceptance of personal strengths and weaknesses

Note. Shaded items were excluded following the first Delphi iteration. Items in boldface were rated by at least 70% of participants as being either “essential” for resident mental health or as having a “large impact” on residents’ experience within a NH.

Round 3 Questionnaire. In the Round 3 questionnaire, participants commented on the final list of psychosocial needs and whether the items should be changed. Overall, participants’ written feedback conveyed that they thought the list was a comprehensive and valid representation of what was most important to their NH resident from a psychosocial perspective. Written feedback also assisted in contextualizing the dementia group’s responses in the Delphi survey. This feedback was categorized into five themes. The first theme involved how the severity of residents’ cognitive impairment and physical limitations influenced the relative priority of psychosocial needs. For example, with respect to the purpose and meaning category, one participant commented: “I would normally put that it is ‘essential’ and has a ‘large impact’ for all of the above questions but because of my mom's limited abilities, it isn't as important to her now.” Another

respondent indicated that social needs and those related to control become more salient with nursing home admission:

Residents in personal care homes have lost mental and/or physical capabilities, but many retain their social skills. As they have lost a great deal of control and independence in their personal lives, it is essential for them to be given as many opportunities as possible to retain whatever control and independence they are capable of. Social activities and interactions may be the only area left in their lives where they can exercise control and independence, creating a sense of well-being and self worth.

A second theme of comments indicated that in spite of residents being cognitively impaired, they still appreciated the quality of their interactions with staff, and attention and affection from others. This was articulated by a study participant, who said:

Although Mom suffers with dementia, I have seen staff members talk to her while performing personal care tasks and Mom will sometimes respond with a few words or give them a big smile. Although her reply may not make sense, she does know they are speaking to her.

Another respondent indicated:

My mother is essentially wheelchair bound and rarely opens her eyes. However, I think music and Christian services are encouraging to her (...) and I think it is essential to have interactions with other Christians. [Although] she doesn't speak, and I don't know how much she understands.

Another theme from family members' comments focused on the quality of residents' interactions with staff. More specifically, several respondents indicated that it

was critical for staff to take an interest in residents, treat them with dignity, and take their concerns seriously. For example, one respondent indicated:

One thing that my mother finds extremely important is the sense that her caregivers recognize her as an individual, with her own accomplishments and talents, not as just an old person that needs care. The caregiver can be as loving and compassionate as possible, but if they treat me fairly competent and “present” mother the same as the lady with severe dementia across the hall who is constantly shouting for help and doesn't recognize anyone, it's very upsetting for her. She needs to know that they see her as intelligent, accomplished and someone who still has something to offer.

Another respondent stated: “It is important for residents to maintain their independence and dignity and that they feel that their views/concerns are being heard and are taken into consideration.”

An additional theme emerging from family members' comments pertained to the importance of considering residents' unique preferences when staff are providing care, particularly concerning using touch and humour: “Dad likes hugs from people he is comfortable with but there is one volunteer that hugs everyone all the time and he doesn't like that.” Another respondent comments on her mother's preferences for staff interactions: “She appreciates the staff that show they care. She lets me know when they have been indifferent or grumpy. Those are the days she wishes she wasn't there. She prefers that staff interact in a joking way rather than physical affection.”

Finally, respondents felt it was more important for residents to maintain relationships with family and friends outside of the nursing home than to form new

relationships within the nursing home. One participant commented: “The only thing I might add is continued support of and visits by family members is essential. The resident cannot be left in the PCH without regular visits from family.” Another respondent commented: “Mom will phone family and friends. She enjoys the calls she gets which keep her in touch. She doesn't go out of her way to make new friends but acknowledges and talks with others in the PCH and their family members.” This was echoed by another respondent: “I have observed that relationships with caregivers and visitors are most important. The residents do not socialize together that much unless encouraged by staff.”

Discussion

Phase Two of this research identified the psychosocial needs that are essential and those that are highly important for NH residents with dementia, in terms of their well-being and overall experience within the NH. Family members were an important group of stakeholders to survey given the knowledge they possess about the resident and the role they play in decision-making about care. Family members identified 16 needs across five categories that were important or essential for resident well-being and moderately or largely impactful on residents' experiences within a NH. Of these items, the following six needs were deemed to be “essential” by the majority of family members of residents with dementia, with their respective categories indicated in parentheses: choice to accept or decline help from others (choice and control), access to devices (e.g., walker) that increase independence (personal effectiveness), opportunities to talk with staff about care (personal effectiveness), perceiving that staff are responsive to feedback or requests (personal effectiveness), having warm and caring exchanges with care staff (social connection), and opportunities to maintain relationships with friends and family outside

the PCH (social connection). The items that were excluded from the list were as follows: access to activities outside PCH (choice and control), opportunities to be involved in decision-making about care (choice and control), opportunities for sexual intimacy or sexual expression (social connection), and all the items within the meaning and purpose category. Figure 2 depicts the final categorization of needs into “essential,” “important but not essential,” and “not as important.”

ESSENTIAL

- Choice to accept or decline help from others (choice and control)
- Perceiving that staff are responsive to feedback or requests (personal effectiveness)
- Access to devices (e.g., walker) that increase independence (personal effectiveness)
- Opportunities to talk with staff about care (personal effectiveness)
- Opportunities to maintain relationships with friends and family outside the PCH (social connection)
- Warm and caring exchanges with care staff (social connection)

IMPORTANT BUT NOT ESSENTIAL

- Control over what social, recreational, or religious activities are pursued and when (choice and control)
- Control over room arrangement, inclusion, and placement of personal belongings (choice and control)
- Access to activities within the PCH (choice and control)
- Control over when personal care is performed (e.g., eating, bathing, dressing) (choice and control)
- Doing personal care activities (e.g., dressing and feeding) that are appropriate for one's capabilities (personal effectiveness)
- Access to activities that create a sense of community within the PCH (social connection)
- Opportunities to create new relationships within the PCH (social connection)
- Touch and physical affection (social connection)
- Opportunities to do activities that are fun or pleasurable (fun and pleasure)
- PCH encourages acceptance of personal strengths and weaknesses (self-acceptance)

NOT AS IMPORTANT

- Opportunities to be involved in decision-making about care (choice and control)
- Access to activities outside the PCH (choice and control)
- Opportunities for sexual intimacy or sexual expression (social connection)
- Opportunities to express religious, cultural, or ethnic identity (purpose and meaning)
- Opportunities to pass along knowledge and experiences to younger people (purpose and meaning)
- Contributing to the PCH (e.g., serving on resident council, performing odd jobs) (purpose and meaning)
- Opportunities to set and achieve goals (purpose and meaning)
- Opportunities to reflect on past accomplishments, contributions (purpose and meaning)
- Opportunities to learn new skills (purpose and meaning)

Figure 2. Summary of psychosocial needs for residents with dementia

Note. Need categories are in parentheses. Items are rank ordered within each box by degree of importance

Family members' comments indicated that the final list of needs was a good reflection of what was important to their resident but also highlighted how cognitive impairment can change the relative priority of psychosocial needs. Nonetheless, several family members indicated that despite having severe dementia, residents still appreciate interacting with staff and engaging in meaningful activities. It is noteworthy, however, that the category of meaning and purpose was excluded during the Delphi survey. This will be addressed further in the general discussion. Family members also affirmed the importance of staff treating residents with respect and dignity and personalizing their approach to care. Although family members perceived that residents valued social connection, they preferred to spend time with people more familiar to them as opposed to forming new relationships within the NH.

A limitation of this phase involves the representation of residents from various religious backgrounds. The sample consisted predominantly of family members from the Mennonite and secular facility. I had more difficulty recruiting family members from the Jewish NH and as such, these family members are underrepresented in this sample. Also, facilities ascribing to other religious orientations are not represented in this sample. This restricts the generalizability of the findings as the results may, in part, reflect the religious values and beliefs espoused by the family members and facilities involved as opposed to a broader sample of NH residents.

The general discussion will explore these findings further within the context of relevant theory and published research and address additional limitations and implications for research and practice.

Phase Three: Pilot Survey for Residents Without Dementia

Introduction

While the strong majority of NH residents have dementia (Breitner, 2006), the psychosocial needs of these individuals may differ from those without dementia. There is a lack of research that identifies the psychosocial needs of NH residents without dementia. The objective of Phase Three is to gather exploratory information on the psychosocial needs of NH residents without dementia using a small sample of family members. It should be noted that, after prolonged recruitment efforts, I was able to recruit only a small number of study participants for this phase of the research. Results from this aspect of the research should therefore be considered as preliminary.

Method

Participants. I approached a fourth facility by email and phone call to determine whether they could assist with recruiting family members of residents without dementia. This was a 230-bed, secular facility with a greater concentration of residents without dementia who required long-term care for other reasons (e.g., complex medical conditions). I worked with the facility's research coordinator to recruit family members of residents with a CPS score of 0 or 1. The facility research coordinator agreed to mail a flyer, on my behalf, to 31 eligible family members (Appendix E). One month after the flyer was sent only four family members expressed interest in participating in the study. I

initiated a second mailing, yielding one additional participant for a sample of five. After the second mailing, I met with my committee and we collectively agreed to stop recruiting given the lack of response from other family members.

I gave participants each a \$15 gift card for participating in Phase Three. A summary of participant recruitment and attrition for Phases Two and Three is shown in Figure 3, with family members of residents with dementia displayed in blue and family members of residents without dementia displayed in green.

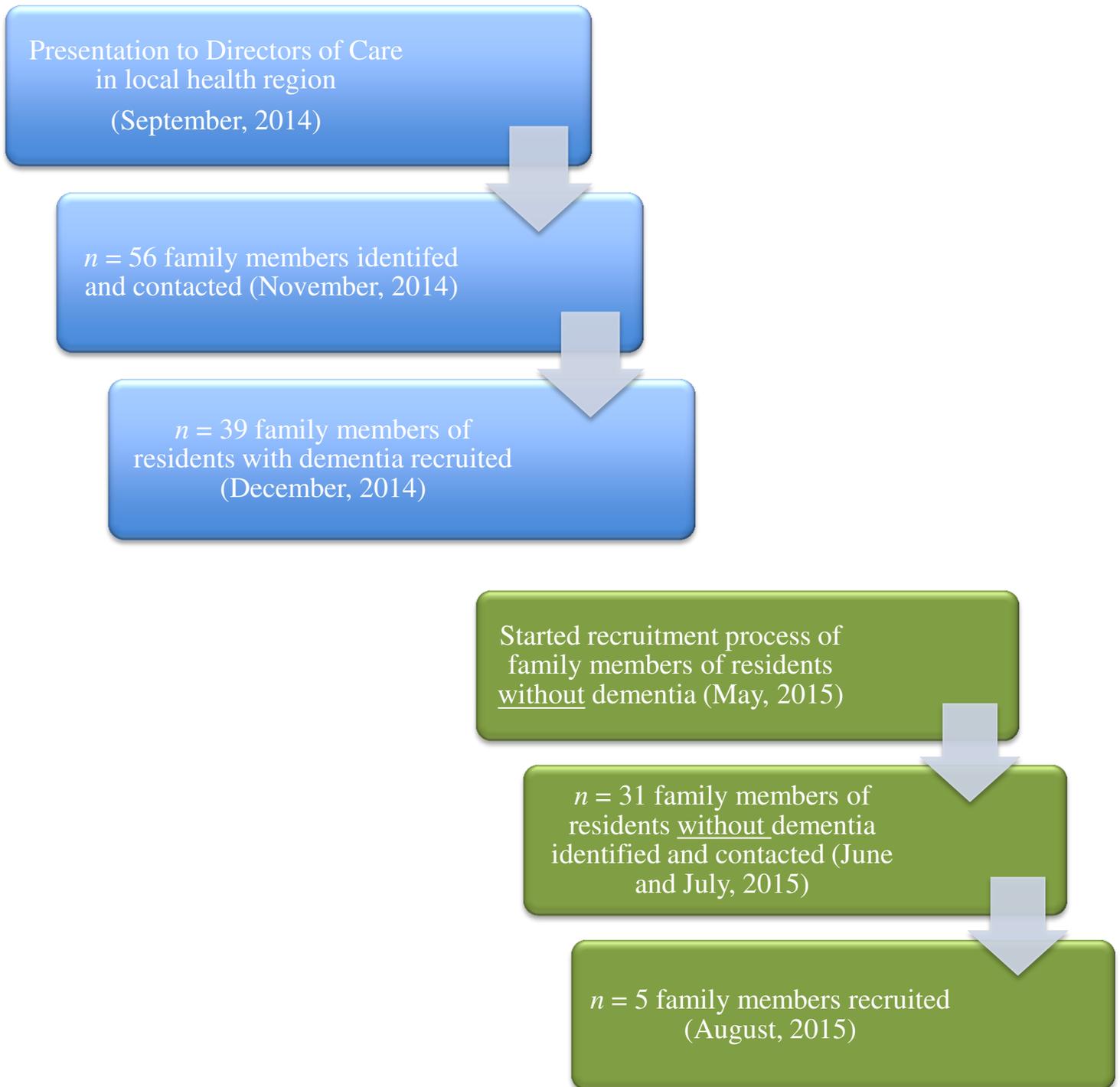


Figure 3. Participant Recruitment for Phases Two and Three

Materials. Phase Three used the identical materials for the Delphi procedure as Phase Two did, i.e., sociodemographic questionnaire, DSRS, and Delphi survey.

Procedure. Phase Three employed the same procedure as did Phase Two. However, the Delphi survey was solely conducted online due to participants' preference. Phase Three used the same definition of consensus as Phase Two did. Due to one participant dropping out of the study after the second Delphi iteration, I did not conduct a final Delphi iteration. Instead, participants provided feedback on the final list of needs, similar to the procedure within Phase Two. After returning their feedback, participants received a thank-you card and gift certificate.

Analyses. I used identical analytic methods for the Phase Three Delphi survey as I did in Phase Two. I also used the same approach with respect to summarizing participants' written comments on the final list of psychosocial needs.

Results

DSRS Scores. The mean DSRS score for the residents without dementia represented in Phase Three was 26.5 (SD = 5.06, range = 19.0-30.0). Two individuals exceeded the cutoff score of 21 (for moderate to severe dementia), despite having been selected for this study by way of their CPS scores of 0 or 1.

Sociodemographic Features. As seen in Table 9, the no-dementia group consisted of $n = 2$ males and $n = 3$ females. Four respondents were between the ages of 55 and 59 (80%) and were the children or stepchildren of the resident (80%). Respondents were in "good" (60%) or "excellent" (40%) health. All five participants reported "mild" degrees of stress (100%). Four respondents visited their resident at least

twice a month or more (80%) for 1–3 hours (80%). Four family members had a male NH resident (80%) who was over the age of 80 (100%), widowed (80%), and deemed in “good” (80%) or “excellent” (20%) physical health.

Table 9

Phase Three Participant Demographics

	Family Members of Residents without Dementia) (<i>n</i> = 5)
Sex	
Male	2 (40%)
Female	3 (60%)
Age	
40-54	0 (0%)
55-59	4 (80%)
70-84	1 (20%)
Health	
Excellent	2 (40%)
Good	3 (60%)
Fair	0 (0%)
Poor	0 (0%)
Stress	
Mild	5 (100%)
Moderate	0 (0%)
High	0 (0%)
Relationship to Resident	
Child or stepchild	4 (80%)
Niece or nephew	0 (0%)
Spouse	0 (0%)
Other	1 (20%)
Frequency of visits	
Less than once a month	1 (20%)
Once a month	0 (0%)
Twice a month	1 (20%)
Once a week	2 (40%)
Daily or nearly every day	1 (20%)
Length of Visits	
Less than one hour	1 (20%)
1-3 hours	3 (60%)

3-5 hours	0 (0%)
More than 5 hours	1 (20%)
Age of resident	
<60	0 (0%)
60-69	0 (0%)
70-79	0 (0%)
80-89	2 (40%)
90+	3 (60%)
Resident sex	
Male	4 (80%)
Female	1 (20%)
Resident marital status	
Married or common-law	0 (0%)
Widowed	4 (80%)
Separated or divorced	1 (20%)
Single	0 (0%)
Resident physical health	
Excellent	1 (20%)
Good	4 (80%)
Fair	0 (0%)
Poor	0 (0%)

Summary of Delphi Iterations. Given the small sample size of the no-dementia group and the difficulties this poses to interpreting data from a Delphi survey, the results of the Delphi round will not be presented in detail here. Readers can consult Appendix K for the results of the first and second Delphi iterations and the final questionnaire with the no-dementia group in their entirety. A third Delphi round was not conducted due to the attrition of one participant. The final list of psychosocial needs from the two Delphi iterations with the no-dementia group is displayed in Appendix L and is briefly summarized here. The final list of needs for residents without dementia retained all categories except for pleasure and fun. Items that were indicated as being particularly important in both dimensions by the majority of the no-dementia group included all needs

within the personal effectiveness category, choice to accept or decline help from others (choice and control), control over room arrangement, inclusion and placement of personal belongings (choice and control), opportunities to maintain relationships with friends and family outside the PCH (social connection), and warm and caring interactions with staff (social connection).

The final list of needs for residents without dementia compared to those with dementia is displayed in Table 10. The small sample size of the no-dementia group limits the extent to which we can conclude that observed differences in the two lists of needs are reliable, therefore, cautious interpretation is necessary. Both lists retained all of the items in the personal effectiveness and self-acceptance categories and the majority of items within the choice and control and social connection categories. Both lists excluded access to activities within the NH, sexual intimacy and expression, and the majority of items within the purpose and meaning category. Conversely, the final list for residents with dementia retained access to activities within the NH (personal effectiveness), access to activities that create a sense of community within the NH (social connection), and the fun and pleasure category, whereas these were excluded for residents without dementia. In contrast, the final list for residents without dementia retained opportunities to be involved in decision making about care (choice and control), opportunities to form new relationships within the NH (social connection), and opportunities to reflect on past accomplishments (purpose and meaning); these items were excluded for residents with dementia. Again, these differences should be interpreted with caution given the small size of the no-dementia group, but the preliminary data here suggests that there is considerable overlap in the content of both lists.

Table 10

Final list of Psychosocial Needs for Residents with versus without Dementia

Residents without Dementia	Residents with Dementia
<p>CHOICE AND CONTROL</p> <ol style="list-style-type: none"> 1. Control over room arrangement, inclusion and placement of personal belongings 2. Choice to accept or decline help from others 3. Control over which social, recreational, or religious activities are pursued and when 4. Opportunities to be involved in decision-making about care 5. Control over when personal care is performed (e.g., eating, bathing, dressing) 	<p>CHOICE AND CONTROL</p> <ol style="list-style-type: none"> 1. Choice to accept or decline help from others 2. Control over which social, recreational, or religious activities are pursued and when 3. Control over room arrangement, inclusion and placement of personal belongings 4. Access to activities within the PCH 5. Control over when personal care is performed (e.g., eating, bathing, dressing)
<p>PERSONAL EFFECTIVENESS</p> <ol style="list-style-type: none"> 1. Doing personal care activities (e.g., dressing, feeding) that are appropriate for one’s capabilities 2. Perceiving that staff are responsive to feedback or requests 3. Access to devices (e.g., walker) that increase independence 4. Opportunities to talk with staff about care 	<p>PERSONAL EFFECTIVENESS</p> <ol style="list-style-type: none"> 1. Perceiving that staff are responsive to feedback or requests 2. Access to devices (e.g., walker) that increase independence 3. Opportunities to talk with staff about care 4. Doing personal care activities (e.g., dressing, feeding) that are appropriate for one’s capabilities
<p>SOCIAL CONNECTION</p> <ol style="list-style-type: none"> 1. Opportunities to maintain relationships with friends and family outside the PCH 2. Warm and caring exchanges with care staff 3. Touch and physical affection 4. Opportunities to create new relationships within the PCH 	<p>SOCIAL CONNECTION</p> <ol style="list-style-type: none"> 1. Opportunities to maintain relationships with friends and family outside the PCH 2. Warm and caring exchanges with care staff 3. Opportunities to create new relationships within the PCH 4. Access to activities that create a sense of community within the PCH 5. Touch and physical affection

PURPOSE AND MEANING

1. Opportunities to reflect on past accomplishments and contributions

PLEASURE AND FUN

1. Opportunities to do activities that are fun or pleasurable

SELF-ACCEPTANCE

1. PCH encourages acceptance of personal strengths and weaknesses

SELF-ACCEPTANCE

1. PCH encourages acceptance of personal strengths and weaknesses

Note. Items in boldface were deemed by >70% of respondents to be “essential.” Items are ordered based on % agreement.

Discussion

Phase Three provides preliminary information on the psychosocial needs that are most important for NH residents without dementia. There were significant difficulties recruiting family members of residents without dementia, which resulted in a small sample size. This limits the extent to which the findings can be interpreted reliably and compared to the sample of residents with dementia. These challenges notwithstanding, the lists of psychosocial needs for residents with and without dementia share similarities. Items that showed a high degree of agreement within the non-dementia sample were all the needs within the personal effectiveness category, choice to accept or decline help from others (choice and control), control over room arrangement, inclusion and placement of personal belongings (choice and control), opportunities to maintain relationships with friends and family outside the PCH (social connection), and warm and caring interactions with staff (social connection). Interestingly, the pleasure and fun category was eliminated following the second Delphi. These findings will be discussed in the general discussion, as will the implications, limitations and suggestions for future research.

Phase Four: Focus Group with Staff

Introduction

The purpose of Phase Four is to understand further how care providers assist NH residents to meet their psychosocial needs, and to describe factors that impede or facilitate staff in this regard. The results of this phase will complement our understanding of the psychosocial needs of NH residents and the role that staff play in meeting these needs. The findings will prompt additional examination of how facilities can support staff in their efforts to improve resident psychological and social well-being.

Method

Participants. I sought a sample of eight to ten nursing home staff members to participate in one focus group for 60 minutes. This number of participants is consistent with published recommendations from Massey (2011). One of the facilities that assisted with recruitment for Phase Two agreed to participate in Phase Four. The resident care manager helped recruit a heterogeneous sample of staff from various disciplines and diverse work experiences. The resident care manager approached staff to provide them with written information about the study (Appendix I) and instructed them to contact him if they were interested in participating. Ten staff members agreed to participate. This consisted of two health care aids, one dietary and housekeeping aid, one nursing education manager, one chaplain, one recreation staff member, one registered nurse, one resident care manager, one rehabilitation assistant, and one licensed practical nurse. I gave each participant a \$15 gift card to a bookstore for participating.

Materials. The focus group discussion guide with nursing home staff consisted of the following questions (accompanied by the Phase Two list of psychosocial needs) (a)

How do you currently meet these needs for residents in this facility? (b) What facilitates your ability to meet these needs? (c) What impedes your ability to meet these needs? (d) Would you add to or change anything about this list of needs? The discussion group guide with my verbal instructions is provided in Appendix J.

Procedure. Approximately one month after completing Phase Three, I met with the 10 staff members who volunteered to participate in the staff focus group. I started the focus group with a verbal description of the study and summary of the risks and benefits of participating. I instructed participants to read and complete the information and consent form if they agreed to participate. I recorded and transcribed the content of the focus group. I also took notes during the focus group to identify which participants spoke and when. I distributed a paper copy of the list of psychosocial needs and allotted several minutes for focus group participants to read the list. Approximately 15 minutes was allotted for each question to permit time for participants to ask questions and to complete the informed consent procedures. At the end of the focus group, I thanked participants for their participation and gave them each a gift card. I transcribed the content from an audio recording I had made of the focus group.

Analyses. Considering recommendations by Massey (2011), I coded the focus group content for both articulated data and emergent data. Articulated data occur in direct response to questions within the discussion guide. These data are often characterized by beliefs, attitudes, experiences, and opinions in reference to the question posed by the moderator (Massey, 2011). Participant comments or reactions to other group members can also be considered articulated data. The first step in analyzing articulated data from focus groups involves separating people's responses to questions

and determining if participants answered each question or not. If an answer addresses the question that was posed in the group, the answer is assembled with other people's responses to the question. If it addresses another question, it is moved to the group of responses associated with that question. If an exchange does not answer any of the questions posed, it is left separate. Subsequently, the analysis combines, summarizes, and interprets the answers to each of the articulated questions.

Emergent data is another level of data that can be analyzed from focus groups. This level of data analysis involves examining the group processes and implicit assumptions emerging from discussions that are not predicted. In other words, this form of data analysis seeks to identify new insights from participants by examining the individual, social, and cultural issues elicited through questioning (Massey, 2011). This data can appear in stories, anecdotes, explanations, and conversations among participants that seem to address an unasked question. As such, analysis of this data often involves inferring unstated attitudes, opinions, and motivations.

To analyze the focus group data, I read the transcribed focus group and categorized participant responses that were articulated data, that is, direct responses to questions. Following this, I reread transcripts for emergent data. My field notes and observations during the focus group were also used to support the emergent data I identified within the transcript. Consistent with other published research using focus group methodology (O'Brien, 1993; Powell, Single, & Lloyd, 1996) the reliability of the data analysis is enhanced by having at least one other individual read and analyze the transcribed data. Ms. Lindsay Berard, a research assistant who is trained in qualitative data analysis, also read through the transcript and independently coded the articulated and

emergent data. Her feedback was used to help revise my initial interpretation of the data and summarize my conclusions. The discrepancies in our coding were minor and were resolved through discussion and revisions to theme titles. Members of the research team (i.e., Drs. Thompson, Doupe and Mackenzie) helped further refine the themes at the manuscript-writing stage. Dr. Thompson suggested the final framework for the articulated data.

Results

Articulated Data. The articulated data from each question are described below, with the major themes summarized in Figure 4.

1. Factors that promote residents' psychosocial needs

- Health Care Provider
 - Person-centred approaches to care
 - Individualized care
 - Self-care
- Resident
 - Meeting basic needs
 - Opportunities to exert control
- Nursing Home Environment
 - Staff communication
 - Workplace culture
 - Facility policies and procedures

2. Challenges faced by staff in helping residents meet their psychosocial needs

- Administrative obligations
- Lack of information about residents
- Communication challenges due to dementia
- Conflict between staff, family members and residents
- Balancing the needs of residents with varying levels of assistance required

- Lack of time

3. Suggested revisions to the list of needs

- Removing need for sexual intimacy and expression
- Adding need for privacy
- Expanding item regarding decision making about care

Figure 4. Summary of Articulated Data from Staff Focus Group

Facilitating residents' psychosocial needs. I combined participants' responses to the first two focus group questions into one overarching theme addressing the factors that promote residents' psychosocial needs. This theme consisted of subthemes that involve the health care provider, the resident, and the NH environment. The interplay between these factors conceivably helps facilitate residents' psychosocial needs. Factors involving the health care provider that staff perceived as instrumental in meeting residents' psychosocial needs included person-centred care, individualized care, and staff self-care.

Person-centred care. First, staff indicated that providing person-centred care was instrumental in meeting residents' psychosocial needs. There were a number of staff comments highlighting the importance of being genuine, warm, respectful and dignified with residents. Staff thought this was exemplified through the use of humor, physical affection, using people's names, looking at them at eye level, smiling, expressing interest and asking questions. For example, one participant indicated: "Even if you're just passing by and see a person sitting there, just say hello or say their name. Acknowledge them. And ask them how they are doing (...) they really appreciate that." Another

participant highlighted the importance of being moderately self-disclosing with residents and treating them “like an adult.”

They need to get to know you. You don't need to put everything in your life on a platter but a little bit of a personality, a little bit of a joke, something about your family, your kids, so they see that you're sharing, and care enough to give, it's like you're treating them like an adult. And you're not putting them down.

Other elements of person-centred care that were highlighted included validating residents' feelings, respecting their refusals, and building trust. Staff indicated that it was important to be able to identify and validate when residents were fearful or anxious about something and provide encouragement and support for them to participate but also to respect whenever possible when residents say “no.” A staff member commented:

Picking up on [his] comment about fears and anxieties, to just acknowledge the fact that sometimes you may be facing something pretty scary and not skirting around those issues. I think that's really, really, important, to acknowledge that life isn't always rosy but we are here to provide care and the supports that you need to face those challenges.

Another staff member added to the above comment, “And having the discernment to detect whether it's an anxiety or fear (...) or whether there's an absolute refusal and not wanting to participate that you need to respect.” Other staff comments highlighted the importance of being compassionate toward residents, building trust with them, anticipating challenges, and accommodating their preferences as much as possible.

Individualized care. The second element of staff behaviour that was perceived as facilitating residents' psychosocial needs involved providing individualized care.

Although the person-centred interactions discussed above are specific to individual residents, this theme referred to the importance of having knowledge and information specific to residents and using that information to offer them care that is tailored to their needs and preferences. Staff saw this as instrumental to helping residents meet their needs for autonomy and social connection. Providing individualized care was seen as an ongoing process that starts prior to admission with health care providers learning about a resident's history, and continuing at admission with care providers reviewing resident responses to an admission questionnaire. During resident stays, staff get to know their personalities, preferences and challenges and make decisions based on this knowledge. One participant touched on this theme:

Even just the seating arrangements, one of the residents was expressing that the resident she was seated across from (...) didn't participate in conversation and she really missed that and so her spouse would come to sit with her at certain times. So we arranged it so that her spouse would sit together and we rearranged so that the other resident would be seated in a more appropriate spot and just making it more of an individualized process (...) [it communicated] that they matter, and their needs are important and they know that or that [they] are a priority.

Another participant highlighted how understanding participant preferences at admission can help in planning care and assist in meeting the need for choice and control:

Choice, even on admission we have the family and the resident and complete questionnaires about things like, do you prefer a male or female caregiver, male or female physician, do you have a particular religious affiliation, are there any

groups you belong to (...) so that we can get a baseline and start planning care right from day one.

An additional participant provided an example of how knowing about a particular resident's fear of falling assisted him to make a more informed decision about the type of assistance to provide. This helped reassure the resident and increase her self-confidence:

Awareness of fears or anxieties that they may have can sometimes be very helpful. [I had a] situation yesterday where I just got an absolute refusal from someone who was very capable of walking and it turns out she had very recently fallen and was afraid to fall again. So instead of providing stand-by assistance, which would have been adequate for her, I used a transfer belt and assured her that I would hold the handle properly and together there was no way that she would fall (...) before the walk was over she asked "Can we go dancing tomorrow?"

Staff self-care. The third factor involving health care providers that was seen as helpful in promoting residents' psychosocial needs was staff self-care. Specifically, staff highlighted the importance of self-reflection, perspective taking, having private opportunities to share negative feelings with other staff, and having positive attitudes.

One staff member indicated:

I think one [important] thing is remembering why residents have moved into long term care. If everything was hunky-dory and fine they'd be out in the community. They're here for a reason and sometimes (...) in the business and the stress of the day [it's helpful to have] places to let those concerns or comments out to try and

keep that safe environment behind closed doors. You got to put on that face sometimes unfortunately.

Another staff member highlighted other aspects of self-care that indirectly helped staff to meet residents' needs: "Probably attitude. Loving your job, loving the residents. Not taking everything personal. [It's] hard to do that." Another staff member illustrated the importance of being aware of her feelings toward certain residents:

I think it's also to be aware of your own feelings in certain situations with certain behaviors and stuff. If you're feeling one way about a behavior you know and instead of avoiding that situation, finding it within yourself to see what you can do to overcome it. There was a situation I remember one resident coming up saying "Why does so and so always get a hug and I don't get a hug?" It was a situation where this resident yelled out and spit and stuff like that but she needed [a hug] too. I think it's just being aware of your own true feelings and that everybody is an individual and [with unique] needs.

In addition to factors involving staff that were seen as instrumental to meeting residents' psychosocial needs, there were also factors at the resident level that were seen as important in facilitating their psychosocial needs: meeting basic needs and having opportunities to exert control.

Meeting basic needs. First, a staff member perceived that residents need to have their basic needs (e.g., feeding, dressing, toileting) met first prior to satisfying their psychosocial needs. She indicated, "just meeting their basic needs is important [before] meeting their psychosocial needs as well... basic needs that are essential."

Opportunities to exert control. Staff indicated that exerting control in as many ways possible was central for residents' psychosocial well-being. Staff seemed to be acutely aware of residents' feeling a loss of control when admitted to a NH and as a result, their need of numerous opportunities to make choices for themselves. One way that staff tried to accomplish this was to ask residents for permission to provide care, to attend social events and to involve them in daily care decisions:

I know from my perspective, because I do orientation for new staff, we really highlight the importance of giving residents that opportunity to express themselves and to voice their choices and how important that is for combating things like depression and apathy. So part of it is also educating staff that that's an important part of care. We do need to meet their basic needs but those decisions that they make [such as choosing a] blue shirt [or] red shirt, make a difference.

Along with asking residents for permission, another staff member indicated that by residents making requests and having the facility respond to these requests, this increased residents' perceived control.

Most are coming in here not by choice so whatever we can give back to them to put control or some sort of control, they may not be always able to have control over what time they get up or how they're bathed but I think staff here do the best they can to accommodate if there's, coming from recreation, there's a certain program that they really want to [attend], I mean you just have to ask because it's never been a problem to switch your bath day or hairdressing day to accommodate this persons' likes and dislikes.

There were also a number of factors involving the NH environment that staff saw as facilitating residents' psychosocial needs: staff communication, workplace culture, and facility policies and procedures.

Staff communication. First, participants commented that communication between staff members, especially regarding resident likes and dislikes, facilitates continuity of care. In turn, residents may perceive staff to be more responsive and genuinely caring. For example, one participant touched on the importance of interprofessional communication in responding to resident behavior:

It's so important to communicate with staff, even day to day likes or dislikes, or this person if having an off day or something and not getting defensive as staff and being mature about it and say "Thanks I didn't know that" or to be approachable or let them know what's going on and observe. It doesn't matter whether it's housekeeping or OT or REC.

Workplace culture. Second, workplace culture was seen as contributing to staff members' abilities to meet residents' psychosocial needs. Staff highlighted several aspects of their work environment that were conducive to residents' psychosocial well-being, such as interdisciplinary teamwork, refraining from being "territorial," being supportive of other coworkers, and frequent communication between staff, especially with respect to understanding particular residents. For example, one staff member highlighted the importance of cooperation between different disciplines in helping residents to meet their psychosocial needs:

I think the importance of interdisciplinary cooperation and teamwork (...) I think [our facility] does that very well. How everybody works together as a team rather

than looking at their department with you know, tunnel vision and “I’m here to get my job done and I’m not so concerned about whether you get yours done.” I think the cooperation and just one person supporting the next person in whatever department wherever possible that’s really helpful to allowing all of us to help meet the needs of residents.

Facility policies and procedures. A third aspect of the nursing home environment that staff saw as being instrumental in meeting residents’ psychosocial needs involved facility policies and procedures. One comment underscored the importance of having facility policies related to resident rights, safety and respect in addition to workplace codes of conduct. Training for staff across all areas of practice was also highlighted as being instrumental in terms of helping learn about how to communicate with, and better care for, residents with dementia. For example, one staff member reported:

I think on a broader, organizational level you have a ton of policies that relate to resident safety and respect, workplace code of conduct, resident rights and those kinds of things but also (...) focusing on a strategic plan that’s being centred around person-centred care and investing in the education of staff for dementia care (...) So it’s giving staff those skills. [Because] you’re not always coming on board with them. So that’s part of it too. I think just having the managers trained too so it’s not just front line staff or other departments but everybody understands the concepts and are on the same page.

A staff member further elaborated on training initiatives to improve communication with residents and person-centred care:

A lot of the residents here have dementia so we've partnered with the region to accelerate training for our staff so that they have a better understanding of how to communicate with residents with different types of dementias because they're expressing themselves in ways that we don't necessarily understand so we're trying to find out how we can communicate with them and then meet their needs because many of them can't say it. They're trying to so it's trying to understand that process. So we've made that one of our strategic plans already so that [the] workplace [provides] whole person-centred care.

Facility practices that enable interdisciplinary communication were also identified as useful in facilitating better care of residents. For example, one staff member highlighted an initiative aimed at improving information sharing between staff:

I know even working with the communication process with the team because there might be somebody who, for example, in his walking program, has a special relationship with a resident and has a great way of communicating with him then sharing that information with the rest of the team so that everybody can [capitalize] and gain that knowledge too. So, these huddle sessions, we're trying to incorporate them more into our care planning so that everybody can be involved and we can learn from each other. We can create that consistency so that there isn't different exchanges between people so we can keep that level of comfort for that resident across departments.

Staff also mentioned that creating a home-like environment that incorporates residents' interests is helpful in meeting residents' psychosocial needs. For example, one participant voiced:

I think we try, from an environmental perspective here, to create a home-like environment that isn't sterile and having places that residents can go to. We have a teahouse area where they can have a cup of tea or have their family members around them and just get away from feeling like they're in an institution. We have an atrium area, park-like area with animals...so if there was an interest in animals (...) they could still somewhat meet those needs. So it's like trying to make life in here more enjoyable.

Challenges to meeting residents' psychosocial needs. Staff members' discussions of the challenges of meeting resident psychosocial needs clustered into six themes: administrative obligations; lack of information about residents; communication challenges due to dementia; conflict between staff, family members and residents; balancing the needs of residents; and lack of time.

Administrative obligations. Some staff members expressed that it was difficult at times to balance adherence to long-term care regulations with residents' wishes. Furthermore, required paperwork and facility audits were seen as obstacles to having more lengthy interactions with residents. For example, one staff member noted:

Long-term care is very heavily regulated. There's a lot of audits and a lot of paperwork and so staff are having to complete a lot of those forms too and it does take away from just being able to sit with a resident and have a simple conversation. So those things sometimes, they can still happen but they may be briefer than you might like them to be.

Lack of information about residents. Second, staff identified that a lack of information about residents made it challenging to meet their psychosocial needs. One

staff member perceived that other departments had access to information about residents that would be helpful to know but this was not readily communicated with other staff.

For example, a staff member who had worked in both the housekeeping and dietary departments expressed:

Our department doesn't know a lot of personal stuff about the residents like all these [other] people do because they interact with them more. We just usually clean but I started to notice they give dietary, we know a lot, like you get to know more about them (...) more about them than you do in housekeeping. You go into a person's room for instance and you don't know (...) how they're feeling that day or what's going on 'cause you know you don't interact with them much on a personal level when you're just there to clean their room like [other] people do. So that's a little challenging, you know? It is nice to be able to hear about what's up with this person today (...) It's good to hear because it makes you be able to interact with them better and know what's going on with them.

Another staff member agreed with this concern and added that although the facility was attempting to enhance the exchange of information between departments, this also came with the concern of sharing too much information:

I know that issue in particular is something that we've been looking at through our dementia care program because if you look at percentage of time spent with residents it's the housekeeping aids that are spending a lot of time in the rooms. [They're] actually getting information that we don't necessarily know so that's why having those huddles really helps but also (...) we have white boards in the conference room so we can communicate with anyone. So like, important

information (...) like an outbreak, or whatever things that people need to know (...) or if something is going on that we can document it. We're trying to find different ways that can break down barriers. I mean there's a fine line between giving away too much information because you know it's not as much as you need to know. But it is helpful especially when you're dealing with someone who has a particular form of dementia. They're not all the same so understanding what type of dementia someone has and what that person is going through can really help you understand how to interact with them.

Communication challenges due to dementia. The third theme identified in staff members' responses to this question was communication challenges due to dementia. Staff expressed that the presence of dementia often made it challenging for staff to understand, and residents to express, their needs, e.g., "Sometimes the resident's condition does not allow for them to clearly vocalize what they want. You spend your time trying to figure out what they're needing from gestures and whatnot and you try your best not to get them frustrated." Staff also added that they found it challenging to balance potential safety risks with wanting to give residents with dementia what they want. One staff member commented:

There are some residents who can't walk but they don't understand and they think they can still get up and walk and then they say, "Come and help me." Just the other day a resident said, "Come here," and I said, "What do you need?" He said, "I want to get up and walk," but he doesn't understand so you have you explain it to him over again. But that would be for me [a] safety [issue]. Or they want to go

outside and go out the front door well we can't allow them out because of safety concerns so there's a lot of times that safety presents a challenge.

Another staff member elaborated on other safety concerns and how this might be prioritized over needs for control over room arrangement:

There has to be some kind of a balance like the residents need to have some control of the layout of their room for example, how much furniture can they have in there and what kind of furniture can they have in there. Maybe something is a tripping risk. Or maybe they have this favourite chair that is no longer safe to use or they want their room arranged in a different way but that doesn't facilitate getting to the bathroom safely or a multitude of issues.

Conflict between staff, family members and residents. Staff indicated that conflict between staff, family members and residents occasionally makes it difficult to meet residents' psychosocial needs. Staff mentioned that family members may have a different opinion of what their resident needs than the resident does. The following excerpt is from an exchange between several staff members in the focus group:

Staff A: I think we're seeing sometimes with even families, families getting in the way of what the resident really wants and we're asked to [meet] those needs that the resident wants.

Staff B: And not the family.

Staff C: Exactly. Definitely.

Staff D: Or the expectations that families have the same, like they're at home and they have that expectation. And the facility, it caters to individual needs, yes, but there is reality and reality is that you have 46 residents or whatever in a wing.

Staff A: And that's all the time that family, what they want is best for their loved one. So that's why they come into a conflict.

This exchange exemplifies the occasional discrepancy between family members' expectations and those of residents, combined with what staff perceive as being feasible in terms of accommodating resident and family needs. Staff perceived that family members' expectations, even if they are in conflict with those of residents or staff, are well-intentioned.

Balancing the needs of residents. The fifth theme that arose from staff members' responses to this question involved balancing the needs of residents with varying levels of care required. Staff expressed that it was difficult to coordinate the delivery of care when some residents required more assistance and others were more independent, for example:

The dining room residents who are more independent eating their meals...when they're getting their meals and you [also] have the residents on the satellites who need more help with meal assistance and the resident[s] in main dining rooms finish their meals a lot sooner and [because] they finish sooner, they start coming back. Meanwhile the residents who need more help are still getting that help for breakfast and the other residents are calling that they need assistance and need help for toileting or there's an outing happening and you need to get them ready. So it's that balance between two groups, different levels of care.

Another staff member agreed that this challenge is particularly salient within the context of meeting basic physical needs, such as feeding, "Sometimes these people can't even finish their meals because you get taken away from feeding them and then by the time you come back someone has taken the meal from the table thinking they're

finished.” This challenge may also relate to lacking information or inadequate communication, as discussed in an earlier theme.

Time pressures. Staff also mentioned that time pressures presented challenges in helping residents meet their psychosocial needs. The previously mentioned quote also reflects the need for staff to work efficiently even though this can inadvertently prevent residents from getting particular needs met. Similarly, staff expressed that it was challenging to coordinate basic care with attending recreation events or other appointments. One recreation staff member indicated:

I mean when you're doing an outing with someone, it's lickity split, come on, the bus is leaving at 2:30 but you know these [health care aides] are stressed. But these are just a few barriers and somehow we get through the summer with the outings and through breakfast and through lunch and it works but there's still that barrier.

Another staff member similarly indicated:

This is probably a good problem to have but one of the things that I run into is conflict with other events. Because I have a long list of things I'd like to accomplish and I do need to work around the residents' involvement in other available programs. So I try to be as accommodating as possible and striking that balance.

Suggested changes to the list of needs. Responses to this question were few and relatively brief. One respondent suggested removing the need for sexual intimacy and expression from the list, primarily because of the challenges associated with getting this need met within a nursing home setting, but not necessarily because it was unimportant.

Another respondent suggested adding an item that would address residents' need for privacy, citing that she had observed variability between residents in terms of the amount of desired time alone and that it was important to strike the right balance. Another respondent suggested that the item involving participation in decision-making about care be expanded to include attending care conferences and directing care decisions.

Emergent data. In addition to the articulated data, which specifically answered questions within the discussion guide, the focus group yielded a considerable amount of emergent data. These included attitudes, opinions, and motivations expressed either explicitly or implicitly by focus group participants, or topics that were not an obvious response to a question. An independent coder, who was a first year graduate student with prior experience analyzing qualitative data from focus groups, assisted with data analysis. We clustered this data into six themes, which included: (a) tension between resident choice and staff choice, (b) positive impression management of the facility, (c) the narrative of NH admission as "loss," (d) efforts to shape residents' experience of the NH, (e) using terms of endearment, and (f) "natural" skill in relating to residents.

Tension between resident choice and staff choice. Several comments and anecdotes from staff members highlighted an ongoing tension between residents making their own choices versus staff making choices on their behalf. The articulated data from the focus group reflected that staff understood and valued the importance of resident choice and autonomy. At other times, however, they made statements that implied that they knew what was in the best interest of residents and were justified in acting on their behalves. This was apparent in conversations about how safety concerns can present obstacles to meeting residents' psychosocial needs. Staff had indicated that they declined

certain resident requests to due fears of residents being harmed (see quote on page 96-97). Some staff members also perceived themselves to be more aware of residents' interests than were family members. "That's when it's important to advocate as respectfully as possible for the resident and sometimes they're not in agreement and sometimes it's just a process of them wrapping their heads around this whole process. It's difficult for them too." Another example of the tension between resident choice and staff choice concerned participation in recreation or social activities:

Staff: Another thing coming back to choice is respecting a refusal. I know that it all depends on a person's cognition and dementia and whether toileting or bathrooming have to be done but when it comes to choices that are not mandatory services, I'll say like recreation or whatever, to respect that choice. We already know which residents need a little bit more care in how we approach and some people we may not ask...[because when you] say "It's time to go and exercise," you know every single time it's going to be a refusal, right? But you know that whenever they go they really enjoy it and [they] say they're glad they came that's fine. But if somebody is really adamant and does not want to join you, you know (...) that personality and again giving them that choice.

Julie: So knowing when to put on a little pressure?

Staff: Push a little bit and [knowing] the way you would say it . . . it wouldn't be "Would you like to go?" it would be "Let's go" or "We're going to go now, it's time, let's go stretch your muscles" [because] you're going to get a "no" every time. It's the approach and respecting that "no" means "no." It's important to us and the community, right? So it should be important to these people too right?

The above comment communicates an understanding of residents' right to decline to participate in recreational activities but it also implies that resident refusals are not always in the residents' best interest, especially if staff members are familiar with the resident and anticipate that he or she would enjoy attending an event. It is in these cases that staff feel justified in being more directive in terms of taking residents to recreation events, e.g. "Let's go," "It's time to go now," instead of asking for permission.

Positive impression management of the facility. Second, there was a tendency for the nursing education manager to identify facility initiatives in response to problems identified by other staff during the focus group, perhaps as a means of portraying the facility and staff in a positive light. For example, after a staff member indicated that lacking information about residents was a barrier to helping residents meet their psychosocial needs, the nursing education manager discussed a new initiative being implemented which attempted to facilitate better interdepartmental communication. In response to other staff members' comments about the importance of staff professionalism, self-care, and authenticity with residents, the nursing education manager cited how organizational policies specify the workplace code of conduct and resident rights and how their strategic plan focuses on providing more training for staff to work with residents with dementia.

NH admission as a loss. Third, two staff members commented on their perception of NH admission as a "loss" with respect to resident identity and control. One staff member described a personal experience with a family member being admitted to a NH to illustrate how the admission process can proceed quickly and often without the

resident being in control. It was also seen as a grieving process of a former identity and living independently:

Coming in sometimes not necessarily by choice [was] brought closer to home with a family member of mine that had recently got paneled for housing in a long-term care facility (...) The whole process of watching the family go through things (...) just being in the profession I am, my heart went out to this family member (...) it seemed to be was that she went from her home to the hospital and then because they realized that she wouldn't be able to go back home because of a huge fall risk for her and at the next point it was "OK it's going to have to be a facility" but she never got a chance to go back home. And this was the home that she had been in all her life, that her husband built the home basically. So she lived there, raised her children there, and then bang, bang, bang, all these changes. I think I would describe it as a carpet being pulled out from underneath her. Everything as far as independence, it was like all gone in the course of day. The decision-making process was taken away from her almost. And it was very interesting to see it from a personal perspective and in a family situation like that.

Efforts to shape residents' experience of the NH. Staff members also expressed a motivation to shape how residents experience the NH. While some staff tried to help residents perceive the NH as a "new home," other staff appreciated how the NH might never be perceived as "home" for some residents. Others tried to encourage residents to view the facility as a vacation. "I think we try, from an environmental perspective here, to create a homelike environment that isn't sterile and having places that residents can go to (...) and just get away from feeling like they're in an institution." However, another

staff member later commented, “But no matter what we do, it’s not home. This is your all-inclusive resort, as I say.”

Terms of endearment. One staff member also discussed using terms of endearment with residents. She perceived that referring to residents using terms such as “dear” or “sweetheart” were “not always a bad thing.” She qualified that:

If you really don’t know somebody then it’s best to stick with first name and last name- what they like, what they prefer to be called. Once that relationship grows, I don’t know how many times you can give someone a hug. Even if you say “dear” I don’t think that’s belittling if you know them and have a relationship. Then it’s OK. But if you don’t, calling them sweetie...[it’s] like the girls at the checkout, you know?

The staff member’s final comment, combined with tone of voice and facial expression suggested that she became annoyed when she was on the receiving end of terms of endearment, especially when she is less familiar with the individual.

Natural skill relating to residents. Finally, one staff member perceived that some staff are “naturally” more skilled than others at interacting with residents, especially residents with dementia. This individual also implied that this ability is amenable to change with training and that this training should involve all staff, even those in management.

I mean there are some people that are great and are naturals with interacting with residents but there are others who need a little bit more, you know...more skill building that can be there. So it’s giving staff those skills. [Because] you’re not always coming on board with them. So that’s part of it too. I think just having

the managers trained too so it's not just front line staff or other departments but everybody understands the concepts and are on the same page.

Discussion

Phase Four provided valuable information regarding how NH staff help meet residents' psychosocial needs, what facilitates these efforts and what challenges they encounter. The results complement the data gleaned from both residents and family members, which collectively provide a more holistic understanding of psychosocial needs within NHs. The focus group also yielded emergent data which helped contextualize staff members' responses. There were themes focusing on health care providers, the resident, and the NH environment in terms of how residents are enabled to meet their psychosocial needs. With respect to the health care provider theme, adopting person-centred approaches to care which are individualized to the resident was seen as instrumental. Further, staff indicated that engaging in self-care practices helped indirectly facilitate residents' psychosocial needs. Regarding resident factors, having basic needs met and opportunities to exert control were both seen as facilitating their psychosocial needs. In terms of factors in the NH environment that contribute to resident well-being, staff communication, workplace culture and facility policies and procedures were all perceived as being important.

Staff identified several challenges in meeting residents' psychosocial needs: administrative obligations; lacking information about residents; communication difficulties due to dementia; conflict between staff, family members and residents; balancing the needs of different residents; and time shortages. The emergent themes from the focus group acknowledged tension between resident choice and staff choice,

positive impression management of the facility, the narrative of NH admission as “loss,” efforts to shape residents’ experience of the NH, terms of endearment, and certain staff being more naturally skilled than others in relating to residents. The results of the focus group are further discussed in the general discussion, in addition to the limitations and implications of these findings.

General Discussion

This dissertation is among the few studies to develop and validate a list of psychosocial needs important to NH residents. This study is unique in that the list of psychosocial needs is based on previous research, theories of psychosocial need, feedback from cognitively intact NH residents and family members of NH residents. The research is also novel in its use of a Delphi survey to establish consensus on the essential, and other highly important psychosocial needs to NH residents with dementia based on the perspective of their family members. These findings suggested that six needs falling across the categories of choice and control, personal effectiveness, and social connection are critical to the well-being of NH residents with dementia, according to their family members. By incorporating the views of both residents and their family members, we have a more holistic understanding of the psychosocial needs that are salient to NH residents. Finally, this study provides valuable information on how NH staff help residents meet their psychosocial needs and identifies challenges they encounter in this regard. The collective perspectives of NH residents, family members, and NH staff in this study aligns with prior theory, but also provides a unique contribution to existing research, and sheds light on promising areas for future research and intervention.

This general discussion will first highlight the psychosocial needs that were deemed essential and highly important for residents with dementia and offer potential explanations for these findings using theories that were central to the development of the list, i.e., Ryff's psychological well-being model (1989), Socioemotional Selectivity Theory (Carstensen, 1992), Self-Determination Theory (Ryan & Deci, 2000), and the theory of Social Production Functions (Ormel et al., 1999). Following this discussion, I will contextualize the results of the staff focus group in light of other related research. This will be followed by a review of the limitations of this research and its implications for research and practice.

Which are the Most Important Psychosocial Needs of NH Residents and Why?

Choice and control. The rated importance of items within the category of choice/control speaks to how essential these psychological needs are for NH residents. Perceived control is reflected in Ryff's (1992) and Self Determination Theory's construct of autonomy (Ryan & Deci, 2000), and Social Production Function's construct of behavioural confirmation (Ormel et al., 1999). From the perspective of Self Determination Theory (Ryan & Deci, 2000), the list of needs may reflect how changing individual and environmental factors in NHs influence the ways in which choice and control is experienced. NH residents' perceived autonomy may change given that the vast majority of these individuals will inevitably have certain behaviours, such as self-care, externally regulated. Items such as "choice to accept or decline help from others" may represent modified efforts to meet the need for autonomy. Although residents cannot always complete certain tasks themselves, choosing to accept or decline help and adapting how they exert their autonomy may provide a sense of internal control over

behaviour. This modified conceptualization of autonomy is consistent with the idea of *relational autonomy* that has been described in NH bioethics literature, which acknowledges the greater number of barriers to autonomy that exist in NHs (Sherwin & Winsby, 2011). There is data suggesting that these barriers may not come at the expense of perceived autonomy, which is promising. Older adults tend to have higher levels of perceived autonomy in meeting their goals compared to younger and middle-aged adults (Mackenzie, Karaolyas, & Starzyk, 2017).

Personal effectiveness. The rated importance items in the personal effectiveness category speaks to how NH residents need to have experiences which remind them of their capability and ability to create change in their environment. The items within the personal effectiveness category align with Ryff's (1992) construct of environmental mastery, SDT's construct of competence (Ryan & Deci, 2000), and SPF's construct of status (Steверink, Lindenberg, & Ormel, 1998). From the perspective of SDT, the needs within the personal effectiveness category may reflect the changing means by which NH residents meet their need for perceived competence. Individuals admitted to NHs can have difficulties handling the demands of the external environment and completing tasks of daily living. The final list of needs for both residents with and without dementia suggests that residents still find it essential to meet this need in adapted ways, such as having access to assistive devices to maximize independence or perceiving that staff are responsive to requests. Other published research on NH resident competency highlights the important role that caregivers play in encouraging NH residents to engage in tasks that increase their sense of personal effectiveness (Custers, Westerhof, Kuin, Gerritsen, & Riksen-Walraven, 2012). This is consistent with what has been written about SDT in late

life (Ryan & LaGuardia, 1995), which suggests that psychosocial needs remain universal and salient throughout life. How needs are met does change, however, and this is heavily dependent on available inner resources, external supports (e.g., NH staff), and obstacles.

Social connection. Close and meaningful relationships with others are considered critical for well-being throughout the lifespan. This was certainly reflected in the final list of psychosocial needs. All the theories used to develop the list of needs highlighted the fundamental need for social connection, whether that be through Ryff's construct of positive relations with others (1992), SDT's construct of relatedness (Ryan & Deci, 2000), or SPF's construct of affection (Ormel et al, 1999). It is not surprising that multiple items and comments from the Delphi survey emphasized the relative importance of relationships with others, particularly with individuals who are well known and emotionally close. For example, having opportunities to maintain relationships with individuals outside the NH (e.g., family and friends) was indicated as being more important than creating new relationships with other NH residents. From the perspective of Socioemotional Selectivity Theory (Carstensen & Turk-Charles, 1994), this preference may be a product of developmental shifts in time perspective and a motivation to optimize emotional experiences in the present moment. Establishing new relationships within the NH may have more uncertain emotional payoffs, which could lead residents to focus preferentially on their existing relationships. Nonetheless, this speculation should be tempered by the fact that family members were reporting on behalf of residents. Therefore, the degree to which residents prioritize familiar relationships and their motivation for doing so is unclear. However, these findings are also similar to other published research highlighting the key role that continued family involvement has in

resident adjustment to NHs (Gaugler, 2005a). The importance of having warm interactions with staff could also reflect older adults' desire to optimize the quality of their life in the present moment. Comments from family members of residents with dementia also underscored how important interactions with staff are, even when residents may not be able to fully engage in these interactions due to cognitive impairment.

Self Determination Theory (Ryan & Deci, 2000) provides an additional explanation for why particular needs within the social connection category were either identified as highly important or were excluded. The need for relatedness is thought to be universal throughout a person's life span but the means by which these needs are met can change depending on both internal and external resources and potential obstacles.

Regarding internal resources, some data suggests that older adults endorse having more intrinsically motivated values compared to younger adults, such as those for emotional intimacy and community (Kasser & Ryan, 2001; Mackenzie, Karaolyas, & Starzyk, 2017). These motives are important for meeting social needs and facilitating well-being in late life. The final list of needs for social connection speaks to the alternative ways in which these needs are met in NHs given different internal and external resources and potential obstacles. Social needs could be met through maintaining close bonds to family members and existing friends, along with warm, caring interactions with staff members.

As an extension of Social Production Functions theory, Steverink and colleagues' theory of successful aging (Steverink et al., 1998), offers a more general explanation for the final list of psychosocial needs. This theory posits that the available resources to satisfy needs changes with age despite needs themselves remaining the same in terms of their importance. While this is consistent with Self-Determination Theory (Ryan & Deci,

2000), Steverink et al.'s successful aging theory (1998) argues that compromised ability to meet certain needs results in more effort being directed toward needs which are more likely to be satisfied (i.e., need substitution) (Steverink et al., 1998). For example, given that status is often achieved from having a paying job or being recognized for a particular skillset, retirement could result in more effort being directed toward meeting the need for affection. From this perspective, the dynamic process of need substitution and compensation is what characterizes successful aging (Steverink et al., 1998). This framework is also consistent with the Selective Compensation and Optimization theory of aging (Baltes & Baltes, 1990). The findings of this study could reflect changing opportunities to meet the needs for status and behavioural confirmation in a NH setting, which could result in the need for affection becoming more salient, and more likely to be satisfied given the available resources. This aligns with other published research indicating that with advancing age and compromised physical health, needs for behavioural compensation and status are satisfied less frequently than the need for affection (Steverink & Lindenberg, 2006). However, Steverink and Lindenberg (2006) note that it is also possible that older adults' social needs and goals may shift as they experience declines in physical health and cognitive functioning, and relinquish status. This would be compatible with the age-related shift in socioemotional goals and motivations specified within SST (Carstensen et al., 2011; Scheibe & Carstensen, 2010).

The preceding review highlights a number of possible explanations for why certain needs were identified as being essential for NH resident well-being. From the theories summarized above, SDT (Ryan & Deci, 2000) appears to provide the most parsimonious representation of the needs deemed to be essential for NH residents. The

six items that exhibited the highest degree of agreement in terms of being “essential” for NH residents’ mental health were from the categories of choice and control, personal effectiveness, and social connection, which align with SDT’s basic psychological needs for autonomy, competence and relatedness. Fun and pleasure, rated in this study as being ‘important but not essential’ for well-being, is not a psychological need *per se* from the perspective of SDT. However, other published research considers pleasure and fun to be an outcome of meeting the needs for autonomy, competence and relatedness, also referred to as hedonic well-being (Ryan & Deci, 2001). Broader theory and research distinguishes hedonic from eudaimonic well-being. The former revolves around the pursuit of pleasure (Ryan & Deci, 2001), whereas the latter is characterized by realizing one’s potential and living authentically according to one’s values (Ryan & Deci, 2001). Hedonic well-being focuses more so on outcomes such as positive affect whereas eudaimonic well-being focuses on the processes involved in living well (Ryan, Huta, & Deci, 2008). This could suggest that the list of psychosocial needs represents needs related to both eudaimonic and hedonic well-being.

Which Psychosocial Needs are Less Important to NH Residents and Why?

Besides examining which needs were deemed to be important for resident well-being, it is also important to consider why certain needs were removed from the list.

Sexual intimacy and expression. It is notable that the need for sexual intimacy and expression was excluded from the final list of psychosocial needs. It is possible that this is no longer an important or essential component of the need for relatedness among NH residents. This finding could also reflect that there are a number of significant obstacles to meeting the need for sexual intimacy and expression within a NH, resulting

in pursuing other, more feasible means to meet the need for relatedness (e.g., physical affection and warm and caring interactions with staff). Alternatively, this could also be a product of family members feeling uncomfortable commenting on this need, or anticipating difficulties getting this need met, such as physical frailty or inability to provide consent. This finding could also be attributed to ageist beliefs, which involve the assumption that older adults are asexual (Weeks, 2002). Any of these factors may have contributed to family members deeming needs for sexual intimacy and expression unimportant.

Purpose and meaning. Socioemotional Selectivity Theory (Carstensen, 1992) offers a possible explanation for why the purpose and meaning category and an item in the choice and control category (“opportunities to be involved in decision-making about care”) were excluded. Many of the items in the purpose and meaning category could be viewed as future-oriented tasks, such as setting and achieving goals, learning new skills, and contributing to the functioning of the nursing home. These tasks should theoretically become less important with age due to their uncertain and delayed emotional payoffs. “Opportunities to be involved in decision making about care” also ended up being excluded from the list of psychosocial needs for residents with dementia. SST literature indicates that older adults tend to limit how much health information they seek due to a preference for receiving positive over negative information. This attentional bias is referred to as the *positivity effect* (Lockenhoff & Carstensen, 2004). It could be speculated that NH residents may want to be less involved in care decisions in order to limit their exposure to potentially negative information. It should be noted, however, that because family members were responding on behalf of NH residents it is unclear whether

residents want to limit their involvement in decision making about care or whether this is more reflective of family members' perspectives.

Summary of Delphi Survey

In summary, the findings of the Delphi survey for residents with dementia indicate that the needs for choice and control, personal effectiveness, and social connection are perceived to be critical for well-being. Consistent with how psychosocial needs have been defined in broader literature, these needs were identified as not only being important but essential for residents' mental health. The findings are in keeping, to a certain extent, with each of the theories included within this study. Self-Determination Theory, however, appears to provide the most parsimonious explanation of the findings. From the perspective of SDT (Ryan & Deci, 2000) and the theory of SPF (Ormel et al., 1999), the final list of needs speaks to the universality of psychosocial needs such as autonomy, competence and relatedness but also reflects that there may be changes in abilities, opportunities and resources available to meet psychosocial needs. The final list of needs reflects several adapted means by which NH residents meet their psychosocial needs. These findings suggest that efforts to help residents meet their psychosocial needs should be focused in particular on needs for choice and control, personal effectiveness, and social connection.

The findings of Phase Four are discussed next in light of other published research related to staff efforts to help residents meet their psychosocial needs. I will also discuss aspects of NH culture reflected in the emergent data that offer additional information about challenges to meeting psychosocial needs within this setting.

Staff and NH residents' psychosocial needs

The results of the focus group conducted with staff was helpful in developing a preliminary understanding of how various factors involving staff, residents and the NH environment facilitate residents' psychosocial needs. Staff members were able to identify which factors they felt enabled or hindered their efforts to meeting residents' psychosocial needs. The disciplines represented included nursing, recreation, therapeutic services, spiritual care, housekeeping, dietary services, and nursing education. The views of these staff members were largely consistent with each other in terms of the factors that enable or hinder them to meet residents' psychosocial needs.

What Facilitates Residents' Psychosocial Needs? Staff members perceived that providing person-centred, individualized care was instrumental for helping residents meet their psychosocial needs. More specifically, staff perceived that the way in which they interacted with residents individually was critical in terms of enhancing resident well-being. Speaking with residents in a warm, caring, and genuine manner and conveying knowledge and appreciation for the individual was perceived by staff as being critical to enhancing resident well-being. Given the perceived importance that staff interactions have on resident well-being, it may not be surprising that staff also perceived that engaging in self-care indirectly facilitated well-being. Their comments suggested that when they hold a positive attitude toward their work, they are better able to be understanding, warm, and genuine with residents. Staff also recognized the importance of residents having opportunities to make decisions, and saw this as facilitating the psychosocial needs of choice and control and social connection. Factors that involved the NH environment included staff communication, the workplace culture, and facility policies and procedures.

Many of the staff, resident and facility factors that staff members identified as being instrumental to meeting residents' psychosocial needs are reflective of the *culture change* movement in long-term care. This movement emphasizes consideration and respect of older adults who reside in NHs and the individuals who care for them (White et al., 2012). This movement is guided by a person-centred philosophy of care, which is characterized by "resident direction, a homelike atmosphere, close relationships, staff empowerment, collaborative decision-making, and quality improvement processes" (White et al., 2012, pp.525). Staff members' comments reflected the importance that this particular facility places on close relationships, resident direction and staff collaborative decision-making, in particular. Although staff comments suggested that these elements of person-centred care assist residents to meet their psychosocial needs, there is a limited amount of research that has empirically examined this. There is a large amount of literature investigating the effect that person-centred care interventions have on resident quality of life. These interventions are multifaceted but can involve enhancing the NH environment, increasing opportunities for resident social stimulation and interaction, leadership and management changes, staffing models focused on staff empowerment, assigning residents to the same care staff, and adopting an individualized philosophy of care (Brownie & Nancarrow, 2013). A recent systematic review of the effectiveness of these interventions documented that person-centred care approaches can help to decrease resident loneliness and helplessness (Brownie & Nancarrow, 2013). Thus, although very little published research has examined how person-centred care approaches might assist residents in meeting their psychosocial needs, preliminary data in other related outcomes is promising. Additional research is required that specifically examines the extent to

which person-centred models of care and their associated interventions are effective in helping residents to meet the psychosocial needs identified in the current study.

The roles of the NH staff communication and workplace culture in resident well-being were highlighted in this study. These factors have been extensively written about, with a considerable amount of published literature discussing the complex and dynamic systems inherent within these organizations (Anderson, Issel, & McDaniel, 2003; Bishop et al., 2008; Testad, Mikkelsen, Ballard, & Aarsland, 2010; Toles & Anderson, 2011). Similar to the aspects of staff culture highlighted in this study as being important, published research has documented how open communication among NH staff, active participation in decision making, and leadership that emphasizes relationships among staff is related to better resident physical health outcomes such as reductions in the number of resident falls, use of restraints, and challenging behaviour (Anderson et al., 2003; Toles & Anderson, 2011). An important topic of future research involves examining whether residents reap psychological and social benefits from residing in a facility where staff members engage in frequent, constructive communication with one another, feel engaged in decision-making and valued by their coworkers. Staff in this study also highlighted the indirect importance of their own self-care in order to assist residents in meeting their psychosocial needs. This is consistent with a larger body of literature associating resident well-being with staff members' stress (Redfern, Hannan, Norman, & Martin, 2002; Zimmerman, Williams, et al., 2005), empathic attitudes toward residents (Hollinger-Samson & Pearson, 2000), and job satisfaction (Brodaty, Draper, & Low, 2003; Redfern et al., 2002; Zimmerman, Williams, et al., 2005). Taken together, staff comments regarding the factors that enable them to help residents to meet their

psychosocial needs appear to be consistent with broader literature on nursing home culture, staff organization and self-care.

What Challenges do Staff Encounter in Meeting Residents' Psychosocial Needs?

The challenges that staff members identified in meeting residents' psychosocial needs include administrative obligations; lacking information about residents; communication challenges due to dementia; conflict between family, residents and staff; and lack of time. These challenges mirror what has been written in related literature on the obstacles to enhancing NH resident quality of life. Notably, there has been much discussion of the extent to which NHs prioritize resident safety over quality of life and how much risk should be assumed in service of maximizing quality of life (Kane, 2001). For example, a staff member in this study declined a resident's request to go outdoors due to safety concerns. Kane (2001) aptly remarked that "one is likely to be considered naive or quixotic to recommend a more normal system of life and care for people who have lost cognitive capability and whose function is anything but normal. The urge is to protect, to regiment, and to sequester such individuals" (p. 303). The challenge for NH care providers that has been identified repeatedly in the literature on nursing home care has been how to appropriately manage risk without unduly impeding residents' psychosocial well-being and quality of life (Hancock et al., 2006; Kane, 2001; Sherwin & Winsby, 2011; Zimmerman, Sloane, et al., 2005). New models of dementia care are currently experimenting with how to better balance the need for risk management with mental health and quality of life. For example, the "dementia village" in the gated community of Hogewey, Amsterdam, houses 152 residents with dementia in small group homes, where they are free to walk around the grounds, shop in stores, sit in pubs, and cook meals

(Hurley, 2012). Research on this innovative approach is still in its infancy, however, similar approaches to long-term care are being adopted in Italy, Switzerland and Germany (Hurley, 2012). North American counterparts are limited but the Eden Alternative (Brownie, 2011) and the Green House Project (Kane, Lum, Cutler, Degenholtz, & Yu, 2007) share a similar philosophy of care. There are no known plans to create a Canadian “dementia village” but the Alzheimer’s Society of Canada is supporting a movement toward “Dementia Friendly Communities” and “Dementia Friendly Care Homes” (Lidhran, 2015). These initiatives aim to improve how older adults navigate their physical environment (e.g., clearer signage and directional information) and reduce stigma about dementia in order to promote older adults’ engagement in their communities. To accomplish this, the Alzheimer Society of Canada is offering education and information toolkits for the private sector, municipal government, and the general public. Additional research on these initiatives and different nursing home environments will be helpful to clarify how to help meet residents’ psychosocial needs while ensuring their safety and minimizing risk. It will also be critical to examine how feasible and cost-effective these environments are, given that they would likely require a higher staff-resident ratio.

An additional challenge that staff members identified in trying to help residents meet their psychosocial needs concerned residents’ family members. It was encouraging to observe the degree of agreement between family members and staff in terms of what is important for residents’ psychosocial well-being. Family members’ comments on the Delphi survey as well as staff comments in the focus group suggested their mutual recognition of the importance of resident choice and control, quality of relationships with

staff members, and providing individualized care. Nonetheless, staff members indicated that family members' expectation that the NH be as homelike as possible was occasionally at odds with what the NH could accommodate. Relationships between staff, residents and family members has received significant empirical attention (Lau, Shyu, Lin, & Yang, 2008; Bauer, 2007; Brodaty et al., 2003; Gjerberg, Førde, & Bjørndal, 2011; Pillemer et al., 2003; Utley-Smith et al., 2009). This research has indicated that family members tend to see themselves as helping to preserve the resident's identity and assisting staff to provide individualized care (Gaugler, 2005a). Despite family members' good intentions, staff may experience their interactions with some family members as being difficult, challenging and conflict-ridden (Utley-Smith et al., 2009). Similar to the concerns expressed by staff within this study, other research has indicated that staff expectations can occasionally conflict with that of family members (Utley-Smith et al., 2009). These findings suggest that there is room for improvement in terms of the relationship between family members of NH residents and staff. There has been some research examining the effectiveness of interventions to improve communication between family members and staff, and also between staff regarding family members' concerns (Majerovitz, Mollott, & Rudder, 2009; Marziali, Mackenzie, & Tchernikov, 2015; Pillemer et al., 2003). Research generally supports the value of these interventions and suggests that they may help to improve family members' and staff attitudes toward each other, reduce conflict with one another, and to reduce the likelihood of staff quitting (Pillemer et al., 2003). Staff members' perception of working collaboratively and in tandem with family members may also have an additional benefit of improving staff well-being and self-care, which was implicated within this dissertation as facilitating resident

psychosocial needs. Other research suggests that burnout in nursing staff in particular is related to perceived conflict with patients and their families (Demerouti, Bakker, Nachreiner, & Schaufeli, 2000). Although the nature of this relationship is unclear, interventions to improve communication between staff and family members in addition to those that improve staff well-being are both likely to benefit both staff and residents.

Staff members in this study also identified that a lack of time was another obstacle to helping residents meet their psychosocial needs. Having a limited amount of time to spend with individual residents could interfere with staff having meaningful connections with them, which could impede needs for social connection. Time pressure could also limit the extent to which staff members are able to facilitate resident choice and autonomy in certain circumstances. For example, encouraging a resident to select their clothing for the day or complete other self-care tasks would almost certainly take more time than staff selecting clothing or completing a self-care task for the resident. Perceived time pressure could also increase levels of stress among staff, which could negatively influence staff attitudes and self-care. Nursing staff have indicated that perceived time pressure is a significant stressor within nursing home settings (Lapane & Hughes, 2007). The findings here suggest that more could be done to ensure adequate staffing levels and feasible workloads within nursing homes. Facilities face considerable challenges in terms of staffing within nursing homes. Standards set by the provincial government of Manitoba specify that nursing home staff must provide a minimum of 3.6 hours of daily care per resident. However, other research conducted within US long-term care facilities suggests that a minimum of 4.1 hours of daily resident care is required to avoid endangering residents (Harrington, Zimmerman, Karon, Robinson, & Beutel,

2000). Additional time as well as more staff may better assist NHs to meet residents' psychosocial needs. There is some data to suggest that a high staff-resident ratio is beneficial for residents' cognitive functioning and social involvement (Harrington, Woolhandler, Mullan, Carrillo, & Himmelstein, 2001). Nonetheless, even minimal increases in the number of staff and hours of daily resident care comes with a significant cost increase to provincial health care systems (McGillis Hall, Doran, & Pink, 2004). Further examination of how to use current numbers of staff more efficiently may be a more realistic plan in terms of improving staff members' perceived time constraints. This may better equip them to help meet residents' psychosocial needs.

The emergent data generated within the staff focus group assists in placing the results of this dissertation within a context of NH culture. The emergent themes highlighted staff members' assumptions, beliefs and values that could have implications for how residents' psychosocial needs are perceived and facilitated. The issue of autonomy was discussed throughout the Phase Four focus group. Staff expressed an acute awareness of how being admitted to a NH represented a loss of independence, choice, and control on many fronts. Furthermore, daily life within NHs often involves staff exerting choice and control on residents' behalf. However, staff also recognized the importance of creating opportunities for residents to exert control whenever it was safe for them to do so. The results of the Delphi survey reinforced the importance of this. The findings here concerning autonomy also resemble other published literature describing how traditional conceptualizations of autonomy are no longer applicable or helpful within NHs. Traditional definitions of autonomy connote independence, self-sufficiency, and agency, which can be threatened as a result of disability (Sherwin &

Winsby, 2011). Staff affirmed how autonomy, as it's traditionally defined, is increasingly unfeasible when physical and cognitive health declines and dependency on others increases. As resident autonomy (in the traditional sense) decreases, care providers tend to adopt paternalistic attitudes and behaviours and use their own judgement of what is best for an individual when making decisions for them (Sherwin & Winsby, 2011). However, such attitudes and behaviours may be not only warranted but necessary when providing care to individuals who are significantly cognitively impaired. Given that traditional definitions of autonomy view dependence and reliance on others as an impediment to autonomy, Sherwin & Winsby's (2011) previously mentioned concept of *relational autonomy* may be a more useful construct in NH settings. From this perspective, they argue that "as [much] as possible, nursing homes should try to assist residents in maintaining control over matters of importance to them by fostering a facility culture marked by increased resident options and a care model that prioritizes the social well-being of elderly residents over the completion of care regimens" (p.189). This conceptualization may help guide staff efforts to promote meaningful experiences of autonomy in NH settings. The items developed in the Delphi survey would also appear to fit well within the concept of relational autonomy.

Emergent data from the staff focus group also highlighted other aspects of NH culture which may inadvertently make it more difficult for residents to meet their psychosocial needs. A staff member voiced that using terms of endearment (e.g., "sweetheart", "dear") with residents may not necessarily be a "bad thing" as long as one is reasonably familiar with residents and their preferences. A considerable amount of research has advised against the use of this language and considers it a component of

elderspeak, which also includes speaking at a slower rate, exaggerated intonation, elevated pitch and volume, greater repetition, and simpler vocabulary and grammar than normal adult speech. Adoption of such language is common in nursing home settings and although it does not necessarily reflect an intention to patronize residents, it may inadvertently reinforce dependency and engender isolation and low mood among residents (Williams, Kemper, & Hummert, 2003). This style of speech also tends to increase the probability of resisting care among residents with dementia (Herman & Williams, 2009). Educational interventions have been shown to be effective in reducing NH staff members' use of elderspeak (Williams et al., 2003) and should continue to be implemented.

Limitations

Along with the many strengths of this dissertation, there are limitations. The sample of family members of residents without dementia in Phase Three is very small and therefore limits the conclusions that can be drawn from these results. There were significant challenges recruiting family members of residents without dementia. Following the first recruitment initiative, I launched two subsequent efforts at an additional facility. Even after two recruitment mailings at this facility, only five family members consented to participate. The underrepresentation of residents without dementia in this study may reflect a larger trend of older adults without dementia to reside in the community longer and receive more home care services in order to delay NH placement (Young, Kalamaras, Kelly, Hornick, & Yucel, 2015). However, when residents without dementia are admitted to NHs, they appear to have a greater degree of functional impairment and comorbidity, more frequent physician visits, and more hospitalizations

compared to residents with dementia (Burton et al., 2001). Residents without dementia in this study reportedly had other physical health problems that made it difficult to live independently, such as visual and hearing impairments. The small number of residents without dementia represented in this study limits the degree to which the findings can be directly compared to residents with dementia. However, from the preliminary data I collected from five family members, there appear to be a number of similarities in terms of the psychosocial needs retained for the residents with and without dementia. However, additional research is necessary to provide information about how residents without dementia may be unique compared to residents with dementia in terms of their psychosocial needs.

Relatedly, the recruitment difficulties I encountered within this study suggest that there are challenges in research associated with engaging caregivers of residents without dementia. In examining the sociodemographic features of the family members within this study, there were no obvious differences between the family members of residents with dementia versus those without that might shed light on why recruitment was more difficult.

There is a limited body of research comparing the experiences of family members of NH residents with dementia to those without dementia. One study indicated that family members of residents with dementia tend to report being exposed to more stressors and perceive these stressors as being more disturbing than stressors experienced by family members of residents without dementia (Lévesque, Ducharme, & Lachance, 1999). Family members of residents with dementia also reported having more social support available and engaging in more direct caregiving tasks than family members of

residents without dementia. There was no difference, however, between frequency of visits between the two samples or the use of coping strategies within this study (Lévesque et al., 1999). Extending the results of Lévesque and colleagues (1999) to this study, it is possible that the family members of residents with dementia experienced more stress regarding their residents' NH experience and as a result felt more compelled to participate and share their experiences. There was greater variability in self-reported stress among family members of residents with dementia compared to those without dementia, who all reported their stress levels as "mild." Nonetheless, additional research is needed to understand the experience of both family members of NH residents without dementia and the residents themselves with respect to meeting psychosocial needs.

A second limitation of this dissertation also relates to family members reporting on behalf of residents. Family members provided information on residents with dementia that would have been increasingly difficult to obtain if residents themselves had been sampled given the complexities associated with determining informed consent in the presence of cognitive impairment (Cubit, 2010; Grady, 2015; Warner, McCarney, Griffin, Hill, & Fisher, 2008). Furthermore, there may have been added concern about the ability of residents with severe dementia to reflect on and communicate their psychological needs. Using family members' reports on the psychosocial needs of residents carries some risk, however, of misrepresenting NH residents' needs. Family members may over report or underreport the importance of certain needs based on their perception of what is important as opposed to what residents perceive. I attempted to minimize this by recruiting family members who visited their resident frequently and who perceived

themselves to be in an informed position to comment on the psychosocial needs of their resident.

Nonetheless, I cannot rule out the possibility that certain needs might have been rated differently had residents commented on them directly. For example, the need for sexual expression and intimacy was eliminated following the first Delphi iteration with both family members of residents with and without dementia. It is unclear whether this is because sexual needs are less important for residents' mental health and well-being due to the challenges of meeting this need, or because family members were uncomfortable commenting on the importance of this need or held ageist in their beliefs about it. Other published literature does not support the belief that older adults are asexual (Bauer et al., 2012, 2014; Tarzia, Bauer, Fetherstonhaugh, & Nay, 2013) nor does it suggest that individuals residing in long term care, including those with dementia or physical disabilities, do not continue to desire sexual intimacy (Bauer, McAuliffe, & Nay, 2007; Tarzia et al., 2013). In a rare qualitative study with NH residents on sexual needs and barriers to meeting these needs, residents (including those with dementia) reported that they still perceived themselves to be sexual beings with a desire to express these feelings (Bauer et al., 2012). However, they perceived that a lack of privacy within the NH environment, negative attitudes from staff, and discontinuation of external relationships were significant barriers to meeting these needs. Other published research surveying family members' attitudes toward NH residents' sexuality has observed general difficulties recruiting participants for this research. The limited existing data suggests that family members are respectful of residents' rights for sexual expression, but only

approved of certain sexual behaviour and thought staff should keep them informed about their relative's sexual behaviour (Bauer et al., 2014).

There is reason to believe, then, that family members have conflicting beliefs about the sexual behaviour of NH residents, despite residents indicating that this is still an important aspect of their identity and well-being. It is helpful to note that within the Phase One focus group with residents, none of the residents suggested that needs for sexual expression and intimacy were irrelevant, unimportant, or warranted exclusion. Taken together, family members may not be in an ideal position to comment on the entirety of residents' psychosocial needs, especially those concerning topics such as sexuality, which might be uncomfortable for them to discuss or consider. As a result, the need for sexual intimacy and expression should still be considered important to facilitate within a NH context, especially in light of other published research using samples of NH residents (Bauer et al., 2012). That being said, the value of including family members' perspectives in this study should not be understated. They provided a unique perspective on NH residents' psychosocial needs that is valuable considering that they can be closely involved in NH residents' daily lives and making decisions regarding care. Further, given the cognitive limitations imposed by dementia, family members are likely in the best position to comment on residents' psychosocial needs. Their perspective helped provide a more comprehensive understanding of NH residents' psychosocial needs.

An third limitation of this study concerns the use of the Dementia Severity Rating Scale (Clark & Ewbank, 1996) as an indicator of dementia. The DSRS was initially selected as an indicator of dementia due to evidence suggesting that it is a well-validated measure capable of being used by laypersons and is strongly correlated with other

neuropsychological and functional indicators of dementia diagnoses (Clark & Ewbank, 1996). Due to the large number of family members who were classified as having a resident with dementia following the first Delphi iteration, there was concern that the DSRS cutoff score was overly conservative. CPS scores were then collected to determine to what extent DSRS were in agreement with this measure. Although the two measures were highly correlated ($r = 0.88$), there were eight residents who were originally designated as having dementia via the DSRS who had CPS scores of zero or one, which corresponds with being cognitively intact. Future researchers should be advised that when physician diagnoses of dementia are not feasible to obtain, researchers should use an empirically validated measure of dementia, preferably one that is from a health care professional, such as the CPS.

Another limitation with respect to the measurement tools in this study concerns the scale used to assess the impact of each psychosocial need on residents' experience in a NH. Items were rated on a scale with the following options: "no impact," "minimal impact," "neutral," "moderate impact" and "large impact." The "neutral" label may not have been fitting to capture ratings between "moderate impact" and "minimal impact" as it implies a lack of impact. It is possible that participants may have rated items as having "minimal impact" instead of "neutral" if the latter term did not fit with their perspective.

Although this research contributes much needed information about how staff members attempt to help residents meet their psychosocial needs and the challenges they encounter, there were limitations associated with using a heterogeneous focus group to gather this information. The focus group yielded diverse information from staff representing various disciplines including nursing, recreation, therapeutic services,

housekeeping, dietary services, spiritual care, and nursing education. The interaction and group dynamics between participants is often thought to be one of the major advantages of focus groups. In this study, the focus group generated broad themes regarding psychosocial needs in NHs as well as rich emergent data which helped to contextualize these themes within a particular NH culture. However, there can be aspects of focus group dynamics that threaten the validity and reliability of data generated. For example, participants can censor, conform, sabotage, or overly direct the group discussion (Farnsworth & Boon, 2010). Within this study, the nursing education manager frequently discussed programs, facility policies, and procedures that addressed problems identified by other group participants. This may have stemmed from a motivation to present the facility in a positive light. Relatedly, some staff may have been less likely to disclose information during the focus group due to their relationships with other group members. For example, nursing assistants may have been less likely to disclose challenges specific to working with RNs or nursing managers with these individuals present. Participant disclosure in focus groups is also affected by the moderator, with some studies citing that the degree of participants' perceived similarity with the facilitator can encourage or discourage disclosure (Farnsworth & Boon, 2010). Therefore, participants' perception of me may have either facilitated or inhibited their disclosure.

As someone external to their facility, I may have been presumed to be too removed from the facility and too dissimilar to staff, which may have limited participants' disclosures. However, I attempted to highlight my shared experiences with focus group participants at the beginning of our meeting. I disclosed that I had worked in the recreation department of a NH for several years before I started graduate school and

began researching aging and mental health. This may have helped me to appear similar to participants and encouraged disclosure. Taken together, it seems reasonable to assume that participants' disclosures within the focus group are a conservative representation of their opinions and beliefs regarding the psychosocial needs of NH residents. Future research may wish to conduct a more in-depth examination of staff perceptions of psychosocial needs in NHs by interviewing staff individually, which would help minimize problematic dynamics inherent in focus groups.

Implications for Research and Practice

There are several implications for future research and practice that emerged from the findings of this dissertation. The findings documented that needs for choice and control, personal effectiveness, and social connection in particular are essential for residents within NHs. However, it may require some creativity and flexibility on the part of care providers in order to help residents meet these needs. There is a large body of literature that has examined psychosocial interventions broadly designed to improve residents' well-being but not necessarily the specific psychosocial needs identified in the present research. Testad and colleagues' (2014) recent systematic review of psychosocial interventions for NH residents with dementia identified a wide range of interventions including, for example, physical exercise, music therapy, social interaction, and reminiscence. The outcomes of interest in this review consisted mostly of resident depressive symptoms, anxiety or agitation, and challenging behaviours. There is a significant need for research examining how existing interventions might improve the specific psychosocial needs identified in this dissertation. For example, music therapy could address needs for both pleasure and fun and social connection if it involved friends

and family. Physical exercise could help meet needs for personal effectiveness if it enabled residents to complete the personal care tasks that they are capable of doing. There is some evidence indicating that exercise for individuals with dementia helps improve their ability to perform activities of daily living (Forbes, Forbes, Blake, Thiessen, & Forbes, 2015).

The final list of needs within this study also provides ideas for new interventions that could be developed. Especially due to the fact that the list of psychosocial needs identified here are highly meaningful to residents. For example, future research could examine the effects of having routine opportunities to meet with staff and discuss aspects of care results in a greater perception of competence among residents and perhaps by extension, enhances their life satisfaction.

Likewise, facilities could examine how having varying degrees of control over scheduling personal care influences residents' perceived levels of autonomy. Relatively simple interventions targeting residents' perceived autonomy have had surprisingly powerful effects on residents' mental and physical health. Langer and Rodin's (1976) landmark study documented how assigning NH residents personal responsibility for a house plant resulted in greater levels of resident activity, participation, and well-being. This intervention also resulted in better physical health and lower mortality rates at an 18-month follow up (Rodin & Langer, 1977). This seminal research in addition to the findings here, underscore the importance of continued exploration of interventions that target resident choice and control as well as personal effectiveness and social connection. Intervention research will also be helpful in clarifying the feasibility of implementing psychosocial interventions in addition to their effectiveness.

Scheduling pleasant activities for NH residents should continue to be implemented. Residents rely primarily on activities organized by their NH and engage less often in self-directed activities (Tak, Kedia, Tongumpun, & Hong, 2015). The findings from this study affirm the importance of these activities and also suggest that residents should be engaged in pleasurable activities that fit with their individual preferences and ability levels. A recent randomized controlled study examined the influence of incorporating positive activities individualized to the preferences and abilities of NH residents with dementia (Van Haitsma et al., 2015). This intervention, compared to usual care, resulted in increased positive affect (e.g., pleasure and alertness) and positive verbal and nonverbal behaviour among residents. These promising results reinforce the importance of routine engagement in pleasurable activities that are tailored to individual residents' preferences as much as is feasible within a NH context. Other published research has provided helpful tools for NH care providers to develop and evaluate individualized leisure activities for residents with dementia (Tak et al, 2015).

In addition to exploring how different psychosocial interventions could address the needs identified on the list within this study, the results of this study also have possible implications for how NH facilities provide care. Consistent with new models of dementia care that are emerging (Hurley, 2012), data from this study support the importance of providing opportunities for residents to meet their psychosocial needs that are in service of emotional well-being in the present. Facilitating frequent visits with family and friends from outside the NH is a task on which NHs could focus their efforts. There is data to suggest that NH residents' contact with their family members and friends decreases by half following admission (Port et al., 2001). There are a number of

variables that are related to the frequency and extent of family member involvement and many of which may not be in the control of the NH (Gaugler, 2005a). Nonetheless, identifying and minimizing the barriers at the facility level is worthy of further examination.

The importance of residents' relationships with staff highlighted here suggest that it could be beneficial to provide staff with more supports in the form of additional time and training to facilitate building warm, empathic relationships with residents. Previous research has suggested that the number of staffing hours devoted to resident care is related to better resident quality of life (Harrington et al., 2000). There has been no formal examination of how quantity of care might influence the quality of relationships between residents and staff, nor did this study offer direct evidence in this regard. However, it seems reasonable to expect that staff having more time with residents could foster warm, caring relationships. Staff within this study also acknowledged that perceived time pressure often interfered with their attempts to connect with residents, further underscoring the importance of facilitating staff-resident relationships. One means of doing this includes having smaller staff-resident ratios, which may help staff spend more time with the residents while providing care. There is some data to suggest that staff working in NHs with a smaller number of residents reported greater levels of perceived cohesion between residents and staff (Gaugler, 2005b). Another option is increasing the involvement of NH volunteers, who may be able to spend more time with residents individually and do not come at an increased cost to NH facilities.

Other supports that could facilitate good relationships between staff and residents include additional training or education. There is a considerable amount of published

research examining interventions that improve NH staff communication with residents (Allen-Burge, Burgio, Bourgeois, Sims, & Nunnikhoven, 2001; Burgio et al., 2001; McCallion, Toseland, Lacey, & Banks, 1999; Sprangers, Dijkstra, & Romijn-Luijten, 2015). Some of these interventions have focused on reducing elderspeak (Williams et al., 2003), and others have focused on non-verbal and verbal communication strategies specific to residents with dementia (Sprangers et al., 2015) or using external aids (Burgio et al., 2001). While these interventions appear to be associated with a variety of positive outcomes, including better staff communication with residents (Burgio et al., 2001) and decreases in resident aggressive behaviour (McCallion et al., 1999) it is unclear how residents experience these interventions and if this instilled warmth and caring that was indicated as being essential in this study. Future research will be helpful in understanding how residents experience communication with staff.

An additional area of future research that will be important to pursue involves determining how resident psychosocial need satisfaction relates to additional resident and staff outcomes. It seems reasonable to assume that satisfying psychosocial needs should relate to a number of positive outcomes among NH residents and perhaps more broadly across facilities. For example, the satisfaction of psychosocial needs could correlate positively with resident life satisfaction and quality of life, and negatively with distress, low mood, and disruptive behaviour. Given other research correlating NH resident autonomy to mortality (Rodin & Langer, 1977), it would also be useful to explore the relationship between the psychosocial needs identified here and physical health outcomes and mortality rates. NH staff may also be affected by resident psychosocial need satisfaction. For example, if residents report having satisfied psychosocial needs and in

turn experience a higher quality of life, staff could be positively impacted by experiencing their work as more satisfying and reporting lower rates of stress and burnout. In order for residents to meet their psychosocial needs, however, staff may be required to change how they provide care, which may involve increased time or effort. It will be critical for future research to identify feasible and realistic means for staff to help meet residents' psychosocial needs.

It would also be useful to devote future research to further understanding the psychosocial needs of NH residents without dementia and the challenges experienced by their family members. Although the focus group conducted within Phase One of this study included residents without dementia, it did not specifically ask them to indicate their most important psychosocial needs or the challenges they encounter in meeting these needs. Additional research with this population would be helpful in order to gain more understanding of their unique needs. Learning how to engage family members of residents without dementia in research may be challenging if recruitment in this study is any indication.

It would also be useful to focus future research on staff and their efforts to assist residents to meet their psychosocial needs. This research should attempt to explore challenges such as conflict between staff and family, lack of time, and miscommunication. This research has been conducted to a certain extent, although not with the direct aim of bettering residents' psychosocial well-being. The Partners in Caregiving intervention (Pillemer et al., 2003) has been examined as a means to improve communication between nursing home staff and family members of residents. The intervention is shown to be effective in reducing conflict between staff and family

members, which was one of the barriers identified by staff within this study. It would be worthwhile to examine what effect, if any, these interventions have on residents' psychosocial need fulfillment and the extent to which they facilitate well-being. Likewise, it would be useful to examine interventions designed to improve information sharing between staff, which was also identified by staff as an obstacle to residents meeting their psychosocial needs. Observational studies have identified that positive communication patterns between medical and front-line NH staff tend to be associated with more frequent communication, better self-organization and innovation in providing care compared to facilities which adopt a vertical "chain of command" (Colón-Emeric et al., 2006). Although it seems reasonable to expect that this could improve residents' medical care, it is unclear to what extent this would influence residents' psychosocial well-being. Direct examination of how these communication styles influence resident psychosocial well-being is required. It will also be critical to devote future research to clarify how to balance NH residents' need for autonomy with the need for NH facilities to minimize risk of harm. Additional study of new approaches to NH design and models of care such as the previously mentioned "dementia village" in Amsterdam (Hurley, 2012) could provide additional information in this regard.

This study relied heavily on focus groups to gather data from both residents and staff, to understand important perceived psychosocial needs and how care is approached to help meet these needs. Although this study did not employ a formal mixed methodological design, qualitative and quantitative methodologies could be strategically combined in future research (Klassen, Creswell, Plano-Clark, Smith, & Meissner, 2012), first to develop a psychometrically valid tool to assess residents' perceived psychosocial

needs, followed by feedback gathered from residents and staff regarding their experience with using this tool, and the perceived benefits in resident care and quality of life associated with its use.

From a practice perspective, the results of this study underscore the importance of efforts to shift the view of NHs as health-care institutions to person-centred facilities that provide long-term care (Koren, 2010). The findings from the Delphi survey and the focus group with staff offer possible ideas for how NHs could implement aspects of person-centred care and what decision makers would consider encouraging at a facility level though regulated standards. NHs in Manitoba are expected to meet a set of 26 standards which involve a variety of aspects of resident care, some of which include the presence of care plans for each resident; limited use of restraints; access to physician, nursing and pharmacy services; and maintaining a clean, safe, environment. These standards could be modified to specifically incorporate elements of person-centred care and in doing so, hopefully facilitate residents' psychosocial needs. For example, with respect to fostering resident direction, NHs should encourage staff to ask residents' permission prior to providing care and work together with residents to create a schedule for providing care that is, as much as possible, within their control. NHs could also offer frequent opportunities for residents to talk with staff about care and monitor the outcomes of these discussions. With respect to creating a homelike atmosphere, it could be helpful for residents and their families to have more control over the arrangement of their rooms and the placement of their belongings, and have access to activities that create a sense of community within the NH. Residents should also be encouraged to continue to do personal care activities that they are still capable of and find enjoyable. In terms of close

relationships, it is critical for NHs to help residents maintain their current relationships with family and friends. Minimizing barriers to spending time with friends and family would be beneficial for residents. Staff should also be encouraged to maintain high-quality relationships with residents, and NHs can facilitate this by promoting staff self-care and offering education on bettering communication and relationships with residents. With respect to the staff empowerment and collaborative decision-making components of person-centered care, the results of the staff focus group suggest that enabling open communication and cooperation between staff across all disciplines is one of the most important things that could contribute to resident well-being. In terms of quality improvement processes, NHs could initiate regular monitoring of residents psychosocial well-being. Akin to routine monitoring of blood sugar or blood pressure levels, staff could implement a regular “mental health check-up” to gather information regarding to what extent residents are meeting their needs for choice, personal effectiveness, social connection, pleasure and fun, and self-acceptance. Routine monitoring of these markers of psychological well-being could not only help identify and address unmet needs, but the mere act of talking with residents about how they are doing psychologically and socially may help residents feel cared for and connected to their care providers.

Conclusion

Canada’s aging population has brought NH care into sharper focus. Although NHs have traditionally emphasized medical models of care, the culture change movement (Koren, 2010) has prompted facilities to broaden continuums of care to address the psychological and social needs of residents in addition to their physical health concerns. Despite the implementation of various psychosocial interventions within NH settings,

little research to date has identified the types of psychosocial needs most important to NH residents. Furthermore, current research examining residents' needs has underutilized theories of psychological and social needs and the perspectives of residents and their family members. There has also been little research that has identified how staff assist residents to meet these needs and the challenges they encounter in this regard. This dissertation helps to address these research gaps by using theory and the collective perspectives of family members, residents, and staff to establish the important psychosocial needs for residents and understand how staff assist residents to meet these needs. The most important psychosocial needs were predominantly in the categories of choice and control (choice to accept or decline help from others), personal effectiveness (perceiving that staff are responsive to requests, access to devices that increase independence, and opportunities to talk with staff about care), and social connection (opportunities to maintain relationships with friends and family outside the nursing home, and warm and caring exchanges with staff). Previous theory and research suggests that these psychosocial needs are universal throughout the lifespan (Ryan & Deci, 2000). The current study also highlights how residing in a NH can limit residents' abilities, opportunities and resources to meet these needs. Staff highlighted a number of efforts to help meet these needs which included, but were not limited to, offering person-centred and individualized care and encouraging residents to exert control wherever possible. Staff identified several obstacles to meeting residents' psychosocial needs such as administrative obligations, time pressures, conflict with family members, and communication challenges due to dementia. These findings add to a limited body of literature on residents' psychosocial needs and may help shape future care practices in

NH settings. Additional research examining the effectiveness and outcomes associated with psychosocial interventions to help meet the psychosocial needs identified in the present study will be critical. Likewise, further research is necessary to develop and effectively measure strategies that care providers can use to help residents more successfully meet their psychosocial needs. These changes would better align NH facilities with the person-centred model of care and may help to improve residents' psychological and social well-being and quality of life. Such efforts may not only be transformative for individuals who reside in NHs but for the broader network of family members and staff associated with this system.

References

Ahearn, D. J., Jackson, T. B., McIlmoyle, J., & Weatherburn, A. J. (2010). Improving end of life care for nursing home residents: An analysis of hospital mortality and readmission rates. *Postgraduate Medical Journal*, *86*(1013), 131–5.

<http://doi.org/10.1136/pgmj.2008.076430>

Alderfer, C.P. (1969). An empirical test of a new theory of human needs. *Organizational Behavior and Human Performance*, *4*, 142-175.

Alice Lau, W. Y., Lotus Shyu, Y. I., Lin, L. C., & Yang, P. S. (2008). Institutionalized elders with dementia: Collaboration between family caregivers and nursing home staff in Taiwan. *Journal of Clinical Nursing*, *17*(4), 482–490.

<http://doi.org/10.1111/j.1365-2702.2007.01955.x>

Allen-Burge, R., Burgio, L. D., Bourgeois, M. S., Sims, R., & Nunnikhoven, J. (2001). Increasing communication among nursing home residents. *Journal of Clinical Geropsychology*, *7*(3), 213–230.

<http://doi.org/http://dx.doi.org/10.1023/A:1011343212424>

Anderson, R. A., Issel, L. M., & McDaniel Jr, R. R. (2003). Nursing homes as complex adaptive systems: Relationship between management practice and resident outcomes. *Nursing Research*, *52*(1), 12–21. <http://doi.org/10.1097/00006199-200301000-00003>

Aneshensel, C. S., Pearlin, L. I., Levy-Storms, L., & Schuler, R. H. (2000). The transition

from home to nursing home mortality among people with dementia. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 55(3), S152–S162. <http://doi.org/10.1093/geronb/55.3.S152>

Ang, Y. H., Au, S. Y., Yap, L. K., & Ee, C. H. (2006). Functional decline of the elderly in a nursing home. *Singapore Medical Journal*, 47(3), 219–224.

Arling, P. A., Abrahamson, K., Miech, E. J., Inui, T. S., & Arling, G. (2014). Communication and effectiveness in a US nursing home quality-improvement collaborative. *Nursing and Health Sciences*, 16(3), 291–297. <http://doi.org/10.1111/nhs.12098>

Baltes, P. B., & Baltes, M. M. (1990). *Psychological perspectives on successful aging: The model of selective optimization with compensation. Successful aging: Perspectives from the behavioral sciences*. <http://doi.org/10.1017/CBO9780511665684.003>

Banerjee, S., Samsi, K., Petrie, C.D., Alvir, J., Treglia, M., Schwam, E.M., & Valle, M. (2009). What do we know about quality of life in dementia? A review of the emerging evidence on the predictive and explanatory value of disease specific measures of health related quality of life in people with dementia. *International Journal of Geriatric Psychiatry*, 25, 15-24. doi:10.1002/gps.2090

Barca, M.L., Engedal, K., Laks, J., & Selbaek, G. (2011). Quality of life among elderly

patients with dementia in institutions. *Geriatric Cognitive Disorders*, 31, 435–442.
doi:000328969 [pii] 10.1159/000328969.

Bauer, M. (2007). Staff–family relationships in nursing home care: A typology of challenging behaviours. *International Journal of Older People Nursing*, 2(3), 213–218. <http://doi.org/10.1111/j.1748-3743.2007.00075.x>

Bauer, M., Fetherstonhaugh, D., Tarzia, L., Nay, R., Wellman, D., & Beattie, E. (2012). “I always look under the bed for a man”. Needs and barriers to the expression of sexuality in residential aged care: The views of residents with and without dementia. *Psychology and Sexuality*, 4(3), 1–14.
<http://doi.org/10.1080/19419899.2012.713869>

Bauer, M., McAuliffe, L., & Nay, R. (2007). Sexuality, health care and the older person: An overview of the literature. *International Journal of Older People Nursing*, 2(1), 63–68. <http://doi.org/10.1111/j.1748-3743.2007.00051.x>

Bauer, M., Nay, R., Tarzia, L., Fetherstonhaugh, D., Wellman, D., & Beattie, E. (2014). “We need to know what’s going on”: Views of family members toward the sexual expression of people with dementia in residential aged care. *Dementia*, 13(5), 571–85. <http://doi.org/10.1177/1471301213479785>

Belanger, A., & Caron-Malenfant, M. (2005). *Population projections for Canada, provinces and territories: 2005-2031*. Statistics Canada.

- Beloosesky, Y., Nenaydenko, O., Gross Nevo, R. F., Adunsky, A., & Weiss, A. (2013). Rates, variability, and associated factors of polypharmacy in nursing home patients. *Clinical Interventions in Aging, 8*, 1585–1590.
<http://doi.org/10.2147/CIA.S52698>
- Beerens, H.C., Zwakhalen, S.M., Verbeek, H., Ruwaard, D., & Hamers, J.P. (2013). Factors associated with quality of life of people with dementia in long-term care facilities: A systematic review. *International Journal of Nursing Studies, 50*, 1259–1270. doi:S0020-7489(13)00044-8 [pii] 10.1016/j.ijnurstu.2013.02.005
- Bishop, C. E., Weinberg, D. B., Leutz, W., Dossa, A., Pfefferle, S. G., & Zinzivage, R. M. (2008). Nursing assistants' job commitment: Effect of nursing home organizational factors and impact on resident well-being. *The Gerontologist, 48* (Spec No(1)), 36–45. http://doi.org/48/suppl_1/36 [pii]
- Boulkedid, R., Abdoul, H., Loustau, M., Sibony, O., & Alberti, C. (2011). Using and reporting the Delphi method for selecting healthcare quality indicators: A systematic review. *PloS One, 6*(6), e20476. <http://doi.org/10.1371/journal.pone.0020476>
- Breitner, J. C. S. (2006). Dementia-epidemiological considerations, nomenclature, and a tacit consensus definition. *Journal of Geriatric Psychiatry and Neurology, 19*(3), 129–36. <http://doi.org/10.1177/0891988706291081>
- Brody, H., Draper, B., & Low, L. F. (2003). Nursing home staff attitudes towards residents with dementia: Strain and satisfaction with work. *Journal of Advanced*

Nursing, 44(6), 583–590. <http://doi.org/10.1046/j.0309-2402.2003.02848.x>

Brownie, S. (2011). A culture change in aged care : The Eden alternative. *Australian Journal of Advanced Nursing*, 29(1), 63–68.

Brownie, S., & Nancarrow, S. (2013). Effects of person-centered care on residents and staff in aged-care facilities: A systematic review. *Clinical Interventions in Aging*. <http://doi.org/10.2147/CIA.S38589>

Burgio, L. D., Allen-Burge, R., Roth, D. L., Bourgeois, M. S., Dijkstra, K., Gerstle, J., ... Bankester, L. (2001). Come talk with me: Improving communication between nursing assistants and nursing home residents during care routines. *The Gerontologist*, 41(4), 449–460. <http://doi.org/10.1093/geront/41.4.449>

Burnell, K. J., Selwood, A., Sullivan, T., Charlesworth, G. M., Poland, F., & Orrell, M. (2015). Involving service users in the development of the support at home: Interventions to enhance life in dementia carer supporter programme for family carers of people with dementia. *Health Expectations*, 18(1), 95–110. <http://doi.org/10.1111/hex.12012>

Burton, L. C., German, P. S., Gruber-Baldini, A. L., Hebel, J. R., Zimmerman, S., & Magaziner, J. (2001). Medical care for nursing home residents: Differences by dementia status. *Journal of the American Geriatrics Society*, 49(2), 142–147.

- Campbell, S. M., Braspenning, J., Hutchinson, A., & Marshall, M. N. (2003). Research methods used in developing and applying quality indicators in primary care. *BMJ (Clinical Research Ed.)*, *326*(7393), 816–9.
<http://doi.org/10.1136/bmj.326.7393.816>
- Carlsen, B., & Glenton, C. (2011). What about N? A methodological study of sample-size reporting in focus group studies. *BMC Medical Research Methodology*, *11*(1), 26. <http://doi.org/10.1186/1471-2288-11-26>
- Carstensen, L. L. (2006). The influence of a sense of time on human development. *Science*, *312*(5782), 1913–1915. <http://doi.org/10.1126/science.1127488>
- Carstensen, L. L. (1992). Motivation for social contact across the life span: A theory of socioemotional selectivity. In J. E. Jacobs (Ed.), *Nebraska Symposium on Motivation* (Vol. 40, pp. 209–254). Nebraska: University of Nebraska Press.
- Carstensen, L. L., & Mikels, J. A. (2005). At the intersection of emotion and cognition: Aging and the positivity effect. *Current Directions in Psychological Science*, *14*(3), 117–121.
- Carstensen, L. L., Turan, B., Scheibe, S., Ram, N., Ersner-Hershfield, H., Samanez-Larkin, G. R., & Nesselroade, J. R. (2011). Emotional experience improves with age: Evidence based on over 10 years of experience sampling. *Psychology and Aging*, *26*(1), 21–33. <http://doi.org/10.1037/a0021285>

Carstensen, L. L., & Turk-Charles, S. (1994). The salience of emotion across the adult life span. *Psychology and Aging, 9*(2), 259–264.

Carter, M. W., & Porell, F. W. (2005). Vulnerable populations at risk of potentially avoidable hospitalizations: The case of nursing home residents with Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias, 20*(6), 349–358. <http://doi.org/10.1177/153331750502000605>

CGA Association of Canada. (2005). *Growing up: The social and economic implications of an aging population*. Accessible at <https://core.ac.uk/download/pdf/6922689.pdf>.

Charles, S. T. (2010). Strength and vulnerability integration: A model of emotional well-being across adulthood. *Psychological Bulletin, 136*(6), 1068–1091. <http://doi.org/10.1037/a0021232>

Chateau, D., Doupe, M., Walld, R., Soodeen, R., Ouelette, C., & Rajotte, L. (2012). *Projecting Personal Care Home Bed Equivalent needs in Manitoba Through 2036*. Accessible at http://mchp-appserv.cpe.umanitoba.ca/reference/MCHP_pch_days_report_WEB.pdf.

Clark, C., & Ewbank, D. (1996). Performance of the Dementia Severity Scale: A caregiver questionnaire for rating severity in Alzheimer's disease. *Alzheimer's Disease and Associated Disorders, 10*, 31–39.

- Cohen-Mansfield, J., Parpura-Gill, A., & Golander, H. (2006). Salience of self-identity roles in persons with dementia: Differences in perceptions among elderly persons, family members and caregivers. *Social Science & Medicine (1982)*, *62*(3), 745–57. <http://doi.org/10.1016/j.socscimed.2005.06.031>
- Colón-Emeric, C. S., Ammarell, N., Bailey, D., Corazzini, K., Lekan-Rutledge, D., Piven, M. L., ... Anderson, R. (2006). Patterns of medical and nursing staff communication in nursing homes: Implications and insights from complexity science. *Qualitative Health Research*, *16*(2), 173–188. <http://doi.org/10.1177/1049732305284734>
- Cubit, K. (2010). Informed consent for research involving people with dementia: A grey area. *Contemporary Nurse*, *34*(2), 230–236. <http://doi.org/10.5172/conu.2010.34.2.230>
- Custers, A. F. J., Westerhof, G. J., Kuin, Y., Gerritsen, D. L., & Riksen-Walraven, J. M. (2012). Relatedness, autonomy, and competence in the caring relationship: The perspective of nursing home residents. *Journal of Aging Studies*, *26*(3), 319–326. <http://doi.org/10.1016/j.jaging.2012.02.005>
- Deci, E. L., & Ryan, R. M. (2000). The “what” and “why” of goal pursuits: Human Needs and the Self-Determination of Behavior. *Psychological Inquiry*, *11*(4), 227–268. http://doi.org/10.1207/S15327965PLI1104_01
- Deci, E. L., & Ryan, R. M. (2015). *Self-Determination Theory*. International

Encyclopedia of the Social & Behavioral Sciences. Elsevier.

<http://doi.org/10.1016/B978-0-08-097086-8.26036-4>

Demerouti, E., Bakker, a B., Nachreiner, F., & Schaufeli, W. B. (2000). A model of burnout and life satisfaction amongst nurses. *Journal of Advanced Nursing*, *32*(2), 454–464. <http://doi.org/10.1046/j.1365-2648.2000.01496.x>

Doumit, J., & Nasser, R. (2010). Quality of life and wellbeing of the elderly in Lebanese nursing homes. *International Journal of Health Care Quality Assurance*, *23*(1), 72–93. <http://doi.org/10.1108/09526861011010695>

Doupe, M., Fransoo, R., Chateau, D., Dik, N., Burchill, C., Soodeen, R., & Guenette, W. (2011). *Population aging and the continuum of older adult care in Manitoba*. Winnipeg. Available at http://mchp-appserv.cpe.umanitoba.ca/reference/LOC_Report_WEB.pdf.

Estabrooks, C. A., Poss, J. W., Squires, J. E., Teare, G. F., Morgan, D. G., Stewart, N., ... Norton, P. G. (2013). A profile of residents in prairie nursing homes. *Canadian Journal on Aging*, *32*(3), 223–31. <http://doi.org/10.1017/S0714980813000287>

Farnsworth, J., & Boon, B. (2010). Analysing group dynamics within the focus group. *Qualitative Research*, *10*, 605–624. <http://doi.org/10.1177/1468794110375223>

Fleuren, M., Wiefferink, K., & Paulussen, T. (2004). Determinants of innovation within health care organizations: Literature review and Delphi study. *International*

Journal for Quality in Health Care, 16(2), 107–23.

<http://doi.org/10.1093/intqhc/mzh030>

Forbes, D., Forbes, S. C., Blake, C. M., Thiessen, E. J., & Forbes, S. (2015). Exercise programs for people with dementia. *The Cochrane Database of Systematic Reviews*, 4, CD006489. <http://doi.org/10.1002/14651858.CD006489.pub4>

Gaugler, J. E. (2005a). Family involvement in residential long-term care: A synthesis and critical review. *Aging & Mental Health*, 9(2), 105–18.

<http://doi.org/10.1080/13607860412331310245>

Gaugler, J. E. (2005b). Staff perceptions of residents across the long-term care landscape. *Journal of Advanced Nursing*, 49(4), 377–386. <http://doi.org/10.1111/j.1365-2648.2004.03301.x>

Gaugler, J. E., Duval, S., Anderson, K. A., & Kane, R. L. (2007). Predicting nursing home admission in the U.S: A meta-analysis. *BMC Geriatrics*, 7, 13.

<http://doi.org/10.1186/1471-2318-7-13>

Gill, T. M., Gahbauer, E. A., Han, L., & Allore, H. G. (2009). Factors associated with recovery of prehospital function among older persons admitted to a nursing home with disability after an acute hospitalization. *Journals of Gerontology: Series A Biological Sciences and Medical Sciences*, 64(12), 1296–1303.

<http://doi.org/10.1093/gerona/glp115>

- Gjerberg, E., Førde, R., & Bjørndal, A. (2011). Staff and family relationships in end-of-life nursing home care. *Nursing Ethics, 18*(1), 42–53.
<http://doi.org/10.1177/0969733010386160>
- Grabowski, D. C., Aschbrenner, K. A., Rome, V. F., & Bartels, S. J. (2010). Quality of mental health care for nursing home residents: A literature review. *Medical Care Research Review, 67*(6), 627–656. <http://doi.org/10.1177/1077558710362538>
- Grady, C. (2015). Enduring and emerging challenges of informed consent. *New England Journal of Medicine, 372*(9), 855–862. <http://doi.org/10.1056/NEJMra1411250>
- Green, J. (2000). The role of theory in evidence-based health promotion practice. *Health Education Research, 15*(2), 125–129. <http://doi.org/10.1093/her/15.2.125>
- Hancock, G. A., Woods, B., Challis, D., & Orrell, M. (2006). The needs of older people with dementia in residential care. *International Journal of Geriatric Psychiatry, 21*(1), 43–9. <http://doi.org/10.1002/gps.1421>
- Harrington, C., Woolhandler, S., Mullan, J., Carrillo, H., & Himmelstein, D. U. (2001). Does investor ownership of nursing homes compromise the quality of care? *American Journal of Public Health, 91*(9), 1452–1455.
<http://doi.org/10.2105/AJPH.91.9.1452>
- Harrington, C., Zimmerman, D., Karon, S. L., Robinson, J., & Beutel, P. (2000). Nursing

home staffing and its relationship to deficiencies. *The Journals of Gerontology· Series B: Psychological Sciences and Social Sciences*, 55(5), S278–S287.

<http://doi.org/10.1093/geronb/55.5.S278>

Hasson, F., Keeney, S., & McKenna, H. (2000). Research guidelines for the Delphi survey technique. *Journal of Advanced Nursing*, 32(4), 1008–15.

Hasson, H., & Arnetz, J. E. (2008). Nursing staff competence, work strain, stress and satisfaction in elderly care: A comparison of home-based care and nursing homes.

Journal of Clinical Nursing, 17(4), 468–481. <http://doi.org/10.1111/j.1365-2702.2006.01803.x>

Havig, A. K., Skogstad, A., Kjekshus, L. E., & Romøren, T. I. (2011). Leadership, staffing and quality of care in nursing homes. *BMC Health Services Research*,

11(1), 327. <http://doi.org/10.1186/1472-6963-11-327>

Haynes, S. N., Richard, D. C. S., & Kubany, E. S. (1995). Content validity in psychological assessment : A functional approach to concepts and methods

introduction to content validity. *Psychological Assessment*, 7(3), 238–247.

<http://doi.org/10.1037//1040-3590.7.3.238>

Helvik, A. S., Engedal, K., Benth, J. S., & Selbæk, G. (2014). A 52 month follow-up of functional decline in nursing home residents - degree of dementia contributes. *BMC*

Geriatrics, 14(1), 45. <http://doi.org/10.1186/1471-2318-14-45>

- Henderson, J. N., & Vesperi, M. S. (1995). *The Culture of Long Term Care: Nursing Home Ethnography*. Santa Barbara: Greenwood Publishing Group.
- Hendrie, H. C. (1998). Epidemiology of dementia and Alzheimer's disease. *The American Journal of Geriatric Psychiatry*, 6(2 Suppl 1), S3-18.
- Herman, R. E., & Williams, K. N. (2009). Elderspeak's influence on resistiveness to care: Focus on behavioral events. *American Journal of Alzheimer's Disease and Other Dementias*, 24(5), 417-23. <http://doi.org/10.1177/1533317509341949>
- Hollinger-Samson, N., & Pearson, J. L. (2000). The relationship between staff empathy and depressive symptoms in nursing home residents. *Aging & Mental Health*, 4(1), 56-65. <http://doi.org/http://dx.doi.org/10.1080/13607860055982>
- Hsu, C., & Sandford, B. (2007). The Delphi technique: Making sense of consensus. *Practical Assessment Research & Evaluation*, 12(10), 1-8.
- Hurley, D. (2012). "Village of the Demented" draws praise as new Care model. *Neurology Today*, 12-13.
- Jones, A. L., Dwyer, L. L., Bercovitz, A. R., & Strahan, G. W. (2009). The national nursing home survey: 2004 overview. *Vital and Health Statistics· Series 13, Data from the National Health Survey*, (167), 1-155.
<http://doi.org/10.1111/j.1532-5415.2009.02552.x>

Jorm, A. F. (2015). Using the Delphi expert consensus method in mental health research.

Australian & New Zealand Journal of Psychiatry, 49(10), 887–897.

<http://doi.org/10.1177/0004867415600891>

Kane, R. (2001). Long-term care and a good quality of life: Bringing them closer together. *The Gerontologist, 41*(3), 293–304.

<http://doi.org/10.1093/geront/41.3.293>

Kane, R. A. (2003). Definition, measurement, and correlates of quality of life in nursing homes: Toward a reasonable practice, research, and policy agenda. *The*

Gerontologist, 43(2), 28–36. http://doi.org/10.1093/geront/43.suppl_2.28

Kane, R. L., Kane, R.A., Bershadsky, B., Degenholtz, H., Kling, K., Toten, A., & Jung, K. (2005). Proxy sources for information on nursing home residents' quality of life. *Journal of Gerontology: Social Sciences, 60B*, S318-S325.

Kane, R. A., Lum, T. Y., Cutler, L. J., Degenholtz, H. B., & Yu, T. C. (2007). Resident outcomes in small-house nursing homes: A longitudinal evaluation of the initial green house program. *Journal of the American Geriatrics Society, 55*(6), 832–839. <http://doi.org/10.1111/j.1532-5415.2007.01169.x>

Karakaya, M. G., Bilgin, S. C., Ekici, G., Köse, N., & Otman, A. S. (2009). Functional mobility, depressive symptoms, level of independence, and quality of life of the elderly living at home and in the nursing home. *Journal of the American Medical Directors Association, 10*(Nov), 662–666.

<http://doi.org/10.1016/j.jamda.2009.06.002>

Kasser, T., & Ryan, R. M. (2001). Be careful what you wish for: Optimal functioning and the relative attainment of intrinsic and extrinsic goals. In P. Schmuck & K. Sheldon (Eds.), *Life goals and well-being: Towards a positive psychology of human striving* (pp. 116–131). Ohio, USA: Hongrefe and Huber.

Kasser, V., & Ryan, R. M. (1999). The relation of psychological needs for autonomy and relatedness to vitality, well-being, and mortality in a nursing home. *Journal of Applied Social Psychology*, 935–954.

Keeney, S., Hasson, F., & McKenna, H. (2006). Consulting the oracle: Ten lessons from using the Delphi technique in nursing research. *Journal of Advanced Nursing*, 53(2), 205–12. <http://doi.org/10.1111/j.1365-2648.2006.03716.x>

Keyes, C. L. M. (2005). Mental illness and/or mental health? Investigating axioms of the complete state model of health. *Journal of Consulting and Clinical Psychology*, 73(3), 539–548.

Keyes, C. L. M. (2007). Promoting and protecting mental health as flourishing: A complementary strategy for improving national mental health. *American Psychologist*, 62(2), 95–108.

Kiely, D. K., & Flacker, J. M. (2003). The protective effect of social engagement on 1-

year mortality in a long-stay nursing home population. *Journal of Clinical Epidemiology*, *56*(5), 472–478. [http://doi.org/10.1016/S0895-4356\(03\)00030-1](http://doi.org/10.1016/S0895-4356(03)00030-1)

Klassen, A.C., Creswell, J., Plano Clark, V.L., Smith, K., & Meissner, H.I. (2012). Best practices in mixed methods for quality of life research. *Quality of Life Research*, *21*, 377-380. doi:10.1007/s11136-012-0122-x

Koren, M. J. (2010). Person-centered care for nursing home residents: The culture-change movement. *Health Affairs (Project Hope)*, *29*(2), 312–7. <http://doi.org/10.1377/hlthaff.2009.0966>

Kröger, E., Tourigny, A., Morin, D., Côté, L., Kergoat, M.-J., Lebel, P., ... Benounissa, Z. (2007). Selecting process quality indicators for the integrated care of vulnerable older adults affected by cognitive impairment or dementia. *BMC Health Services Research*, *7*, 195. <http://doi.org/10.1186/1472-6963-7-195>

Lapane, K. L., & Hughes, C. M. (2007). Considering the employee point of view: Perceptions of job satisfaction and stress among nursing staff in nursing homes. *Journal of the American Medical Directors Association*, *8*(1), 8–13. <http://doi.org/10.1016/j.jamda.2006.05.010>

Lawton, M.P. (1994). Quality of life in Alzheimer disease. *Alzheimer Disease and Associated Disorders*, *8* (Suppl 3), 138-150.

Lee, J. S., Chau, P. P., Hui, E., Chan, F., & Woo, J. (2009). Survival prediction in nursing home residents using the Minimum Data Set subscales: ADL self-performance

hierarchy, cognitive performance and the changes in health, end-stage disease and symptoms and signs scales. *European Journal of Public Health, 19*(3), 308–312. <http://doi.org/10.1093/eurpub/ckp006>

Lévesque, L., Ducharme, F., & Lachance, L. (1999). Is there a difference between family caregiving of institutionalized elders with or without dementia? *Western Journal of Nursing Research, 21*(4), 472–91.

<http://doi.org/http://dx.doi.org/10.1177/01939459922043992>

Levy, C., & Wojtusiak, J. (2015). Illness trajectories among nursing home residents.

Journal of Pain and Symptom Management, 49(2), 342.

<http://doi.org/10.1016/j.jpainsymman.2014.11.053>

Li, Y., Cai, X., Mukamel, D. B., & Glance, L. G. (2010). The volume–outcome relationship in nursing home care: An examination of functional decline among long-term care residents. *Medical Care, 48*(1), 52–7.

<http://doi.org/10.1097/MLR.0b013e3181bd4603>

Lichtenberg, F. R. (2012). The effect of pharmaceutical innovation on the functional limitations of elderly Americans: Evidence from the 2004 National Nursing Home Survey. *Advances in Health Economics and Health Services Research, 23*, 73–101. [http://doi.org/10.1108/S0731-2199\(2012\)0000023006](http://doi.org/10.1108/S0731-2199(2012)0000023006)

Lidhran, G. (2015). Exploring dementia villages and other care models in Canada.

Retrieved from <http://safecarebc.ca/op-ed-exploring-dementia-villages-and-other->

care-models-in-canada/#_edn5

Lindenberg, S. (1996). Continuities in the theory of social production functions. In S.

Lindenberg & H. Gazeboom (Eds.), *Explanatory sociology: Essays in honor of*

Reinhard Wippler (pp. 169–184). Amsterdam, Netherlands: Thesis Publishers.

Liu, L. M., Guarino, A. J., & Lopez, R. P. (2012). Family satisfaction with care provided by nurse practitioners to nursing home residents with dementia at the end of life.

Clinical Nursing Research, *21*(3), 350–67.

<http://doi.org/10.1177/1054773811431883>

Lockenhoff, C. E., & Carstensen, L. L. (2004). Socioemotional selectivity theory, aging, and health: The increasingly delicate balance between regulating emotions and making tough choices. *Journal of Personality*, *72*(6), 1395–1424.

<http://doi.org/10.1111/j.1467-6494.2004.00301.x>

Mackenzie, C., Karaolyas, E., & Starzyk, K. (2017). *Differences in Eudaimonic and*

Hedonic Well-Being Across the Adult Lifespan: A Cross-Sectional

Survey of Younger, Middle-Aged, and Older Adults. Manuscript submitted for review.

Magaziner, J., Zimmerman, S., Gruber-Baldini, A. L., Van Doorn, C., Hebel, J. R.,

German, P., ... Baumgarten, M. (2005). Mortality and adverse health events in

newly admitted nursing home residents with and without dementia. *Journal of*

the American Geriatrics Society, 53(11), 1858–1866.

<http://doi.org/10.1111/j.1532-5415.2005.53551.x>

Majerovitz, S. D., Mollott, R. J., & Rudder, C. (2009). We're on the same side:

Improving communication between nursing home and family. *Health*

Communication, 24(1), 12–20. <http://doi.org/10.1080/10410230802606950>

Martin-Cook, K., Hynan, L.S., Rice-Koch, K., Svetlik, D.A., & Weiner, M.F. (2005).

Responsiveness of the quality of life in late-stage dementia scale to psychotropic drug treatment in late-stage dementia. *Geriatric Cognitive Disorders*, 19, 82-85.

doi:82353 [pii] 10.1159/000082353

Marziali, E., Mackenzie, C. S., & Tchernikov, I. (2015). Acceptability of an e-learning program to help nursing assistants manage relationship conflict in nursing homes.

American Journal of Alzheimer's Disease and Other Dementias, 30(1),

55–60. <http://doi.org/http://dx.doi.org/10.1177/1533317514551482>

Maslow, A. (1943). A Theory of Human Motivation. *Psychological Review*, 50, 5.

Massey, O. T. (2011). A proposed model for the analysis and interpretation of focus

groups in evaluation research. *Evaluation and Program Planning*, 34(1), 21–8.

<http://doi.org/10.1016/j.evalprogplan.2010.06.003>

McCallion, P., Toseland, R. W., Lacey, D., & Banks, S. (1999). Educating nursing assistants to communicate more effectively with nursing home residents with

dementia. *The Gerontologist*, 39(5), 546–558.

<http://doi.org/10.1093/geront/39.5.546>

McGillis Hall, L., Doran, D., & Pink, G. H. (2004). Nurse staffing models, nursing hours, and patient safety outcomes. *Journal of Nursing Administration, 34*(1), 41–5.

<http://doi.org/10.1097/00005110-200401000-00009>

McClelland, D.C. (1965). Toward a theory of motive acquisition. *American Psychologist, 20*, 321-333.

McGregor, M.J., Tate, R.B., Ronald, L.A., McGrail, K.M., Cox, M.B., Berta, W., &

Broemeling, A.M. (2010). *Trends in long-term care staffing by facility*

ownership in British Columbia: 1996-2006. Available at

<http://www.statcan.gc.ca/pub/82-003-x/2010004/article/11390-eng.htm>

Menec, V., MacWilliam, L., Sooden, R., & Mitchell, L. (2002). *The health and*

health care use of Manitoba's Seniors: Have they changes over time?

Available at <http://mchp-appserv.cpe.umanitoba.ca/reference/seniors.pdf>

Milan, A., & Bohnert, N. (2011). *Living arrangements of seniors*. Available at

https://www12.statcan.gc.ca/census-recensement/2011/as-sa/98-312-x/98-312-x2011003_4-eng.cfm

Mjorud, M., Kirkevold, M., Rosvik, J., Saelback, G., & Engedal, K. (2014). Variables

associated to quality of life among nursing home residents with dementia. *Aging and Mental Health, 18*, 1013-1021.

Moore, K. L., Boscardin, W. J., Steinman, M. A., & Schwartz, J. B. (2012). Age and sex

variation in prevalence of chronic medical conditions in older residents of U.S. nursing homes. *Journal of the American Geriatrics Society*, *60*(4), 756–64.
<http://doi.org/10.1111/j.1532-5415.2012.03909.x>

Morris, J. N., Fries, B. E., Mehr, D. R., Hawes, C., Phillips, C., Mor, V., & Lipsitz, L. A. (1994). MDS Cognitive Performance Scale. *Journal of Gerontology*, *49*(4), M174–M182. <http://doi.org/10.1093/geronj/49.4.M174>

Morrison, R. S. (2009). Suffering in silence: Addressing the needs of nursing home residents. *Journal of Palliative Medicine*, *12*(8), 671–672.
<http://doi.org/10.1089/jpm.2009.9584>

Mukamel, D. B., Caprio, T., Ahn, R., Zheng, N. T., Norton, S., Quill, T., & Temkin-Greener, H. (2012). End-of-life quality-of-care measures for nursing homes: Place of death and hospice. *Journal of Palliative Medicine*, *15*(4), 438–46.
<http://doi.org/10.1089/jpm.2011.0345>

O'Brien, K. (1993). Using focus groups to develop health surveys: An example from research on social relationships and AIDS-preventive behavior. *Health Education & Behavior*, *20*(3), 361–372. <http://doi.org/10.1177/109019819302000307>

O'Connor, B. P., & Vallerand, R. J. (1994). Motivation, self-determination, and person-environment fit as predictors of psychological adjustment among nursing home residents. *Psychology and Aging*, *9*(2), 189–94.

Ormel, J., Lindenberg, S., Steverink, N., & Verbrugge, L. M. (1999). Subjective well-

being and social production functions. *Social Indicators Research*, 46(1), 61–90.

<http://doi.org/10.1023/A:1006907811502>

Palan Lopez, R. (2009). Doing what's best: Decisions by families of acutely ill nursing home residents. *Western Journal of Nursing Research*, 31(5), 613–26.

<http://doi.org/10.1177/0193945909332911>

Pillemer, K., Sutor, J. J., Henderson, C. R., Meador, R., Schultz, L., Robison, J., & Hegeman, C. (2003). A cooperative communication intervention for nursing home staff and family members of residents. *The Gerontologist*, 43(2), 96–106.

http://doi.org/10.1093/geront/43.suppl_2.96

Port, C. L., Gruber-Baldini, A. L., Burton, L., Baumgarten, M., Hebel, J. R., Zimmerman, S. I., & Magaziner, J. (2001). Resident contact with family and friends following nursing home admission. *The Gerontologist*, 41(5), 589–596.

<http://doi.org/http://dx.doi.org/10.1093/geront/41.5.589>

Powell, R. A., Single, H. M., & Lloyd, K. R. (1996). Focus groups in mental health research: Enhancing the validity of user and provider questionnaire. *International Journal of Social Psychiatry*, 42, 193–206.

<http://doi.org/10.1177/002076409604200303>

Redfern, S., Hannan, S., Norman, I., & Martin, F. (2002). Work satisfaction, stress, quality of care and morale of older people in a nursing home. *Health and Social*

Care in the Community, 10(6), 512–517. <http://doi.org/10.1046/j.1365->

2524.2002.00396.x

- Rodin, J., & Langer, E. J. (1977). Long-term effects of a control-relevant intervention with the institutionalized aged. *Journal of Personality and Social Psychology*, *35*(12), 897–902. <http://doi.org/10.1037/0022-3514.35.12.897>
- Rosemond, C. a, Hanson, L. C., Ennett, S. T., Schenck, A. P., & Weiner, B. J. (2012). Implementing person-centered care in nursing homes. *Health Care Management Review*, *37*(3), 257–66. <http://doi.org/10.1097/HMR.0b013e318235ed17>
- Ryan, R. M., & Deci, E. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, *(55)*, 68–78.
- Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, *55*(1), 68–78. <http://doi.org/10.1037/0003-066X.55.1.68>
- Ryan, R. M., Huta, V., & Deci, E. L. (2008). Living well: A self-determination theory perspective on eudaimonia. *Journal of Happiness Studies*, *9*(1), 139–170. <http://doi.org/10.1007/s10902-006-9023-4>
- Ryan, R. M., & La Guardia, J. G. (2000). What is being optimized?: Self-determination theory and basic psychological needs. In *Psychology and the Aging Revolution: How we Adapt to Longer Life* (pp. 145–172).

<http://doi.org/10.1037/10363-008>

Ryan, R. M., & LaGuardia, J. G. (1995). What is being optimized?: Self-Determination

Theory and basic psychological needs. In *Psychology and the Aging*

Revolution: How we Adapt to Longer Life (pp. 145–172). American

Psychological Association.

Ryan, R. R., & Deci, E. L. (2001). On happiness and human potentials: A review of

research on hedonic and eudaimonic well-being. *Annual Review of Psychology*,

52, 141–166.

Ryff, C. D. (1989). Happiness is everything, or is it? Explorations on the meaning of

psychological well-being. *Journal of Personality and Social Psychology*, *57*,

1069–1081.

Ryff, C. D., & Essex, M. J. (1992). The interpretation of life experience and well-being:

The sample case of relocation. *Psychology and Aging*, *7*(4), 507–517.

Ryff, C. D., & Keyes, C. L. (1995). The structure of psychological well-being revisited.

Journal of Personality and Social Psychology, *69*(4), 719–727.

<http://doi.org/10.1037/0022-3514.69.4.719>

Ryff, C. D., & Singer, B. (1996). Psychological well-being: Meaning, measurement, and

implications for psychotherapy research. *Psychotherapy and Psychosomatics*,

65(1), 14–23. <http://doi.org/10.1159/000289026>

- Scheibe, S., & Carstensen, L. L. (2010). Emotional aging: Recent findings and future trends. *J Gerontol B Psychol Sci Soc Sci*, *65B*(2), 135–144.
<http://doi.org/10.1093/geronb/gbp132>
- Schenk, L., Meyer, R., Behr, A., Kuhlmeier, A., & Holzhausen, M. (2013). Quality of life in nursing homes: Results of a qualitative resident survey. *Quality of Life Research*, *22*(10), 2929–2938. <http://doi.org/10.1007/s11136-013-0400-2>
- Seitz, D., Purandare, N., & Conn, D. (2010). Prevalence of psychiatric disorders among older adults in long-term care homes: A systematic review. *International Psychogeriatrics*, *22*(7), 1025–39. <http://doi.org/10.1017/S1041610210000608>
- Sherwin, S. B., & Winsby, M. (2011). A relational perspective on autonomy for older adults residing in nursing homes. *Health Expectations*, *14*(2), 182–190.
<http://doi.org/10.1111/j.1369-7625.2010.00638.x>
- Shield, R. R., Wetle, T., Teno, J., Miller, S. C., & Welch, L. (2005). Physicians “missing in action”: Family perspectives on physician and staffing problems in end-of-life care in the nursing home. *Journal of the American Geriatrics Society*, *53*(10), 1651–7. <http://doi.org/10.1111/j.1532-5415.2005.53505.x>
- Shier, V., Khodyakov, D., Cohen, L. W., Zimmerman, S., & Saliba, D. (2014). What does the evidence really say about culture change in nursing homes?
Gerontologist, *54* [Supplemental material]. <http://doi.org/10.1093/geront/gnt147>

Shin, I.S., Carter, M., Masterman, D., Fairbanks, L., & Cummings, J.L. (2005).

Neuropsychiatric symptoms and quality of life in Alzheimer disease. *American Journal of Geriatric Psychiatry, 13*, 469-474. doi:10.1176/appi.ajgp.13.6.469

Shin, J. H. (2013). Relationship between nursing staffing and quality of life in nursing homes. *Contemporary Nurse, 44*(2), 133–143.

<http://doi.org/10.5172/conu.2013.44.2.133>

Spilsbury, K., Hewitt, C., Stirk, L., & Bowman, C. (2011). The relationship between nurse staffing and quality of care in nursing homes: A systematic review.

International Journal of Nursing Studies, 48(6), 732–750.

<http://doi.org/10.1016/j.ijnurstu.2011.02.014>

Sprangers, S., Dijkstra, K., & Romijn-Luijten, A. (2015). Communication skills training in a nursing home: Effects of a brief intervention on residents and nursing aides.

Clinical Interventions in Aging, 10, 311–319.

<http://doi.org/10.2147/CIA.S73053>

Statistics Canada. (2010). *Estimates of population, by age group and sex for*

Canada, provinces, and territories. Ottawa. Accessible at

<http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/demo31a-eng.htm>.

Steverink, N., & Lindenberg, S. (2006). Which social needs are important for subjective well-being? What happens to them with aging? *Psychology and Aging, 21*(2),

281–90. <http://doi.org/10.1037/0882-7974.21.2.281>

- Steverink, N., Lindenberg, S., & Ormel, J. (1998). Towards understanding successful ageing: Patterned change in resources and goals. *Ageing and Society, 18*, 441–467. <http://doi.org/doi:null>
- Tak, S. H., Kedia, S., Tongumpun, T. M., & Hong, S. H. (2015). Activity engagement: Perspectives from nursing home residents with dementia. *Educational Gerontology, 41*(3), 182–192. <http://doi.org/10.1080/03601277.2014.937217>
- Tamura, B. K., Bell, C. L., Inaba, M., & Masaki, K. H. (2012). Factors associated with polypharmacy in nursing home residents. *Clinical Geriatric Medicine, 28*(2), 199–216. <http://doi.org/10.1016/j.cger.2012.01.004>
- Tarzia, L., Bauer, M., Fetherstonhaugh, D., & Nay, R. (2013). Interviewing older people in residential aged care about sexuality: Difficulties and challenges. *Sexuality and Disability, 31*(4), 361–371. <http://doi.org/10.1007/s11195-013-9297-5>
- Testad, I., Corbett, A., Aarsland, D., Lexow, K. O., Fossey, J., Woods, B., & Ballard, C. (2014). The value of personalized psychosocial interventions to address behavioral and psychological symptoms in people with dementia living in care home settings: A systematic review. *International Psychogeriatrics / IPA, 26*(7), 1083–98. <http://doi.org/10.1017/S1041610214000131>
- Testad, I., Mikkelsen, A., Ballard, C., & Aarsland, D. (2010). Health and well-being in care staff and their relations to organizational and psychosocial factors, care staff and resident factors in nursing homes. *International Journal of Geriatric*

Psychiatry, 25(8), 789–797. <http://doi.org/10.1002/gps.2419>

Thomas, J. M., Cooney, L. M., & Fried, T. R. (2013). Systematic review: Health-related characteristics of elderly hospitalized adults and nursing home residents associated with short-term mortality. *Journal of the American Geriatrics Society*. <http://doi.org/10.1111/jgs.12273>

Toles, M., & Anderson, R. A. (2011). State of the science: Relationship-oriented management practices in nursing homes. *Nursing Outlook*, 59(4), 221–227. <http://doi.org/10.1016/j.outlook.2011.05.001>

United Nations. (2002). *World Population Aging*. Available at <http://www.un.org/esa/population/publications/worldageing19502050/>

Utley-Smith, Q., Colón-Emeric, C. S., Lekan-Rutledge, D., Ammarell, N., Bailey, D., Corazzini, K., ... Anderson, R. A. (2009). The nature of staff–family interactions in nursing homes: Staff perceptions. *Journal of Aging Studies*, 23(3), 168–177. <http://doi.org/10.1016/j.jaging.2007.11.003>

Van Dijk, P., Mehr, D. R., Ooms, M. E., Madsen, R., Petroski, G., Frijters, D. H., ... Ribbe, M. W. (2005). Comorbidity and 1-year mortality risks in nursing home residents. *Journal of the American Geriatrics Society*, 53(4), 660–665. <http://doi.org/10.1111/j.1532-5415.2005.53216.x>

Van Dijk, P., van de Sande, H., Dippel, D., & Habbema, J. D. (1992). The nature of excess mortality in nursing home patients with dementia. *Journal of*

Gerontology, 47(2), M28-34.

Van Doorn, C., Gruber-Baldini, A. L., Zimmerman, S., Hebel, J. R., Port, C. L., Baumgarten, M., ... Magaziner, J. (2003). Dementia as a risk factor for falls and fall injuries among nursing home residents. *Journal of the American Geriatrics Society*, 51(9), 1213–1218. <http://doi.org/10.1046/j.1532-5415.2003.51404.x>

Van Haitsma, K. S., Curyto, K., Abbott, K. M., Towsley, G. L., Spector, A., & Kleban, M. (2015). A randomized controlled trial for an individualized positive psychosocial intervention for the affective and behavioral symptoms of dementia in nursing home residents. *Journals of Gerontology: Series B Psychological Sciences and Social Sciences*, 70(1), 35–45. <http://doi.org/10.1093/geronb/gbt102>

Van Rensbergen, G., & Nawrot, T. (2010). Medical conditions of nursing home admissions. *BMC Geriatrics*, 10, 46. <http://doi.org/10.1186/1471-2318-10-46>

Vasse, E., Moniz-Cook, E., Rikkert, M. O., Cantegreil, I., Charras, K., Dorenlot, P., ... Vernooij-Dassen, M. (2012). The development of quality indicators to improve psychosocial care in dementia. *International Psychogeriatrics*, 24(6), 921–30. <http://doi.org/10.1017/S1041610211002523>

Vourlekis, B. S., Gelfand, D. E., & Greene, R. R. (1992). Psychosocial needs and care in nursing homes: Comparison of views of social workers and home administrators. *The Gerontologist*, 32(1), 113–119.

- Warner, J., McCarney, R., Griffin, M., Hill, K., & Fisher, P. (2008). Participation in dementia research: rates and correlates of capacity to give informed consent. *Journal of Medical Ethics, 34*(3), 167–170.
<http://doi.org/10.1136/jme.2006.019786>
- Weech-Maldonado, R., Meret-Hanke, L., Neff, M. C., & Mor, V. (2004). Nurse staffing patterns and quality of care in nursing homes. *Health Care Management Review, 29*(2), 107–116. <http://doi.org/10.1097/00004010-200404000-00004>
- Weeks, D. J. (2002). Sex for the mature adult: Health, self-esteem and countering ageist stereotypes. *Sexual and Relationship Therapy, 17*(3), 231–240.
<http://doi.org/10.1080/14681990220149031>
- Wellens, N. I. H., Flamaing, J., Tournoy, J., Hanon, T., Moons, P., Verbeke, G., ... Milisen, K. (2013). Convergent validity of the Cognitive Performance Scale of the interRAI acute care and the mini-mental state examination. *The American Journal of Geriatric Psychiatry, 21*(7), 636–645.
<http://doi.org/10.1016/j.jagp.2012.12.017>
- Wetle, T., Shield, R., Teno, J., Miller, S. C., & Welch, L. (2005). Family perspectives on end-of-life care experiences in nursing homes. *The Gerontologist, 45*(5), 642–650. <http://doi.org/10.1093/geront/45.5.642>
- Wetzels, R. B., Zuidema, S. U., de Jonghe, J. F. M., Verhey, F. R. J., & Koopmans, R. T. C. M. (2010). Course of neuropsychiatric symptoms in residents with dementia in

nursing homes over 2-year period. *The American Journal of Geriatric Psychiatry*, *18*(12), 1054–1065. <http://doi.org/10.1097/JGP.0b013e3181f60fa1>

White, H. K., Corazzini, K., Twersky, J., Buhr, G., McConnell, E., Weiner, M., & Colon-Emeric, C. S. (2012). Prioritizing culture change in nursing homes: Perspectives of residents, staff, and family members. *Journal of the American Geriatrics Society*. <http://doi.org/10.1111/j.1532-5415.2011.03840.x>

Williams, K., Kemper, S., & Hummert, M. L. (2003). Improving nursing home communication: An intervention to reduce elderspeak. *The Gerontologist*, *43*(2), 242–247. <http://doi.org/10.1093/geront/43.2.242>

Wister, A. V., & Speechley, M. (2015). Inherent tensions between population aging and health care systems: What might the Canadian health care system look like in twenty years? *Journal of Population Ageing*, *8*(4), 227–243. <http://doi.org/10.1007/s12062-015-9123-1>

Xie, S. X., Ewbank, D. C., Chittams, J., Karlawish, J. H. T., Arnold, S. E., & Clark, C. M. (2009). Rate of decline in Alzheimer disease measured by a Dementia Severity Rating Scale. *Alzheimer Disease and Associated Disorders*, *23*(3), 268–274. <http://doi.org/10.1097/WAD.0b013e318194a324>

Young, Y., Kalamaras, J., Kelly, L., Hornick, D., & Yucel, R. (2015). Is aging in place delaying nursing home admission? *Journal of the American Medical*

Directors Association, 16(10), e1-6. <http://doi.org/10.1016/j.jamda.2015.07.017>

Zimmerman, S., Dobbs, D., Williams, C. S., & Reed, P. S. (2004). Attitudes and Perceptions of Staff Caring for Residents with Dementia. In *Conference Papers - American Sociological Association*. Accessible at http://citation.allacademic.com/meta/p_mla_apa_research_citation/1/0/8/7/9/p108799_index.html?type=info&PHPSESSID=4m2eu11ha15s1lbmdinnb3uj22

Zimmerman, S., Sloane, P. D., Williams, C. S., Reed, P. S., Preisser, J. S., Eckert, J. K., ... Dobbs, D. (2005). Dementia care and quality of life in assisted living and nursing homes. *The Gerontologist*, 45 Spec No(1), 133–146. http://doi.org/10.1093/geront/45.suppl_1.133

Zimmerman, S., Williams, C. S., Reed, P. S., Boustani, M., Preisser, J. S., Heck, E., & Sloane, P. D. (2005). Attitudes, stress, and satisfaction of staff who care for residents with dementia. *The Gerontologist*, 45, 96–105.

Appendix A

Information and Consent Form for Phase One Participants

UNIVERSITY
OF MANITOBA**Information and Consent Form**

Study Name: Psychosocial needs of nursing home residents: Perspectives of Family Members

Principal Investigator: Julie Erickson, M.A., PhD Candidate, Psychology, University of Manitoba, (xxx)-xxx-xxxx, umeric27@myumanitoba.ca

Research Supervisors: Dr. Corey Mackenzie, Associate Professor, Psychology, University of Manitoba, (xxx)-xxx-xxxx, corey.mackenzie@umanitoba.ca; Dr. Malcolm Doupe, Assistant Professor, Community Health Sciences, University of Manitoba, (xxx) xxx-xxxx, malcolm_doupe@cpe.umanitoba.ca.

This consent form, a copy of which you may have your records and reference at this time, 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, you should feel free to contact us. Please take the time to read this carefully and to understand any accompanying information.

Who am I? I am Julie Erickson, a PhD student in Clinical Psychology conducting my thesis research under the supervision of Dr. Corey Mackenzie and Dr. Malcolm Doupe at the University of Manitoba. I am not affiliated with any nursing home in Manitoba in any way.

What am I doing? I am interested in the perspectives of nursing home residents and their family members on what nursing home residents need for their psychological and social well-being. I am conducting one focus group with residents and their family members.

What does participation involve? Participating involves attending one hour-long, in-person focus group held at a nursing home. In the focus group, I will give you a list of items that I think are the psychological and social needs of nursing home residents. I would like your feedback on this list and whether you think items should be added or taken out. I will audio record your responses to help me revise the list of items after the focus group. Participation is completely voluntary. Should you choose to withdraw from

the study at any point, you may do so without penalty. You will still be entered into a draw for a \$20 gift card to Tim Hortons or Amazon.ca.

Please note that if you are a nursing home resident, I require your permission to consult with nursing staff at your facility to confirm that you are cognitively healthy and are able to provide informed consent. Your signature on this form indicates your permission for me to do so.

What are the risks? Some participants may experience distress when talking about psychological and social well-being of residents in nursing homes. I do not expect this distress to be long lasting. I will do my best to ensure that the focus group environment is constructive, positive and friendly in nature. I will also tell participants that the content of the focus group is expected to remain confidential. If you are distressed following the focus group, please let me know and I will direct you to helpful resources.

What are the benefits? All participants will be entered into a draw to win a \$20 gift card Tim Hortons or Amazon.ca. Your valuable feedback will help me revise a list of psychological and social needs to make it more relevant to nursing home residents. I will be using this revised list of needs in the next stage of my research and hopefully, to better the quality of life of nursing home residents.

Privacy and Confidentiality: I will do my best to ensure that your data will be anonymous. However, if for some reason you reveal identifying information during the focus group, I will make sure all of the answers you provide will be kept confidential. Keep in mind that because you are participating in a group with other residents and/or family members, I cannot guarantee your confidentiality. I will audio record the focus group and the audio files will be kept in a locked cabinet within a locked office within the Duff Roblin building at the University of Manitoba. Only my research supervisors and I will have access to the audio files. I will only collect your contact information for the purposes of contacting you in the event you would like a summary of my findings or if you win the \$20 gift card. Your contact information will not be linked to the responses you provide in the focus group. This information will also be kept in a locked cabinet within a locked office within the Duff Roblin building at the University of Manitoba. Once the study is complete, I will destroy the audio files and any participant contact information. I estimate that this will be by October, 2015. I am bound by the Vulnerable Persons Act to report any knowledge or suspicion of abuse or neglect of a vulnerable person.

What will I do with the results? Once all the data are collected and analyzed for this project, I plan to share this information with the research community through seminars, conferences, presentations, and journal articles. When presenting the results of this research, I will in no way focus on individual participants' responses and will instead present the findings in summary form. If you would like a copy of the results, please let me know verbally. I will use the contact information you provided to send you a summary of my findings by July 2015.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way. This research has been approved by the Psychology/Sociology Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at xxx-xxxx.

Your signature below indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time or refrain from answering any questions you prefer to omit, without prejudice or consequence. If you wish to withdraw, simply let me know at any time. If you do choose to withdraw from this study, I will destroy any data that you have provided and not include it in the analysis. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Signature: _____

Date: _____

Appendix B

Phase One Psychosocial Needs

Autonomy

1. Control over which activities of daily living are performed and when (e.g., eating, bathing, dressing)
2. Choice to pursue or decline assistance from others
3. Control over which social, recreational, or religious activities are pursued and when
4. Access to activities within the PCH
5. Access to activities outside the PCH
6. Opportunities to be involved in decisions related to one's care
7. Control over room arrangement, inclusion and placement of personal belongings

Competence

8. Doing activities of daily living (e.g., dressing, feeding) that are appropriate for one's capabilities
9. Access to assistive devices (e.g., walker) that maximize independence
10. Opportunities to talk with PCH staff about care
11. Feeling that staff are responsive to resident feedback or requests

Relatedness

12. Opportunities to maintain important relationships with friends and family outside the PCH
13. Opportunities to form and maintain new relationships within the PCH
14. Access to activities that create a sense of community within the PCH
15. Warm and caring exchanges with care staff
16. Touch and physical affection
17. Opportunities for sexual intimacy or sexual expression

Purpose and Meaning

18. Opportunities to express religious, cultural, and ethnic identity
19. Opportunities to interact with and contribute to younger people
20. Contributing to the functioning of the nursing home (e.g., serving on resident council, performing odd jobs)
21. Opportunities to set and achieve goals
22. Opportunities to reflect on past accomplishments and contributions

Pleasure and Fun

23. Opportunities to do activities that are fun or pleasurable

Self-Acceptance

24. PCH provides opportunities to foster self-acceptance of personal strengths and weaknesses

Appendix C

Discussion Guide for Phase One Focus Group

Instructions (read aloud): Thank-you for agreeing to participate in this focus group.

Before we begin, I would like to draw your attention to something you read in the information and consent form about confidentiality. I ask that you don't reveal the names of group participants or the content of our discussion with individuals outside this group. This will help everyone feel comfortable sharing information in an open and honest fashion.

Here is a list of psychological and social needs that I think are critical for the well-being of nursing home residents. Please take a few minutes to read through the list.

1. Would you add any needs to this list?
2. Would you exclude any needs from this list?
3. Does this list reflect the psychosocial needs of residents with dementia?

Appendix D

Information and Consent Form for Phase Two and Three Participants

UNIVERSITY
OF MANITOBA**Information and Consent Form**

Study Name: Psychosocial needs of nursing home residents: Perspectives of Family Members

Principal Investigator: Julie Erickson, M.A., PhD Candidate, Psychology, University of Manitoba, (xxx)-xxx-xxxx, umeric27@myumanitoba.ca

Research Supervisors: Dr. Corey Mackenzie, Associate Professor, Psychology, University of Manitoba, (xxx) xxx-xxxx, corey.mackenzie@umanitoba.ca; Dr. Malcolm Doupe, Assistant Professor, Community Health Sciences, University of Manitoba, (xxx) xxx-xxxx, malcolm_doupe@cpe.umanitoba.ca.

This consent form, a copy of which you may have your records and reference at this time, 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, you should feel free to contact us. Please take the time to read this carefully and to understand any accompanying information.

Who am I? I am Julie Erickson, a PhD student in Clinical Psychology conducting my thesis research under the supervision of Dr. Corey Mackenzie and Dr. Malcolm Doupe at the University of Manitoba. I am not affiliated with any nursing home in Manitoba in any way.

What am I doing? I am interested the perspectives of family members on what nursing home residents need for their psychological and social well-being. I am asking family members of nursing home residents (both with and without dementia) to complete three online questionnaires that evaluate the importance of different psychological and social needs.

What does participation involve? Participating involves completing three online questionnaires within the span of three months. Each questionnaire should take 20 to 30 minutes to complete. On the first questionnaire you will be asked to provide information about yourself such as your age, gender, overall health, and your relationship to a nursing home resident (e.g., son, daughter, spouse). You will also be asked questions regarding whether your family member who resides in a nursing home has dementia. You will then be given a list of psychological and social needs and asked a series of questions regarding the importance of each need to your family member. The second and third questionnaires

are similar to the first, in that you'll be given a list of psychosocial needs relevant to nursing home residents and asked a series of questions about their importance. You will be sent an email prompt and a link to all three questionnaires. After receiving the email prompt you will have two weeks to complete each questionnaire.

Participation is completely voluntary. Should you choose to withdraw from the study at any point, you may do so without penalty. You will receive a \$15 gift card to McNally Robinson Bookstore for participating, regardless of whether you complete the study in its entirety or not.

What are the risks? Reflecting on psychological and social well-being of your family member who resides in a nursing home could bring up difficult feelings. I do not expect this distress to be long-lasting. If you continue to feel distressed following the focus group, please feel free to consult the list of resources provided at the end of the survey.

What are the benefits? Your responses will help further develop a list of psychological and social needs so that it is most helpful to nursing home residents and their care providers. All participants will receive a \$15 gift card to McNally Robinson Bookstore.

Privacy and Confidentiality: I will do my very best to ensure that your questionnaire responses and contact information remain confidential. All of your questionnaire responses are only accessible by me through a password-protected online account. I will only collect your contact information for the purposes of prompting you to complete the questionnaire and in the event you would like a summary of my findings. This information will also be kept on a password-protected computer within a locked office in the Duff Roblin Building at the University of Manitoba. Once the study is complete, I will destroy the questionnaire data and participant contact information. I estimate that this will be by October, 2015. I am bound by the Vulnerable Persons Act to report any knowledge or suspicion of abuse or neglect of a vulnerable person.

What will I do with the results? Once all the data are collected and analyzed for this project, I plan to share this information with the research community through seminars, conferences, presentations, and journal articles. When presenting the results of this research, I will in no way focus on individual participants' responses and will instead present the findings in summary form. If you would like a copy of the results, please let me know verbally. I will use the contact information you provided to send you a summary of my findings by June 2016.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way. This research has been approved by the Psychology/Sociology Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at xxx-xxxx.

Your signature below indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time or refrain from answering any questions you prefer to omit, without prejudice or consequence. If you wish to withdraw, simply let me know at any time. If you do choose to withdraw from this study, I will destroy any data that you have provided and not include it in the analysis. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Signature: _____

Date: _____

Appendix E

Recruitment Flyer for Phase Three Family Members of Residents without Dementia



UNIVERSITY
OF MANITOBA

INVITATION TO PARTICIPATE IN RESEARCH

My name is **Julie Erickson** and I am a **PhD Candidate in Clinical Psychology at the University of Manitoba**. I am not affiliated with Deer Lodge. My dissertation research is examining which psychological and social needs are most important to personal care home residents.

I am currently recruiting **family members of Deer Lodge residents who do NOT have dementia to complete a three-part, online survey over the next three months about which psychological and social needs are most important for residents**. Each survey will take approximately 20 minutes to complete. You will be emailed a website link to complete each survey.

Your responses will give helpful information on what personal care home residents need for their psychological and social well-being. Participants will receive a \$15 gift certificate to McNally Robinson Books for their time.

If you would like more information about the research study or would like to participate, please contact me at umeric27@myumanitoba.ca OR (xxx)-xxx-xxxx.

This research has been approved by the University of Manitoba Research Ethics Board.

Appendix F

Phase Two and Three Family Member Questionnaire

Name: _____

Phone number: _____

Email address: _____

How do you prefer to be contacted: _____

1. What is your age?

- a. Under 40
- b. 40 to 54
- c. 55 to 69
- d. 70 to 84
- e. 85 +

2. What is your gender?

- a. Male
- b. Female

3. Compared to others your age, how would you describe your physical health?

- a. Excellent
- b. Good
- c. Fair
- d. Poor

4. How would you rate your current levels of stress?

- a. None
- b. Mild
- c. Moderate
- d. High

5. What is your relationship to the nursing home resident you are responding in relation to?

- a. Parent, parent in-law, or step-parent
- b. Uncle or aunt
- c. Spouse or common-law partner
- d. Sibling

- e. Other: _____
- 6. On average, how often do you visit this resident?**
- a. Less than once a month
 - b. Once a month
 - c. Twice a month
 - d. Once a week
 - e. Daily or nearly every day
- 7. On average, what is the duration of each visit?**
- a. Less than one hour
 - b. 1-3 hours
 - c. 3-5 hours
 - d. 5+ hours
- 8. What is the age of the nursing home resident?**
- a. Under 60
 - b. 60-69
 - c. 70-79
 - d. 80-89
 - e. 90+
- 9. What is the gender of the nursing home resident?**
- a. Male
 - b. Female
- 10. What is the marital status of nursing home resident?**
- a. Married or common-law
 - b. Widowed
 - c. Separated or divorced
 - d. Single
- 11. How would you describe the nursing home resident's physical health?**
- a. Excellent
 - b. Good
 - c. Fair
 - d. Poor

Appendix G
Dementia Severity Rating Scale³

Date:

Person completing form:

Relationship to resident:

In each section, circle the number that most closely applied to the patient. Please circle only one number per section.

MEMORY

0 – Normal

1 – Occasional “benign” forgetfulness of no consequence

2 – Mild consistent forgetfulness with partial recollection of events

3 – Moderate memory loss, more marked for recent events and severe enough to interfere with everyday activities.

4 – Severe memory loss; only well-learned material retained with newly learned material rapidly lost.

5 – Usually unable to remember basic facts such as the day of the week, month and/or year, when last meal was eaten, or the name of the next meal.

6 – Unable to determine due to speech and language difficulty and/or ability to follow instructions

7 – Makes no attempt to communicate and is no longer aware of surroundings.

ORIENTATION

0 – Normal

1 – Some difficulty with time relationships, but not severe enough to interfere with everyday activities.

2 – Frequently disoriented in time and sometimes disoriented to new places.

3 – Almost always disoriented in time and usually disoriented to place.

4 – Unable to answer questions related to time of day or name of present location.

5 – Is unaware of respondent and makes no attempt to respond

JUDGEMENT

0 – Normal

1 – Only doubtful impairment in problem-solving ability.

2 – Moderate difficulty in handling complex problems but social judgement usually maintained.

3 – Severe impairment in handling problems, social judgement usually impaired.

4 – Unable to exercise judgement in either problem solving or social situations.

SOCIAL INTERACTIONS/COMMUNITY AFFAIRS

0 – No alteration in ability to participate in community affairs

1 – Only mild impairment of no practical consequence but clearly different from previous years. Still able to work (if applicable) but performance not up to previous standards.

³ Scale included with permission by Dr. D. Ewbank

2 – Unable to function independently in community activities, although still able to participate to some extent and to casual inspection, may appear normal. Unable to hold a job, or if still working, requires constant supervision.

3 – No pretense of independent function outside home. Unable to hold a job but still participates in home activities with friends. Casual acquaintances are aware of a problem.

4 – No longer participates in any meaningful way in home-based social activities involving people other than the primary caregiver.

HOME ACTIVITIES/RESPONSIBILITIES

0 – Normal

1 – Some impairment in activities such as money management and house maintenance, but no effect on the ability to shop, cook or clean. Still watched TV and reads newspaper with interest and understanding.

2 – Unable to perform activities related to money management or complex household tasks (e.g., maintenance). Some difficulty with shopping, cooking, and/or cleaning.

Losing interest in the newspaper and TV.

3 – No longer able to shop, cook, or clean without considerable help and supervision. No longer able to read the newspaper or watch TV with understanding.

4 – No longer engages in any home-based activities.

PERSONAL CARE

0 – Normal

1 – Needs occasional prompting but washes and dresses independently

2 – Requires assistance with dressing, hygiene, and personal upkeep.

3 – Totally dependent for help. Does not initiate personal care activities.

SPEECH/LANGUAGE

0 – Normal

1 – Occasional difficulty with word finding but able to carry on conversations.

2 – Unable to think of some words, may occasionally make inappropriate word substitutions

3 – No longer spontaneously initiates conversation but can usually answer questions using sentences.

4 – Answers questions but responses are often unintelligible or inappropriate. Able to follow simple instructions.

5 – Speech usually unintelligible or irrelevant. Unable to answer questions or follow verbal instructions.

6 – No response. Vegetative.

RECOGNITION

0 – Normal.

1 – Occasionally fails to recognize more distant acquaintances or casual friends.

2 – Always recognizes family and close friends but usually not more distant acquaintances

3 – Alert, occasionally fails to recognize family and/or close friends

4 – Only occasionally recognizes spouse or caregiver

5 – No recognition or awareness of the presence of others

FEEDING

0 – Normal

1 – May require help cutting food and/or have limitations as to the type of food but otherwise, able to eat independently

2 – Generally able to eat independently but may require some assistance

3 – Needs to be fed. May have difficulty swallowin or requires feeding tube.

INCONTINENCE

0 – Normal

1 – Rare incontinence. Bladder incontinence (generally less than one accident per month)

2 – Occasional bladder incontinence (an avverage of two or more times per month)

3 – Frequent bladder inconsistent despite assistance (more than once per week)

4 – Total incontinence

MOBILITY/WALKING

0 – Normal

1 – May occasionally have some difficulty driving or taking public transportation but fully independent for walking without supervision.

2 – Able to walk outside wihtout supervision for short distances but unable to drive or take public transportation

3 – Able to walk within the home without supervision but cannot go outside unaccompanied

4 – Requires supervision within the home, but able to walk without assistance (may use cane or walker).

5 – Generally confined to a bed or chair. May be able to walk a few steps with help.

6 – Essentially bedridden. Unable to sit or stand.

Appendix H

Phase Two First Delphi Survey

Psychosocial needs are the minimum requirements for mental health and well-being. Please read each need listed within each section and circle how important you think the need is, what impact the need has on the resident’s experience in a personal care home, and if you choose, provide comments.

Section One: Choice and Control

	How important would you say this need is for the resident’s mental health?	What impact does this have on the resident’s experience of living in a personal care home (PCH)?
	1 = Essential 2 = Important but not Essential 3 = Unessential 4 = Don’t know or undecided	1 = Large impact 2 = Moderate impact 3 = Neutral 4 = Minimal impact 5 = No impact
Control over when personal care is performed (e.g., eating, bathing, dressing)	1 2 3 4	1 2 3 4 5
Choice to accept or decline help from others	1 2 3 4	1 2 3 4 5
Control over which social, recreational, and religious activities are pursued and when	1 2 3 4	1 2 3 4 5
Access to activities within the PCH	1 2 3 4	1 2 3 4 5
Access to activities outside the PCH	1 2 3 4	1 2 3 4 5
Opportunities to be involved in decision-making about care	1 2 3 4	1 2 3 4 5

Control over room arrangement, inclusion and placement of personal belongings	1 2 3 4	1 2 3 4 5
Please provide comments to help us understand your ratings:		

Section Two: Personal Effectiveness

	How important would you say this need is for the resident’s mental health?	What impact does this have on the resident’s experience of living in a personal care home (PCH)?
	1 = Essential 2 = Important but not Essential 3 = Unessential 4 = Don’t know or undecided	1 = Large impact 2 = Moderate impact 3 = Neutral 4 = Minimal impact 5 = No impact
Doing personal care activities (e.g., dressing, feeding) that are appropriate for one’s capabilities	1 2 3 4	1 2 3 4 5
Access to devices (e.g., walker) that increase independence	1 2 3 4	1 2 3 4 5
Opportunities to talk with staff about care	1 2 3 4	1 2 3 4 5
Perceiving that staff are responsive to feedback or requests	1 2 3 4	1 2 3 4 5
Please provide comments to help us understand your ratings:		

Section Three: Social Connection

	How important would you say this need is for the resident’s mental health?	What impact does this have on the resident’s experience of living in a personal care home (PCH)?
	1 = Essential 2 = Important but not Essential 3 = Unessential 4 = Don’t know or undecided	1 = Large impact 2 = Moderate impact 3 = Neutral 4 = Minimal impact 5 = No impact
Opportunities to maintain relationships with friends and family outside the PCH	1 2 3 4	1 2 3 4 5
Opportunities to create new relationships within the PCH	1 2 3 4	1 2 3 4 5
Access to activities that create a sense of community within the PCH	1 2 3 4	1 2 3 4 5
Warm and caring exchanges with care staff	1 2 3 4	1 2 3 4 5
Touch and physical affection	1 2 3 4	1 2 3 4 5
Opportunities for sexual intimacy and sexual expression	1 2 3 4	1 2 3 4 5
Please provide comments to help us understand your ratings:		

Section Four: Purpose and Meaning

	How important would you say this need is for the resident’s mental health?	What impact does this have on the resident’s experience of living in a personal care home (PCH)?

	1 = Essential 2 = Important but not Essential 3 = Unessential 4 = Don't know or undecided	1 = Large impact 2 = Moderate impact 3 = Neutral 4 = Minimal impact 5 = No impact
Opportunities to express religious, cultural, and ethnic identity	1 2 3 4	1 2 3 4 5
Opportunities to pass along knowledge and experiences to younger people	1 2 3 4	1 2 3 4 5
Contributing to the PCH (e.g., serving on resident council, performing odd jobs)	1 2 3 4	1 2 3 4 5
Opportunities to set and achieve goals	1 2 3 4	1 2 3 4 5
Opportunities to reflect on past accomplishments and contributions	1 2 3 4	1 2 3 4 5
Opportunities to learn new skills	1 2 3 4	1 2 3 4 5
Please provide comments to help us understand your ratings:		

Section Five: Pleasure and Fun

	How important would you say this need is for the resident's mental health?	What impact does this have on the resident's experience of living in a personal care home?
	1 = Essential 2 = Important but not Essential 3 = Unessential 4 = Don't know or undecided	1 = Large impact 2 = Moderate impact 3 = Neutral 4 = Minimal impact 5 = No impact

Opportunities to do activities that are fun or pleasurable	1 2 3 4	1 2 3 4 5
Please provide comments to help us understand your ratings:		

Section Six: Self-Acceptance

	How important would you say this need is for the resident’s mental health?	What impact does this have on the resident’s experience of living in a personal care home (PCH)?
	1 = Essential 2 = Important but not Essential 3 = Unessential 4 = Don’t know or undecided	1 = Large impact 2 = Moderate impact 3 = Neutral 4 = Minimal impact 5 = No impact
PCH encourages acceptance of personal strengths and weaknesses	1 2 3 4	1 2 3 4 5
Please provide comments to help us understand your ratings:		

Appendix I

Phase Four Information and Consent Form for Staff

UNIVERSITY
OF MANITOBA**Information and Consent Form**

Study Name: Psychosocial needs of nursing home residents: Perspectives of Family Members

Principal Investigator: Julie Erickson, M.A., PhD Candidate, Psychology, University of Manitoba, (xxx)-xxx-xxxx, umeric27@myumanitoba.ca

Research Supervisors: Dr. Corey Mackenzie, Associate Professor, Psychology, University of Manitoba, (xxx) xxx-xxxx, corey.mackenzie@umanitoba.ca; Dr. Malcolm Doupe, Assistant Professor, Community Health Sciences, University of Manitoba, (xxx) xxx-xxxx, malcolm_doupe@cpe.umanitoba.ca.

This consent form, a copy of which you may have in your records and reference at this time, 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, you should feel free to contact us. Please take the time to read this carefully and to understand any accompanying information.

Who am I? I am Julie Erickson, a PhD student in Clinical Psychology conducting my thesis research under the supervision of Dr. Corey Mackenzie and Dr. Malcolm Doupe at the University of Manitoba. I am not affiliated with any nursing home in Manitoba in any way.

What am I doing? I am interested in the perspectives of nursing home staff on what is important for nursing home resident psychological and social well-being. I am conducting a focus group with 6 to 10 nursing home staff at a nursing home facility.

What does participation involve? Participating involves attending one hour-long, in-person focus group held at the nursing home in which you work. In the focus group, I will give you a list of items that residents and their family members think are the psychological and social needs of nursing home residents. I would like you to read the list and tell me how you assist residents in meeting these needs and what challenges you encounter in helping residents meet these needs. I will audio record your responses. Participation is completely voluntary. Should you choose to withdraw from the study at any point, you may do so without penalty. You will still be given a \$15 gift card for participating.

What are the risks? Some participants may experience distress when talking about psychological and social well-being in nursing homes. I do not expect this distress to be long lasting. I will do my best to ensure that the focus group is constructive, positive and friendly in nature. I will also tell participants that the content of the focus group is expected to remain confidential. If you are distressed following the focus group, please let me know and I will direct you to helpful resources.

What are the benefits? Your feedback will provide valuable information to nursing homes on how they can help residents better their psychological and social well-being. All participants will be given a \$15 gift certificate for McNally Robinson Books.

Privacy and Confidentiality: I will do my best to ensure that your data will be anonymous. However, if for some reason you reveal identifying information during the focus group, I will make sure all of the answers you provide will be kept confidential. Keep in mind that because you are participating in a group with other staff, I cannot guarantee your confidentiality. I will audio record the focus groups and the audio files will be kept in a locked cabinet within a locked office within the Duff Roblin building at the University of Manitoba. Only my research supervisors and I will have access to the audio files. I will only collect your contact information for the purposes of contacting you in the event you would like a summary of my findings. Your contact information will not be linked to the responses you provide in the focus group. This information will also be kept in a locked cabinet within a locked office within the Duff Roblin building at the University of Manitoba. Once the study is complete, I will destroy the audio files and any participant contact information. I estimate that this will be by October, 2015. I am bound by the Vulnerable Persons Act to report any knowledge or suspicion of abuse or neglect of a vulnerable person.

What will I do with the results? Once all the data are collected and analyzed for this project, I plan to share this information with the research community through seminars, conferences, presentations, and journal articles. When presenting the results of this research, I will in no way focus on individual participants' responses and will instead present the findings in summary form. If you would like a copy of the results, please let me know verbally. I will use the contact information you provided to send you a summary of my findings by June, 2016.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way. This research has been approved by the Psychology/Sociology Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at xxx-xxxx.

Your signature below indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time or refrain from answering any questions you prefer to

omit, without prejudice or consequence. If you wish to withdraw, simply let me know at any time. If you do choose to withdraw from this study, I will destroy any data that you have provided and not include it in the analysis. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Signature: _____

Date: _____

Appendix J

Discussion Guide for Phase Four Focus Group

Instructions (read aloud): Thank-you for agreeing to participate in this focus group.

Before we begin, I would like to draw your attention to something you read in the information and consent form about confidentiality. I ask that you don't reveal the names of group participants or the content of our discussion with individuals outside this group. This will help make everyone feel comfortable sharing information in an open and honest fashion.

1. After reading this list of psychological and social needs (see next page), what are some ways that you meet these needs?
2. Are there any needs that are particularly difficult to meet?
3. What could nursing homes be doing differently to help you meet your psychological and social needs?
4. Are there any needs that you would add or change in this list?

Appendix K

Results

Round 1 of Delphi Survey with No-Dementia Group

Table 11 displays the results of the first round of the Delphi survey with the no-dementia group, with ratings of the importance of each psychosocial need for resident mental health. With a sample size of $n = 5$ it is difficult to conclude that particular items exhibited a large degree of agreement from respondents but several items were rated by 80 to 100% of respondents as being “essential” for resident mental health, which came from the choice and control, personal effectiveness and social connection categories: choice to accept or decline help from others (choice and control); control over room arrangement, inclusion and placement of personal belongings (choice and control); access to devices (e.g., walker) that increase independence (personal effectiveness); opportunities to talk with staff about care (personal effectiveness), doing personal care activities (e.g., dressing, feeding) that are appropriate for one’s capabilities (personal effectiveness); perceiving that staff are responsive to feedback or requests (personal effectiveness); and warm and caring exchanges with care staff (social connection). Items that had more variable ratings of importance on this dimension were primarily from the purpose and meaning category and included: opportunities to express religious, cultural, or ethnic identity; contributing to the PCH (e.g., serving on resident council, performing odd jobs); and opportunities to learn new skills.

Table 11

Round 1 of Delphi Survey with the No-Dementia Group: Rated Importance of Psychosocial Needs for Resident Well-Being (n=5)

	Essential	Important but not essential	Unessential	Don't Know	Consensus Y/N
CHOICE AND CONTROL					
Control over room arrangement, inclusion and placement of personal belongings	4 (80.0%)	1 (20.0%)	0 (0%)	0 (0%)	Y
Choice to accept or decline help from others	4 (80.0%)	1 (20.0%)	0 (0%)	0 (0%)	Y
Access to activities within the PCH	3 (60.0%)	1 (20.0%)	1 (20.0%)	0 (0%)	Y
Opportunities to be involved in decision-making about care	3 (60.0%)	2 (40.0%)	0 (0%)	0 (0%)	Y
Control over which social, recreational, and religious activities are pursued and when	2 (40.0%)	3 (60.0%)	0 (0%)	0 (0%)	Y
Access to activities outside the PCH	1 (20.0%)	3 (60.0%)	1 (20.0%)	0 (0%)	Y
Control over when personal care is performed (e.g., eating, bathing, dressing)	1 (20.0%)	4 (80.0%)	0 (0%)	0 (0%)	Y
PERSONAL EFFECTIVENESS					
Doing personal care activities (e.g., dressing, feeding) that are appropriate for one's capabilities	5 (100%)	0 (0%)	0 (0%)	0 (0%)	Y
Perceiving that staff are responsive to feedback or requests	5 (100%)	0 (0%)	0 (0%)	0 (0%)	Y
Access to devices (e.g., walker) that increase independence	4 (80.0%)	0 (0%)	1 (20.0%)	0 (0%)	Y

Opportunities to talk with staff about care	4 (80.0%)	1 (20.0%)	0 (0%)	0 (0%)	Y
SOCIAL CONNECTION					
Warm and caring exchanges with care staff	4 (80.0%)	1 (20.0%)	0 (0%)	0 (0%)	Y
Opportunities to maintain relationships with friends and family outside the PCH	4 (80.0%)	1 (20.0%)	0 (0%)	0 (0%)	Y
Opportunities to create new relationships within the PCH	3 (60.0%)	1 (20.0%)	1 (20.0%)	0 (0%)	Y
Access to activities that create a sense of community within the PCH	3 (60.0%)	1 (20.0%)	1 (20.0%)	0 (0%)	Y
Touch and physical affection	2 (50.0%)	2 (40.0%)	0 (0%)	0 (0%)	Y
Opportunities for sexual intimacy or sexual expression	1 (20.0%)	0 (0%)	4 (80.0%)	0 (0%)	N
PURPOSE AND MEANING					
Opportunities to reflect on past accomplishments and contributions	3 (60%)	2 (40.0%)	0 (0%)	0 (0%)	Y
Opportunities to set and achieve goals	2 (40.0%)	3 (60.0%)	0 (0%)	0 (0%)	Y
Opportunities to express religious, cultural, or ethnic identity	1 (20.0%)	2 (40.0%)	2 (40.0%)	0 (0%)	N
Opportunities to pass along knowledge and experiences to younger people	1 (20.0%)	4 (80.0%)	0 (0%)	0 (0%)	Y
Opportunities to learn new skills	1 (20.0%)	2 (40.0%)	2 (40.0%)	0 (0%)	N
Contributing to the PCH (e.g., serving on resident council, performing odd jobs)	0 (0%)	2 (40.0%)	2 (40.0%)	1 (20.0%)	N
PLEASURE AND FUN					
Opportunities to do activities that are fun or pleasurable	2 (40.0%)	2 (40.0%)	1 (20.0%)	0 (0%)	Y

SELF-ACCEPTANCE

PCH encourages acceptance of personal strengths and weaknesses	4 (80.0%)	1 (20.0%)	0 (0%)	0 (0%)	Y
--	-----------	-----------	--------	--------	---

Table 12 summarizes how the no-dementia group rated the impact of each psychosocial need on residents' experience within the NH for the first iteration. These ratings were highly consistent with how important each need was rated for resident mental health. A number of items were rated by 80 to 100% of respondents as having a "large impact" on residents' nursing home experience and they came from the choice and control, personal effectiveness and social connection categories: control over room arrangement, inclusion and placement of personal belongings (choice and control); doing personal care activities (e.g., dressing, feeding) that are appropriate for one's capabilities (personal effectiveness); access to devices (e.g., walker) that increase independence (personal effectiveness); opportunities to talk with staff about care (personal effectiveness); perceiving that staff are responsive to feedback or requests (personal effectiveness), opportunities to maintain relationships with friends and family outside the PCH (social connection); and warm and caring exchanges with care staff (social connection). Items that had more variable ratings of importance on this dimension included: access to activities within the PCH (choice and control); access to activities outside the PCH (choice and control); access to activities that create a sense of community within the PCH (social connection); opportunities for sexual intimacy or sexual expression (social connection); opportunities to express religious, cultural, or ethnic identity (purpose and meaning); contributing to the PCH (e.g., serving on resident council, performing odd jobs) (purpose and meaning), opportunities to set and achieve goals (purpose and meaning); and opportunities to learn new skills (purpose and meaning).

Items that did not reach consensus were access to activities within the PCH, access to activities outside the PCH; access to activities that create a sense of community within the PCH; opportunities for sexual intimacy or sexual expression; opportunities to express religious, cultural, or ethnic identity; contributing to the PCH (e.g., serving on resident council, performing odd jobs); opportunities to set and achieve goals; and opportunities to learn new skills.

Table 12

Round 1 of the Delphi Survey with the No-Dementia Group: Rated Impact of Psychosocial Needs for Residents' Stay in Nursing Home (n=5)

	Large Impact	Moderate Impact	Neutral	Minimal Impact	No Impact	Consensus Y/N
CHOICE AND CONTROL						
Control over room arrangement, inclusion, and placement of personal belongings	4 (80.0%)	1 (20.0%)	0 (0%)	0 (0%)	0 (0%)	Y
Choice to accept or decline help from others	3 (60.0%)	1 (20.0%)	0 (0%)	1 (20.0%)	0 (0%)	Y
Opportunities to be involved in decision-making about care	3 (60.0%)	2 (40.0%)	0 (0%)	0 (0%)	0 (0%)	Y
Control over when personal care is performed (e.g., eating, bathing, and dressing)	2 (40.0%)	3 (60.0%)	0 (0%)	0 (0%)	0 (0%)	Y
Control over which social, recreational, or religious activities are pursued and when	2 (40.0%)	2 (40.0%)	1 (20.0%)	0 (0%)	0 (0%)	Y
Access to activities within the PCH	2 (40.0%)	1 (20.0%)	1 (20.0%)	0 (0%)	1 (20.0%)	N
Access to activities outside the PCH	1 (20.0%)	2 (20.0%)	1 (20.0%)	0 (0%)	1 (20.0%)	N
PERSONAL EFFECTIVENESS						
Opportunities to talk with staff about care	5 (100.0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	Y
Perceiving that staff are responsive to feedback or requests	5 (100.0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	Y
Doing personal care activities (e.g., dressing, feeding) that are appropriate for one's capabilities	4 (80.0%)	1 (20.0%)	0 (0%)	0 (0%)	0 (0%)	Y
Access to devices (e.g., walker) that increase independence	4 (80.0%)	1 (20.0%)	0 (0%)	0 (0%)	0 (0%)	Y
SOCIAL CONNECTION						
Warm and caring exchanges with care staff	4 (80.0%)	1 (20.0%)	0 (0%)	0 (0%)	0 (0%)	Y

Opportunities to maintain relationships with friends and family outside the PCH	4 (80.0%)	1 (20.0%)	0 (0%)	0 (0%)	0 (0%)	Y
Touch and physical affection	2 (50.0%)	2 (50.0%)	0 (0%)	0 (0%)	0 (0%)	Y
Opportunities to create new relationships within the PCH	2 (40.0%)	2 (40.0%)	0 (0%)	1 (20.0%)	0 (0%)	Y
Access to activities that create a sense of community within the PCH	1 (20.0%)	1 (20.0%)	1 (20.0%)	1 (20.0%)	1 (20.0%)	N
Opportunities for sexual intimacy or sexual expression	1 (20.0%)	0 (0%)	1 (20.0%)	0 (0%)	3 (60.0%)	N
PURPOSE AND MEANING						
Opportunities to reflect on past accomplishments and contributions	1 (25.0%)	3 (75.0%)	0 (0%)	0 (0%)	0 (0%)	Y
Opportunities to express religious, cultural, or ethnic identity	1 (20.0%)	2 (40.0%)	1 (20.0%)	0 (0%)	1 (20.0%)	N
Opportunities to pass along knowledge and experiences to younger people	1 (20.0%)	3 (60.0%)	1 (20.0%)	0 (0%)	0 (0%)	Y
Contributing to the PCH (e.g., serving on resident council, performing odd jobs)	1 (20.0%)	1 (20.0%)	1 (20.0%)	0 (0%)	2 (40.0%)	N
Opportunities to set and achieve goals	1 (20.0%)	1 (20.0%)	1 (20.0%)	1 (20.0%)	0 (0%)	N
Opportunities to learn new skills	0 (0%)	1 (25.0%)	1 (25.0%)	1 (25.0%)	1 (25.0%)	N
PLEASURE AND FUN						
Opportunities to do activities that are fun or pleasurable	1 (25.0%)	2 (50.0%)	0 (0%)	0 (0%)	1 (25.0%)	Y
SELF-ACCEPTANCE						
PCH encourages acceptance of personal strengths and weaknesses	2 (40.0%)	2 (40.0%)	1 (20.0%)	0 (0%)	0 (0%)	Y

Round 2 of Delphi Survey with No-Dementia Group

Table 13 displays the results of the second Delphi iteration for the no-dementia group's rated importance of each psychosocial need for resident mental health. Two notable items were rated by 100% of respondents as being "essential" for mental health, both of which were from the personal effectiveness category: doing personal care activities (e.g., dressing, feeding) that are appropriate for one's capabilities and perceiving that staff are responsive to feedback or requests. The no-dementia group was more variable in their ratings of the importance of opportunities to pass along knowledge and experiences to younger people (purpose and meaning), and pleasure and fun. Items are ordered within each category based on the percentage agreement. Items in boldface were rated by at least 70% of respondents as being "essential."

Table 13

Round 2 of the Delphi Survey with the No-Dementia Group: Rated Importance of Psychosocial Needs for Resident Well-Being (n=4)

	Essential	Important but not essential	Unessential	Don't Know	Consensus Y/N
CHOICE AND CONTROL					
Control over room arrangement, inclusion and placement of personal belongings	3 (75.0%)	1 (25.0%)	0 (0%)	0 (0%)	Y
Choice to accept or decline help from others	3 (75.0%)	1 (25.0%)	0 (0%)	0 (0%)	Y
Control over which social, recreational, or religious activities are pursued and when	2 (50.0%)	1 (25.0%)	1 (25.0%)	0 (0%)	Y
Opportunities to be involved in decision-making about care	2 (50.0%)	2 (50.0%)	0 (0%)	0 (0%)	Y
Control over when personal care is performed (e.g., eating, bathing, dressing)	1 (25.0%)	3 (75.0%)	0 (0%)	0 (0%)	Y
Access to activities outside the PCH					
Access to activities within the PCH					
PERSONAL EFFECTIVENESS					
Doing personal care activities (e.g., dressing, feeding) that are appropriate for one's capabilities	4 (100.0%)	0 (0%)	0 (0%)	0 (0%)	Y
Perceiving that staff are responsive to feedback or requests	4 (100.0%)	0 (0%)	0 (0%)	0 (0%)	Y
Access to devices (e.g., walker) that increase independence	3 (75.0%)	0 (0%)	0 (0%)	1 (25.0%)	Y
Opportunities to talk with staff	3 (75.0%)	1 (25.0%)	0 (0%)	0 (0%)	Y

about care

SOCIAL CONNECTION

Opportunities to maintain relationships with friends and family outside the PCH **3 (75.0%)** 1 (25.0%) 0 (0%) 0 (0%) Y

Warm and caring exchanges with care staff **3 (75.0%)** 1 (25.0%) 0 (0%) 0 (0%) Y

Touch and physical affection **3 (75.0%)** 0 (0%) 0 (0%) 1 (25.0%) Y

Opportunities to create new relationships within the PCH 2 (50.0%) 1 (25.0%) 1 (25.0%) 0 (0%) Y

Access to activities that create a sense of community within the PCH
 Opportunities for sexual intimacy or sexual expression

PURPOSE AND MEANING

Opportunities to pass along knowledge and experiences to younger people 2 (50.0%) 0 (0%) 2 (50.0%) 0 (0%) N

Opportunities to reflect on past accomplishments and contributions 0 (0%) 4 (100.0%) 0 (0%) 0 (0%) Y

Opportunities to set and achieve goals
 Contributing to the PCH (e.g., serving on resident council, performing odd jobs)

Opportunities to express religious, cultural, and ethnic identity

Opportunities to learn new skills

PLEASURE AND FUN

Opportunities to do activities that are fun or pleasurable	1 (25.0%)	1 (25.0%)	1 (25.0%)	1 (25.0%)	N
SELF-ACCEPTANCE					
PCH encourages acceptance of personal strengths and weaknesses	2 (50.0%)	1 (25.0%)	1 (25.0%)	0 (0%)	Y

Note. Shaded items were excluded following the first Delphi iteration. Items in boldface were rated by at least 70% of participants as “essential”

Table 14 displays how the no-dementia group rated the impact of each psychosocial need on the experience of living in a NH. The following items were rated by 100% of respondents as having a “large impact” on residents’ experience in a NH: control over when personal care is performed (e.g., eating, bathing, and dressing) (choice and control); choice to accept or decline help from others (choice and control); and warm and caring exchanges with staff (social connection). The no-dementia group was more variable in their ratings of the importance of opportunities to create new relationships within the PCH (social connection); opportunities to pass along knowledge and experiences to younger people (purpose and meaning); opportunities to reflect on past accomplishments and contributions (purpose and meaning); and pleasure and fun.

The pleasure and fun category and opportunities to pass along knowledge and experiences to younger people (purpose and meaning) item did not achieve sufficient consensus and were therefore eliminated following this round. Due to concerns over a dwindling sample that was small to begin with, a third Delphi iteration was not conducted. A summary of the final list of psychosocial needs for this sample is displayed in Appendix P.

Table 14

Round 2 of the Delphi Survey with the No-Dementia Group: Rated Impact of Psychosocial Needs for Residents' Stay in Nursing Home (n=3)

	Large Impact	Moderate Impact	Neutral	Minimal Impact	No Impact	Consensus Y/N
CHOICE AND CONTROL						
Control over when personal care is performed (e.g., eating, bathing, dressing)	3 (100%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	Y
Choice to accept or decline help from others	3 (100%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	Y
Control over what social, recreational, and religious activities are pursued and when	1 (33.3%)	2 (66.7%)	0 (0%)	0 (0%)	0 (0%)	Y
Opportunities to be involved in decision-making about care	1 (33.3%)	2 (66.7%)	0 (0%)	0 (0%)	0 (0%)	Y
Control over room arrangement, inclusion and placement of personal belongings	1 (33.3%)	2 (66.7%)	0 (0%)	0 (0%)	0 (0%)	Y
Access to activities outside the PCH						
Access to activities within the PCH						
PERSONAL EFFECTIVENESS						
Doing personal care activities (e.g., dressing, feeding) that are appropriate for one's capabilities	2 (66.7%)	1 (33.3%)	0 (0%)	0 (0%)	0 (0%)	Y
Access to devices (e.g., walker) that increase independence	2 (66.7%)	1 (33.3%)	0 (0%)	0 (0%)	0 (0%)	Y
Perceiving that staff are responsive to feedback or requests	2 (66.7%)	1 (33.3%)	0 (0%)	0 (0%)	0 (0%)	Y
Opportunities to talk with staff about care	1 (33.3%)	2 (66.7%)	0 (0%)	0 (0%)	0 (0%)	Y

SOCIAL CONNECTION

Warm and caring exchanges with care staff	3 (100%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	Y
Opportunities to maintain relationships with friends and family outside the PCH	1 (33.3%)	2 (66.7%)	0 (0%)	0 (0%)	0 (0%)	Y
Touch and physical affection	1 (33.3%)	2 (66.7%)	0 (0%)	0 (0%)	0 (0%)	Y
Opportunities to create new relationships within the PCH	0 (0%)	2 (66.7%)	0 (0%)	0 (0%)	1 (33.3%)	N
Access to activities that create a sense of community within the PCH						
Opportunities for sexual intimacy or sexual expression						

PURPOSE AND MEANING

Opportunities to pass along knowledge and experiences to younger people	1 (33.3%)	1 (33.3%)	0 (0%)	0 (0%)	1 (33.3%)	N
Opportunities to reflect on past accomplishments and contributions	1 (33.3%)	1 (33.3%)	0 (0%)	0 (0%)	1 (33.3%)	N
Opportunities to set and achieve goals						
Contributing to the PCH (e.g., serving on resident council, performing odd jobs)						
Opportunities to express religious, cultural, or ethnic identity						
Opportunities to learn new skills						

PLEASURE AND FUN

Opportunities to do activities that are fun or pleasurable	1 (33.3%)	1 (33.3%)	0 (0%)	0 (0%)	1 (33.3%)	N
--	-----------	-----------	--------	--------	-----------	---

SELF-ACCEPTANCE

PCH encourages acceptance of personal strengths and weaknesses	2 (66.7%)	1 (33.3%)	0 (0%)	0 (0%)	0 (0%)	Y
--	-----------	-----------	--------	--------	--------	---

Note. Shaded items were excluded following the first Delphi iteration. Items in boldface were rated by at least 70% of participants as having “large impact”

Round 3 Questionnaire with No-Dementia Group

A final questionnaire provided respondents the opportunity to comment on their responses, the final list, and add any items. In contrast with the sample of family members of residents with dementia, this sample provided relatively few comments. One family member contextualized their responses by mentioning that his or her family member has impaired vision and hearing and there are unique challenges associated with this:

My father can only interact outside of his room with assistance from another person. He is blind and deaf. Hearing aids help for hearing but are not 100% effective. He can use the phone, listen to literature (...) TV and radio. He cannot always control the TV and radio as to station or channel. He uses a wheelchair but cannot move alone outside his room. He walks with a walker but only with assistance and guidance.

Another participant expressed frustration over the fact that the items were, in his opinion, too broad and all equally as important to residents such that he felt unable to rank the items:

I only completed part of the questionnaire because I found your questions to be too encompassing, i.e., they are motherhood and apple pie statements. Yes, my father would like as much control of his life as possible but meal times are fixed. Yes, being able to use a walker would be great but he is blind! I'm not sure what the questions hope to determine but I could have answered essential to them all.

Appendix L

Final Psychosocial Needs List (Non-Dementia Sample)

>70% of respondents rated each item as “essential” or “important but not essential” for resident mental health or as having a “large” or “moderate” impact on residents’ stay in a nursing home

Items in boldface were rated by >70% of participants as being rated as ‘Essential’

CHOICE AND CONTROL

- **Control over room arrangement, inclusion and placement of personal belongings**
- **Choice to accept or decline help from others**
- Control over what social, recreational, and religious activities are pursued and when
- Opportunities to be involved in decision making about one’s care
- Control over when personal care is performed (e.g., eating, bathing, and dressing)

PERSONAL EFFECTIVENESS

- **Doing personal care activities (e.g., dressing, feeding) that are appropriate for one’s capabilities**
- **Perceiving that staff are responsive to feedback or requests**
- **Access to devices (e.g., walker) that increase independence**
- **Opportunities to talk with staff about care**

SOCIAL CONNECTION

- **Opportunities to maintain relationships with friends and family outside the PCH**
- **Warm and caring exchanges with care staff**
- **Touch and physical affection**
- Opportunities to create new relationships inside the PCH

PURPOSE AND MEANING

- Opportunities to reflect on past accomplishments and contributions

SELF-ACCEPTANCE

- PCH encourages acceptance of personal strengths and weaknesses