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THE CORRELATION OF SIZE OF CORE NETWORK AND FREQUENCY OF CONTACTS WITH AGITATION AND POSITIVE AFFECT IN ELDERLY WITH DEMENTIA

by

Amal Al-Ghassani

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ABSTRACT

THE CORRELATION OF SIZE OF CORE NETWORK AND FREQUENCY OF CONTACTS WITH AGITATION AND POSITIVE AFFECT IN ELDERLY WITH DEMENTIA

by

Amal Al-Ghassani

The University of Wisconsin-Milwaukee, 2017
Under the Supervision of Dr. Christine Kovach

In the country of Oman, care needs of older adults are primarily provided by family members in the home. The study was guided by socioemotional selectivity theory, the environmental vulnerability hypothesis, and the need-driven dementia-compromised behavior theories. The central premise was that the size of the person's activities of daily living (ADL) core network and frequency of contact with the ADL core network would predict agitation and affect. A smaller core network with a higher frequency of contact may be better at identifying and treating the person's unmet needs. A secondary premise was that the emotional closeness of the core network to the care recipient would predict the density of the ADL and instrumental activities of daily living (IADL) care provided. The purpose was to examine the associations between size and frequency of contact with the care providing core network and agitation and affect of PWD.

The convenience sample of 98 PWD living in their homes was obtained from the Al Batinah South region in Oman. Participants' were mostly female (63.3%) with a mean age of 80 years. Seventy-seven participants were classified with severe dementia and 21 had mild to moderate levels of dementia. Variables were measured through report from caregivers and the PWD using valid and reliable instruments.

Unlike what was hypothesized, results did not show a significant association between size of and frequency of contact with ADL and IADL core networks and agitation and affect. Also, results did not show a significant association between closeness of IADL and ADL caregivers or the size of core networks to the density of IADL and ADL care provided. Caregivers continued to care and have the same frequency of contact throughout the progress of dementia. Findings are inconsistent with Western studies showing older adults prefer a smaller, closer social network that provides them with meaningful interactions. Differences in findings may be explained by the strong Omani cultural value to personally care for older parents. Understanding these relationships is critically important to designing interventions in Oman for home health care.

DEDICATION

To

My Parents

My Children
Nasser, Shahed, Razan & Sam Al-Badaai

My husband

&

My Brothers and Sisters

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CHAPTER 1

This chapter begins by introducing the factors associated with agitation and affect in persons with dementia (PWDs). The prevalence of agitation and the consequences of agitation in older adults with dementia (PWDs) are provided. The significance of the rising numbers of older adults with dementia, both internationally and in the Arab countries, is highlighted. Next, this chapter introduces the concept of social networks and their potential significance to the well being of older adults with dementia. The purpose of the proposed dissertation study is given, and the conceptual framework is introduced. Models guiding this study will be discussed in detail in Chapter 2. Because this study will be conducted in Oman, the health care system and older adult care in Oman are discussed.

Introduction to the Problem

Agitated behavior among persons with dementia (PWDs) is associated with multiple negative consequences. The need-driven dementia-compromised behavior (NDB) model indicates that agitation not only leads to negative outcomes but that agitation may be a consequence of an unmet need (Algase, 1996). The NDB model suggests that agitation and negative outcomes associated with it can be tempered by understanding the needs of PWDs. Although agitation can be found in all age groups, it is most commonly seen among older adults with dementia (Kong, 2005).

To accomplish the aims of this study, multiple theories and models are used. The agitation in people suffering from dementia is multidimensional. Different theoretical approaches will be used to guide the understanding of different aspects of the phenomena. Several theoretical models explain this agitated behavior, including the needs-driven dementia-compromised behavior (NDB) model, the socioemotional selectivity theory (SST), and the progressively lowered stress threshold (PLST) model. Each explains a different philosophical background that recognizes various aspects of the problem, which are explained in more detail below and in the next chapter. The models explain why the size of the person's activities of daily living (ADL) core network and frequency of contact with the ADL core network may predict agitation and affect. A lower-density core network with a higher frequency of contact may be better at identifying and treating the person's unmet needs. A secondary premise is that the emotional closeness of members of the core network to the care recipient will predict the density of the ADL and instrumental activities of daily living (IADL) care provided. Understanding these relationships is critically important to designing interventions in Oman for home health care and assigning community health nurses.

In the literature, there is common agreement regarding the negative consequences of agitation in older adults. Some authors have described agitation as an eruption of aggressive behavior (Dewing, 2010), while other researchers have described negative consequences for clients' family caregivers and the health care system (Cohen-Mansfield & Billig, 1986; Kong, 2005).

Client

Some of the commonly identified consequences of agitation for clients with dementia include negative affect, aggressive behavior, physiological changes such as weight loss and dehydration, institutionalization, falls, changes in activities of daily living (ADL), social life changes, and isolation (Bankole et al., 2012; Cohen-Mansfield & Billig, 1986; Dewing, 2010; Kong, 2005), as well as receiving sedative drugs (Howard et al., 2001).

Family Caregivers

Taking care of older adult patients with dementia and agitation is challenging and stressful, and it can affect one’s overall quality of life. According to the stress model, caregivers of older adults commonly experience stress, depression, frustration, decreased quality of life, family dysfunction, and burnout (Bankole et al., 2012; Boult & Wieland, 2010; Cohen-Mansfield & Billig 1986; Kong, 2005).

Health Care System

Cohen-Mansfield and Billig (1986) identified increased costs and high patient/staff ratios to be the most common consequences of agitation relevant to the health care system. Bankole et al. (2012) discussed how failing to have the correct approach to manage agitation might eventually lead to poor ranking of an institution, staff burnout, and high turnover or decreased staff retention.

While multiple psychotropic drugs have been used to suppress agitated behavior in older adults, these drugs have serious side-effect profiles (Johnson et al., 2011). Psychotropic drugs are considered inappropriate for use as chemical restraints to treat agitation because of these drugs’ failure to address the patients’ unmet needs (Howard et al., 2001). Multiple nondrug therapies have been tested to treat agitation, but their efficacy has been limited (Johnson et al., 2011). Among older adult patients with dementia (PWDs), the size and frequency of their contact with their core network (the more intimate part of their social network) may affect the identification and treatment of their unmet needs and the amount of stress they experience. Several geriatric theories suggest that older adults may prefer a smaller core network with a higher frequency of contact, which may stress the person less and be a better way of identifying and treating the person’s unmet needs (Burgio et al., 2000).

Prevalence and Significance

Dementia is a devastating neurological disorder that has become a major public health concern around the world. The agitated behaviors of PWDs are associated with multiple negative consequences. Some authors have described agitation consequences as an eruption of aggressive behavior (Dewing, 2010), Other researchers have categorized them as consequences for patients, such as distress, frustration, and institutionalization; consequences for caregivers, such as discomfort, frustration, and difficulties in family function (Dewing, 2010), and other consequences, including high costs and high patient/staff ratios (Cohen-Mansfield & Billig 1986; Kong, 2005).

The burden of dementia will take the forefront among aging issues as the geriatric population increases worldwide. It is estimated that more than 50% of older adults living in U.S. long-term care facilities have dementia (Dewing, 2010), and 86% of those in the United States who are diagnosed with dementia demonstrate aggression (Taft, 1989). Dementia is also expected to become a major public health issue in Arab countries; among nursing home residents, 60% of those in Lebanon and 14% of those in Qatar were found to have dementia (Benamer, 2014). In Oman, the older adult population represents 5.2% of the total population, and this figure is expected to reach 10% by 2025 and 20% by 2050 (Bhattacharjee, 2013). This dissertation study will be conducted in Oman, where data on PWDs is not reported or not existing. Thus, data will be extracted from the United States, the United Kingdom, and other Arab countries showcase the prevalence of dementia in this age group.

Introduction to Social Networks

According to the AARP (2010), in the United States, regardless of cultural differences and preferences, if given the choice, up to 90% of older adults prefer to stay in their own home for as long as possible. Nikmat, Hawthorne, and Al-Mashoor (2015) found that older adults with dementia living at home experienced higher quality of life, performed more ADLs, and socialized more often when compared with those living in long-term institutions. Burgio et al. (2000) emphasized the social environments of older adult residents with dementia. Episodes of agitation decreased significantly when older adult residents received verbal and touch interactions from their caregivers. Also, the study indicated that PWDs living in environments scoring high on privacy personalization—like their own homes—tended to have lower scores on the Psychotic Problem Scale. Moreover, the degree of social withdrawal among these same residents decreased as personalized care increased from immediate caregivers. There might be other unspecified factors not included in this study that correlate with outcomes of older PWDs, such as frequency of social contacts and use of psychotic medications.

Older PWDs who live in homes with extended families may receive support and care from a few or many people. The term “ADL core network” describes individuals who provide help with hygiene, moving, and eating tasks. ADLs involve caring for and moving the body, and include walking, bathing, dressing, toileting, brushing teeth, and eating (Lawton et al., 1998). The ADL core network is generally smaller than a larger social network that provides instrumental caregiving (i.e., IADL; Srivastava, 2005). IADLs help people to live independently and include shopping, cooking, bill paying, and managing medications. The core network of people is mainly responsible for the patient’s wellbeing. The ADL core network usually consists of two to ten people from a larger network. Also, the caregiver’s relationship to and frequency of contact with the PWDs may vary (Zunzunegui et al., 2005). People in the ADL and IADL core network may vary in their emotional closeness to the care recipient. This closeness may be associated with the amount of IADL and ADL assistance provided. Although no studies have been done in Oman examining and exploring similar factors, the family network is critical in caring for older adults in Oman.

Decision-Making

Decision-making is defined as the thought process that someone goes through to select the most logical choice from different available options (Oxford Dictionaries, 2014). One example of decision-making relates to health care choices. Older adults participate in decisions concerning their care, such as diagnostic procedures and interventions, including end-of-life care. Persons with dementia, however, might have some limitations to making appropriate decisions, depending on the severity of the dementia. Persons with mild to moderate dementia have the capacity to make some but not all decisions (Moorhouse & Mallery, 2012). Some progressing symptoms of dementia may reduce the PWD's mental competence to make decisions, such as memory loss and difficulty communicating with self and others (Smebye, Kirkevold, & Engedal, 2012). In this case, there is a need for a substitute decision-maker or caregiver who is close and knows the PWD's current status (Smebye et al., 2012).

Who Is the Primary Decision Maker in Oman?

In Oman, the family is acknowledged as the main source of informal care. Care for older parents becomes automatically a shared responsibility among children, as a moral code of conduct to honor and respect elders. Those immediate family members who are also the primary caregivers also play the role of decision makers for older parents with dementia (Hafiz, 2015). This informal family caregiving reduces pressure on the Omani government to care for its older residents (Sibai & Yamout, 2012).

Gap in Knowledge

There is a need for more research on the influence of multiple environmental and social context variables on home care outcomes for PWDs. Some studies have indicated a relationship between social network interaction and outcomes such as agitation, but none of these studies have specifically examined the correlations among outcomes among PWDs, the size of their core network, and the frequency of contact (Burgio et al., 2000; Giles et al., 2004; Srivastava, 2005). Specialized research is recommended in this area. Such studies could also produce evidence of an association between poor outcomes and the size of a person's core network or the frequency of contact with care providers in their core network.

Carpentier et al. (2008) encouraged professionals and informal caregivers to consider concepts related to service integration. Poor coordination between family caregivers and institutions negatively affects the quality of care provided to PWDs (Abbott et al., 2015). Considering the factors that contribute to home care outcomes, it is essential to identify ways to create effective long-term linkages among family members as caregivers, social systems, and formal care institutions (Carpentier et al., 2008).

No evidence in the literature shows the contribution of the ADL and the IADL core networks to agitation or affect in older adults with dementia. It is not known whether associations exist between agitation symptoms and the size of the person's core network or the frequency of contact with care providers in the core network. This dissertation explored and examined factors influencing agitation among older PWDs. Accordingly, the purpose of this study was to examine the association between size and frequency of contact of the ADL core network with the agitation and affect of PWDs. The primary hypothesis is that, controlling for the severity of dementia and comorbid problems, the size and frequency of contact with the ADL core network will predict the agitation and affect of people with dementia.

Purpose of the Proposed Study

This study was based on the premise that the size and frequency of contact of the ADL core network of PWDs contribute to agitation and affect in PWDs. The size of the ADL core network and frequency of contact with this smaller group was expected to have the most influence on agitation and affect. However, this study also examined the relative contributions of the IADL core network to the outcomes. The IADL core network is defined as caregivers or carers who help an older adult with at least one activity of daily living, as defined by Katz (1963) and Lawton et al. (1998). Instrumental help may include activities such as managing medication, planning their finances, cooking, cleaning, and shopping. This IADL core network can include either unpaid or paid caregivers, or both. Paid caregivers may include categories such as nurses, social workers, and counselors (Drentea, 2007). The ADL core network differs in providing assistance with activities such as dressing, personal hygiene, eating, and transferring.

Accordingly, the purpose of this study was to examine the association between the size and frequency of contact of the ADL core network with the agitation and affect of PWDs. In addition, there were two secondary hypotheses. First, we examined whether the size and frequency of contact with the IADL core network are associated with the agitation and affect of PWDs. We also examined whether the emotional closeness of the ADL and IADL caregivers predicts the density of the ADL and IADL networks and the amount of care they provide.

Hypotheses and Research Questions

The following research questions were examined in this study:

1) What is the level of agitation among older adult PWDs in Oman?
2) With what frequency does older adult PWDs have contact with their ADL and IADL core networks?
3) Are there differences in the size of ADL and IADL core network between those with early and later-stage dementia?

The hypotheses that this study will address are the following:

Main hypothesis. Controlling for the severity of dementia and comorbid problems, the size (IV) and frequency (IV) of contact with the ADL core network will predict the agitation (DV) and affect (DV) of PWDs.

Secondary hypotheses.

1. Controlling for severity of dementia and comorbid problems, the size (IV) and frequency (IV) of contact with the IADL core network (IV) will predict agitation (DV) and affect (DV) of PWDs.
2. Controlling for the severity of dementia and comorbid problems, the closeness of IADL and ADL caregivers (IV) as well as the size of caregiver core networks will predict the density of IADL and ADL care provided (DV).

Contributions to Nursing

This dissertation study could be used as a foundational study for future intervention research. The next plan is to develop a study to describe the factors/needs associated with agitated behavior and affect in older PWDs. Following this study, the plan is to formulate a study to examine the association between the factors/needs found in Study 1, such as the size and frequency of contact with the ADL core network and the agitation and affect of people with dementia.

The results will be used to design the next study, which will examine the effectiveness of smaller ADL and/or IADL core networks with higher frequency of contact in reducing the level of agitation among PWDs and meeting the person’s needs. Ultimately, the results of both studies could yield recommendations to be used by the Ministry of Health in Oman to enhance the effectiveness of planning for nursing care of older PWDs and their agitation. This research program will provide nurses with evidence-based knowledge regarding agitation to help them intervene effectively. The results of the planned studies above will direct the development of an intervention designed to decrease agitation.

Introduction to Concepts and Theory

The agitation in people suffering from dementia is multidimensional. Different theoretical approaches were used to guide the understanding of different aspects of the phenomena. Several theoretical models explain this agitated behavior, including the needs-driven dementia-compromised behavior (NDB) model, the socioemotional selectivity theory (SST), and the progressively lowered stress threshold (PLST) model. Each explains a different philosophical background that recognizes various aspects of the problem. These models explain how the size of an older PWD's ADL or IADL core network and the PWD's frequency of contact with that network may predict outcomes such as agitation and affect. A smaller ADL or IADL core network with a higher frequency of contact may be better at identifying and treating unmet needs. Understanding these relationships is critical to designing interventions in Oman for home health care and assigning community health nurses to care for PWDs.

These models will be discussed in detail in Chapter 2; however, a brief description of the theories, as well as conceptual definitions, is included here:

Theory Description

Needs-driven dementia-compromised behavior (NDB). Algase et al. developed the NDB theory in 1993. It has changed the existing view of dementia as being disruptive to a perspective of understanding to effectively and appropriately respond to the needs of older PWDs.

This theory changed the existing view of agitation from simply being disruptive to a meaningful behavior that is often an expression of unmet needs. Hence, understanding changes in behavior, such as increased agitation and changes in affect, can help caregivers to identify the unmet needs of older adults with dementia and effectively manage their care. According to the NDB model, people with dementia have many unmet needs associated with increased agitated behavior and poor outcomes, such as depression and more negative affect.

Agitation and negative affect are seen as attempts to communicate physical or psychic distress when unmet needs arise (Algase et al., 1996). Behavior viewed in this way is seen as a symptom of unmet needs. For example, a person who feels overwhelmed by stress from too many caregivers might start calling out. A caregiver who has limited frequency of contact with a PWD may be less likely to anticipate and understand the PWD’s needs.

It is unknown whether there is an association between poor outcomes and the size of a person’s ADL or IADL core network or the person’s frequency of contact with care providers in the ADL core network. However, the NDB model explains that agitation not only leads to negative outcomes, but may also be a consequence of an unmet need (Algase, 1996). It suggests that understanding and meeting the needs of PWDs can temper agitation and the negative outcomes associated with it.

Socioemotional selectivity theory (SST). The SST explains that when people grow older and see their future as limited, their goals in social relationships shift from the long term to more short-term and immediate benefits (Conway, Magai, Jones, Fiori, & Gillespie, 2013).

Laura Carstensen developed the SST in 1991. According to this theory, a meaningful emotional state becomes the priority, which is more easily obtained with close social partners than from social partners who are not close. People tend to be more selective and narrow their social networks as they grow older, while maintaining relationships with those who satisfy them emotionally (Kalat & Shiota, 2007).

As a person grows to old age, they will begin to focus on emotional aspects and become more focused on spending quality time with loved ones in smaller social networks (Carstensen, 1991). Moreover, the SST also asserts that as people age, they tend to prefer a smaller social network that provides meaningful interactions (Mark, 2012; Penningroth & Scott, 2012). This explains why they become more satisfied with a smaller network as they narrow their social interactions.

For example, interactions with larger social networks may divert their focus from quality time with loved ones. An older person might feel overwhelmed by stress from too many caregivers. Either of these can lead to agitation. A caregiver who has greater frequency of contact with a PWD may be able to provide more meaningful interaction and will be more likely to minimize agitation episodes.

The progressively lowered stress threshold (PLST) model. Hall and Buckwalter (1987) developed the PLST model to guide formal and informal caregivers who were struggling to provide care that met the needs of PWDs (Smith, Gerdner, Hall, & Buckwalter, 2004). The PLST model, also known as the environmental vulnerability model, explains that PWDs have a decreased threshold for tolerating external stressors. If an interaction between a PWD and caregiver/core network stresses the PWD, then the general process of meeting needs will be highly stressful and associated with poor outcomes, such as agitation and negative affect. A smaller core network with a higher frequency of contact will be better at identifying and treating needs. A smaller core network is also less likely to exceed a PWD’s stress threshold. A larger network outside of the core network will be less likely to be able to identify and meet needs, and more likely to increase agitation and negative affect.

Operational Definitions

Dementia. Dementia is a set of symptoms that may be caused by a number of illnesses, characterized by decline in multiple areas of function such as progressive loss of cognitive function, memory, reasoning, communication skills, and ability to carry out daily activities (Brooke et al., 2014). The mini-mental status exam (MMSE) measures the severity of dementia. This tool is easy to administer and widely used, with scores ranging from 0–30. Higher scores indicate greater cognitive ability (Ellis, 2006).

Agitation. Responses to either internal or external stimuli or both, as described by older adults' behavioral or verbal disruptiveness, inappropriateness, and aggressiveness, vary in degree depending on the older adults individualized thresholds (Kolanowsk et al., 2011). The operational definition of agitation comes from a rating scale of 29 items, completed by structured interview using the Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, Marx, & Rosenthal, 1989). According to Cohen-Mansfield (1989), the CMAI saw its most common use in assessing agitation among older adults. Factor analysis revealed three factors of agitation, including aggressive behavior, physically nonaggressive behavior, and verbally agitated behavior. This study uses the same conceptual and operational definitions as the scale.

IADL and ADL core network. Immediate caregivers provide more physically intimate care, and are mainly responsible for the older adult's physical wellbeing. The PWD himself or herself identifies a core network and its size by self-report, following a consent procedure. The core usually consists of two to 10 people from a larger network (Srivastava, 2005).

IADL core network. The IADL core network is defined as caregivers or carers who help an older adult with at least one activity of daily living, as defined by Katz (1963) and Lawton et al. (1998). Instrumental help may include activities such as managing medication, planning their finances, cooking, cleaning, and shopping. This IADL core network can include either unpaid or paid caregivers, or both. Paid caregivers may include categories such as nurses, social workers, and counselors (Drentea, 2007).

ADL core network. The ADL core network differs from the IADL core network by providing assistance with activities such as dressing, personal hygiene, eating, and transferring. A checklist of caregiver activities will be used to identify and separate the IADL and ADL core networks. This checklist includes seven instrumental activities and five non-instrumental activities.

Closeness. Emotional closeness for older adults is described as one of the most important components of relationships (Antonucci, 2001). It is defined as the closeness the caregiver feels for the PWD and a relationship with which the individual could not live without (Kahn & Antonucci, 1980; Mejía & Hooker, 2015). Mejía and Hooker (2015) discussed that closeness is individually defined and is carefully maintained throughout living processes. As explained by Carstensen, Isaacowitz, and Charles (1999), as people grow into old age, their perception of future time decrease; therefore, their social priorities become directed toward emotional closeness. Mejía and Hooker (2015) found that the closest people to an older person had a greater influence on the older person's emotional well-being than those who were not identified as close. Closeness can be measured by using the Social Convoy Questionnaire (SCQ; Lang, 1996). Kahn and Antonucci developed the SCQ in 1980 using a circle diagram to identify the closeness with PWDs according to the circles provided. The circles are categorized as inner ("Feel very close, so close that it would be hard to imagine life without)"; middle ("Don't feel quite so close as those in the inner circle but are still very close)"; and outer ("Feel less close but who are still important").

Frequency of contact. Is the number or periods of regularly occurring close association or communication with social and caregiver partners closer to the PWDs (Oxford Dictionaries, 2014). The client's or caregiver's frequency of contact was operationally defined by days in a typical 30-day month through self-report once, following consent procedures.

Affect. Humans have a range of affects, from negative (−) to positive (+), and express negative affects when experiencing problems like pain, physical discomfort, fatigue, fever, or sleep disruption, which can be due to adverse side effects of medication, impaired vision or hearing, and brain injuries. They experience more positive affects when others address these problems. Positive and negative affect are defined operationally for caregivers to observe and document using the Positive and Negative Affect Schedule (PANAS). The PANAS is a brief scale comprising 20 items, with 10 items measuring positive affect. Each item is rated on a 5-point Likert Scale, ranging from 1 = *very slightly or not at all* to 5 = *extremely*, to measure the extent to which the affect has been experienced in a specified time frame (Crawford & Henry, 2004).

Stress thresholds. Stress threshold refers to the amount of stress an individual can tolerate before anxiety symptoms or reactions appear. Narvaez (2012) noted that people who suffer from prolonged periods of stress often have a lower stress threshold than individuals who live a stable, happy life.

Comorbid problems. Caregivers will measure comorbid problems operationally using the Cumulative Illness Rating Scale (CIRS-G) to reflect common problems among older adults (Miller et al., 1992). The CIRS-G scoring system measures morbidity or the chronic medical illness burden while considering the severity of chronic diseases in 14 items representing individual body systems. The severity ratings are: 0 (*no problem affecting that system*), 1 (*current mild problem or past significant problem*), 2 (*moderate disability or morbidity and/or requires first-line therapy*), 3 (*severe problem and/or constant and significant disability and/or hard to control chronic problems*), and 4 (*extremely severe problem and/or immediate treatment required and/or organ failure and/or severe functional impairment*). The modified CIRS now appears in a manual of guidelines (Miller et al., 1992).

Background on Proposed Study Setting and Sample

Proposed Study

This study was conducted with community-dwelling older adults with dementia in Oman receiving home care by visiting nurses, mainly by family caregivers. Oman is the site for the study because older adult individuals with dementia have received little attention in Oman. A research for published studies on agitation and core networks among older PWDs in Oman revealed no information on this population. Also, Oman was chosen for its convenience due to its geographic proximity to me. The study used a descriptive correlational design because it is not feasible to randomly assign older PWDs according to size of their core network and their frequency of contact.

Overview of Oman's Health Care System

The following is an overview of the general health care system and health policies related to organizations and Ministry of Health in the Sultanate of Oman. Since 1970, His Majesty Sultan Qaboos has prioritized the development of health and education in the country. According to the results of a study by the World Health Organization (WHO) that covered 191 countries between 2000 and 2011, the Sultanate of Oman was ranked first in the world for health system efficiency and effective use of available financial resources in health services. Oman is also rated eighth in the world in terms of the comprehensiveness of its health care (WHO, 2011).

Oman has several different types of hospitals, including public, private, and military establishments. Health care services include primary, secondary, and tertiary health care (Ministry of Health [MoH], 2011). The MoH is the main health care provider in the country, and it is the regulatory body for the entire health sector. It is responsible for the provision, coordination, and stewardship of the health sector (MoH, 2011).

Health Care Policies for Home Care in Oman

The MoH is responsible for developing policies and programs for the health sector and for implementing them, along with the private sector and other related ministries such as the Ministry of Social Development (MoSD). The government of Oman funds the health care system. It has paid special attention to the health sector and its development. About 5.1% of the government's budget is spent on the health sector (Ministry of National Economy, 2010). The public health service provides free health care for Omani citizens and for foreigners working in the government sector. Private health care services are mostly paid out of pocket or by private insurance and are not covered by the government. Not everyone can afford to purchase private health insurance. Therefore, for the most part, private companies offer it to employees and their families. Health insurance in Oman is established for foreigners, for the use of private hospitals, and for some types of road traffic accidents, which fall under the automobile insurance system (Ministry of National Economy, 2010).

The Constitution of the Sultanate of Oman includes a regulation related to health care and old age in Oman. Article 12 states:

> The State guarantees assistance for the citizen and his family on cases of emergency, sickness, incapacity, and old age in accordance with the social security system. It also encourages society to share the burdens of dealing with the effects of public disasters and

> calamities. . . . The State cares for public health and for the prevention and treatment of diseases and epidemics. It endeavors to provide health care for every citizen and to encourage the establishment of private hospitals, clinics, and other medical institutions under State supervision and in accordance with the rules laid down by law (*The White Book—The Basic Law of the Sultanate of Oman*, 1996).

All health strategic plans, according to the direction of His Majesty, Sultan Qaboos bin Said, should provide equity in health distribution among the people of all regions of Oman. This means an equal distribution of health institutions, workers, and services based on population density and according to international standards to provide safe and holistic care for the public.

Another law related to health care and old age in Oman is the Social Insurance Law, which was initiated by Royal Decree No. 72/91 and came into force on July 1, 1992; according to this law, Omani employees are entitled to receive social service benefits based on their most recent aggregate basic salary at the end of their employment service (*The White Book—The Basic Law of the Sultanate of Oman*, 1996). By subscribing to the Social Insurance System, "the employee will be insured against old age, disability, and death, followed by various stages, including insurance against work injuries and occupational diseases, in addition to providing insurance coverage to the Omani nationals who are working abroad and alike" (The White Book-The Basic Law of the Sultanate of Oman, 1996, Article 12). More recent planned reforms of health care in the public and private sectors include incorporating elements of geriatrics, social care, and other home-based services as long-term care.

The Older Adult Population in Oman

In Oman, the older adult population (age 60 and up) represents almost 5.2% of the total population (MoH, 2013). This number is expected to reach 10% by 2025 and 20.9% by 2050

(United Nations, 2012). It is also worth noting that the life expectancy at birth in Oman has increased; it averaged 61.9 years from 1980 to 1985, but it rose to 74.9 years between 2005 and 2010, and is projected to reach 83.8 years from 2045 to 2050 (United Nations, 2012).

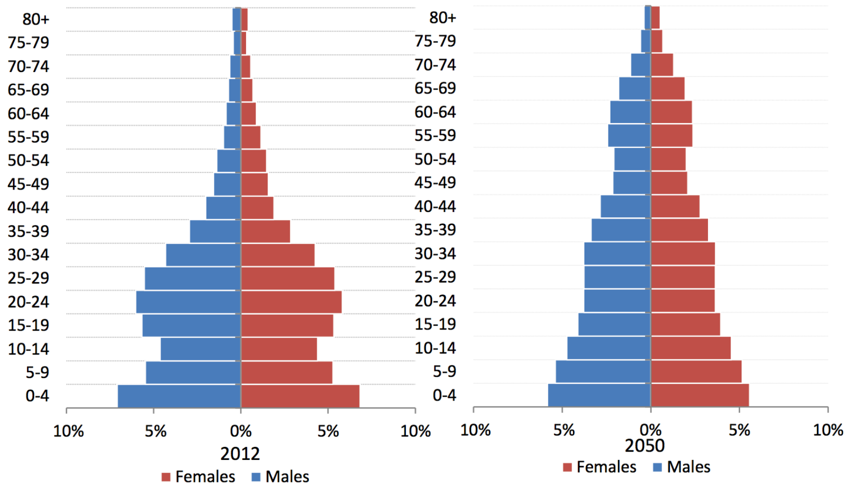


Figure 1. Age structure of the Omani population in 2013 and the expected structure in 2050.

Dementia in Oman

Unfortunately, no statistics represent the actual number of dementia cases across Oman at this time. However, data from the United States, United Kingdom, and other Arab countries reflect the prevalence of dementia among this age group. At present, there is no dementia registry in Oman, and many PWDs are not diagnosed. This can be explained by the lack of awareness among the public, as many assume that cognitive impairment is age related (Al-Zadjali et al., 2014).

Care for Older Adults in Oman

Description of Omani families. DeFrain and Asay (2012) described Omani society as "traditional, consisting of characteristics that constitute an Islamic society such as tribal identity and loyalty, male dominance, a strict code of conduct and social support" (p. 46). An Omani family consists of, on average, six to 15 members. Most Omani families have three or four generations living under one roof; the father is powerful and the main provider in the family. However, husbands and wives share control of mutual concerns and most everyday matters. Nowadays, it is common in Oman for both parents to work.

Older adults' care in Oman. Occasionally, the average Omani household will include extended family members such as grandparents. The average Omani household will include extended family members like grandparents. In Omani society, like many others, care for the elderly has traditionally fallen to siblings and children. However, changes in family lifestyle and growing urbanization have forced changes in this type of care among some families. Oman has a unique tradition stemming from its Islamic roots and culture. Elderly are regarded as very valuable and are well respected in their families. It is very rare to see youth dropping their frail parents at hospitals or social centers

Home care in Oman. Home care is one of the services that community health nurses provide for Omani citizens, including older people with disabilities and those who require care management and monitoring (Al-Zadjali et al., 2014). Recently, in addition to home care, an older adult care program has been integrated into community health services in Oman. This program was initiated to provide comprehensive assessments and screenings for older persons, with the aim to promote optimal health among older adults by enhancing the strengths of patients and their families to maximize patients' independence (Al-Zadjali et al., 2014).

Chapter Summary

This chapter introduced the problem of agitation among community-dwelling PWDs and the failure of current drug and non-drug treatments. Three theoretical models were described that inform the study's central premise. The results of this study will be used to design the next study, which will examine the effectiveness of smaller core networks with higher frequency of contact in reducing levels of agitation in PWDs and meeting their needs. Ultimately, the results of both studies could yield recommendations to be used by the Ministry of Health in Oman to enhance the effectiveness of planning for nursing care of older adults with dementia and agitation. This research program will provide nurses with evidence-based knowledge regarding agitation for them to intervene effectively.

CHAPTER 2

Introduction to the Chapter

The purpose of this study was to examine the associations between the size and frequency of ADL and IADL core networks as well as contact frequency with agitation and affect among people with dementia in Oman. The size and frequency of contact of the ADL core network were hypothesized to predict the agitation and affect of PWDs. In addition, it was hypothesized that, controlling for the severity of dementia and comorbid problems, the size of (IV) and frequency (IV) of contact with the IADL core network (IV) will predict the agitation (DV) and affect (DV) of PWDs; and controlling for the severity of dementia and comorbid problems, the closeness of IADL and ADL caregivers (IV) as well as caregiver size will predict the density of the IADL and ADL care provided (DV).

In Chapter 2 of this non-traditional dissertation proposal, two manuscripts are presented: The first manuscript describes the needs-driven dementia-compromised behavior (NDB) model, the socioemotional selectivity theory (SST), and the progressively lowered stress threshold (PLST) model, and defines concepts within these theories to help explain the salience of caregiver networks to outcomes for older adults with dementia. The second manuscript is a systematic literature review that describes and analyzes both quantitative and qualitative studies to identify, discuss, and examine factors associated with care outcomes in older adult patients with dementia. These factors include the environment, caregivers, and social interactions.

Section 2.1-Manuscript One

Size of Core Network: Why Less May Be More for Older Adults with Dementia

Introduction

Dementia is a devastating neurological disorder that has become a major public health concern among aging societies around the world. According to Alzheimer's Disease International (2015), an estimated 44.4 million people have dementia around the world, and the number is rising. This number will increase in the next 15 years to 75.6 million. According to Johnson, Taylor, Watson, and Huei-chuan (2011), there are 700,000 people with dementia in the United Kingdom alone. It was estimated that more than 50% of older adults in the United States living in long-term care facilities have dementia (Dewing, 2010), and 86% of those diagnosed with dementia in the United States demonstrate aggression as a result of agitation (Taft, 1989). The burden of dementia will take the forefront of aging issues as the geriatric population continues to grow worldwide. According to the Administration on Aging (2004), the number of older adults aged 65 and older is expected to reach 71.5 million in the United States by 2030.

According to the AARP's (2010) report, 22.4 million households in the United States today already provide care to a family member over 50. It is estimated that one-third of all people with dementia live on their own (Mirando-Costillo, 2010). In the United States, this means that roughly one in seven Americans with dementia live alone in their communities (Alzheimer's Association, 2015). The number of people with dementia who will live in their home is expected to rise (Alzheimer's Society, 2012).

In the United States, regardless of cultural differences and preferences, if given the choice, up to 90% of older adults prefer to stay in their own home for as long as possible (AARP, 2010). Nikmat, Hawthorne, and Al-Mashoor (2015) found that older adults with dementia living at home experienced higher quality of life, activities of daily living, and socialization when compared with those living in long-term institutions. Burgio et al. (2000) placed greater emphasis on the social environment of older adult residents with dementia. Episodes of agitation were shown to decrease significantly when older adult residents received verbal and touch interactions from their caregivers. Also, the study indicated that persons with dementia (PWDs) living in environments scoring high on privacy personalization—like their own home—tended to have lower scores on the psychotic problem scale. Moreover, the degree of social withdrawal among these same residents decreased as personalized care increased from immediate caregivers. Other unspecified factors that were not included in this study may be correlated with the outcomes of older adults with dementia, such as frequency of social contacts and use of psychotic medications.

However, older adults with dementia might experience feelings of isolation and neglect at home due to distant separation from their friends and society (Burgio et al., 2000). Maintaining ongoing friendships and social support has been demonstrated to decrease agitation (Kutner, Brown, Stavisky, Clark, & Green, 2000). A study by Cohen-Mansfield et al. (1990) on five older adults with a history of agitated behaviors, such as screaming and disruptive behaviors, showed that those behaviors mostly occurred when the residents were alone. This was also supported by Burgio et al. (2000), who reported that more aggressive behaviors were most common when their subjects were left alone or located more than 3 feet away from significant caregivers.

Although number of studies about the phenomenon of agitation have been published, most of that literature is pharmacologic in nature (Dewing, 2010; Kong, 2008). Pharmacological intervention, such as the use of anticonvulsants, antidepressants, antipsychotics, and beta-blockers, is considered the most common method to manage agitation (Ho, Lai, Jeng, Tang, Sung, & Chen, 2011). This pharmacological intervention might be beneficial in reducing agitation, but it can be more harmful for patients with dementia than for them to remain untreated for their agitation symptoms. These medications often induce drowsiness, which can decrease or prevent patient participation in their care (Zafonte, 1997). A literature review revealed that few studies discuss the social context of agitation.

Older persons with dementia who live in homes with extended families may receive support and care from a few or many people. The term "core network" has been used to describe a social support structure that is more intimate and consists of immediate caregivers who are part of a larger social network (Srivastava, 2005). The core network of people is mainly responsible for the patient's wellbeing. It usually consists of two to four people from a larger network. Also, the caregiver's relationship to and frequency of contact with the PWD may vary (Zunzunegui et al., 2005). Some studies indicated there is a relationship between social *network* interaction and **agitation**, though none of the studies specifically examined the correlations among agitation in PWDs, the size of their core network, and frequency of contact (Burgio et al., 2000; Metcalfe et al., 2004; Srivastava, 2005).

It is unknown whether the size of a person's core network and the frequency of contact with his or her core network affect the person's outcomes. It is critically important to understand the relationships between the size of core network and frequency of contact, as doing so may help to identify and treat the person's unmet needs by studying the effectiveness of smaller core networks with higher frequency of contact in reducing levels of agitation in PWDs. The purpose of this paper is to describe the salience of caregiver network to outcomes for older adults with dementia. Three theories will be introduced, followed by an explanation of the relationship between core networks and outcomes. Empirical evidence that directly relates to core network will also be reviewed.

Theoretical Underpinnings

The needs-driven dementia-compromised behavior (NDB) model, socioemotional selectivity theory (SST), and progressively lowered stress threshold (PLST) model will be used to explain why the size of a core network and frequency of contact with the core network may predict outcomes such as agitation and affect in older people with dementia.

Figure 2 provides a diagram outlining the interface of social context variables to theories and outcomes.

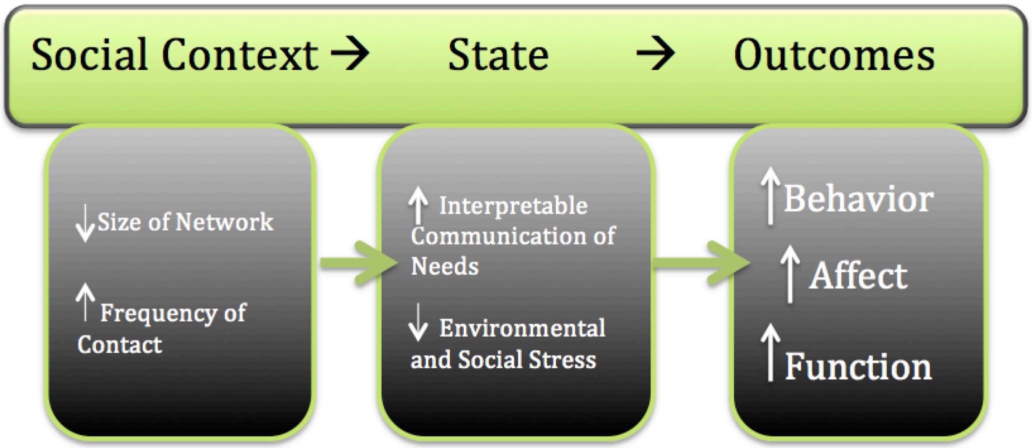


Figure 2. Diagram outlining the interface of social context variables to theories and outcomes.

Needs-Driven Dementia-Compromised Behavior (NDB) Model

The NDB model changed the existing view of agitation from being simply disruptive, in an attempt to understand the needs of older adults with dementia to effectively manage their care. According to it, people with dementia have many unmet needs associated with increased agitated behavior and poor outcomes, such as depression and more negative affect.

People with dementia have impaired communication and may display decreased cognitive insight into their needs and symptoms (Bankole et al., 2012). The model indicates that dementia-related behavior occurs because caregivers cannot comprehend the needs of the PWDs, nor can the PWDs make their needs known.

Agitation and negative affect are seen as attempts to communicate physical or psychic distress when unmet needs arise (Algase et al., 1996). Behavior, viewed in this way, is seen as a symptom of unmet needs. For example, a person who feels overwhelmed by stress from too many caregivers might start calling out. A caregiver who has limited frequency of contact with a PWD may be less likely to anticipate or understand the PWD’s needs.

It is unknown whether poor outcomes are associated with the size of a person’s core network or the person’s frequency of contact with care providers in his or her core network. However, the NDB model explains that agitation not only leads to negative outcomes but may also be a consequence of an unmet need (Algase, 1996). It suggests that understanding and meeting the needs of people with dementia can temper agitation and the negative outcomes associated with it.

Socioemotional Selectivity Theory (SST)

The SST suggests that people become more selective and value more emotional activities as they age (Conway, Magai, Jones, Fiori, & Gillespie, 2013). It also explains that as we age, our focus shifts to the present, away from the future. As people grow to old age, they will begin to focus on emotional aspects and become more focused on spending quality time with loved ones in smaller social networks (Carstensen, 1991). Because older adults place greater value on emotional aspects, they feel more satisfied with individuals who they know and with whom they have a meaningful relationship. Moreover, the SST also asserts that as people age, they tend to prefer a smaller social network that provides them with meaningful interactions (Mark, 2012; Penningroth & Scott, 2012). This explains why PWDs become more satisfied with a smaller network as PWDs narrow their social interactions.

For example, interactions with larger social networks may divert their focus from quality time with loved ones. An older person might feel overwhelmed by stress from too many caregivers. Either of these can lead to agitation. A caregiver who has more frequent contact with a PWD may be able to provide more meaningful interaction and will be more likely to minimize agitation episodes. External groups can create some stress on the cognitive abilities of those with dementia (Zeisel, Silverstein, Hyde, Levkoff, Lawton, & Holmes, 2003) by placing these older adults in a position to receive care from persons other than their immediate core network, which may be overwhelming and can result in increased agitation and poor health, eventually interfering with care delivery. The SST focuses on what is meaningful and important to PWDs, rather than dealing with them as a homogenous group (Hicks, Trent, Davis, & King, 2012).

The Progressively Lowered Stress Threshold (PLST) Model

The PLST model, also known as the environmental vulnerability model, explains that PWDs have a decreased threshold for tolerating external stressors. If an interaction between PWDs and their caregiver/core network stresses the PWDs, then the general process of meeting needs will be highly stressful and associated with poor outcomes, such as agitation and negative affect. A smaller core network with a higher frequency of contact will be better at identifying and treating a PWD's needs. Also, a smaller core network is also less likely to exceed a PWD's stress threshold. A larger network outside of the core network will be less likely to be able to identify and meet needs, and more likely to increase agitation and negative affect.

The following table provides a summary of the interface among concepts, theory, and outcomes:

Table 1

Explanations for the Interface Among Concepts, Theory, and Outcomes

Concept	**Theory**	**Theoretical Mechanism of Action**	**Outcomes**
Decrease caregivers and network density	NDB	Decrease caregiver density→increase recognition→increase understanding of unmet need cues and anticipation needs→needs met	Needs met Decreased agitation Decreased negative affect

Decrease density caregivers and frequency of contact	SST	Decrease caregivers density→ increase quality time with loved ones → decrease PWD stress; and more frequent contact between caregivers and PWDs→ provide more meaningful interaction→ decrease agitation	Increased meaningful activity Decreased agitation Decreased negative affect
Decrease density of caregivers and affect	PLST	Decrease caregiver density→decrease PWD's stress threshold→ decrease agitation	Decrease stress Decrease agitation Decrease negative affect

Very few researchers have discussed the importance of environmental stressors and adaptation to them (Cohen-Mansfield, 1990, 2000; Lawton, 1986). Lawton (1986) emphasized understanding the influence of the social environment, particularly when examining the effects of social networks on older adults with agitation. Stressors such as changes in routine, environment, or caregiver make PWDs anxious and might lead to some agitated behaviors or symptoms. Similarly, visitors and unfamiliar staff can be very overwhelming for PWDs, who have a difficult time adapting (McCloskey, 2004). Giummarra et al. (2004) indicated that a social environment with too many social networks could have adverse effects on wellbeing, which may involve disappointments and conflict. Studies have shown that disturbed social routines are associated with unstable emotional status (Moniz-Cook, Stokes, & Agar, 2003).

Other Theoretical References

I reviewed several models for this proposed area of research, such as the person–environment congruence model, health belief model, behavioral model, and stress and adoption framework. In the next section, I will discuss the person–environment congruence model as an alternative model that was not used as a basis for this research study.

Person–Environment (P-E) Congruence Model

The P-E congruence model stems from Lewin's (1935) theory that presents a relationship between persons and their environment (Kahana, 1982). Kahana (1982) had proposed this model after critics argued that the original P-E fit by Lewin (1951) treats a person as a passive receiver of the environment, rather than as an active and a dynamic agent. This model discusses how well environmental characteristics and individual characteristics fit with each other (Dawis, 1992). A person's behavior is a consequence of environmental fit and the person's needs (Kahana, 1982).

Individual characteristics. Individual characteristics include personality, biological factors, psychological factors, and values.

Environmental characteristics. Environmental characteristics include cultural values, other individual characteristics, role demand, and social environment (Edwards, 2008). The model explains that people move to an environment that suits their needs and preferences. However, the person might exhibit feelings of disappointment, stress, helplessness, and agitation when incongruence occurs (Kahana & Kahana, 1996).

Changing from one environment to another, decreasing or losing cognitive capacity, financial distress, loss of social support, and loss of employment are some factors that may decrease congruence (Dawis, 1992). Unstable environmental factors might clash with stable individual characteristics, leading to stress or discomfort (Dawis, 1992). The interaction between environment and individual is flexible most of time, but becomes stressful with changes or illnesses associated with aging, such as losing physical independence or cognitive competency (Kahana, 1982).

A literature review indicates great use of this model in nursing science and gerontology

(Morgan, Stewart, Darcy, & Werezak, 2004). It has provided extensive details about the environment, personal relationships, and aging process of older adults, but may need further elaboration and research that studies the integration of sociocultural factors with environment–person interactions (Vischer, 2008).

Although the P-E congruence model could be useful to identify a relationship between persons and their environment, my proposed dissertation study focuses on examining the association between the size and frequency of contact with the core network and the agitation and affect of people with dementia. Most studies that have used the P-E congruence model in older adults included a limited sample or cognitively intact older adults who could freely express their needs verbally (Kahana, Lovegreen, Kahana, & Kahana, 2003). This model focuses more on the environment surrounding the person, without looking at the person's internal needs, emotions, or stress threshold, which makes it a poor fit for my area of focus. Although it explains the process by which the environment influences a person and his or her needs, it does not account for personal dimensions such as needs or values (Vischer, 2008). No existing evidence examines this model on cognitively impaired older adults such as PWDs, who are the focus of this study (Washburn & Sands, 2006). On the other hand, the three theories I selected—the SST and the NDB and PLST models—are unique in their relevance to nursing and geriatric PWDs. The work done by using the three theories that I selected for this dissertation study show more integration for possibly identifying a relationship between social networks of PWDs and outcomes such as agitation and affect.

There is a need to further examine the influence of multiple social context variables on outcomes for PWDs as well as whether the size of the person's core network and the person's frequency of contact with healthcare providers in the core network are associated with outcomes for PWDs. This may reduce agitation and improve positive affect. I anticipate that the above three models selected for this dissertation study are a good fit for the study's purposes and therefore for answering its questions.

Conclusion and Recommendation

While multiple psychotropic drugs have been used to suppress agitated behavior, these drugs have serious side effect profiles and are considered to be inappropriately used as chemical restraints in treating agitation because of the drug's failure to address the person's unmet needs (Howard et al., 2001). Multiple non-drug therapies have been tested to treat agitation, but their efficacy has been limited (Johnson et al., 2011). No evidence in the literature shows core network's contribution to agitation or affect in older adults with dementia. There is a need to further examine the influence of multiple social context variables on outcomes for PWD. Understanding whether the size of the person's core network and the person's frequency of contact with healthcare providers in the core network are associated with outcomes for PWDs may reduce agitation and improve positive affect.

Section 2.2-Manuscript Two

Factors Associated With Home Care Outcomes of Older Adult Patients With Dementia Living in the Community

Introduction

Due to the consequences of increasing dementia rates, there is an urgent need to address dementia-related issues in older adults living at home. Managing patients with dementia (PWDs) is a difficult task for caregivers in all cultures. Several factors contribute to this challenge, including a lack of interest in providing care for challenging patients, a lack of trained personnel, and a lack of standardized scales (Halabi & Zafar, 2010).

A PWD loses the ability to interact in dialogue to negotiate and discuss new information, events, and stimuli (Baker, 2012). Caregivers thus become more focused on identifying and meeting the physiological needs of older adults with dementia, including their safety, health, nourishment, and shelter (Baker, 2012). PWDs have many unmet needs associated with increased agitated behavior and poor outcomes, including depression and negative affect. Caregivers do not clearly understand these needs (Algase et al., 1996).

Purpose

Limited studies exist that examines the importance of environmental stressors, particularly adaptation to such stressors (Cohen-Mansfield et al., 1990; Cohen-Mansfield, 2000; Lawton, 1986). Lawton (1986) emphasized that understanding the influence of the social environment is important, particularly when examining the effects of social networks on older adults with agitation. Similarly, new social networks, visitors, and unfamiliar staff members can be very overwhelming for PWDs, who have a difficult time adapting to new environments and can easily end up in a stressful state (McCloskey, 2004). The purpose of this literature review is to describe and analyze both quantitative and qualitative studies from primary sources to identify, discuss, and examine the factors that are associated with older adult PWDs' care outcomes.

Method

The articles were found by searching electronic databases such as MEDLINE (PubMed) and the Cumulative Index of Nursing and Allied Health Literature (CINAHL) using combinations of the search terms *dementia*, *older adults*, *factors*, *environment*, *social*, and *caregiver*. Over 11,399 articles were identified, some of which dated to before the 1970s. The review was refined further with more specific keywords such as *dementia*, *environmental* *factors*, *social factors*, and *caregiver factors*. This yielded a total of 238 articles, but only 19 were deemed relevant for review because of their relevance to the topic. The criteria for inclusion were research papers published in the English language between 1997 and 2015 that focused exclusively on PWDs. Some articles were selected from disciplines other than nursing, including medicine and psychology.

In an attempt to synthesize this large amount of information, the articles were placed in evidence tables according to factors associated with the care outcomes of older adults with PWDs. The first evidence table (see Appendix H) contained articles that described environmental factors (Cohen-Mansfield & Werner, 1998; Garre-Olmo et al., 2012; Gitlin et al., 2001; Kostka & Jachimowicz, 2010; Morgan & Stewart, 1997; Nikmat et al., 2015; Zeisel et al., 2003). The second evidence table (see Appendix I) contains articles that describe caregiver-related factors (Alvira et al., 2015; Jaglal et al., 2007; Karlsson et al., 2015; Qadir et al., 2013; Stephan et al., 2015; Wang et al., 2014). The third evidence table (see Appendix J) contains articles that describe social network factors (Burgio et al., 2000; Carpentier et al., 2008; de Vocht et al., 2015; Giles et al., 2004; Nay et al., 2015; Nicholls et al., 2013).

In this paper, these groups of articles will first be described in terms of (a) the level of evidence, (b) the health care issue and the targeted population, (c) the nature of the intervention, and (d) the study results. The groups of articles will then be analyzed regarding (a) generalizability, (b) strengths and weaknesses, (c) relevance to nursing practice, and (d) their influence on future nursing research. Before describing the factors associated with the home care outcomes of older adult PWDs, background information regarding home care for PWDs is briefly presented and home care in Oman is briefly described.

Home Care for Patients With Dementia

Regardless of cultural differences, if given the choice, up to 90% of older adults prefer to stay in their own homes for as long as possible (Administration on Aging, 2011). According to the Administration on Aging (AARP) (2011), 22,400,000 households in the United States today already provide care to a family member over 50. However, it is estimated that one-third of all PWDs in the world live on their own (Mirando-Costillo, 2010). In the United States, roughly one in seven Americans with dementia lives alone (Alzheimer's Association, 2015). The number of people with dementia who live alone in their homes is also expected to rise (Alzheimer's Society, 2012).

There are currently no nursing home facilities for older citizens in Oman, and the government does not encourage the establishment of such facilities because it believes that the community will be able to take care of older adults, as emphasized by religion and tradition(Al-Zadjali, 2014).

Home care is one of the services that community health nurses provide for older people with disabilities and for those who require care management and monitoring (Al-Zadjali, 2014). Recently, in addition to home care, an older adult care program was integrated into community health services in Oman. This older adult care program was initiated to provide comprehensive assessment and screening of older persons. It aims to promote optimal health among older adults by enhancing the strengths of patients and their families to maximize patients' independence (Al-Zadjali, 2014). In addition to these services, the Ministry of Health (MoH) and the Ministry of Social Development (MoSD) jointly initiated a collaborative service for older adults that is directed at providing trained caregivers, also known as sitters, to take care of older adults who have no family caregiver. Each registered older adult undergoes a comprehensive socioeconomic environmental assessment and is then referred to a social worker. The patient is then visited by a team that identifies the necessary intervention (MoH, 2014).

Although several factors are associated with the home care outcomes of older adult PWDs, environmental and social factors need to receive more attention, especially among older adults living in the community. Physical, clinical, and cultural factors also influence home care outcomes for older adults with dementia (Kunik et al., 2003). Environmental and social factors include changes in routine, environment, or caregiver, and these factors can make PWDs become anxious, leading to agitated behaviors and other symptoms. The purpose of this article is to discuss the environmental and social factors that affect home care outcomes in older adult PWDs.

Environment: Factors in Care and Outcomes

Descriptions of Studies

Of the seven studies that tested the environment as a factor in home care outcomes, one was a Level I randomized control trial (RTC; Gitlin et al., 2001) and six were Level III descriptive, cross-sectional studies (Cohen-Mansfield & Werner, 1998; Garre-Olmo et al., 2012; Gitlin et al., 2001; Kostka & Jachimowicz, 2010; Morgan & Stewart, 1997; Nikmat et al., 2015; Zeisel et al., 2003).

Nikmat et al.'s (2015) study was based on the person–environment system in terms of the adaptation of the perceived consequences of dementia. The authors compared the quality of life (QoL) of people with dementia in nursing homes to that of people in home care and identified factors that differentiated their QoL. The sample included 49 people with dementia who were 60 or older; the participants were recruited from government nursing homes and hospitals in Malaysia (Nikmat et al., 2015). The home-care participants had higher-quality relationships with their children than those in the hospital; the home-care participants also obtained statistically significant higher Barthel index scores, indicating a greater level of autonomy in the performance of activities of daily living (ADLs; Nikmat et al., 2015).

Zeisel et al.'s (2003) study was based on the conceptual model used by Beck and colleagues. In the study, Zeisel et al. (2003) tested the associations between environmental home special care units' design features and the incidences of aggression, agitation, social withdrawal, depression, and psychotic problems among persons with Alzheimer's disease or a related disorder who were living there. The results showed significant correlations between each behavioral health measure and the residents' characteristics, the nonenvironmental facility characteristics, and the environmental characteristics (Zeisel et al., 2003). Older adults who had more privacy and lived in their own rooms showed less anxiety and less aggressive behavior (Zeisel et al., 2003). The authors also found that older adults with dementia living in a "less institutional environment" expressed lower levels of aggression, depression, and isolation than those living in a "more institutional setting" (p. 708).

Cohen-Mansfield and Werner (1998) tested the effects of an enhanced environment as a global variable on the behavior and mood, as well as on the manifestation of pacing and wandering behaviors, of nursing home residents who pace frequently. The results of observing and monitoring the activities of 21 nursing home residents with dementia showed a positive effect on their mood and behavior when the environment of the corridors was modified with new visual, auditory, and olfactory stimuli.

Morgan and Stewart (1997) studied older adults with dementia who had both staff and family caregivers and who lived in long-term care facilities. Morgan and Stewart (1997) tested the perceptions of family and staff caregivers with regard to the relationship between the environment and behavior in persons with dementia. The results of interviewing nine staff members and nine family members indicated the importance of both the physical and social environments. Social environment elements, such as staff–resident interactions and activity programming, were associated with behaviors exhibited by PWDs (Morgan & Stewart, 1997). Quieter, less-crowded units and slower-paced units had a positive impact on older adults with dementia (Morgan & Stewart, 1997).

Garre-Olmo et al.'s (2012) study was based on Lawton's environmental docility hypothesis, which states that environmental pressure contributes to behavioral outcomes as personal competence decreases. Garre-Olmo et al. (2012) tested the relationship between QoL and environmental factors, such as temperature, noise, and lighting, among nursing home residents with severe dementia. The observations of 160 nursing home residents with severe dementia showed that high temperature, high noise levels, and low lighting levels were associated with negative behavioral signs and negative affective mood (Garre-Olmo et al., 2012).

Gitlin et al.'s (2010) study was based on a competence-environmental press framework and recent advances in control theory. Gitlin et al. (2001) tested short-term effects of a home environmental intervention on self-efficacy and upset in caregivers and the daily functioning of dementia patients. An occupational therapist provided 90-min sessions every other week spaced over 3 months. The therapist provided educational, physical, and social environmental modifications. The results from 171 families of dementia patients showed that an environmental approach has a positive impact on both the caregiver and the person with dementia that may slow the progression of IADLs and dependence of patients as well as enhance self-efficacy and reduce upset for select caregivers.

Kostka and Jachimowicz's (2010) topic of interest was the preventive and health-promoting psychological measures aimed at improving QoL in the older population in different environments, such as community dwellings, long-term care homes, and veteran homes. Kostka and Jachimowicz (2010) tested the relationship of dispositional optimism, health locus of control, and self-efficacy to QoL in older subjects differing in levels of disability and institutionalization. This study described the relationship of QoL to dispositional optimism, health locus of control, and self-efficacy in older patients living in three different environments; community dwellings, long-term facilities, and veteran homes. The results showed that QoL generally decreased with a growing level of dependence and institutionalization. Also, community-dwelling older adults had the highest physical activity indices and MMSE compared to those living in long-term homes and veteran homes, and internal and external loci of control were the highest in elders in veteran homes compared to those in community dwellings and long-term care homes.

Analysis of Studies

The strength of these articles (see Appendix B) lies in their investigations of the association between environmental factors and care outcomes for older adults with dementia. Kolanowski et al. (2011) identified different factors that can be associated with behavioral symptoms in older PWDs. These factors include background risk factors, such as "neuropathology, cognitive deficits, physical function, and premorbid personality," and proximal precipitating factors, such as "qualities of the physical and social environment, and physiological and psychological need states" (Kolanowski et al., 2012, p. 1032). Garre-Olmo et al. (2012) also identified physical environmental factors, such as temperature, noise, and lighting, as being associated with QoL among nursing home residents with severe dementia. These findings were congruent with Cohen-Mansfield and Werner's (1998) study, which reported high satisfaction levels among older adults with dementia when some modifications were added to the corridors, such as integrating new posters of nature, bird sounds, and flower smells. Residents were observed to be smiling and calm, and to have less regression and agitation (Cohen-Mansfield & Werner, 1998).

Physical environment design is an important area of focus when planning the care of older adults with Alzheimer’s disease and other forms of dementia (Gitlin et al., 2001). The environment plays a significant role in how a person interacts with others and aids that person in understanding his or her soundings (Zeisel et al., 2003). Too much or too little stimulation can cause disruptive behaviors such as agitation in PWDs (Kovach, 2000). Nikmat, Hawthorne, and Al-Mashoor (2015) found that older adults with dementia who lived at home experienced a higher QoL and participated in more activities of daily life, including socialization, than did PWDs living in long-term institutions. Institutionalized older adults with dementia experience overwhelming stimulation from new environments, including nursing homes (Bakker, 2003). This was also supported by Zeisel et al. (2003), who emphasized that conventional environments are structured for residents who are cognitively intact and that these environments might not be suitable for those with Alzheimer’s or other forms of dementia.

Based on Volkers et al.’s (2011) literature review, experimental studies on animals by Winocur (1998) and Bell et al. (2009) showed that environmental conditions have greater effects on older rats than younger rats, especially in environments without opportunities for physical activity and with little or no social interaction. Similarly, in humans, lonely and sedentary people exhibited a faster decline in both cognitive and physical function than socially and physically active people (Angevaren et al., 2008). Angevaren et al. (2008) found that the environmental factor of institutionalization further aggravates cognitive decline in older adults, and observed that institutionalized older adults’ cognitive functioning was worse than the cognitive functioning of community-dwelling older adults (Winocur & Moscovitch, 1990). Egerton and Brauer (2009) stated that nursing homes reflect a passive environment, despite the positive attitude toward physical exercise. They found that ambulatory residents end up sitting down or lying in bed for long periods when they are not ill and spend only 137 min per day upright, including standing and walking.

A social environment, including the nature of social support at home, is reflected by structural and functional components as well as the nature of the support provided (Mark, 2012). Structural elements include network size and relational bonds, such as social integration, attachment, and assistance (Moniz-Cook & Clarke, 2011). An interview from an older qualitative study by Morgan and Stewart (1997), which was about the perceptions of family members and nursing staff regarding how physical and social environments affect PWDs, revealed that the social environment has more impact than the physical environment on both QoL and functional ability among older adults with dementia. Participants in the study identified several needs for the social environment: human contact, supervision, stimulation, meaningful activity, and flexibility (Morgan & Stewart, 1997).

Shifting living from one environment to another, such as from one's own home to a long-term care facility, can cause feelings of loneliness. Kostka and Jachimowicz (2010) identified that institutions are often an impoverished environment because residents experience social isolation more than older adults in a community dwelling, since it becomes difficult for them to maintain their social relationships with loved ones. Scocco et al. (2006) reported that about half of the older adults living in nursing homes experience loneliness.

Five of the studies included an adequate sample size, making the results more generalizable; the exceptions include the study by Morgan and Stewart (1997), which included a small sample size of 18 people (nine staff members and nine family members), and the study by Cohen-Mansfield and Werner (1998), which included 27 nursing home residents.

While only one study addressed the component of the home care setting (Nikmat et al., 2015), the information gained from the other five articles contributes to expanding the understanding of environmental factors associated with the care of older adults with dementia. Researchers and health care professionals can utilize this information to expand their knowledge by testing these factors' home care outcomes.

Caregivers: Factors in Home Care and Outcomes

Descriptions of Studies

While there have been many studies of caregivers of people with dementia, this review was limited to studies that examined factors within the caregiver that were associated with outcomes in PWDs. Six of the selected studies tested the effect of the caregiver as a factor in care outcomes. All of these studies were Level III; two were descriptive cross-sectional studies (Alvira et al., 2015; Stephan et al., 2015), one was a multiple comparative case study design (Jaglal et al., 2007), two were qualitative research studies using focus groups (Karlsson et al., 2015; Qadir et al., 2013), and one used the double hermeneutic approach (Wang et al., 2014).

Alvira et al. (2015) used an interest group of informal caregivers for people with dementia across eight European countries. Alvira et al. (2015) tested the associations between PWDs' reactions to informal caregivers and those patients' health outcomes; the results of 2,014 participants (people with dementia living at home or in long-term care institutions and their informal caregivers) showed that self-esteem and lack of family support correlated with caregiver burden and poor psychological well-being ($p < .005$). Alvira et al. (2015) also found associations between disrupted schedules and caregiver burden, poor psychological well-being, and lower QoL.

Karlsson et al. (2015) focused on improving dementia care and services, especially the development of best-practice strategies for the transition from home care to institutional long-term care facilities. Karlsson et al. (2015) tested views of intersectoral information, communication, and collaboration throughout the continuum of dementia care among persons with dementia and their informal caregivers in eight European countries. Based on focus group interviews with 137 persons with dementia and their informal caregivers, Karlsson et al. found that the following were important: establishing a trusting relationship with caregivers and professionals, having professional knowledge and commitment, and offering varied services and care adapted to patients' needs.

Stephan et al.'s (2015) study was based on the concept of aging in place. Stephan et al. (2015) tested the perceptions of informal caregivers and health care professionals regarding potential reasons for the institutionalization of older PWDs in eight European countries. After investigating 1,160 persons with dementia, Stephan et al. found that caregiver burden or inability to provide care, neuropsychiatric symptoms, overall deterioration, and care dependency were potential reasons for the institutionalization of older PWDs.

Wang et al. (2014) used structuration theory as a guide for researchers to identify different possible types of dementia care through collaborative reflection with caregivers. The authors examined the social, cultural, and political factors affecting family caregiver practice in dementia care. In-depth, semistructured interviews of 23 family caregivers of PWDs showed that relying on family caregivers to care for people with dementia without the supervision of dementia services from the public health care system generates negative health outcomes for both care recipients and caregivers (Wang et al., 2014).

The Jaglal et al. (2007) study was based on the concept of continuity, and focused on the direct experiences of clients and providers. Jaglal et al. (2007) tested whether sociodemographic and health characteristics, type of support network, and amount of service use among care recipients and caregivers were associated with experiences in the care process. Jaglal et al. showed that if caregivers received home support and care recipients received emotional support from their social support networks, patients were more likely to be satisfied with their experiences.

Qadir et al. (2013) focused on the traditional approach of familial caregiving in Pakistan. Qadir et al. (2013) tested **caregivers' awareness**, **attitudes** toward family members suffering from **dementia** and experiences with being **burdened.** In-depth interviews were conducted with 12 **caregivers** of **patients** diagnosed with dementia in Rizwalpindi/Islamabad, Pakistan; Qadir et al. showed that the social and financial **burden** of **dementia** on families of **caregivers** in Pakistan might be exacerbated if those caregivers do not have support. The following analysis will summarize caregiver factors and the PWDs outcomes that were studied.

Analysis of Studies

The six studies that tested factors within the caregiver were associated with outcomes in PWDs. The authors of these studies all agreed that caregivers' burden and stress were identified as specific factors associated with quality of care (Alvira et al., 2015; Jaglal et al., 2007; Karlsson et al., 2015; Qadir et al., 2013; Stephan et al., 2015; Wang et al., 2014). Factors such as caregiver burden and poor psychological well-being caused by caregivers' low self-esteem and lack of family support led to negative outcomes, such as disrupted schedules and lower QoL of PWDs (Alvira et al., 2015). Alvira et al. (2015) showed a positive association between lack of family support and the caregiver's psychological well-being in all studied countries. The more support caregivers received during the process of caring for the PWDs, the less negative affect they experienced (Alvira et al., 2015). Other within-caregiver factors include trusting relationships, communication, and collaboration between professionals and family caregivers (Karlsson et al., 2015); services from the public health care system (Wang et al., 2014); sociodemographic and health characteristics and type of support network (Jaglal et al., 2007); and social and financial **burden** (Qadir et al., 2013). Qadir et al. (2013) also identified the important issue that people in developing countries lack general awareness about dementia and the constant care it requires, which prevents them from properly coping with dementia. Jaglal et al. (2007) concluded that older adults with dementia received higher-quality in-home care and assistance if their caregivers received more emotional support from their social support networks. Egdell (2012) stated that caregivers often emphasize the importance of proper provision of information regarding support services and that professionals should be aware of the support services not only for PWDs but also for their informal caregivers. The results of Jaglal et al. (2007) were congruent with those of Karlsson et al. (2015) and Stephan et al. (2015), who also found that it is important for caregivers to have trusting relationships with professionals, achieve professional knowledge and commitment, and offer a variety of services and care adapted to patients' needs. These factors enhanced PWDs' positive patient outcomes and trust, and made them more likely to be satisfied with their care experience (Jaglal et al., 2007; Karlsson et al., 2015).

On the other hand, Wang et al. (2014) described how social changes played a big role in weakening the traditional family care model, which has led to many challenges for both PWDs and their caregivers. The increased caregiver burden or inability of the immediate caregiver to provide care for the PWDs, social and financial burden, and lack of supervision of dementia services from the public health care system are factors associated with negative health outcomes for both care recipients (PWDs) and caregivers, as well as increased institutionalization of PWDs (Qadir et al., 2013; Stephan et al., 2015; Wang et al., 2014). Wang et al. (2014) described people with dementia as living in "empty nests" because most of them relied on their spouses to care for them and few relied on their adult children. Due to the lack of family caregiver resources and lack of caregiver support, many older adult PWDs were institutionalized in a nursing home (Wang et al., 2014). The decision to place an older adult relative permanently in a long-term care facility is described as one of the most difficult decisions for family caregivers during the care-giving process (Sury et al., 2013). After the decision has been made, caregivers usually experience feelings of guilt and sadness (Sury et al., 2013).

A disrupted schedule and caregiver burden were also found to be associated with negative psychological well-being and poor QoL (Alvira et al., 2015). Studies also identified factors associated with the unstable emotional statuses of both older people with dementia and their caregivers, such as excess conversation, busy periods, and disturbed social routine (Alvira et al., 2015; Moniz-Cook & Clarke, 2011). External groups and immediate family members can cause stress on the cognitive abilities of those with dementia (Wang et al., 2014; Zeisel et al., 2003) by placing those individuals in a position to receive care from multiple caregivers outside of their immediate core network, which may be overwhelming and lead to increased agitation and poor health, eventually even interfering with care delivery.

Two studies in Appendix C were found to have small sample sizes (Qadir et al., 2013; Wang et al., 2014), which can be considered a weakness that may limit the generalizability of the results. Also, language transfer bias was a possibility in four studies (Alvira et al., 2015; Karlsson et al., 2015; Qadir et al., 2013; Stephan et al., 2015) in which answers had to be translated into English for documentation. Again, none of the six studies addressed the home care setting component; the information gained from the findings contributes to an expanded understanding of caregiver factors associated with the care of older adults with dementia.

Social Network: Factors in Home Care and Outcomes

Descriptions of Studies

Of the six studies that tested social networks as a factor in care outcomes, one was Level I and used a mixed-methods approach (Nicholls et al., 2013); the other five studies were Level III. Of those five studies, two were exploratory studies (Nay et al., 2015; Carpentier et al., 2008), one was a descriptive cross-sectional study (Burgio et al., 2000), one was a longitudinal study (Giles et al., 2004), and one was a pretest/posttest study (de Vocht et al., 2015).

Carpentier et al.'s (2008) study was based on the multilevel network model of Pescosolido (1996) and Martuccelli (2004), who emphasized the importance of social structures in analyzing community services and the importance of individual trajectories, historical context, social structure, and challenges throughout life. Carpentier et al. (2008) tested the interactions between health care practitioners and caregivers of people with Alzheimer's disease. The study of 20 practitioners drawn from seven urban groups resulted in heterogeneous professional groups and the establishment of contacts in the early stages of dementia; these contacts between formal and informal service networks seemed beneficial (Carpentier et al., 2008).

Giles et al. (2004) based their study on several models that share concepts, showing that disability results from a complex relationship among an individual's health, environment, personal attributes, and psychosocial factors. Giles et al. (2004) tested the effects of total and specific social networks made up of children, relatives, friends, and confidants on mobility disabilities and Nagi's (1976) functional tasks in older adults in Australia. Testing the 1,477 participants showed that, after controlling for a range of health, environmental, and personal factors, relatives' social networks protected against mobility disability and Nagi tasks (Giles et al., 2004).

Burgio et al. (2000) focused on investigating the relationships among residents' gender, staff's social interaction, and agitation. The results of testing 46 nursing home residents with clinically significant agitation showed that touch and verbal interaction were significant factors leading to agitation in a significant proportion of residents (Burgio et al., 2000).

Nay et al.'s (2015) study used grounded theory to guide its sampling and data analysis. Nay et al. (2015) tested what social participation actually means to family caregivers of people with dementia. The semistructured interviews of 33 family caregivers (17 spouses and 16 adult children) revealed that caregivers go through a process in which the ways they have previously participated socially are compromised, which often prompts an exploration of new ways in which to remain socially engaged (Nay et al., 2015).

Nicholls et al.'s (2013) study was based on Simard's (2007) high-touch protocol based on the End-of-Life Namaste Care Program for people with dementia. Nicholls et al. (2013) explored the role of social relationships in improving the delivery of palliative care to people with advanced dementia. The data were derived from focus groups conducted at three residential aged care facilities located in metropolitan and regional areas of New South Wales, Australia; the data revealed that social relations provide meaning and role satisfaction for both providers and recipients of care (Nicholls et al., 2013).

Finally, de Vocht et al.'s (2015) study focused on assessing the impact of a daily, one-on-one, half-hour-long individualized interaction on the behavior and QoL of care-dependent residents with dementia. In the study, de Vocht et al. observed 15 care-dependent residents with dementia and interviewed health care professionals and direct relatives. The results showed that interaction offered on a one-on-one basis and tailored to individual preferences significantly improved positive interactive behaviors among care-dependent residents with dementia during the intervention.

Analysis of Studies

According to the socioemotional selectivity theory (SST), the size of a person's core network decreases as he or she ages (Penningroth & Scott, 2012). This decreased number of contacts is the intentional result of a tendency to become more selective about who is in the social network and to increase utilitarian attention on present needs, rather than on future plans (Penningroth & Scott, 2012). As the person grows older, he or she also begins to focus on emotional aspects and becomes more focused on spending quality time with loved ones in smaller social networks (Penningroth & Scott, 2012).

One strength of this group of articles was the fact that four out of six (Carpentier et al., 2008; Giles et al., 2004; Nay et al., 2015; Nicholls et al., 2013) were based on theoretical models. The second strength was that they all reported statistically significant results, indicating associations between "social interaction" or "social networks" with QoL, meaning, and improved positive interactive behavior between PWDs and caregivers.

People with dementia have impaired communication and may display decreased cognitive insight into their needs and symptoms (Cohen-Mansfield & Billig, 1986). However, multiple studies have shown positive correlations among active social interactions, improved physical function, and positive affect among older adults with dementia (Al-Sabahi et al., 2013; Giles et al., 2004; Nicholls et al., 2013). Active participation in social networks is beneficial for comfortable, secure, and productive aging and well-being. An Australian study by Giles et al.

(2004) investigated the impact of older patients' social networks, and found that social networks with home caregivers from a core network, such as children, had significant protective effects by delaying the onset of disability and improving recovery.

On the other hand, de Vocht et al. (2015) found that one-on-one interaction tailored to individual preferences, which is easily implemented in home settings, significantly improved the positive interactive behaviors of care-dependent residents with dementia during the intervention. Social interaction was also found to be significantly associated with caregivers' satisfaction (Nay et al., 2015); de Vocht et al. (2015) emphasized that the caregivers of PWDs highly value social networks and social participation because socializing reinforces their identities as active community members and ensures that they do not lose themselves as they provide care. Additionally, the study showed that meaningful social interaction is linked with improved and positive health outcomes (Nowak & Davis, 2007).

However, older adults with dementia who live at home might experience feelings of isolation and neglect due to separation from their friends and society (Burgio et al., 2000). Maintaining ongoing friendships and social support has been demonstrated to decrease agitation (Nicholls et al., 2013; Zarit et al., 2004). Cohen-Mansfield et al. (1990) focused on five older adults with histories of agitated and/or disruptive behaviors, such as screaming, and showed that those behaviors occurred most often when the residents were alone. These findings were also supported by the earlier study of Burgio et al. (2000), which reported that aggressive behaviors were most common when subjects were left alone or located more than 3 feet away from significant caregivers.

Burgio et al. (2000) placed great emphasis on the social environments of older adult residents with dementia. Episodes of agitation were shown to decrease significantly when older adult residents received verbal and tactile interactions from their caregivers. The study also indicated that PWDs with high privacy personalization scores tended to have lower scores on the Psychotic Problem Scale.

In addition, while Mark (2012) identified that larger social networks and more social participation can improve both physical and psychological stressors, thus lowering mortality, Moniz-Cook and Clarke (2011) indicated that having too many social networks could have adverse effects on well-being, which may involve disappointment and conflict. Other unspecified factors not included in this study, such as frequency of social contact and use of psychotic medications, may be correlated with outcomes for older adults with dementia. The size of a core network and the number of caregivers depend on the severity of the situation. In some cases, a spouse can provide sufficient care for a patient, but in other cases, a patient might need a team of 10 to provide adequate care (Srivastava, 2005).

Conclusion

There is a need for more research on the influence of multiple environmental and social context variables on home care outcomes for PWDs. Some studies have indicated relationships between social network interaction and outcomes such as agitation, but none of these studies have specifically examined the correlations among PWD outcomes, the size of PWDs' core network, and their frequency of contact (Burgio et al., 2000; Giles et al., 2004; Srivastava, 2005). Specialized research is recommended in this area. Such studies could also produce evidence of an association between poor outcomes and the size of a person's core network or the frequency of contact with care providers in the person's core network.

Carpentier et al. (2008) encourages professionals and informal caregivers to consider concepts related to service integration. Poor coordination between family caregivers and institutions negatively affects the quality of care provided to PWDs (Abbott et al., 2015). In considering the factors that contribute to home care outcomes, it is essential to identify ways to create effective long-term linkages between family members as caregivers, social systems, and formal care institutions (Carpentier et al., 2008).

Chapter Summary

Descriptions of the three theories and definitions of concepts within these theories were discussed in the first manuscript to help explaining the salience of the caregiver network to outcomes for older adults with dementia. This chapter provides an overview to fully explain the concepts involved in this study.

The second manuscript included in this chapter provides a detailed literature review of the environmental and social factors associated with the home care outcomes of older adult patients with dementia. An overview was provided about the influence of these factors, particularly when examining their effects on agitated older adults, since older adults with dementia may be become more vulnerable to environmental and social stimuli, such as changes in their routine, environment, or caregivers.

CHAPTER THREE

Chapter Introduction

This study was based on the premise that the size and frequency of contact of the ADL core network of PWDs contributes to agitation and affect in PWDs. The purpose of this study was to examine the associations between size and frequency of the ADL core network contact with agitation and affect of people with dementia. In addition, there were two secondary hypotheses. We examined whether the size and frequency of contact with the IADL core network are associated with agitation and affect of people with dementia. We also examined whether emotional closeness of the ADL and IADL caregiver predicts density of ADL and IADL amount of care provided.

The research methods used to gain information about this association between size and frequency of core network contact frequency with the agitation and affect of people with dementia are described in this chapter. Also, this chapter discusses the design, sample selection procedure, instrument utilized, data collection methods, and data analysis techniques.

Method

Research Design

The study utilized a cross-sectional, descriptive, correlational design to demonstrate the associations that ADL and IADL core network size as well as contact frequency have with PWDs' agitation and affect. This design is best for this dissertation study because it was not feasible to randomly assign PWDs according to size of their core network and the frequency of contact, and because of my interest in understanding the relationships between the variables.

Hypotheses and Research Questions

The research questions that this study addressed were as follows:

1) What is the level of agitation among older adult PWDs in Oman?
2) With what frequency do older adult PWDs have contact with their ADL and IADL core networks?
3) Are there differences in the size of ADL and IADL core network between those with early and later stage dementia?

This study addressed the following hypotheses:

Main hypothesis. Controlling for the severity of dementia and comorbid problems, the size (IV) and frequency (IV) of contact with the ADL core network (IV) will predict the agitation (DV) and affect (DV) of PWDs.

Secondary hypotheses.

1. Controlling for the severity of dementia and comorbid problems, the size (IV) and frequency (IV) of contact with the PWDs' IADL core networks (IV) will predict the agitation (DV) and affect (DV) of PWDs.
2. Controlling for the severity of dementia and comorbid problems, the closeness of IADL and ADL caregivers (IV) as well as the size of caregiver core networks will predict the density of IADL and ADL care provided (DV).

Research Setting

The Batinah South region of Oman was the site for this study because of convenience, due to its geographic closeness to me and because the target population resides there. In addition, the residents of this region originate from the same area. Al Batinah South region is located southwest of Oman's gulf coast. A majority of the residents in this region are locals who originated from the same area. A total of 15,551 older adults aged 60 years and above live in this region, which represent 12% of the total older adults in Oman.

Sample

The study used convenience sampling. A power analysis based on effect sizes was used to determine the sample size needed to protect against Type II error (Polit & Beck, 2012). To calculate the sample size, a statistician used the A-priori Sample Size Calculator for Multiple Regression (Cohen, Cohen, West, & Aiken, 2003). A sample size of 69 was obtained from the a priori power analysis with 80% power for detecting a medium-sized effect with a .05 significance level when two independent variables and two controlling variables were included in the model. The study ended up including 98 older adults with dementia and their caregivers. A reportable event was then submitted and IRB concluded that there were no new risks occurred from this event.

The following inclusion criteria was also used: (1) adults aged 65 and older (the most commonly used age to signal older adulthood); (2) dementia, as measured by the Mini Mental Status Exam (MMSE); (3) caregivers who understand Arabic in a way that is evident during the consent procedures (it was not within this study's budget to use translation tools or hire a translator to work with non-Arabic-speaking participants).

Instruments and Measures

Two of the predictor measures (CMAI & PANAS) were translated to Arabic, which was crosschecked with an English language professor at the Sultan Qaboos University. These two measurement tools were left with primary caregivers for a week. The caregiver observed the PWD for agitation and PANAS. In visit 1, the SPI asked how much behavior they had and their affect in the previous week (CMAI #1 & PANAS #1). The caregivers had the tools for a week before the SPI visit#2. The SPI completed PANAS #2 and CMAI #2 based on the previous weeks agitation and affect.

Outcome measures.

Agitation. Agitation was measured using the CMAI instrument (Cohen-Mansfield, Marx, & Rosenthal, 1989). The CMAI is a likert rating scale consisting of 29 items that was completed in a structured interview. The measurement was ordinal, follows consent procedures, and was measured once. According to Cohen-Mansfield et al. (1989), the CMAI is most commonly used to assess agitation in older adults. In a nursing home, the average internal consistency reliability is κ = .92 (.88–.92). Factor analysis revealed four factors representing agitation: Physically aggressive behavior, physically nonaggressive behavior, verbally aggressive behavior, a nd verbally non aggressive behavior.

Affect. Positive and negative affect was measured using the Positive and Negative Affect Schedule (PANAS). The PANAS is a brief scale developed by Watson, Clark, and Tellegen (1988) comprising 20 items, with 10 items measuring positive affect. Each item is rated on a 5-point Likert scale, ranging from 1 = *very slightly or not at all* to 5 = *Extremely*, to measure the extent to which the affect has been experienced in a specified time frame (Crawford & Henry, 2004). The Cronbach's alpha values obtained ranged from .86 to .90 for positive affect (PA) and .84 to .87 for negative affect (NA) (Watson et al., 1988). The affect can be measured in various contexts, such as at the present moment or in past periods. Thus, the scale can measure state affect. The measurement was ordinal, follows consent procedures, and was measured once.

Amount of care. Amount of care is the density of care, as defined by hours (hr) of care provided per week. In this case, lower density of caregiving indicates fewer *hr* of care. Density of caregiving was determined via self-report (from the client or ADL and IADL caregiver).

Predictor measures.

IADL and ADL core network. The ADL and IADL core networks was measured using a checklist of caregiver activities to separate the two categories. This checklist includes seven IADLs and five ADLs, as defined by Katz (1963) and Lawton et al. (1998). The Katz index of ADLs has good internal consistency, with a Cronbach's α of .92 (Glajchen, Homel, Tsoi, Chan, & Portenoy, 2013).

Closeness. Closeness was measured using the Social Convoy Questionnaire (SCQ) (Lang, 1996). Kahn and Antonucci developed SCQ in 1980 using the circle diagram to identify the closeness of PWDs to others according to the circles provided. The circles are categorized as inner ("Feel very close, so close that it would be hard to imagine life without)"; middle ("Don't feel quite so close as those in the inner circle, but are still very close)"; and outer ("Feel less close but who are still important"). The test–retest reliability for a community sample of adults and children was .80, while the inter-rater reliability between samples was .71 (Dunn et al., 2005).

Size of network. The size of the PWDs' networks was determined via a self-report (from the client or the caregivers) through the ADL and IADL checklist; this one-time interval measurement follows consent procedures.

Frequency of contact. The average frequency of contact in days during a typical 30-day month with one or several ADL and IADL caregivers was determined via a self-report (from the client or the caregivers); this one-time interval measurement follows consent procedures.

Other measures.

Comorbid problems. Comorbid problems were measured using the Cumulative Illness Rating Scale for Geriatrics (CIRS-G; Miller et al., 1992). The measurement was ordinal, follows consent procedures, and was measured once. The CIRS was initially developed by Linn et al.

(1968) and was later revised by Miller et al. (1992) to reflect common problems among older adults. The CIRS-G scoring system measures morbidity or chronic medical illness burden using 14 items representing individual body systems, while considering the severity of chronic diseases. The severity ratings are 0 (*no problem affecting that system*), 1 (*current mild problem or past significant problem*), 2 (*moderate disability or morbidity* and/or *requires first-line therapy*), 3 (*severe problem* and/or *constant and significant disability* and/or *hard-to-control chronic problems*), and 4 (*extremely severe problem* and/or *immediate treatment required* and/or *organ failure* and/or *severe functional impairment*). The CIRS-G has been tested with older adults. It provides a quantitative rating of chronic illness burden geared toward geriatric patients, and can be successfully applied in medically and psychiatrically impaired older adult subjects. This modified CIRS was operationalized with a manual of guidelines. It showed good interrater reliability (i.e., intraclass correlations of .78 and .88) in a subsample of 10 outpatients and 10 inpatients) for total scores (Miller et al., 1992).

Age. Age (in years) was determined via a self-report (from the client or caregiver). This interval measurement occurred once and follows consent procedures.

Gender. Gender was determined via a self-report (from the client or caregiver); this one-time nominal measurement follows consent procedures.

Severity of dementia. The severity of dementia was measured using the MMSE. This tool was chosen for its selection criteria and interaction variable. It is easy to administer, is widely used, and has a substantial number of validity and reliability studies supporting its use. The MMSE consists of 30 questions that measure orientation, registration, recall, attention, calculation, and language (Ellis, 2006). Scores on the MMSE range from 0 to 30, and higher scores indicating greater cognitive ability (Ellis, 2006). Its test–retest reliability on a standardization study after a 24-hr follow-up was reported as .89 for the same examiner, and .83 for a new examiner (Folstein et al., 1975).

Data Collection Procedures

Human subject considerations

IRB approval was obtained from the Institutional Review Board (IRB) of the University of Wisconsin-Milwaukee (UWM) and the IRB of the Ministry of Health in Oman.

The following procedures was used to recruit participants:

1. Both IRB approval letters were emailed to the head of the Community Health Nursing in the region along with the study's objectives and proposal.
2. A presentation about the study's process and significance was presented to the community health nurses.
3. The community health nursing gives a written flyer or note to the caregivers of PWD about the study and asks them to contact the nurse researcher (NR)
4. The NR sat up appointment #1 with family member
5. The inclusion criteria was discussed, and an eligible client list was created.
6. I asked the caregiver on the phone for the home address when I set up the appointment.
7. Verbal agreement to visit the participants' homes was obtained from the participants.
8. The assigned community health nurse and SPI distributed consent forms at visit #1 to the clients or their legally authorized representatives.
9. CHN staff conducted a chart review for diagnoses after obtaining the consent from participants
10. A list of eligible clients was created.

11. Demographics: Age, gender from medical record
12. Mental status exam from medical record or was done at visit #1
13. CIRS-G (medical problems) from medical record

Table 2

Summary of On-Site Consent and Research Process

Timing, Procedures/Measures	**By Whom**
Orientation - The study purpose, process, and significance were presented to community health nurses (CHNs). - Set up dates/times of visits	Researcher (SPI)
Eligibility and demographic description: - The waiver form was completed for the PWD - The consent process would take a long time and could burden people with dementia and their caregivers unnecessarily. Care for older parents in Oman automatically becomes a shared responsibility among children, as a moral code of conduct to honor and respect elders. Those immediate family members who are also the primary caregivers also play the role of decision makers for older parents with dementia (Hafiz, 2015). - The SPI conducting the consented activity prior to accessing the medical records - The assigned community health nurse and SPI distributed consent forms at visit #1 to the clients or their legally authorized representatives. - The consent form was explained verbally to the clients or their legally authorized representatives including their right to withdraw from the study. - Verbal assent was obtained from any person with dementia who has a family member provide written consent. - Each person was told that their participation is completely voluntary.	CHN and SPI
Data Collection Translation process: - Two of the predictor measures (CMAI & PANAS) were translated to Arabic using a professional translator - The translated forms were crosschecked with an English language professor at the Sultan Qaboos University in Oman. Data collection: • Neither audio nor video recording was done in the study. • There were 2 visits, which were one week a part • Welcomed the caregivers and clients, and distributed the tool at visit #1 • Eligibility criteria were rechecked, and ineligible subjects were removed. • The caregiver observed the PWD for agitation and PANAS. In visit 1, the SPI asked how much behavior they had and their affect in the previous week (CMAI #1 & PANAS #1). The caregivers had the tools for a week before the SPI visit#2. The SPI completed PANAS #2 and CMAI #2 based	SPI

on the previous weeks agitation and affect. • An offer was made to read all questionnaire items and provide assistance with filling out the forms. • Help was provided as needed in completing the tool, and confidentiality was assured. • To ensure that adequate time for completing the measurement instrument, the SPI allowed 1 hour with each participant. In our preliminary testing it took a family member 20-30 minutes to complete the tools by interview. When the person needed to rest or needed me to return to complete the collection that was arranged. • Each tool was checked for completeness before I receive the results, and an attempt was made to complete any missing items. • When the SPI was asked to wait or come back later in case PWD needed care, I returned at a later time • Subsequent meetings for data collection was scheduled. • Data collection occured in a quiet and convenient location at participants' home, as suggested by a family member. Tools administered via interview were completed: • A mental status exam from medical records within the past three months. If the mental status exam has not been completed in the past three months, this test was administered. • The CMAI was completed in a structured interview during the visit. • Caregivers completed the Positive and Negative Affect Schedule (PANAS) • Caregivers completed the Social Convoy Questionnaire (SCQ) during the visit. • The ADL & IADL checklist Items collected from medical record: • Demographic data (Age in year, gender) • A mental status exam within the past three months • CIRS-G (medical problems)	
Data Management	SPI
Data Analysis	SPI with consultation from statistician

Data Management Plan

The biostatistician and I worked together to implement the data management plan. All forms were kept in a locked Cabinet in the office in Oman Nursing Institute (Where the SPI works) that only SPI has access to.

- For the data entered in the laptop: Password protected laptop computer that only PI had access to for personal use.

- The room key where the papers and laptop was kept with SPI when exiting the building
- The laptop where the data was stored was encrypted
- Ensured that there was no one present in the room when accessing or using either the paper or the electronic stored data. The data management plan will include the also following steps:

- To ensure data accuracy, before presenting the analysis files, the data manager cleaned the data using double data entry or a two-person crosschecking technique. As an additional safeguard, the frequency distributions of all of the variables were checked before proceeding with the analysis.
- The data was checked for sufficient variability in the dependent measures.
- When 25% of the data have been collected, the data manager checked the clients' criteria with the responding sample demographics to identify any problems, such as skew.
- Beginning when 25% of the data have been collected, the data was periodically checked to ensure that the assumptions of the planned statistical analyses can be met.
- To be included in the analysis, every case had a score for both the process and the outcome variables. Thus, any case that was missing any outcome scores or 5% or more of the process scores was excluded. But there was no exclusion necessary in this study.
- The statistical teams at the Nursing College of University of Wisconsin-Milwaukee, methodological experts and I agreed to work together incase any problems raised, or needed any needed modifications. I kept a log by tracing the history of and rationale for any needed modifications.

Data Analysis Plan

Data analysis was conducted using SPSS® version 23. Initially, the distributions of each outcome variable were analyzed using frequency distributions, means, and standard deviations.

Scatter plots for each IV/DV combination were checked for possible nonlinear relationships. The data analysis plan was revised due to nonlinearity. Because variables' distributions were severely skewed, nonparametric tests and medians and interquartile ranges were used to report descriptive results. Descriptive statistics such as mean, standard deviation, frequencies, and range score were used to summarize the sample's characteristics. Continuous variables such as age were described using means and standard deviations. Categorical variables such as gender were described using frequencies, frequency distributions, and percentages. For the hypothesis, **Mann-Whitney U test was used to** examine the difference between ADL and IADL size of core network/ frequency of contact, and between agitations and affect. The differences between closeness, size of core network, and density of care were also tested. A Spearman's rank-order correlation coefficient was used to identify the strength and direction of the association between the size of core network/ frequency of contact, and agitation and affect. The association between closeness/ size of core network and density of care were also examined.

Table 3

Data Analysis Plan

Research Questions/Hypotheses	**Unit of Analysis**	**Variable**	**Measurement Tool**	**Level of Measurement**	**Statistical Test**
Descriptive Questions					
1. What is the level of agitation among older adult PWDs in Oman?	People with dementia (PWDs)	DV: level of agitation	- MMSE - CMAI	- Nominal - Interval	Descriptive statistics Means (if no severe skew is present), ranges, and standard deviations.
2. With what frequency do PWDs have contact with their ADL and IADL core networks?	PWDs	IV: dementia DV: frequency of core network contacts	- MMSE - Self-report	- Nominal - Interval	Descriptive statistics (frequency, mean, *SD*, range)
3. Are there differences in the size of ADL and IADL core network between those with early and later stage dementia?	PWDs	IV: dementia DV: size of core network	- MMSE - ADL and IADL checklist	- Nominal - Interval	*t*-test Descriptive statistics Means (if no severe skew is present), ranges, and standard deviations.

Main Hypothesis	Unit of Analysis	Variable	Measurement Tool	Level of Measurement	Statistical Test
1. Controlling for the severity of dementia and comorbid problems, the size (IV) and frequency (IV) of contact with the ADL core network (IV) will predict the agitation (DV) and affect (DV) of PWDs.	PWDs	IV: size and frequency of contacts DV: agitation and affect	- MMSE - ADL and IADL checklist - CMAI - PANAS - CIRS-G	- Nominal - Interval - Interval - Ordinal - Ordinal	- **Mann-Whitney U test to** examine the difference between ADL size of core network/ frequency of contact, and between agitations and affect. - Spearman's rank-order correlation coefficient to identify the strength and direction of the association between the size of ADL core network/ frequency of contact, and agitation and affect.

Secondary Hypothesis	Unit of Analysis	Variable	Measurement Tool	Level of Measurement	Statistical Test
1. Controlling for the severity of dementia and comorbid problems, the size (IV) and frequency (IV) of contact with the IADL core network (IV) will predict the agitation (DV) and affect (DV) of PWDs.	PWDs	IV: size and frequency of contacts DV: agitation and affect	- MMSE - ADL and IADL checklist - CMAI - PANAS - CIRS-G	- Nominal - Interval - Interval - Ordinal - Ordinal	- **Mann-Whitney U test to** examine the difference between IADL size of core network/ frequency of contact, and between agitations and affect. - Spearman's rank-order correlation coefficient to identify the strength and direction of the association between the size of IADL core network/ frequency of contact, and agitation and affect.

Secondary Hypothesis	**Unit of Analysis**	**Variable**	**Measurement Tool**	**Level of Measurement**	**Statistical Test**
2. Controlling for the severity of dementia and comorbid problems, the closeness of IADL and ADL caregivers (IV) as well as the size of caregiver core network will predict the density of IADL and ADL care provided (DV).	PWDs	IV: closeness of IADL and ADL caregivers and size of caregiver core network DV: density of IADL and ADL care provided	- MMSE - SCQ - Self-report	- Nominal - Interval - Ordinal	- **Mann-Whitney U test to** examine the difference between closeness of ADL &IADL/ size of core network and ADL &IADL density of care - Spearman's rank-order correlation coefficient to identify the strength and direction of the association between closeness of ADL &IADL/ size of core network and ADL &IADL density of care

Limitations

Some of the anticipated limitations of this study include the study design, sample size, difficulty getting information about clients, and uncontrolled variables that may contribute to agitation levels. A correlation study focuses on the relationships between variables but lacks the ability to assess causation between variables. Moreover, the self-report method can increase the possibility of untruths and recall bias. Furthermore, the small sample size may not accurately represent the target population. The generalizability of the results may also be limited, as the investigation is focused on a specific region.

Uncontrolled variables that contributed to the clients' agitation levels was also a limitation of this study. These variables included outside factors that I cannot control and that can affect the results of the study. These uncontrolled variables may include unexpected visitors, accidents, and pain. In addition, reports of agitation from caregivers may be biased and lead to measurement error.

Ethical Considerations

The human subjects were protected and there was no collection of sensitive information. Waiver to obtain informed consent was obtained from IRB. The consent process would take a long time and could burden people with dementia and their caregivers unnecessarily. Care for older parents in Oman automatically becomes a shared responsibility among children, as a moral code of conduct to honor and respect elders. Those immediate family members who are also the primary caregivers also play the role of decision makers for older parents with dementia (Hafiz, 2015). All information collected from the medical record or via interview only contained code numbers for each separate medical record reviewed. That code number cannot be linked back to the subject. All data in reports, presentations or publications of the study will be presented in summary form. All data will be kept in password-protected computers with no identifiers. Only the SPI has access to this data. The SPI obtained both written informed consent and verbal assent from caregivers and clients, and was sure to provide explanations for clients and gave them the opportunity to ask questions.

Chapter Summary

The goal of this cross-sectional descriptive correlational study was to fill the current gaps in the literature about the associations between size and frequency of contact of core network with the agitation and affect of people with dementia. This chapter provided an overview of the sample, data collection procedures, and instruments used in this dissertation study. Moreover, this chapter provided the proposed data analysis techniques for this study. At the end, this chapter discussed the limitations and some ethical considerations for this proposed dissertation study.

CHAPTER 4

Chapter Introduction

This chapter includes the third manuscript of this dissertation. The research study manuscript will include a description of the study design, setting, sample, measurement methods, statistical analysis procedures, and study results of research questions and the study hypotheses. The findings on the associations between size of core network and frequency of contact with agitation and affect are discussed. Limitations and implications of this study will also be presented. After the manuscript, findings on the association of size of core network and frequency of contact with agitation and affect in relation to gender, dementia level, and comorbid problems will be reported under the heading Additional Findings.

Manuscript 3: The Correlation of Size of Core Network And Frequency of Contacts With Agitation And Positive Affect in Elderly with Dementia in Oman

Introduction to the Problem

Agitated behavior among persons with dementia (PWDs) is associated with multiple negative consequences. The need-driven dementia-compromised behavior (NDB) model indicates that agitation not only leads to negative outcomes but also that agitation may be a consequence of an unmet need (Algase, 1996). The NDB model suggests that agitation and negative outcomes associated with it can be tempered by understanding the needs of PWDs.

This study was informed by the NDB model, the socioemotional selectivity theory, and the progressively lowered stress threshold (PLST) model. The models explain why the size of the person's activities of daily living (ADL) core network and frequency of contact with the ADL core network may predict agitation and affect. A lower-density core network with a higher frequency of contact may be better at identifying and treating the person's unmet needs. A secondary premise is that the emotional closeness of members of the core network to the care recipient will predict the density of the ADL and instrumental activities of daily living (IADL) care provided. Understanding these relationships is critically important to designing interventions in Oman for home health care and assigning community health nurses.

While multiple psychotropic drugs have been used to suppress agitated behavior in older adults, these drugs have serious side-effect profiles (Johnson et al., 2011). Psychotropic drugs are considered inappropriate for use as chemical restraints to treat agitation because of these drugs' failure to address the patients' unmet needs (Howard et al., 2001). Multiple nondrug therapies have been tested to treat agitation, but their efficacy has been limited (Johnson et al., 2011). Among older adult patients with dementia (PWDs), the size and frequency of their contact with their core network (the more intimate part of their social network) may affect the identification and treatment of their unmet needs and the amount of stress they experience. Several geriatric theories suggest that older adults may prefer a smaller core network with a higher frequency of contact, which may stress the person less and be a better way of identifying and treating the person's unmet needs (Burgio et al., 2000).

Background

Dementia is a devastating neurological disorder that has become a major public health concern around the world. The agitated behaviors of PWDs are associated with multiple negative consequences. Some authors have described agitation consequences as an eruption of aggressive behavior (Dewing, 2010), Other researchers have categorized them as consequences for patients, such as distress, frustration, and institutionalization; consequences for caregivers, such as discomfort, frustration, and difficulties in family function (Dewing, 2010), and other consequences, including high costs and high patient/staff ratios (Cohen-Mansfield & Billig 1986;

Kong, 2005).

The burden of dementia will take the forefront among aging issues as the geriatric population increases worldwide. It is estimated that more than 50% of older adults living in U.S. long-term care facilities have dementia (Dewing, 2010), and 86% of those in the United States who are diagnosed with dementia demonstrate aggression (Taft, 1989). Dementia is also expected to become a major public health issue in Arab countries; among nursing home residents, 60% of those in Lebanon and 14% of those in Qatar were found to have dementia (Benamer, 2014). In Oman, the older adult population represents 5.2% of the total population, and this figure is expected to reach 10% by 2025 and 20% by 2050 (Bhattacharjee, 2013). This study was conducted in Oman, a country in which no specific data yet exist about older adult PWD.. However, data from the United States, the United Kingdom, and other Arab countries reflect the prevalence of dementia in this age group.

This study aimed to examine the association between the size of and frequency of contact with the ADL core network and the agitation and affect of PWDs (Main Hypothesis). In addition, there were two secondary hypotheses. First, we examined whether the size of and frequency of contact with the IADL core network was associated with the agitation and affect of PWDs. We also examined whether the emotional closeness of the ADL and IADL caregivers predicted the density of the ADL and IADL networks and the amount of care they provided. Three study questions examined were:

4) What is the level of agitation among older adult PWDs in Oman?
5) With what frequency do older adult PWDs have contact with their ADL and IADL core networks?
6) Are there differences in the size of ADL and IADL core networks between those with

early- and later-stage dementia?

In addition, one main hypothesis and two secondary hypotheses were tested.

Main hypothesis.

1. Controlling for the severity of dementia and comorbid problems, the size of (IV) and frequency (IV) of contact with the ADL core network will predict the agitation (DV) and affect (DV) of PWDs.

Secondary hypotheses.

3. Controlling for the severity of dementia and comorbid problems, the size of (IV) and frequency (IV) of contact with the IADL core network (IV) will predict the agitation (DV) and affect (DV) of PWDs.
4. Controlling for the severity of dementia and comorbid problems, the closeness of IADL and ADL caregivers (IV) as well as the size of caregiver core networks will predict the density of IADL and ADL care provided (DV).

METHODS

Study Design, Sample, Setting

A descriptive-correlational design was used in this study, which was conducted in Batinah South region of Oman. The study used convenience sampling. The convenience sample included older adults with dementia who are living in their homes in the community and yielded a sample size of 98 older adults with dementia and their caregivers was included in the study based on the following inclusion criteria: (1) adults aged 65 and older (the most commonly used age to signal older adulthood); with (2) dementia, as measured by the Mini Mental Status Exam (MMSE); and (3) caregivers who understand Arabic in a way that is evident during the consent procedures. Eligible older adults with dementia or their caregivers completed the informed consent and waiver after consent was obtained. Institutional Review Board approval was obtained from the United States and Oman prior to beginning the study. All of the information collected was de-identified and securely stored.

Measures

Two of the predictor measures (CMAI and PANAS) were translated to Arabic, then cross-checked with an English language professor at the Sultan Qaboos University.

Outcome instruments.

Agitation. Agitation was measured using the CMAI (Cohen-Mansfield, Marx, & Rosenthal, 1989). The CMAI is a rating scale consisting of 29 items to be completed in a structured interview. The measurement will be ordinal, follow consent procedures, and be measured once. According to Cohen-Mansfield, Marx, and Rosenthal (1989), the CMAI is most commonly used to assess agitation in older adults. In a nursing home, the average internal consistency reliability is $\kappa = .92$ (.88–.92). Factor analysis revealed four factors representing agitation: physically nonaggressive behaviors, verbally nonaggressive behaviors, physically aggressive behaviors, and verbally aggressive behaviors. Cronbach's alpha for the subscales ranges from 0.84 to 0.89.

In this study, Cronbach's alpha on the 29 CMAI items showed high reliability at $\kappa = .94$, which is above .70 and, therefore, acceptable. Running Cronbach's alpha on the four subscale factors based on Cohen-Mansfield's classification also resulted in reliability coefficients as follows: physically nonaggressive behaviors, $\kappa = .84$; verbally nonaggressive behaviors, $\kappa = .77$; physically aggressive behaviors, $\kappa = .90$; and verbally aggressive behaviors, $\kappa = .80$.

Affect. Positive affect and negative affect were measured using the Positive and Negative Affect Schedule (PANAS). The PANAS is a brief ordinal scale developed by Watson, Clark, and

Tellegen (1988) comprising 20 items, with 10 items that measure positive affect. Each item is rated on a 5-point Likert scale, ranging from 1 = *very slightly or not at all* to 5 = *extremely*, to measure the extent to which the affect has been experienced in a specified time frame (Crawford & Henry, 2004). The Cronbach's alpha values obtained ranged from .86 to .90 for positive affect and .84 to .87 for negative affect (Watson et al., 1988). The affect can be measured in various contexts, such as at the present moment or in past periods. Thus, the scale can measure state affect.

Amount of care. Amount of care is the density of care, as defined by hours (hr) of care provided per week. In this case, lower density of caregiving indicates fewer *hr* of care. Density of caregiving was determined via self-report (from the client or ADL and IADL caregiver).

Predictor instruments.

ADL and IADL core network. The ADL and IADL core networks were measured using a checklist of caregiver activities to separate the two categories. This checklist includes seven IADLs and five ADLs, as defined by Katz (1963) and Lawton et al. (1998). The Katz index of ADLs has good internal consistency, with a Cronbach's α of .92 (Glajchen, Homel, Tsoi, Chan, & Portenoy, 2013).

Closeness. Closeness was measured using the Social Convoy Questionnaire (SCQ; Lang, 1996). Kahn and Antonucci developed the SCQ in 1980 using a circle diagram to identify the closeness of PWDs to others according to the circles provided. The circles are categorized as inner ("Feel very close, so close that it would be hard to imagine life without"); middle ("Don't feel quite so close as those in the inner circle, but are still very close"); and outer ("Feel less close but who are still important"). The test-retest reliability for a community sample of adults and children was .80, while the interrater reliability between samples was .71 (Dunn et al., 2005).

Size of network. The size of the PWDs' networks was determined via a report from the client or the caregivers through the ADL and IADL checklist.

Frequency of contact. The average frequency of contact with one or several ADL and IADL caregivers in days during a typical 30-day month was determined via report from the client or the caregivers.

Other instruments.

Comorbid problems. Comorbid problems were measured using the Cumulative Illness Rating Scale for Geriatrics (CIRS-G; Miller et al., 1992). The CIRS was initially developed by Linn et al. (1968) and was later revised by Miller et al. (1992) to reflect common health problems among older adults. The CIRS-G scoring system measures morbidity or chronic medical illness burden using 14 items representing individual body systems while considering the severity of chronic diseases. The severity ratings are 0 (*no problem affecting that system*), 1 (*current mild problem or past significant problem*), 2 (*moderate disability or morbidity* and/or *requires first-line therapy*), 3 (*severe problem* and/or *constant and significant disability* and/or *hard-to-control chronic problems*), and 4 (*extremely severe problem* and/or *immediate treatment required* and/or *organ failure* and/or *severe functional impairment*). The CIRS-G has been tested with older adults. It provides a quantitative rating of chronic illness burden geared toward geriatric patients, and it can be successfully applied in medically and psychiatrically impaired older adult subjects. This modified CIRS was operationalized with a manual of guidelines. It showed good interrater reliability (i.e., intraclass correlations of .78 and .88) in a subsample of 10 outpatients and 10 inpatients for total scores (Miller et al., 1992).

Age and Gender. Age (in years) and gender were determined via report from the client or caregiver.

Severity of dementia. The severity of dementia was measured using the MMSE. This tool is easy to administer, is widely used, and has a substantial number of validity and reliability studies supporting its use. The MMSE consists of 30 questions that measure orientation, registration, recall, attention, calculation, and language (Ellis, 2006). Scores on the MMSE range from 0 to 30, and higher scores indicate greater cognitive ability (Ellis, 2006). Test-retest reliability on a standardization study after a 24-hr follow-up was reported as .89 for the same examiner, and .83 for a new examiner (Folstein et al., 1975).

Procedures

There were two visits made to participants homes, which were one week a part done by the Student Primary Investigator (SPI). In the first visit, the SPI welcomed the caregivers and clients, and distributed and explained the CMAI and PANAS measurement tools. Also, the Mental Status Exam (MMSE) was administered for those who did not had it done in the past three months prior to data collection.

The caregiver observed the PWD for agitation. In Visit 1, the SPI asked the PWD or the caregiver how much agitated behavior the participant had experienced and how he or she would describe the participant's affect in the previous week (CMAI #1). The caregivers had the tools for a week prior to Visit 2 by the SPI. In Visit 2, the SPI conducted a structured interview (CMAI #2) based on the previous week's agitation. Caregivers also completed the Social Convoy Questionnaire (SCQ) during the SPI second visit.

Statistical Analysis

Data analyses were conducted using SPSS® version 23. Initially, the distributions of each outcome variable were analyzed using frequency distributions, means, and standard deviations. Scatter plots for each IV/DV combination were checked for possible nonlinear relationships. The data analysis plan was revised due to nonlinearity. Because variables' distributions were severely skewed, nonparametric tests and medians and interquartile ranges were used to report descriptive results. Descriptive statistics such as mean, standard deviation, frequencies, and range score were used to summarize the sample's characteristics.

The Mann-Whitney U test was used to examine the difference between ADL and IADL size of core network/ frequency of contact, and between agitations and affect. The differences between closeness, size of core network, and density of care were also tested. A Spearman's rank-order correlation coefficient was used to identify the strength and direction of the association between the size of core network/ frequency of contact, and agitation and affect. The association between closeness/ size of core network and density of care was also examined.

Result

Sample Characteristics

Older adult participant characteristics are shown in Table 4. Ninety-eight participants were included in the analysis. Participants' ages ranged from 65 to 106 with a mean of 80 years (*SD* = 9.0). Participants were mostly female (*n* = 63, 63.3%).

Table 4
Demographic Characteristics of Sample (*N* = 98)

Characteristic	*M*	*SD*	Range
Age in years	80	9	65–106
Characteristic	*n*	%	
Gender			
Male	36	36.7	
Female	62	63.3	

Dementia scores, as measured by the MMSE, ranged from 0 to 27 with a mean of 4.63 (*SD* = 6.0). Participants were divided in two groups based on severity of dementia. Seventy-seven participants were classified with severe dementia with scores of 0 to 10. The remaining 21 were classified as questionable/mild/moderate dementia with scores from 11 to 27. Sixty percent (*n* = 46) of the total number with severe dementia was female, and only 24% (*n* = 5) of the participants with questionable/mild/moderate dementia were male.

Description of Level of Agitation Among PWDs in Oman

Agitation levels among older PWDs in Oman ranged from 1 to 6 with a median of 1.75 for all participants (*M* = 2.2, *SD* = 1.17). Table 5 shows detailed descriptive results of the four CMAI factors: physically nonaggressive behavior, physically aggressive behavior, verbally nonaggressive behavior, and verbally aggressive behavior.

Table 5
Description of CMAI Factors

	N	Minimum	Maximum	Median	Mean	Std. Deviation	Cronbach's alpha
Physically nonaggressive behavior	98	1.0	6.0	1.8	2.3	1.27	0.847
Physically aggressive behavior	98	1.0	6.0	1.3	1.8	1.14	0.904
Verbally nonaggressive behavior	98	1.0	7.0	2.5	2.8	1.75	0.771
Verbally aggressive behavior	98	1.0	7.0	2.0	2.6	1.71	0.808
CMAI TOTAL	98	1.0	6.0	1.8	2.2	1.2	0.942

Note: CMAI = Cohen-Mansfield Agitation Inventory, long form

Verbally nonaggressive behavior was the most frequent type of agitated behavior with a mean score of 2.8 (*SD* = 1.75, range 1–7); physically aggressive behavior was the least frequent type of agitation behavior among these participants with a mean score of 1.8 (*SD* = 1.14, range

1–6.

Among those factors, the most frequently exhibited physically nonaggressive agitated behaviors were general restlessness (4.24; *SD* = 2.14, range 1–7); performing repetitious mannerisms (2.52; *SD* = 2.3, range 1–7); and pacing, 2.45 (*SD* = 2.2, range 1–7). The most frequently exhibited physically aggressive behaviors were spitting (3.19; *SD* = 2.59, range 1–7); grabbing on to people (2.14; *SD* = 1.96, range 1–7); and hitting (2.04; *SD* = 1.87, range 1–7).

Among verbally nonaggressive behaviors, repetitive sentences or questions (3.45; *SD* = 2.50, range 1–7) were the most frequently exhibited behavior, followed by constant unwanted requests for attention (3.29; *SD* = 2.52, range 1–7) and complaining (2.42; *SD* = 2.13, range 1–7). Lastly, the most frequently exhibited verbally aggressive behaviors were strange noises (3.08; *SD* = 2.23, range 1–7); cursing or verbal aggression (2.91; *SD* = 2.39, range 1–7), and screaming (2.59; *SD* = 2.2, range 1–7).

Descriptive statistical analysis showed no statistical significance in the distribution of CMAI totals between females and males, but there was a statistically significant difference in the distribution of the four factors of CMAI. The means of all four factors were higher in females than males. Table 6 shows the descriptive statistics of agitation and gender difference.

Table 6

Description of Agitation and Gender Difference

	Physically Nonaggressive Behavior		Physically Aggressive Behavior		Verbally Nonaggressive Behavior		Verbally Aggressive Behavior	
	Male	Female	Male	Female	Male	Female	Male	Female
N	36	62	36	62	36	62	36	62
Mean	1.89	2.52	1.59	1.90	2.50	2.97	2.16	2.80
Std. Deviation	0.97	1.38	0.97	1.22	1.64	1.81	1.41	1.83

According to Mann-Whitney U test results for independent samples, factor 1 agitation scores were distributed differently between male and female older adults with dementia (0.019*, p* > .05) with mean rank (*male* = 42, *female* = 54). Females exhibited 2.6 times more physically nonaggressive behaviors than males.

Description of PWDs' Frequency of Contact With Their ADL and IADL Core Networks

Frequency of contact with ADL and IADL core networks was measured in days during a typical 30-day month. The mean of PWDs' frequency of contact with their ADL and IADL core networks was 30 and 25 days/month, respectively, for both. Results show that 99% (*n* = 97) of PWDs had contact 30 days/month with their ADL core network and 79% (*n* = 77) had contact 30 days/month with their IADL core network.

The Mann-Whitney U test independent sample results showed that ADL and IADL frequency of contact was the same across the males and females of older adults with dementia (0.446 and 0.590, respectively; *p* > .05).

Results showed that female older adults with dementia with high scores in caregiver frequency of contact had lower agitation levels, physically aggressive behaviors, and verbally aggressive behaviors. Though not statistically significant, a negative correlation was found between frequency of contact and CMAI total (*r* = -.289, *p* > .05), factor 2 (*r* = -.337, *p* > .05), and factor 4 (*r* = -.262, *p* > .05) in females, according to Spearman's rank-order test. No similar correlation was found in males.

Description of the Size of ADL and IADL Core Networks Between Those With Early- and Later-Stage Dementia

Descriptive statistics showed that there was a statistically significant difference between the size of ADL and IADL core networks among the sample size (*P* < 0.001). The mean score of the size of ADL and IADL core networks were 5.67 (*SD* = 3.04) and 1.96 (*SD* = 1.23), respectively. However, there was no significant difference in size distribution of ADL and IADL core networks between those with early- and later-stage dementia (*p* = 0.094 and 0.952, respectively). The mean score for ADL size in the severe stage of dementia was 5.47 (*SD* = 3.12), and it was 1.97 (*SD* = 1.27) for the size of IADL core network in the same MMSE group. The mean score for ADL size in the questionable/moderate stage of dementia was 6.43 (*SD* = 2.67), and it was 1.90 (*SD* = 1.09) for the size of IADL core network in the same MMSE group.

Main Hypothesis: Association of Size of ADL Core Network and Frequency of Contact as Predictors of Agitation and Affect

The relationship between ADL size of core network/frequency of contact and agitation and affect is shown in Table 7. A Spearman's rank-order correlation was used. The notion that size of core network and frequency of contact with the ADL core network predicted agitation and affect was not supported. The test showed that the size of the ADL core network and agitation (*p* = 0.886) and affect (positive: *p* = 0.050; negative: *p* = 0.521) did not correlate. Similarly, there was no correlation between frequency of contact with the ADL core network and agitation (*p* = 0.623) and affect (positive: *p* = 0.805; negative: *p* = 0.297).

Table 7

Correlation of Size of/Frequency of Contact With ADL Core Network With Agitation and Affect

Classification		CMAI Total	Positive Affect	Negative Affect	*n*
Size of ADL	Correlation coefficient	-.015	.198	.066	98
	Sig	.886	.050	.521	
Frequency of contact	Correlation coefficient	.050	.025	-.106	98
	Sig	.623	.805	.297	

Secondary Hypothesis 1: Association of Size of IADL Core Network and Frequency of Contact as Predictors of Agitation and Affect

The relationship between IADL size of core network and frequency of contact with agitation and affect is shown in Table 8. A Spearman's rank-order correlation was used. The notion that size of and frequency of contact with the IADL core network predicted agitation and affect was not supported. The test showed that the size of the IADL core network and agitation (*p* = 0.538) and affect (positive: *p* = 0.708; negative: *p* = 0.977) did not correlate. Similarly, there was no correlation between frequency of contact with the IADL core network and agitation (*p* = 0.196) and affect (positive: *p* = 0.058; negative: *p* = 0.106).

Table 8

Correlation of Size of/Frequency of Contact With IADL Core Network with Agitation and Affect

Classification		CMAI Total	Positive Affect	Negative Affect	*n*
Size of IADL	Correlation coefficient	-.063	.038	-.003	98
	Sig	.538	.708	.977	
Frequency of contact	Correlation coefficient	-.132	-.192	-.164	98
	Sig	.196	.058	.106	

Secondary Hypothesis 2: Association of Closeness of ADL & IADL Caregivers and Size of Caregiver Core Network as Predictors of Density of Care

In this sample, the ADL1 closeness scores ranged from 0 to 13 with a mean of 3.69 (*SD* = 2.56). The ADL2 closeness scores ranged from 0 to 11 with a mean of 1.27 (*SD* = 1.96). The ADL3 closeness scores ranged from 0 to 4 with a mean of 0.76 (*SD* = 1.07) as illustrated in Figure 4 below.

The IADL1 closeness scores ranged from 0 to 9 with a mean of 1.67 (*SD* = 1.39). The IADL2 closeness scores ranged from 0 to 3 with a mean of 0.19 (*SD* = 0.60). The IADL3 closeness scores ranged from 0 to 3 with a mean of 0.17 (*SD* = 0.52).

A Spearman's rank-order correlation was used to examine the PWDs' relationship to the closeness of ADL and IADL, the size of core network, and the density of ADL and IADL care providers. The notion that closeness and size of ADL and IADL core networks predicted the density of care provided was not supported. Closeness of ADL1, ADL2, ADL3 and the size of core network did not correlate with the density of ADL care provided.

Closeness of IADL1 and IADL2 and the size of core network did not correlate with the IADL density of care provided. There was only one significant negative correlation found between closeness of IADL3 and density of IADL care provided ($r = -.480$, $p < .01$).

Discussion

No evidence in the literature shows the contribution of the ADL and IADL core networks to agitation or affect in older adults with dementia. It was not known whether associations exist between agitation symptoms and the size of a person's core network or the frequency of contact with care providers in the core network.

Unlike what was hypothesized in this study, results did not show a significant association between size of and frequency of contact with ADL and IADL core networks and agitation and affect of PWDs. Also, unlike what was hypothesized in this study, results did not show a significant association between closeness of IADL and ADL caregivers or the size of caregiver core networks and the density of IADL and ADL care provided.

In this study, the level of agitation in Oman was similar to the values observed in most other studies in other countries (Calenti et al., 2016; Pelletier & Landreville, 2007). Almost all participants had exhibited one or more agitated behaviors. This might be due to the fact that agitated behaviors increase as the severity of dementia progresses and also to the fact that this study included people with severe stages of dementia who were already having some health or psychological problems. In this study also, verbally nonaggressive behavior was the most frequent type of agitated behavior. Among verbally nonaggressive behaviors, repetitive sentences or questions were the most frequently exhibited behavior. This was congruent with other studies as verbally nonaggressive behavior was the most identified behavior among PWDs (Pelletier & Landreville, 2007).

In this study, some gender differences were found in relation to agitation and agitation factors (CMAI factors: aggressive physical behaviors, nonaggressive physical behaviors, verbal aggressive behaviors, and verbal nonaggressive behaviors). The means of all four CMAI factors were higher in females than males. Unlike the results of other studies from the literature (Pelletier & Landreville, 2007; Qiu et al., 2009), in this study women demonstrated significantly higher aggressive and nonaggressive physical and verbal behaviors than men. Although the above studies from the literature stated that males are more likely to be aggressive than females, this study showed that females exhibited 2.6 times more physically nonaggressive behaviors than males. This might be due to the fact that the number of females was slightly higher than males in this study. Statistics show that dementia-related diseases significantly affect more women than men (Pelletier & Landreville, 2007). Also, this might be due to the fact that women in Oman take on more of the burden of life stressors like raising many children, looking after grandchildren, and working hard for a living.

While the study did not demonstrate significant associations between the size of and frequency of contact with the ADL core network and the agitation and affect of PWDs in total, the results showed a trend for females with dementia. Agitation that included physically aggressive behaviors and verbally aggressive behaviors increased as the frequency of contact decreased in females with dementia. This could be due to some disadvantages of increased frequency of contact, such as disturbing a routine schedule and excess conversation. Existing studies identified factors associated with the unstable emotional statuses of both older people with dementia and their caregivers, such as excess conversation, busy periods, and disturbed social routines (Alvira et al., 2015; Moniz-Cook & Clarke, 2011).

On the other hand, the results showed a trend for males with dementia in relation to size of ADL core network and affect. Negative affect, such as feeling irritable, ashamed, nervous, jittery, afraid, guilty, and hostile, increases as ADL core network size increases. These results are congruent with the theoretical framework of the socioemotional selectivity theory (SST). According to the SST, the size of a person's core network decreases as he or she ages (Penningroth & Scott, 2012). This decreased number of contacts is the intentional result of a tendency to become more selective about who is in the social network and to increase utilitarian attention on present needs rather than on future plans (Penningroth & Scott, 2012). Also, de Vocht et al. (2015) found that one-on-one interaction tailored to individual preferences, which is easily implemented in home settings, significantly improved the positive interactive behaviors of care-dependent residents with dementia during the intervention.

In this study, there were differences in the sizes of ADL and IADL core networks, but there was no significant difference in the size of ADL and IADL core networks between those with early stages of dementia and severe stages of dementia. Also, results of this study showed no significant difference in the distribution of the ADL and IADL frequency of contact across the early and severe stages of dementia. Caregivers continued to care and have the same frequency of contact throughout the progress of dementia. This caregiver behavior may be influenced by the nature of the Omani Islamic culture. The elderly are regarded as very valuable and are well respected in their families. It is very rare to see youth dropping their frail parents at hospitals or social centers. Also, this study was conducted on PWD who live at home, and the majority of them live with their primary caregivers, which makes the frequency of their contact higher throughout the process. This result is not congruent with other studies that have explored caregiving for PWDs. It is estimated that one third of all people with dementia live on their own (Mirando-Costillo, 2010). In the United States, this means that roughly one in seven Americans with dementia lives alone (Alzheimer's Association, 2015). Studies have also shown that social network size, worldwide, decreases not only because of aging but also due to the physical living transition that PWDs face, such as moving from living in their homes to a nursing home. Due to the lack of family caregiver resources and lack of caregiver support, many older adult PWDs are institutionalized in nursing homes (Wang et al., 2014).

The study did not show a significant correlation between closeness and size of ADL and IADL core networks and density of care in PWDs overall. This might be because care for older parents becomes automatically a shared responsibility among children as a moral code of conduct to honor and respect elders. Those immediate family members who are also the primary caregivers also play the role of decision makers for older parents with dementia (Hafiz, 2015). Unlike what was found in this study, other studies have found that un-close and external groups can create stress on the cognitive abilities of those with dementia (Zeisel et al., 2003) by placing these older adults in a position to receive care from persons other than their immediate core network. This may be overwhelming and can result in increased agitation and poor health, eventually interfering with care delivery. Therefore, these results are not congruent with those studies that have shown that older adults prefer a smaller, closer social network that provides them with meaningful interactions (Mark, 2012; Penningroth & Scott, 2012).

Limitations

The study has several limitations in study design, sample size, and methods. Considering the fact that this is a correlation study that focuses on the relationships between variables, it lacks the ability to assess causation between the variables. The small sample size may have had limited statistical power and led to a Type II error. Moreover, using a self-report method increased the possibility of untruths and recall bias. Furthermore, the small sample size may have contributed to an inaccurate representation of the target population. The generalizability of the results may also be limited, as the investigation is focused on a specific region.

Uncontrolled variables that contributed to the participants' agitation levels could have also been a limitation of this study. These variables include outside factors that I cannot control and that could affect the results of the study. These uncontrolled variables may have included unexpected visitors, accidents, and pain. In addition, reports of agitation from caregivers may have had some bias and led to measurement error.

Implications and Recommendations for Future Research

The findings of this study have important implications for recognizing the level of agitation among older adults with dementia in Oman. The results of this dissertation will inform the Omani government that there is an urgent need to address the issue of agitation in older adults with dementia in the next 5-year plan due to the increasing rates of dementia among older adults and the related consequences. Managing agitation in older adults with dementia is a difficult task for caregivers in Oman and in other countries in the region. Different factors make it challenging, including a lack of interest in providing care for the challenged patient, a lack of trained personnel, and a lack of standardized scales (Halabi & Zafar, 2010).

Based on the evidence provided above, the statistics included might serve to attract the Ministry of Health's attention so that it will intervene seriously in Oman by addressing a plan to target the specific issue of dementia care. The Ministry of Health might then allocate a budget for further future research projects on dementia, networks, and agitation in older adults.

Conclusion

While the study did not demonstrate significant associations between the size of core networks and frequency of contact and agitation and affect, the results still demonstrated a correlation between those variables when analysis was conducted based on gender and MMSE grouping. Although this study had examined the relationship between agitation in PWDs and either the size of the core network or the frequency of contact, results raised awareness about issues such as cultural differences and gender differences need further exploration.

Additional Findings

Introduction

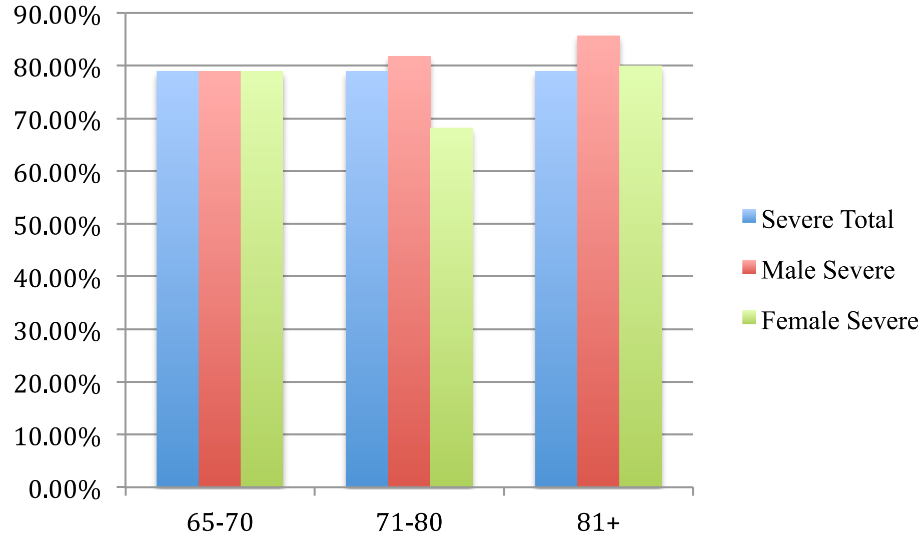
This section of the dissertation includes the results of additional findings of the study. Findings on the associations between size of core network and frequency of contact with agitation and affect are discussed in relation to gender, dementia level, and comorbid problems will be reported. Then a discussion of the main findings will be presented.

Results

Level of Agitation

Description of level of agitation in relation to dementia level

There were no significant differences in MMSE distribution between male and female older adults with dementia aged 65 to 70 years old. Cross-tab results showed that the number of males age 71 and above in late-stage dementia is higher than females within the same age group. About 81% of the males age 71 to 80 were in a late stage of dementia. Figure 3 graphically presents an illustration of MMSE severe scores by gender and age group.



Note: Group as a percent of total participants.

Figure 3. MMSE severe scores by gender and age group.

The Mann-Whitney U test independent samples showed that agitation scores did not differ between those with early and late stages of dementia in males and females (0.062, *p* > .05).

Description of level of agitation in relation to closeness of core network

A negative correlation was found between agitation and closeness of ADL2 as identified by Spearman's rank-order correlation test ($r = .205$; $p < .01$). Agitation increases as the closeness of the ADL2 caregiver decreases. Results showed no significant relationship between agitation and ADL1 or ADL3 closeness.

Description of level of agitation in relation to comorbid problems

As shown in Table 9, descriptive statistics of agitation in relation to comorbid problems in older adults with dementia showed a higher mean of CMAI factor 4 (verbally aggressive behavior) than the other factors in those with no severe problems and those with one or more comorbid problems ($p = .025$).

Table 9
Mean of CMAI Factors by Comorbid Problem

	Severe Comorbidity Problem Groups		Mann-Whitney U	*P*
	No severe problem Mean(Std. Deviation)	One or more problems Mean(Std. Deviation)		
Mean frequency of physically nonaggressive behaviors	2.18(1.19)	2.41(1.27)	821.000	.210
Mean frequency of physically aggressive behaviors	1.71(1.07)	2.15(1.4)	778.500	.107
Mean frequency of verbally nonaggressive behaviors	2.72(1.75)	3.01(1.79)	882.000	.437
Mean frequency of verbally aggressive behaviors	2.36(1.65)	3.08(1.78)	698.500	.025

Table 10 shows that older adults with dementia who scored high in having musculoskeletal/integument problems had lower agitation scores. A negative correlation was found between CMAI total and scores of musculoskeletal/integument problems according to Spearman's rank-order test (*r* = -.247, *p* < .01). Also, participants who scored high in having psychiatric illnesses had higher agitation levels. A moderate positive correlation was found between CMAI total and psychiatric illnesses (*r* = .430, *p* < .01).

Table 10
Correlation of CMAI and Comorbid Problems

	CMAI	
	Correlation Coefficient	Sig. (2-tailed)
Heart	-.045	.657
Vascular	.100	.328
Hematopoietic	.082	.422
Respiratory	.006	.951
Eyes, ears, nose, throat, larynx	-.022	.826
Upper gastrointestinal tract	-.010	.919
Lower gastrointestinal tract	.103	.315
Renal	.090	.379
Genitourinary	.155	.127
Musculoskeletal/integument	-.247-*	.014
Neurological	.097	.344
Endocrine/metabolic	-.035	.735
Psychiatric illness	.430**	.000

Note: * indicate significance of (*p* < .01).

Frequency of Contact

Description of frequency of contact in relation to dementia level

There was no significant difference in the distribution of the ADL frequency of contact across the early and late stages of dementia (0.056, $p > .05$), and there was also no significant difference in the distribution of the IADL frequency of contact across the early and late stages of dementia (0.704, $p > .05$) according to the independent samples Mann-Whitney U test.

Size of ADL and IADL Core Network

Description of size of ADL and IADL core network in relation to gender

Descriptive statistical results were not statistically significant and showed that the mean size of ADL and IADL core network was the same across male and female older adults with dementia. Details are presented in Table 11 below.

Table 11
Describing ADL and IADL Size Between Males and Females

Gender		*N*	Minimum	Maximum	Mean	Std. Deviation
Male	Number of ADL caregivers	36	1	17	6.44	3.581
	Number of IADL caregivers	36	1	6	2.19	1.489
	Valid *N* (listwise)	36				
Female	Number of ADL caregivers	62	1	13	5.23	2.620
	Number of IADL caregivers	62	1	4	1.82	1.048
	Valid *N* (listwise)	62				

Note: Number of caregivers = Size of core network

Description of size of ADL and IADL core network in relation to dementia level

Running the Mann-Whitney U test identified that there was a significant difference in the size of the ADL core networks among females in both early and late stages of dementia (0.048, *p*

> .05) and no difference in the size of IADL core networks between males and females in all stages of dementia.

Closeness of Core Network

Description of closeness of core network in relation to gender

A Spearman's rank-order correlation was then used to examine the participants' closeness of ADL and IADL, size of core network, and density of ADL and IADL care providers. Male and female older adults with dementia who had a larger ADL core network size scored high in the distribution for ADL1 and ADL2 closeness. A positive correlation was found between closeness of ADL1 and size of ADL core network in both male and female older adults with dementia (*male*: $r = .775$; *female*: $r = .564$, $p < .01$) and ADL2 (*male*: $r = .587$; *female*: $r = .534$, $p < .01$), but no significant correlation was found with density of care in both groups.

A significant positive correlation was found between closeness of IADL1 and IADL3 ($r = .697$ and .337, $p < .01$) and size of IADL core network in male PWDs, and between closeness of IADL1 and IADL2 ($r =$. 708 and .283, $p < .01$) in female PWDs. A negative correlation was found between closeness of IADL3 ($r = -.562$, $p < .01$) and density of care in female PWDs.

Description of closeness of core network in relation to dementia Level

A Spearman's rank-order correlation showed a positive correlation between ADL core network and closeness of ADL1 ($r = .703$, $p < .01$) with size of ADL core network in older adults in a severe stage of dementia, and with closeness of ADL2 (early: $r = .595$; severe: $r = .508$, $p < .01$) in both early and severe stages of dementia. Density of care, however, had no significant correlation with all three levels of ADL closeness at any stage of dementia.

There was also a significant positive correlation found between closeness of IADL1 (early: $r = .735$; severe: $r = .690$, $p < .01$) and size of IADL core network in both early and severe stages of dementia. On the other hand, density of care had a significant negative correlation with IADL3 (early: $r = -.461$; severe: $r = -.485$, $p < .01$) in both early and severe stages of dementia. Females in a severe stage of dementia had a higher negative correlation between closeness IADL3 and size of IADL core network ($r = -.622$, $p < .01$). Unlike males, females with early stages of dementia had a positive correlation between closeness of IADL1 and size of IADL core network ($r = .788$, $p < .01$). Also, females with early stages of dementia had a positive correlation between closeness of ADL2 and size of ADL core network ($r = .557$, $p < .01$).

Description of affect in relation to gender

Affect was observed using the PANAS instrument. The caregiver observed the PWD for positive and negative affect. In Visit 1, the SPI asked about participants' affect in the previous week (PANAS #1). The caregivers had the tools for a week prior to Visit 2 by the SPI. The SPI did a structured interview for PANAS #2 based on the previous week's affect.

Results showed that male older adults with dementia who had a larger ADL core network scored higher in negative affect. A positive correlation was found between size of ADL core network and negative affect in male older adults with dementia ($r = .488$, $p < .01$) according to Spearman's rank-order correlation. But there was no correlation between size of ADL core network and frequency of contact and affect in females. Also, there was a negative correlation found between the size of IADL core network and negative affect in female older adults with dementia ($r = -.328$, $p < .01$). No similar correlation was found in males.

Description of affect in relation to comorbid problems

Comorbid problems were measured using the CIRS-G (Miller et al., 1992) for the 98 older adults with dementia. Data were obtained from clients' medical records. Results showed that 71.4% of older adults with dementia had no comorbid problems and 26.6% had one or more comorbid problems, where females represented 68% of the category (one or more comorbid problems) (Table 12). Sixteen percent of the 98 PWDs had heart problems; 56% had vascular problems; 11% had respiratory problems; 83% had eye, nose, throat, and larynx problems; 83.7% had musculoskeletal and integument problems; 45% had endocrine and metabolic problems; and 40% had psychiatric illness.

Table 12
Comorbid Problems by Gender

		Gender			
		Male	Female	Total	*P*
Medical diagnosis Mean		4.19(1.83)	3.84(1.88)	3.97(1.86)	.365
Comorbid problems group	No problem *N* (%)	27(38.6%)	43(61.4%)	70(71.4%)	.646
	One or more problems *N* (%)	9(32.1%)	19(67.9%)	28(26.6%)	

About 22 older PWDs (30.6%) with one or more comorbid problems had two or fewer caregivers, and about six older adults (23.1%) from the same group had three or more caregivers (Table 13).

Table 13
Distribution of IADL Core Network/Severity of Comorbid Problems

		Comorbid Problems Groups		
		No problem	One or more problems	*P*
Number of IADL core network	Two or fewer caregivers	50(69.4%)	22(30.6%)	.614
	Three or more caregivers	20(76.9%)	6(23.1%)	
Number(mean) of IADL caregivers		70(2)	28(2)	.348

Discussion

This study showed that majority of older adults with dementia living at homes had no comorbid problems, and less than 30% only had one or more comorbid problems. Previous studies showed that the presence of dementia can make providing care to be more complicated and can worsen existing conditions due to the PWDs' ability to manage a chronic condition (Bunn et. al, 2014). The results of this study were not congruent with other studies that stated that prevalence of comorbid conditions in people with dementia is high. This might be due to the healthy life style that people had in the setting where this study was conducted. People in Batinah South have the opportunity to eat fresh food from what they grow and raise in their farms. Also, people maintain adequate active life style, which is part of their routine like engaging in crafts, or their daily work. Previous studies showed that active life style and to continue working beyond the age of 65 cut the risk of various age related diseases in half where an elderly person are less likely to have high blood pressure, cancer, diabetes, lung and heart disease, stroke, arthritis, and psychiatric problems when continue working (Au & Chen, 2011; Rothwell et al. 2008). The most prevalent comorbidities in this study were vascular problems, eye, nose, throat, and larynx problems, musculoskeletal and integument problems, endocrine and metabolic problems, and psychiatric illness. This is congruent with other studies in the literature that showed that the most high prevalence of comorbid problems in PWD are hypertension, diabetes, stroke and visual impairment (Plou et al., 2014; Schubert et al., 2006).

Moreover, this study showed that older adults with dementia with no severe problems and those with one or more comorbid problems exhibited more verbally aggressive behaviors than other types of agitation. Results of previous studies explained that verbal disturbing behaviors are most prevalent in early stages of chronic diseases and dementia when verbal abilities are still maintained. In contrast, other aggressive behaviors tend to occur in late stages of dementia, when verbal communication is severely compromised (Desai et al., 2001).

In this study, older adults who scored high in having psychiatric illnesses exhibited also higher agitation levels. This might be linked to disease process. Studies showed that agitation manifested with restlessness, wandering, negativism, complaining, cursing and verbal aggression, and others are more common among PWD who also have other psychological problems such as anxiety and depression (Cheong, 2004).

The study did not demonstrate significant difference in the distribution of the ADL and IADL frequency of contact across the early and late stages of dementia. Caregivers continued to care and have the same frequency of contact throughout the progress of dementia. This caregiver behavior is influenced by the nature of the Omani Islamic culture. The elderly are regarded as very valuable and are well respected in their families. It is very rare to see youth dropping their frail parents at hospitals or social centers. Also, this study was conducted on PWDs who live at home, and the majority of them live with their primary caregivers, which makes the frequency of their contact higher throughout the process. This result is not congruent with other studies that have explored caregiving for PWDs. It is estimated that one third of all people with dementia live on their own (Mirando-Costillo, 2010). In the United States, this means that roughly one in seven Americans with dementia lives alone (Alzheimer’s Association, 2015). Studies have also shown that social network size, worldwide, decreases not only because of aging but also due to the physical living transition that PWDs face, such as moving from living in their homes to a nursing home. Due to the lack of family caregiver resources and lack of caregiver support, many older adult PWDs are institutionalized in nursing homes (Wang et al., 2014).

While the study demonstrate significant difference in the size of the ADL core network between males and females in all stages of dementia, the results showed no difference in the size of IADL core networks between males and females in all stages of dementia. However, the results showed a trend for females with dementia in relation to severity of dementia and the size of ADL core network. Significant difference in the size of the ADL core networks among females in both early and late stages of dementia. This might be due to the fact that the number of females was slightly higher than males in this study. Also, most care providers of patient with dementia in Oman were females that include daughters, daughters in law or female paid caregivers and most of them are not employed. Worldwide, women are the predominant care providers of older adults with chronic and mental illnesses (Sharma et al., 2016). Due to culture influence, there is some role conflict when a female caregiver is involved in providing tasks associated with personal care such as bathing, dressing and managing incontinence for a male PWD. Studies had explained that despite the evidence that indicates that women devote greater time compared to men for caring for both male and female older adults, women prefer providing care for the same gender (Sharma et al., 2016).

The results also showed a trend for females with dementia in relation to size of IADL core network and affect. Negative affect, such as feeling irritable, ashamed, nervous, jittery, afraid, guilty, and hostile, decrease as IADL core network size increases. It was observed that female PWD demonstrated calmer behaviors and showed positive affect when they were surrounded with children and family members. This results is not congruent with the theoretical framework of the socioemotional selectivity theory (SST). According to the SST, the size of a person’s core network decreases as he or she ages (Penningroth & Scott, 2012).

Although this study did not find a significant relationship between agitation and ADL1 or

ADL3 closeness, there was a negative correlation found between agitation and closeness of ADL2. Agitation increases as the closeness of the ADL2 caregiver decreases. This might be due to less feeling of closeness with the network in this circle. A PWD demonstrate less disruptive behaviors thorough out the disease process when having support from next of kin (KP, Devi & Lobo, 2011).

Chapter Summary

The data from a sample of 98 older adults with dementia living in community in Oman were used to examine the correlation between the size of core networks and frequency of contact and agitation and affect. The data were also used to examine the correlation of closeness of caregivers as well as the size of core network with density of care provided after controlling for severity of dementia and comorbid problems. These factors were selected based on the NDB, SST, and PLST models. The NDB model suggests that understanding and meeting the needs of people with dementia can temper agitation and the negative outcomes associated with it. The SST model explains why PWDs become more satisfied with a smaller network as PWDs narrow their social interactions. PLST suggests that a smaller core network with a higher frequency of contact would be better at identifying and treating a PWD's needs. While the study did not demonstrate significant associations between the size of core networks and frequency of contact and agitation and affect, the results still demonstrated a correlation between those variables when analysis was conducted based on gender and MMSE grouping. The following chapter will provide a detailed discussion of the study findings in regard to the correlation of size of core network and frequency of contact with agitation and affect.

CHAPTER 5

Chapter Introduction

This chapter presents a discussion of the findings of this study. Implication for nursing practice, health policy and health education that could improve the health care services for older adults with dementia in Oman will be discussed. This chapter will also discuss some limitation of the study and recommendation for future research will be explained.

Synthesis of Findings

Older persons with dementia who live in homes with extended families may receive support and care from a few or many people who are considered the PWD core network. The core network of people is mainly responsible for the patient's wellbeing (Zunzunegui et al., 2005). Although there are some studies indicated there is a relationship between social network interaction and agitation and affect, none of the studies specifically examined the correlations among agitation in PWDs, affect, the size of their core network, and frequency of contact (Burgio et al., 2000; Metcalfe et al., 2004; Srivastava, 2005).

Unlike what was hypothesized in this study, results did not show a significant association between size of and frequency of contact with ADL and IADL core networks and agitation and affect of PWDs. Also, unlike what was hypothesized in this study, results did not show a significant association between closeness of IADL and ADL caregivers or the size of caregiver core networks and the density of IADL and ADL care provided.

In this study, caregivers continued to care and have the same frequency of contact throughout the progress of dementia. This caregiver behavior is influenced by the nature of the Omani Islamic culture. The elderly are regarded as very valuable and are well respected in their families. It is very rare to see youth dropping their frail parents at hospitals or social centers.

Also, this study was conducted on PWD who live at home, and the majority of them live with their primary caregivers, which makes the frequency of their contact higher throughout the process. This result is not congruent with other studies that have explored caregiving for PWD. It is estimated that one third of all people with dementia live on their own (Mirando-Costillo, 2010). In the United States, this means that roughly one in seven Americans with dementia lives alone (Alzheimer's Association, 2015). Studies have also shown that social network size, worldwide, decreases not only because of aging but also due to the physical living transition that PWDs face, such as moving from living in their homes to a nursing home. Due to the lack of family caregiver resources and lack of caregiver support, many older adult PWDs are institutionalized in nursing homes (Wang et al., 2014).

The study did not show a significant correlation between closeness and size of ADL and IADL core networks and density of care in PWD overall. This might be because care for older parents becomes automatically a shared responsibility among children as a moral code of conduct to honor and respect elders. Those immediate family members who are also the primary caregivers also play the role of decision makers for older parents with dementia (Hafiz, 2015). Unlike what was found in this study, other studies have found that un-close and external groups can create stress on the cognitive abilities of those with dementia (Zeisel et al., 2003) by placing these older adults in a position to receive care from persons other than their immediate core network. This may be overwhelming and can result in increased agitation and poor health, eventually interfering with care delivery. Therefore, these results are not congruent with those studies that have shown that older adults prefer a smaller, closer social network that provides them with meaningful interactions (Mark, 2012; Penningroth & Scott, 2012).

Implications for Nursing Theory

In this study, almost all participants had exhibited one or more agitated behaviors and negative affect. This might be due to the fact that agitated behaviors increase as the severity of dementia progresses and also to the fact that this study included PWDs with severe stages of dementia that were already having some health or psychological problems. Theses results are congruent with the Needs-Driven Dementia-Compromised Behavior (NDB) model, which indicates that people with dementia have many unmet needs associated with increased agitated behavior and poor outcomes, such as depression and more negative affect.

People with dementia have impaired communication and may display decrease cognitive insight into their needs and symptoms (Bankole et al., 2012). The model indicates that dementia-related behavior occurs because caregivers cannot comprehend the needs of the PWDs, nor can the PWDs make their needs known. However, this study did not identify how would the size of ADL and IADL core network and frequency of contact relates to unmet needs because there was no significant difference was found in the distribution of the ADL and IADL frequency of contact across the early and severe stages of dementia. Also, the study did not demonstrate significant associations between the size of and frequency of contact with the ADL core network and the agitation and affect of PWDs.

Findings from the study show that older adult women with dementia have more negative affect as their size of ADL core network increases. Negative affect, such as feeling irritable, ashamed, nervous, jittery, afraid, guilty, and hostile, increases as ADL core network size increases. These results are congruent with the theoretical framework of the socioemotional selectivity theory (SST). According to the SST, the size of a person's core network decreases as he or she ages (Penningroth & Scott, 2012). This decreased number of contacts is the intentional result of a tendency to become more selective about who is in the social network and to increase utilitarian attention on present needs rather than on future plans (Penningroth & Scott, 2012). An older person might feel overwhelmed by stress from too many caregivers. Either of these can lead to negative affect and disruptive behaviors. De Vocht et al. (2015) found that one-on-one interaction tailored to individual preferences, which is easily implemented in home settings, significantly improved the positive interactive behaviors of care-dependent residents with dementia during the intervention.

According to the PLST model, also known as the environmental vulnerability model, explains that PWDs have a decreased threshold for tolerating external stressors (Lawton, 1986). In this study, caregivers continued to care and have the same frequency of contact throughout the progress of dementia. This could have led to more stable social environment, less adverse affects and more stable social routines of PWDs.

Implications for Education, Clinical Practice, and Policy

Implication for Nursing Education

Nursing education in Oman needs to strongly address local issues related to older adults and home care. Oman has a unique scenario, as its citizens' life expectancy increased to 76.2 years in 2012—compared with 49.3 in 1970—which caused the health care system in Oman to face tremendous medical and social challenges in terms of caring for its older adult population. The National Elderly Health Survey (2008) identified some social challenges among older adult in Oman such as widowhood, illiteracy, and low income (National Center for Statistics and Information, 2013).

The general nursing education program in Oman is based on professional nursing competencies. The current version of the nursing curriculum introduces generic competencies, which are the minimum requirements for entry into the nursing profession (MoH, 2012). One of the competencies included in the nursing curriculum is older-adult health care. Some findings of this study can be used to provide some evidence that can be incorporated within the objectives of gerontology nursing courses about PWD care at home settings.

An initiative to create a geriatric community health nursing (GCHN) program began in 2011. The proposed duty of the GCHN was to deal with the geriatric population and ensure that the services provided fully met quality standards. These services would provide creative, compassionate, and individualized care that incorporates the concepts of prevention, curative rehabilitation, and palliation. This program was going to be offered after the basic nursing program at the Oman Specialized Nursing Institute (OSNI); OSNI offers postnursing diplomas and baccalaureate nursing degrees (MoH, 2014). Unfortunately, due to a change in authority at the MoH, the program was not implemented. The MoH should change its policies to encourage a review of the proposed GCHN program so it can be put into action.

Implication for Clinical Practice

Some of the challenges that the Omani health care system is facing regarding home care include increased demand, increased consumer expectations, increased treatment costs, and decreased health workforce expertise (Al Dhawi, West, Spinelli, & Gompf, 2007). The issue of the health workforce shortage in Oman is not different than it is in many other countries. For example, according to World Health Statistics (2012), there are only 43.1 nurses for every 10,000 people in Oman, which is below the European standard of 65 nurses per 10,000 population and the 70.8 nurses per 10,000 population standard for high-income countries.

It is time now to critically reflect, not only upon what kind of care older adults will require in the future but also upon how they can receive higher-quality care through proper planning, budgeting, health care spending, and nursing education. Again, older adults in Oman and around the world are growing in number and particularly as consumers of special services. One way to influence policy makers' decisions is by continuing to conduct more evidence-based research about cost-effective care and cost reduction. The resulting evidence will greatly influence the policies and guidelines concerning older-adult care and benefits. Since the community is an essential partner, the government, society, and the family caregiver should collaborate to provide maximum benefits for all. Society needs to learn that aging is not just about growing old and becoming physically weaker; it is a continuing phase in which adults can be productive and support their own quality of life (Au & Chen, 2011).

Conducting studies related to older-adult care will require qualified experts in the field, which unfortunately is one of the drawbacks in Oman. The government will need to allow interested faculty to become specialized in the field of geriatric care so that they can transfer their knowledge to student nurses and to the community.

Omanisation is a strategy that was adopted in the country to encourage Omani citizens to take charge of most of the country's jobs (Ministry of National Economy, 2010); this also influenced the process of nursing education. Although the Ministry of Health has focused its strategy on developing and training highly qualified members of the Omani workforce in all health-related fields, this new workforce still lacks the necessary expertise.

Implication for Health Policy

Agitation management of older adults with dementia require different policy solutions with interrelated programs cooperation between the government and the other different sectors in the Omani community. There are different approaches that might be proposed by using some of this study results.

Policy Approach 1: The Five-Year Health Development Plan

The MoH adopts five-year plans for the health care system. The eighth five-year health development plan, for 2011 through 2015 included a specific domain for older adults' care. This is considered a major development in the care of older adults in Oman. The main aim was to provide preventive, curative, and rehabilitative health care services for older adults through primary health care and by preparing family members to be active and affective participants in meeting the needs of older adults. Another important objective was to increase public awareness in society to promote community participation in the care of older adults.

The results of this study tells the Omani government that there is an urgent need to address the issue of agitation in older adults with dementia in the next five-year plan due to the increasing rates of dementia among older adults and the related consequences. Managing agitation in older adults with dementia is a difficult task for caregivers in Oman and in other countries in the region. Different factors make it challenging, including a lack of interest in providing care for the challenged patient, a lack of trained personnel, and a lack of standardized scales (Halabi & Zafar, 2010).

Based on the evidence provided above, the statistics included might serve to attract the MoH's attention so that it will intervene seriously in managing older adults with dementia in Oman by addressing a plan to target the specific issue of dementia care. The MoH might then allocate a budget for further future research projects on dementia, networks, and agitation in older adults.

Policy Approach 2: Older Adult Care Program (National Screening)

There is a pressing need for a policy review aimed mainly at agitation control and prevention among PWDs living at home (Pressley, Barlow, Quitel, & Jafri, 2007). One of the approaches to provide better care is through a successful comprehensive assessment of older adults (Al-Zadjali et al., 2014).

As mentioned earlier, the national program of older adult care was initiated in 2009 in some regions in Oman, and it was expanded to all regions by the year 2013 to provide comprehensive assessment and screening of older persons. A policy change based on the results of this study can encourage the national program of older adult care to incorporate more tools that relate to assessing dementia, such as the Mini Mental Status Exam and the Cohen-Mansfield Agitation Inventory, to assess the severity of dementia and agitation, respectively, in older adults. According to Cohen-Mansfield and Billig (1986), their agitation inventory is most commonly used to assess specifically agitation in older adults.

Since the health statuses of older adults change rapidly, their physical and cognitive ability should be assessed more frequently. Comprehensive older-adult assessments should be performed by clinicians who have appropriate skills and training. These assessments should include a focused history of physical, mental, and social health, in addition to medications and relevant risk factors. The implementation of this step helps care providers to have a detailed description of previous history and to identify relationships between factors (Taylor, 2002).

Understanding which of these factors are highly associated with networks, agitation, and negative affect will help care providers to target those who are at greater risk. This would encourage care providers to tailor prevention strategies to at-risk individuals. Facilities should conduct routine quality audits to track performance (Deutschman, 2001). This assessment will serve as a unique source to create a more individualized risk-prevention plan for each older person who is at risk.

Policy Approach 3: A National Older Adult Care Committee

A national steering committee headed by His Excellency the Undersecretary of Planning

Affairs at MoH and composed of national health system experts was formulated to lead the development of “Health Vision 2050.” The same committee also created subteams of multidisciplinary experts from MoH at both national and governorate levels to deal with different aspects of the health system, including older adult care (Health vision 2050, 2014). The results of this study will hopefully provide sufficient recommendations to support the need to formulate an independent national older-adult care committee that would be officially responsible for assessing, prioritizing, and planning for the anticipated care of older adults with dementia who live at home due to increases in the demands of the geriatric population. As mentioned earlier, there are currently no nursing home facilities for older citizens in Oman, and the government does not encourage the establishment of such facilities because it believes that the community will be able to take care of its older adult population, as religion and tradition emphasize. However, the number of older people is increasing, and the number of available caregivers is decreasing. It is estimated that people over the age of 65 will exceed the number of children under 5 by the year 2015; this phenomenon is called the “silver tsunami” (Haven, 2010). Today, only 22.4 million households provide care to a family member over 50 (American Association for Retired People [AARP], 2010).

Policy Approach 4: Promotion of Healthy Lifestyles

Older adults with dementia are at high risk of developing health complications not only due to aging but also due to a lack of self-awareness, which makes it harder to identify and prioritize needs related to their health (Taylor, 2002). As a nation, Oman will be facing many challenges in the coming years, such as trying to figure out how to provide optimal health care for the growing older-adult population. One of the critical questions that remains unanswered is how the country will pay for the extra demand for older-adult care and support these patients.

Caring for older adults is very expensive. The AARP (2010) estimated that the annual cost of long-distance caregivers is $8,728, compared with $5,885 when caregivers live under the same roof and $4,570 when caregivers live close to, but not with, the patients. In other countries, family members end up with placing older adult relative in nursing homes. Currently, this is not an option in Oman, and as a result, some children will place their parents in hospitals to be taken care of, putting more pressure on the government to tackle the issue.

Based on the international evidence and the results of this dissertation, the Omani government might need to consider the need for more funding for long-term care plans and home services in addition to locating alternatives to home care.

A policy change targeting older adults with dementia who live at home can be directed toward healthy living for older people as a response to this challenge of aging. One way that the country can cope with this trend is by encouraging physical activity among older adults. This can include support for creating more accessible public gymnasiums, where older people can get physical exercise, either in poor neighborhoods or in big cities. This could guarantee that older people can practice physical activity under supervision. Promoting physical activity is an important aspect of health promotion for older adults (Au & Chen, 2011). The MoH should continue the integration of its medical and social services to further address the challenges facing this vulnerable group so that older adults can remain healthy and independent and continue to play an active role in society (Al-Sabahi, Al Sinawi, Al-Hinai, & Youssef, 2013).

Policy Approach 5: Intersectorial Cooperation

The budget will need to be fixed not only for providing services but also for all related aspects of aging, such as support for research on the science of aging (Haven, 2010), and social support. This trend will also require training more geriatricians, both nurses and physicians.

According to the American Geriatrics Society (2012), an estimated 30% of older adults today need a geriatrician to help them with the aging process. Currently, there are only around 7,500 certified geriatricians in the United States (Wiener & Tilly, 2015), and it is expected that the need for geriatricians will grow to 30,000 by the year 2030.

The above facts may be met through mutual cooperation and coordination across different sectors and by working collaboratively to deliver higher-quality home care for older adults with dementia. The results of this dissertation will hopefully identify more key points and recommendations for possible areas of intersectorial cooperation.

The MoH and the MoSD jointly initiated a collaborative older adult service. This service is directed at providing trained caregivers, also known as sitters, to take care of older adults who have no family caregiver. Each registered older adult undergoes a comprehensive socioeconomic environmental assessment and is then referred to a social worker. The patient is then visited by a team that identifies the necessary intervention (MoH, 2011). A policy change might include expanding services to specifically cover older adults with dementia who live at home. For example, these services might include training caregivers about caring for PWDs. Therefore, assisting caregivers in their role requires collaborative work and partnerships with different community participants, policy makers, families, and educators (Wiener & Tilly, 2015). To help strengthen caregivers' ability to care for PWDs, they and other community members need to be provided with resources to better identify and use the country's available resources. They need to know about other available financial, health, social, and legal resources.

Limitations

There are several limitations that can be considered for this study. Since convenience sampling was used in this study, generalizability would be limited. Convenience sampling is considered the weakest method of sampling because of the high risk of internal validity biases and the lack of representation of the population. Also, data were collected using cross-sectional descriptive design, which was practical and affordable. Cross-sectional descriptive design involves data collection at one point of time, which makes it difficult to establish a causal relationship. Further future studies might be recommended to examine relationship between the variables over time. Couple of the community health nurses who are completing the tools were new to the environment, this could increase the halo effect.

Although the CMAI instrument was designed and tested in another culture different from where it might be used, the Omani culture might reveal different expectations. There might be some differences in the meanings of the wordings of the variables in the CMAI measurement scale. Eventhough the tool was reviewed in detail to evaluate its suitability to the people, place, and time, some items in the scale, for example, were still understood differently within the Omani community.. Also, having a rating scale in this instrument might have limited the choices and affect the sensitivity of the scale.

Moreover, uncontrolled variables that contribute to the clients' agitation levels could have also been a limitation of this study. These variables include outside factors that I cannot control and that can affect the results of the study. These uncontrolled variables may have included unexpected visitors, accidents, and pain. In addition, reports of agitation from caregivers may have had some bias and lead to measurement error.

Recommendations for Future Research

This study could be used as a foundational study for future intervention research. Agitation was the main variable in this study. Results showed the existence of a relationship between size of core network, frequency of contact with the caregiver and agitation and affect, but this relationship was not statistically significant. A recommendation for a next step is to develop a study to describe factors/needs associated with agitated behavior and affect in older PWDs. Following this study, the plan is to formulate a study to examine the association between the factors/needs found in study 1, such as the size and frequency of contact with the core network and the agitation and affect of people with dementia.

While this study is the first to explore the association of size and frequency of contact with the core network and the agitation and affect of people with dementia, the findings from this study evolved new learning opportunities for studies that need further exploration such as agitation and gender difference. Future longitudinal studies with larger sample sizes are required to confirm the association between size of core network and frequency of contact with agitation and affect. Results will then be used to design the next study, which will examine the effectiveness of smaller core networks with higher frequency of contact in reducing the level of agitation in PWDs and meeting the person's needs.

Also, a future study could be implemented in the city of Muscat and compare the results with the current study results to see if any difference exits between the city and urban areas and later with another Arabian or western culture. Future research can also examine the association of caregiver age, employment status, and length of providing care with agitation and affect of both PWD and the caregivers themselves.

Ultimately, the results of both studies could yield recommendations to be used by the Ministry of Health in Oman to enhance the effectiveness of planning the nursing care of older PWDs and agitation. This program of research will provide nurses with evidence-based knowledge regarding agitation to help them intervene effectively. The results of the above planned studies will direct the development of an intervention designed to decrease agitation.

Chapter Summery

The problems of older adults are not obvious due to family structure, a lack of effective social programs, and insufficient research concerning older adults. Many studies have looked at agitation in PWDs, but few studies have emphasized agitation in a social context. Although this study had examined the relationship between agitation in PWDs and either the size of the core network or the frequency of contact, results raised awareness about issues such as cultural differences and gender differences need further exploration. Since this study indicated a relationship between comorbid problems and agitation in PWDs, there is a necessity to design and develop nursing intervention to help manage and improve the physical and psychological wellbeing in older adults. Moreover, the results of this study raise the awareness for broader exploration of areas relevant to agitation in relation to core network and affect such as implementing some experimental studies that could provide more evidence in the area of agitation and social network.

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APPENDICES

Appendix A

DEMOGRAPHIC DATA

SUBJECT # ____________

Age in years:___________; Gender:______Male_______Female________

Length of starting Caregiving:_________

Number of caregivers providing ADL & IADL and Frequency of contact with PWD in a typical 30-day month

	# Of caregivers	**Frequency of contact**
ADL		
IADL		

Appendix B

THE COHEN-MANSFIELD AGITATION INVENTORY - Long Form

Please read each of the 29 agitated behaviors, and circle how often (from 1-7) each was manifested by the resident during the last 2 weeks:

		Never 1	**Less than once a week 2**	**Once or twice a week 3**	**Several times a week 4**	**Once or twice a day 5**	**Several times a day 6**	**Several times an hour 7**
1.	Pace, aimless wandering	1	2	3	4	5	6	7
2.	Inappropriate dress or disrobing	1	2	3	4	5	6	7
3.	Spitting (include at meals)	1	2	3	4	5	6	7
4.	Cursing or verbal aggression	1	2	3	4	5	6	7
5.	Constant unwarranted request for attention or help	1	2	3	4	5	6	7
6.	Repetitive sentences or questions	1	2	3	4	5	6	7
7.	Hitting (including self)	1	2	3	4	5	6	7
8.	Kicking	1	2	3	4	5	6	7
9.	Grabbing onto people	1	2	3	4	5	6	7
10.	Pushing	1	2	3	4	5	6	7
11.	Throwing things	1	2	3	4	5	6	7
12.	Strange noises (weird laughter or crying)	1	2	3	4	5	6	7
13.	Screaming	1	2	3	4	5	6	7
14.	Biting	1	2	3	4	5	6	7
15.	Scratching	1	2	3	4	5	6	7

16.	Trying to get a different place (e.g., out of the room, building)	1	2	3	4	5	6	7
17.	Intentional falling	1	2	3	4	5	6	7
18.	Complaining	1	2	3	4	5	6	7
19.	Negativism	1	2	3	4	5	6	7
20	Eating/drinking inappropriate substances	1	2	3	4	5	6	7
21.	Hurt self or other (cigarette, hot water, etc.)	1	2	3	4	5	6	7
22.	Handling things inappropriately	1	2	3	4	5	6	7
23.	Hiding things	1	2	3	4	5	6	7
24.	Hoarding things	1	2	3	4	5	6	7
25.	Tearing things or destroying property	1	2	3	4	5	6	7
26.	Performing repetitious mannerisms	1	2	3	4	5	6	7
27.	Making verbal sexual advances	1	2	3	4	5	6	7
28.	Making physical sexual advances	1	2	3	4	5	6	7
29.	General restlessness	1	2	3	4	5	6	7

Name of rater: _________________________

Name of primary caregiver\informant: _________________________

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SCORING THE CMAI

The rating scale for the agitated behaviors is as follows: **1** - Never

2 - Less than once a week but still occurring **3** - Once or twice a week **4** - Several times a week **5** - Once or twice a day

6 - Several times a day **7** - Several times an hour

When a behavior has occurred rarely during one week, and more frequently during another, try to average over the past two weeks to get the frequency which best reflects its occurrence.

If a behavior would occur but is prevented (e.g, pacing prevented by physical restraints or fights prevented by removing person), two approaches can be used: 1) rate the behavior as a separate category "8 - would occur if not prevented" and analyze these cases separately, or: 2) estimate the frequency at which the behavior would occur if not prevented, or the frequency at which it actually occurs when not prevented. Behaviors at irregular frequencies should be averaged. It is important to handle these cases in a consistent manner throughout the project in which the CMAI is used.

Calculating agitation scores: The CMAI contains a diversified group of behaviors. For analysis purposes, it is not useful to calculate a total score by adding all the categories. Analysis can pertain to either specific behaviors of interest, or each of the three factors of agitation described below (see section on psychometric properties). However, researchers may want to do their own factor analysis because factors depend on the population studied. Another possibility is to weigh behaviors according to their disruptive impact and then combine them accordingly. Different agitated behaviors occur under different circumstances and in different people. Therefore, the behaviors do not all have the same meaning, e.g., some may need to be discouraged, and others need to be accommodated. You need to conceptualize your understanding of these behaviors in order to aggregate the behaviors in a meaningful way. Some means of aggregating the behaviors are illustrated in the referenced articles.

Criteria for agitated/not agitated status: The criteria we used were:

Aggressive behavior occurring at least several times a week, i.e., at least one aggressive behavior occurring at a frequency of 4 or at least two aggressive behaviors occurring at a frequency of 3 or at least three aggressive behaviors occurring at a frequency of 2 or two aggressive behaviors occurring at a frequency of 2 and one at a frequency of 3

Physically nonaggressive behavior occurring at least once a day, i.e., at least one physically nonaggressive behavior occurring at a frequency of 5 or least two physically nonaggressive behaviors occurring at a frequency of 4 or least three physically nonaggressive behaviors occurring at a frequency of 3 or least four physically nonaggressive behaviors occurring at a frequency of 2

Verbally agitated behavior occurring at least once a day, i.e., at least one verbally agitated behavior occurring at a frequency of 5 or least two verbally agitated behaviors occurring at a frequency of 4 or least three verbally agitated behaviors occurring at a frequency of 3 or least four verbally agitated behaviors occurring at a frequency of 2

For other studies, different criteria may be needed, depending on the research question, and on the disruptive impact of the behaviors in the particular setting studied.

Detailed Descriptions of Behaviors

1. **Pacing and aimless wandering** - constantly walking back and forth, including wandering when done in a wheelchair. Does not include normal purposeful walking.

2. **Inappropriate dressing or disrobing** - putting on too many clothes, putting on clothing in a strange manner (e.g., putting pants on head), taking off clothing in public or when it is inappropriate (if only genitals are exposed, rated under sexual advances). Does not include a person's ability to dress/undress as in ADL's.

3. **Spitting (including while feeding)** - spitting onto floor, other people, etc.; does not include uncontrollable salivating, or spitting into tissue, toilet, or onto ground outside

4. **Cursing or verbal aggression** - only when using words; swearing, use of obscenity, profanity, unkind speech or criticism, verbal anger, verbal combativeness. Does not include unintelligible noises (rated under screaming or strange noises).

5. **Constant unwarranted request for attention or help** - verbal or nonverbal unreasonable nagging, pleading, demanding (indicate also for oriented people).

6. **Repetitive sentences or questions** - repeating the same sentence or question one right after the other, addressed to a particular person or to no one (complaining, even if oriented and possibly warranted is rated under the complaining section).

7. **Hitting (including self)** - physical abuse, striking others, pinching others, banging self/furniture.

8. **Kicking** - striking forcefully with feet at people or objects.

9. **Grabbing onto people or things inappropriately** - snatching, seizing roughly, taking firmly, or yanking.

10. **Pushing** - forcefully thrusting, shoving, moving putting pressure against another.

11. **Throwing things** - hurling objects, violently tossing objects up in air, tipping off surfaces, flinging, dumping food.

12. **Making strange noises** - including crying, weeping, moaning, weird laughter, grinding teeth, does not include intelligible words.

13. **Screaming** - shouting, piercing howl, making loud shrills.

14. **Biting** - chomping, gnashing, gnawing, either other people or self.

15. **Scratching** - clawing, scraping with fingernails either other people or self.

16. **Trying to get to a different place** - inappropriately entering or leaving a place, such as trying to get out of the building, off the property, sneaking out of room, trying to get into locked areas, trespassing within unit, offices, or other resident's room or closet.

17. **Intentional falling** - purposefully falling onto floor, include from wheelchair, chair, or bed.

18. **Complaining** - whining, complaining about self, somatic complaints, personal gripes or complaining about physical environment or other people.

19. **Negativism** - bad attitude, doesn't like anything, nothing is right, does not include overt verbal anger, such as what can be rated as verbal aggression.

20. **Eating or drinking inappropriate substances** - putting into mouth and trying to swallow items that are inappropriate.

21. **Hurting self or other** - burning self or other, cutting self or other, touching self or other with harmful objects, etc.

22. **Handling things inappropriately**. - picking up things that don't belong to them, rummaging through drawers, moving furniture, playing with food, fecal smearing.

23. **Hiding things** - putting objects out of sight, under or behind something.

24. **Hoarding things** - putting many or inappropriate objects in purse, pockets, or drawers, keeping too many of an item. (Does not include regular collection such as collecting dolls).

25. **Tearing things or destroying property** - shredding, ripping, breaking, stomping on something.

26. **Performing repetitious mannerisms** - stereotypic movement, such as patting, tapping, rocking self, fiddling with something, twiddling with something, rubbing self or object, sucking fingers, taking shoes on and off, picking at self, clothing, or objects, picking imaginary things out of air or off floor, manipulation of nearby objects in a repetitious manner, does not include repetitious words or vocalizations.

27. **Making verbal sexual advances** - sexual propositions, sexual innuendo, or "dirty" talk.

28. **Making physical sexual advances or exposing genitals** - touching a person in an inappropriate sexual way, rubbing genital area, inappropriate masturbation (when not

aloneinownroomor bathroom),unwantedfondlingorkissing.

29. **General restlessness** - fidgeting, always moving around in seat, getting up and sitting down inability to sit still.

In the CMAI-Community Version the following are also included

Exhibiting temper outbursts - exhibiting verbal and nonverbal expressions of anger that are more complex and of longer duration than single agitated behaviors. Can include but not limited to hitting, throwing, cursing, etc.

Exhibiting strange movements - any random or aimless moving of parts of the body, i.e., twitching, rising, pursing lips, chewing, grinding teeth, moving arms or legs in strange ways. Does not include repetitive movements

Appendix C

The Positive and Negative Affect Schedule (PANAS; Watson et al., 1988)

PANAS Questionnaire

This scale consists of a number of words that describe different feelings and emotions. Read each item and then list the number from the scale below next to each word.
Indicate to what extent you feel this way right now, that is, at the present moment
OR indicate the extent you have felt this way over the past week (circle the instructions you followed when taking this measure)

1	**2**	**3**	**4**	**5**
Very Slightly or Not at All	**A Little**	**Moderately**	**Quite a Bit**	**Extremely**

__________	1.	Interested	__________	11.	Irritable
__________	2.	Distressed	__________	12.	Alert
__________	3.	Excited	__________	13.	Ashamed
__________	4.	Upset	__________	14.	Inspired
__________	5.	Strong	__________	15.	Nervous
__________	6.	Guilty	__________	16.	Determined
__________	7.	Scared	__________	17.	Attentive
__________	8.	Hostile	__________	18.	Jittery
__________	9.	Enthusiastic	__________	19.	Active
__________	10.	Proud	__________	20.	Afraid

Scoring Instructions:

Positive Affect Score: Add the scores on items 1, 3, 5, 9, 10, 12, 14, 16, 17, and 19. Scores can range from 10 – 50, with higher scores representing higher levels of positive affect. Mean Scores: Momentary = 29.7 (SD=7.9); Weekly =33.3 (SD=7.2)

Negative Affect Score: Add the scores on items 2, 4, 6, 7, 8, 11, 13, 15,
18, and 20. Scores can range from 10 – 50, with lower scores representing lower levels of negative affect. Mean Score: Momentary= 14.8 (SD=5.4); Weekly =17.4 (SD= 6.2)

The official citation that should be used in referencing this material is Watson, D., Clark, L. A., & Tellegan, A. (1988). Development and validation of brief measures of positive and negative affect: The PANAS scales. Journal of Personality and Social Psychology, 54(6), 1063–1070

Appendix D

The Mini-Mental State Examination

Orientation

			Score	Points
1.	What is the:	Year?	_____	1
		Season?	_____	1
		Date?	_____	1
		Day?	_____	1
		Month?	_____	1
2.	Where are we?	State?	_____	1
		County?	_____	1
		Town or city?	_____	1
		Hospital?	_____	1
		Floor?	_____	1

Registration

		Score	Points
3.	Name three objects, taking one second to say each. Then ask the patient all three after you have said them. Give one point for each correct answer. Repeat the answers until the patient learns all three.	_____	3

Attention and calculation

		Score	Points
4.	Serial sevens. Give one point for each correct answer. Stop after five answers. *Alternate*: Spell WORLD backwards.	_____	5

Recall

		Score	Points
5.	Ask for names of three objects learned in Question 3. Give one point for each correct answer.	_____	3

Language

		Score	Points
6.	Point to a pencil and a watch. Have the patient name them as you point.	_____	2

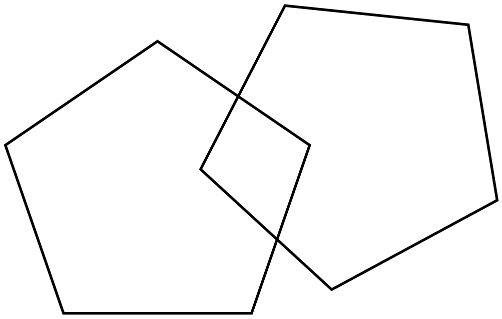
7. Have the patient repeat “No ifs, ands,
or buts.” _____ 1

8. Have the patient follow a three-stage
command: “Take the paper in your right
hand. Fold the paper in half. Put the
paper on the floor.” _____ 3
paper on the floor.” _____ 3

Have the patient read and obey the
following: "CLOSE YOUR. EYES."
(Write in large letters.) _____ 1

10. Have the patient write a sentence of his
or her own choice. (The sentence should
contain a subject and a verb and should
make sense. Ignore spelling errors when
scoring.) _____ 1

11. Enlarge the design printed below to
1 inch per side and have the patient
copy it. (Give one point if all sides and
angles are preserved and if the
intersecting sides form a quadrangle.) _____ 1



Total Points ______

Reprinted from *Journal of Psychiatric Research*, Vol. 12, Folstein, M.F., Folstein, S.E., & McHugh, P.R., "Mini-Mental State: A practical method for grading the cognitive state of patients for the clinician," 189-198, Copyright (1975), with permission from Pergamon Press Ltd, Headington Hill Halt, Oxford OX3 OBW, UK.

Instructions for Administration of Mini-Mental Status Examination

Orientation: Ask for the date. Then ask specifically for parts omitted, e.g., "Can you also tell me what season it is?" One point for each correct answer. Ask in turn "Can you tell me the name of this hospital?" (nursing home, town, county, etc.). One point for each correct answer.

Registration: Ask the patient if you may test his memory. Then say the names of 3 unrelated objects, clearly and slowly, about one second for each. After you have said a 3, ask him to repeat them. This first repetition determines his score (0-3) but keep saying them until he can repeat all 3, up to 6 trials. If he does not eventually learn all 3 recall (see below) cannot be meaningfully tested.

Attention and Calculation: Ask the patient to begin with 100 and count backwards by 7. Stop after 5 subtractions (93, 86, 79, 72, 65). Score the total number of correct answers. If the patient cannot or will not perform this task, ask him to spell the word "world" backwards. The score is the number of letters in correct order. E.g. dlrow = 5, dlorw = 3.

Recall: Ask the patient if he can recall the 3 words you previously asked him to remember. Score 0-3.

Language:
Naming: Show the patient a pencil and ask him what it is. Repeat for wrist watch. Score 0-2, one for each correct answer, 0 if none are named.

Repetition: Ask the patient to repeat the sentence after you. Allow only one trial. Score 0 or 1.

3-Stage command: Give the patient a piece of plain blank paper and repeat the entire command. Score 1 point for each part correctly executed.

Reading: On a blank piece of paper print the sentence, "Close your eyes," in letters large enough for the patient to see clearly. Ask him to read it and do what it says. Score 1 point only if he actually closes his eyes.

Writing: Give the patient a blank piece of paper and ask him to write a sentence for you. Do not dictate a sentence; it is to be written spontaneously. It must contain a subject and verb and be sensible. Correct grammar and punctuation are not necessary.

Copying: On a clean piece of paper, draw intersecting pentagons, each side about 1 inch, and ask him to copy it exactly as it is. All 10 angles must be present and 2 must intersect to score 1 point. Tremor and rotation are ignored.

Level of Consciousness: Estimate the patient's level of sensorium along a continuum, from alert on the left to coma on the right.

Reprinted from *Journal of Psychiatric Research*, Vol. 12, Folstein, M.F., Folstein, S.E., & McHugh, P.R., "Mini-Mental State: A practical method for grading the cognitive state of patients for the clinician," 189-198, Copyright (1975), with permission from Pergamon Press Ltd, Headington Hill Halt, Oxford OX3 OBW, UK.

Appendix E

SCORING SHEET

Cumulative Illness Rating Scale for Geriatrics (CIRS-G)

SUBJECT #
RATER ___________________________ **DATE** ________________________

***Instructions*:** Please refer to the CIRS (G) Manual. Write brief descriptions of the medical problem(s) that justified the endorsed score on the line following each item. (Use the reverse side for more writing space).

Rating Strategy

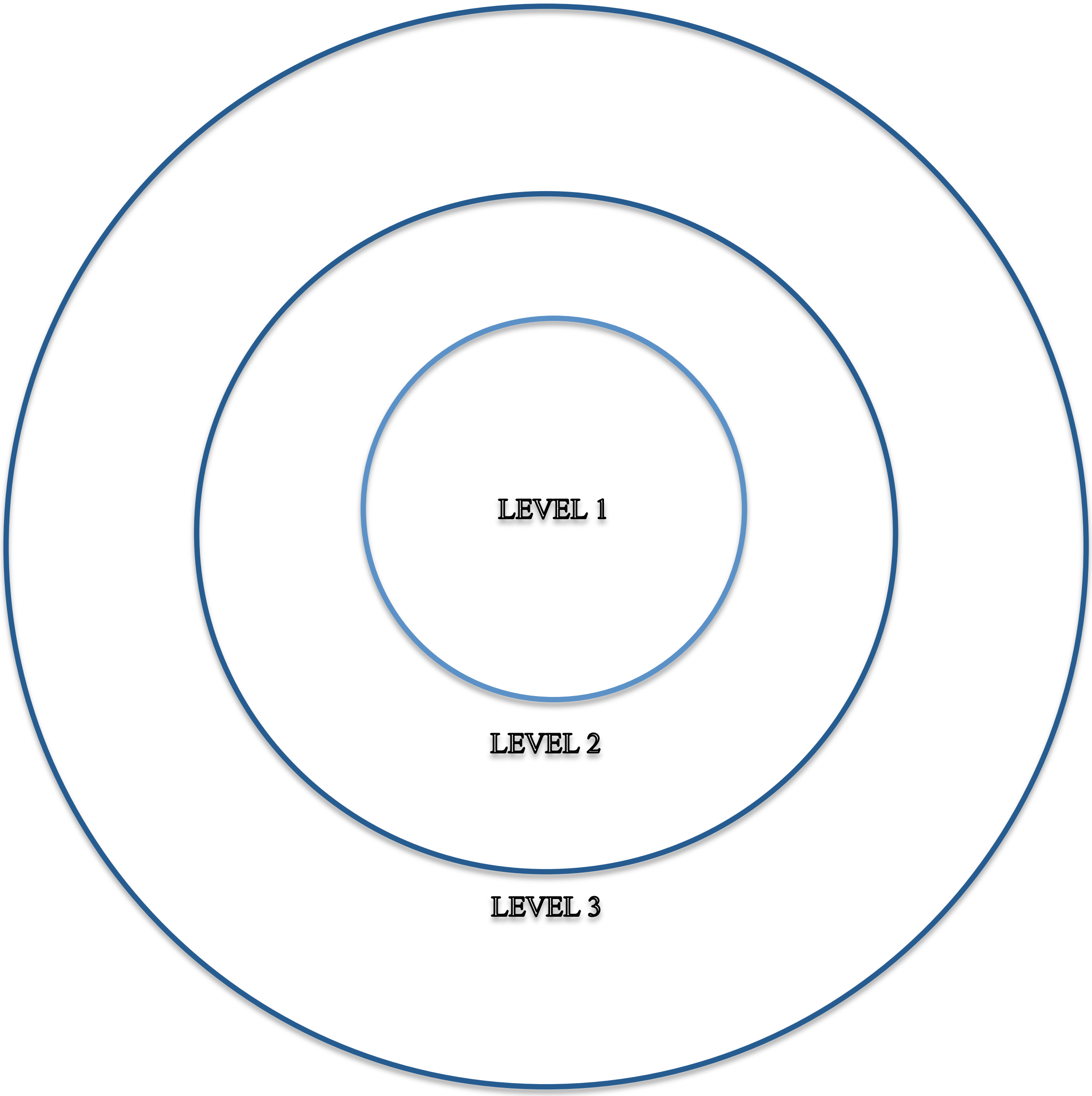
0- No problem
1- Current mild problem or past significant problem
2- Moderate disability or morbidity/requires "first line" therapy
3- Sever/constant significant disability/"uncontrollable" chronic problems
4- Extremely severe/immediate treatment required/end organ failure/severe impairment function

	Score
Heart	
Vascular	
Hematopoietic	
Respiratory	
Eyes, ears, nose, throat, and larynx	
Upper gastrointestinal tract	
Lower gastrointestinal tract	
Liver	
Renal	
Genitourinary	

Musculoskeletal/Integument	
Neurological	
Endocrine/Metabolic	
Psychiatric Illness	
Total Number Categories Endorsed	
Total Score	
Number of categories at level-3 & 4 severity	

Appendix F

Social Convoy Questionnaire (SCQ)



Instruction:

Nominate social partners who are important to you into one of three circles (e.g. son, daughter, doctor, maid..etc.). The inner circle, being the closest to you, indicate emotionally close social partners, ‘‘so close that you [the participant] cannot image life without them.’’ The middle circle indicates rather close social partners, and the outer circle indicates less close social partners.

For analysis Purposes, these relationships are grouped as the following:

1.	2.	3.	4.	5.
Nuclear family (e.g., parents, spouse or significant other, and children)	Extended family (all relatives other than nuclear family members)	Friends (all kinds of friends)	Acquaintances (doctors, nurses, dentists, colleagues, and teachers)	Paid caregivers (nurses, assistance nurses, maids, ect.)

Reprinted from *Elderly people in industrialised societies*, In H. Mollenkopf (Ed.), Lang, F. R. " **Social Convoy Questionnaire (SCQ),**" 41-51, Copyright (1996), with permission from Lang, F.R.

Appendix G

Instrumental and Non-Instrumental Activities of Daily Living Check List

Instructions: Check next to the activity that you as caregiver do to assist your older person with dementia

	IADL	Name		ADL	Name
1.	Basic communication skills		1.	Personal hygiene	
2.	Transportation		2.	Dressing	
3.	Meal preparation		3.	Eating	
4.	Shopping		4.	Maintaining continence	
5.	Housework		5.	Transferring	
6.	Managing medications		6.		
7.	Managing personal finance				

Select the best answers for the questions below:

1. Number of caregivers providing ADL & IADL in a typical 30-day month

In a typical 30-day month, how many caregivers are providing ADL & IADL care?

# Of caregivers	< 2	3--5	6--8	9--11	12--14	>15
ADL						
IADL						

2. Frequency of contact with ADL caregivers in a typical 30-day month

In a typical 30-day month, how many days would you have some contact with your ADL and IADL caregivers?

Frequency of contact	< 5	6--10	11--15	16--20	21--25	Everyday
ADL						
IADL						

Activity description: Instrumental activities:

1. Basic communication skills - such as using a regular phone, mobile phone, email or the Internet
2. Transportation - either by driving oneself, arranging rides or the ability to use public transportation
3. Meal preparation - meal planning, preparation, storage and the ability to safely use kitchen equipment
4. Shopping - the ability to make appropriate food and clothing purchase decisions
5. Housework - doing laundry, cleaning dishes and maintaining a hygienic place of residence
6. Managing medications - taking accurate dosages at the appropriate times, managing re-fills and avoiding conflicts
7. Managing personal finance- budgets, writes checks, pays rent and bills and day-to-day purchases

Non-instrumental:

1. Personal hygiene - bathing, grooming and oral care
2. Dressing - the ability to make appropriate clothing decisions and physically dress oneself
3. Eating - the ability to feed oneself though not necessarily to prepare food
4. Maintaining continence - both the mental and physical ability to use a restroom
5. Transferring - moving oneself from seated to standing and get in and out of bed

---

Adopted from *Gerontologist***,** Vol. 9, Lawton's Instrumental Activities of Daily Living (IADL) Scale; Lawton, M.P., & Brody, E.M. (1969). Assessment of older people: self-maintaining and instrumental activities of daily living.

Appendix H

CONSENT TO PARTICIPATE IN A COMMUNITY DEWELLING RESEARCH STUDY

TITLE OF STUDY: The correlation of size of core network, and frequency of contacts with agitation and positive affect in elderly with dementia

PRINCIPAL INVESTIGATOR: Amal Al-Ghassani, MSN, RN
24-HOUR EMERGENCY PHONE NUMBER: 99885510

Note: This form will be available in both in English and Arabic language

INTRODUCTION

You are being asked to volunteer to take part in this research study because you are a primary care giver of an older adult with some memory problems living at home. Older adults with memory problems might sometimes feel upset or have agitated behaviors. This study involves trying to better understand factors that are associated with different feelings and behaviors by people with some memory problems receiving care at home.

Before deciding whether you want to participate in this research study or not, it is important that you read and understand the following explanation of the study procedures. This consent describes the purpose, procedures, benefits, risks, discomforts and precautions of the study.

WHY IS THIS STUDY BEING DONE?

This study is being done to learn more about the size of the core group caring for older adults with memory problems, the types of assistance provided, and the frequency of contact. We will also determine if the size of the group providing personal care and other types of assistance and the frequency of contact are associated with behaviors and emotions of people with memory problem.
The results of this study could yield recommendations to be used by the Ministry of Health in Oman to improve the nursing care of older adults with memory problems and agitation.

WHAT IS INVOLVED IN THE STUDY?

The nurse researcher will meet with caregiver two times, a total of two visits.
Visit# 1 will take approximately one hour
Visit# 2 will take approximately one hour
For caregiver:
The caregiver will be asked to complete written forms either directly or through the nurse researcher. These forms have questions related to older adult with memory problem's behavior, agitation and positive and negative emotions.
The caregiver will be observing the older adults for agitation and expressions of emotion for a week and document observations in given agitation and positive and negative emotion recording sheets, which were translated to Arabic. Filling these forms by the caregiver

takes approximately 20 minutes each. Filling these forms can be done independently or by the help of the nurse researcher, when required. The nurse researcher will be meeting with the caregiver in visit #2 to do the second recording sheets of agitation and positive and negative emotions based on the previous weeks agitation and expression of emotion.
Also, the nurse researcher will ask the caregiver about the number of people in the social network of the older adult with memory problems, type of care provided and the closeness to each person in the social network.
For the older adults with memory problems:
Older adults with memory problems will be observed for agitation by the caregiver for a week. Older adults with memory problems will be assessed for level of memory problem using the mental status exam by the nurse researcher, which will take approximately 30 minutes to complete. Also, The nurse researcher will review medical charts to obtain information related to the older adult's memory, comorbid problems, and age.

HOW LONG WILL YOU BE IN THE STUDY?

Participation will be for two weeks

WHAT ARE THE RISKS OF THE STUDY?

Minimal risk is anticipated for this study such as fatigue or heightened agitation (or anxiety or stress) when being observed or during the mental status exam.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

There is a minimal risk of **fatigue or heightened agitation (or anxiety or stress) as a result of participating in the study. To minimize these risks, the nurse researcher will communicate in a calm and pleasant manner. If the person becomes fatigued the person will be given a rest break and the option for the interview to continue on another day. If the person becomes distresses, the nurse and will try to calm the person, give a break, and contact their community health nurse if the person is not back to baseline in 30 minutes. Also, the option to complete the testing on another day will be offered.**
Also, if the older adults with memory problems is agitated during the mental status exam, the nurse researcher will try to calm the older adults with memory problems, leave the place and comeback to do the assessment when the caregiver says it is suitable to go back.

WILL YOUR INFORMATION BE KEPT PRIVATE?

Your consent forms will be kept in a secure locked location. Your demographic **information will be confidentially stored** in a secure database accessible only to the investigator. All data will be password protected. Your name or anything that could show who you are will not be put on any paper, poster or publication, and will not be shared with your employer, and will be locked in a 2X locked secure area.

WHAT ARE THE POSSIBLE BENFITS OF PARTICIPATING IN THIS STUDY?

There is no guarantee that you will benefit from your participation. However, your participation in the study would lead to better understanding of provision of care for people with memory problems and dementia and that the Ministry of Health could use this information to address the needs of individuals in long term care at home.

The following people will have access to your identity as a part of this study: Ms. Al-Ghassani.

The following people will have access to the de-identified data you provide:

- The student primary investigator (Ms. Al-Ghassani) and the major professor (Dr.Kovach)

WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

Participation in this study is voluntary and refusal to participate will not affect you in any way. If you have any questions regarding this study you may contact Ms.Al-Ghassani at 99885510 at any time.

CAN I STOP PARTICIPATING IN THIS STUDY?

Your participation in this study is entirely voluntary. You may withdraw from this study at any time. If you decide to take part of the study, you can change your mind later and withdraw from the study.

Who do I contact for questions about my rights or complaints towards my treatment as a research subject?

Contact the **Institutional Review Board (IRB)** at 414-229-3173 or irbinfo@uwm.edu.
IRB is a United States University office in the place where the nurse researcher (NR) is doing her studies to obtain a doctorate in nursing degree

PARTICIPANT CONSENT

I have read, or have had read to me, the information describing the study and it is written in a language that I understand. This form is a giving consent for both the older adults with memory problems and myself. All of my questions have been answered to my satisfaction. I am signing this form voluntarily, indicating my willingness to be in this study. I understand that I am not giving up any of my legal rights by signing this form and I will receive a copy of this signed consent form.

__________________________________ ________________________
Signature of Participant or Printed Name
Legally Authorized Representative Date/Time

__________________________________ ________________________
Signature of Person Obtaining Consent Printed Name Date

Appendix I

VERBAL ASSENT SCRIPT

Project Title: THE CORRELATION OF SIZE OF CORE NETWORK AND FREQUENCY OF CONTACTS WITH AGITATION AND POSITIVE AFFECT IN ELDERLY WITH DEMENTIA

Student Principal Investigator: Amal Al-Ghassani
Supervised by: Dr.Kovach

Note: This form will be available in both in English and Arabic language

Hi my name is Amal. If you have any questions about what I am telling you, you can ask me at any time.
I want to tell you about a research study we are doing. In this study, we want to learn more about the size of the core group caring for older adults with some memory problems, the types of help they give, and how often they are with people they are helping. By being in this study, you will help me to determine if the size of the group providing help and how often they provide help. I also want to see if the size of the group helping or how often they provide help effects feelings and behaviors of people who are receiving some help.

Your primary caregiver (-----------) says it is okay to be in the study. But if you don't want to be in the study, you don't have to be. I won't be upset, and no one else will be upset, if you don't want to be in the study. If you want to be in the study now but change your mind later, that's okay. You can stop at any time. If there is anything you don't understand you should tell me so I can explain it to you
If you get too tired or if this seems like something you don't want to do, just let me know. If you want to stop at any time just tell me and we will stop.
I will meet with you and your primary caregiver for two times for approximately one hour each. Would you like to be in my study and allow me to meet with your primary caregiver and ask questions related to behavior, agitation and positive and negative feelings?

End of verbal script.

To be completed by person obtaining verbal assent from the participant:

Older adult with dementia/Participant's response**:** ☐Yes ☐No

Primary caregiver/Legally authorized person Permission: ☐Yes ☐No
(If "No," do not proceed with assent or research procedures.)

PWD/Participant's Name (printed)

_______________________________________ __________________

Name (printed) and Signature of Principle Investigator Date

Appendix J

STUDY FLYER

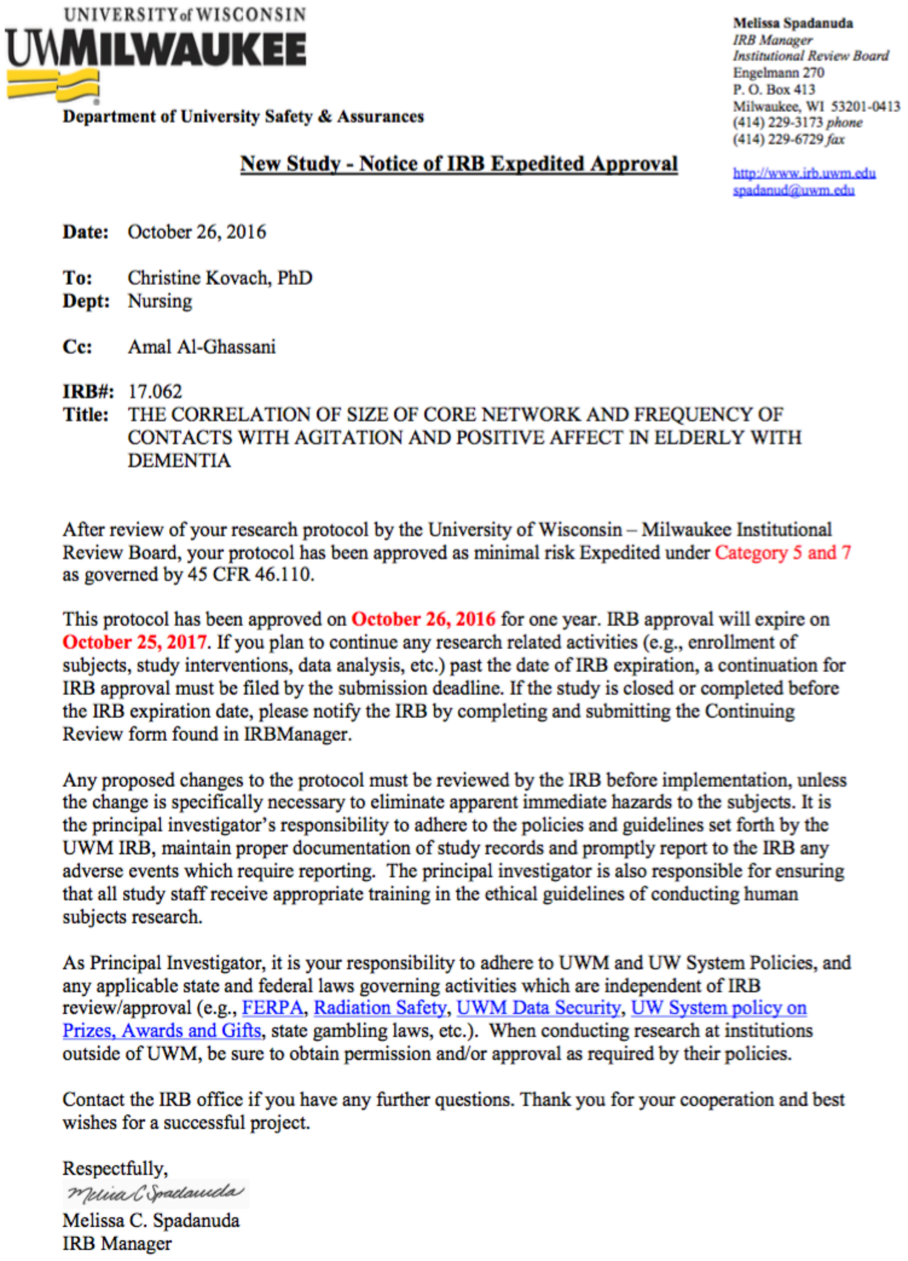
FOR BETTER CARE OF OLDER ADULT WITH DEMENTIA

My name is Amal Al-Ghassani, and I am interested in learning more about caregiving of older adults with dementia. The results of this research study will help in planning and providing better service for your loved ones.

Your help to support this through volunteering to participate in the study is extremely valuable. If you are interested, give your name and contact number to your community health nurse and then I will call you

Appendix K

UWM-IRB APPROVAL



UNIVERSITY of WISCONSIN
UWMILWAUKEE
Department of University Safety & Assurances

Melissa Spadanuda
IRB Manager
Institutional Review Board
Engelmann 270
P. O. Box 413
Milwaukee, WI 53201-0413
(414) 229-3173 *phone*
(414) 229-6729 *fax*

http://www.irb.uwm.edu
spadanud@uwm.edu

New Study - Notice of IRB Expedited Approval

Date: October 26, 2016

To: Christine Kovach, PhD
Dept: Nursing

Cc: Amal Al-Ghassani

IRB#: 17.062
Title: THE CORRELATION OF SIZE OF CORE NETWORK AND FREQUENCY OF CONTACTS WITH AGITATION AND POSITIVE AFFECT IN ELDERLY WITH DEMENTIA

After review of your research protocol by the University of Wisconsin – Milwaukee Institutional Review Board, your protocol has been approved as minimal risk Expedited under Category 5 and 7 as governed by 45 CFR 46.110.

This protocol has been approved on **October 26, 2016** for one year. IRB approval will expire on **October 25, 2017**. If you plan to continue any research related activities (e.g., enrollment of subjects, study interventions, data analysis, etc.) past the date of IRB expiration, a continuation for IRB approval must be filed by the submission deadline. If the study is closed or completed before the IRB expiration date, please notify the IRB by completing and submitting the Continuing Review form found in IRBManager.

Any proposed changes to the protocol must be reviewed by the IRB before implementation, unless the change is specifically necessary to eliminate apparent immediate hazards to the subjects. It is the principal investigator's responsibility to adhere to the policies and guidelines set forth by the UWM IRB, maintain proper documentation of study records and promptly report to the IRB any adverse events which require reporting. The principal investigator is also responsible for ensuring that all study staff receive appropriate training in the ethical guidelines of conducting human subjects research.

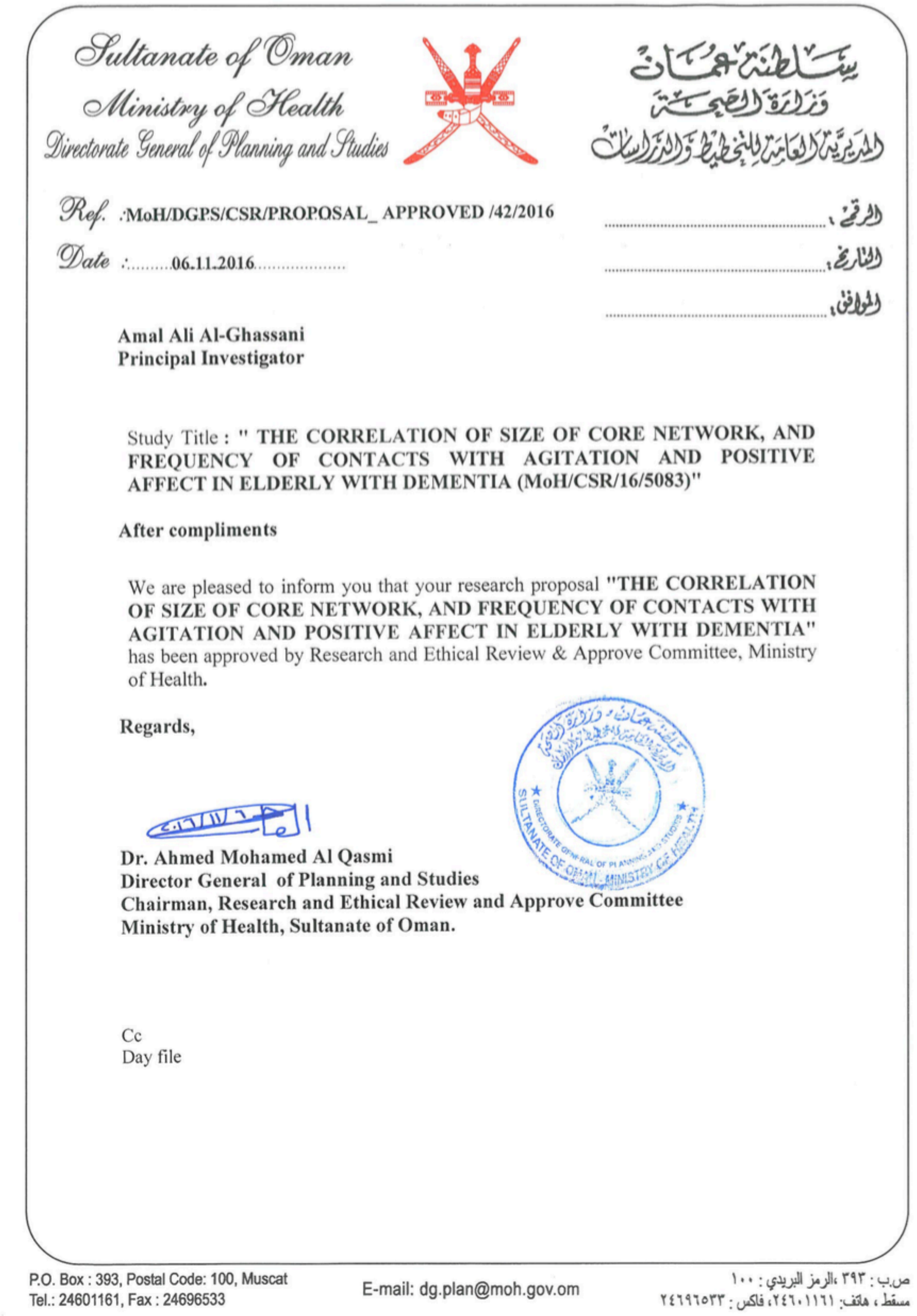
As Principal Investigator, it is your responsibility to adhere to UWM and UW System Policies, and any applicable state and federal laws governing activities which are independent of IRB review/approval (e.g., FERPA, Radiation Safety, UWM Data Security, UW System policy on Prizes, Awards and Gifts, state gambling laws, etc.). When conducting research at institutions outside of UWM, be sure to obtain permission and/or approval as required by their policies.

Contact the IRB office if you have any further questions. Thank you for your cooperation and best wishes for a successful project.

Respectfully,
Melissa C Spadanuda
Melissa C. Spadanuda
IRB Manager

Appendix L

OMAN-IRB APPROVAL



Sultanate of Oman
Ministry of Health
Directorate General of Planning and Studies

سلطنة عمان
وزارة الصحة
المديرية العامة للتخطيط والدراسات

Ref. :MoH/DGPS/CSR/PROPOSAL_ APPROVED /42/2016

Date :........06.11.2016....................

الرقم : ....

التاريخ : ....

الموافق : ....

Amal Ali Al-Ghassani
Principal Investigator

Study Title : **" THE CORRELATION OF SIZE OF CORE NETWORK, AND FREQUENCY OF CONTACTS WITH AGITATION AND POSITIVE AFFECT IN ELDERLY WITH DEMENTIA (MoH/CSR/16/5083)"**

After compliments

We are pleased to inform you that your research proposal **"THE CORRELATION OF SIZE OF CORE NETWORK, AND FREQUENCY OF CONTACTS WITH AGITATION AND POSITIVE AFFECT IN ELDERLY WITH DEMENTIA"** has been approved by Research and Ethical Review & Approve Committee, Ministry of Health.

Regards,

Dr. Ahmed Mohamed Al Qasmi
Director General of Planning and Studies
Chairman, Research and Ethical Review and Approve Committee
Ministry of Health, Sultanate of Oman.

Cc
Day file

P.O. Box : 393, Postal Code: 100, Muscat
Tel.: 24601161, Fax : 24696533

E-mail: dg.plan@moh.gov.om

ص.ب : ٣٩٣ ،الرمز البريدي : ١٠٠
مسقط ، هاتف: ٢٤٦٠١١٦١، فاكس : ٢٤٦٩٦٥٣٣

Appendix M

DATA CODEBOOK

Variable (lABEL SPSS)	Label (Name SPSS)	Coding Level	Level of Measurement /Unit of Analysis
Subject	SUB#	####	
Age	Age	####	Nominal
Gender	Gender	0=Male; 1=Female	Nominal
Primary caregiver Age	PC Age	####	Nominal
Primary caregiver Gender	PC Gender	0=Male; 1=Female	Nominal
Relationship of caregiver	Relat PC	1=Spouse; 2=Daughter; 3=Son; 4=Paid caregiver; 5=Professional caregiver; 6=Neighbors/Friends 7=daughter in law	Nominal
Primary Caregiver employment	PC Employ	0=No; 1=Part time (<8hrsx5days/wk); 2=Fulltime or more (>or equal 8hrsx5days/wk)	Nominal
Time of ADL Help	T ADL Help	#### in months	Nominal
Time of IADL Help	T IADL Help	##### in months	Nominal
Pace, aimless wandering1	Pace1	1=Never; 2= Less than once a week; 3= Once or twice a week; 4= Several times a week; 5= Once or twice a day; 6= Several times a day; 7= Several times an hour	Scale
Inappropriate dress or disrobing1	Dress1		
Spitting1	Spit1		
Cursing or verbal aggression1	Curs1		
Constant unwarranted request for attention or help1	Attention1		
Repetitive sentences or questions 1	Repetetive1		
Hitting1	Hitting1		
Kicking1	Kicking1		
Grabbing onto people1	Grabbing1		
Pushing1	Pushing1		
Throwing things1	Throwing1		
Strange noises1	Noise1		
Screaming1	Screaming1		
Biting1	Biting1		
Scratching1	Scratching1		
Trying to get a different place1	Out room1		
Intentional falling1	Falling1		
Complaining1	Complaining1		
Negativism1	Negetive1		
Eating/drinking inappropriate substances1	Eating1		
Hurt self or other1	Hurt1		

Handling things inappropriately1	Handling1		
Hiding things1	Hiding1		
Hoarding things1	Hoarding1		
Tearing things or destroying property1	Tearing1		
Performing repetitious mannerisms1	Repetious1		
Making verbal sexual advances1	V sexual1		
Making physical sexual advances1	P sexual1		
General restlessness1	Restlessness1		
Pace, aimless wandering2	Pace2D	1=Never; 2= Less than once a week; 3= Once or twice a week; 4= Several times a week; 5= Once or twice a day; 6= Several times a day; 7= Several times an hour	Scale
Inappropriate dress or disrobing2	Dress2		
Spitting2	Spit2		
Cursing or verbal aggression2	Curs2		
Constant unwarranted request for attention or help2	Attention2		
Repetitive sentences or questions 2	Repetetive2		
Hitting2	Hitting2		
Kicking2	Kicking2		
Grabbing onto people2	Grabbing2		
Pushing2	Pushing2		
Throwing things2	Throwing2		
Strange noises2	Noise2		
Screaming2	Screaming2		
Biting2	Biting2		
Scratching2	Scratching2		
Trying to get a different place2	Outroom2		
Intentional falling2	Falling2		
Complaining2	Complaining2		
Negativism2	Negetive2		
Eating/drinking inappropriate substances2	Eating2		
Hurt self or other2	Hurt2		
Handling things inappropriately2	Handling2		
Hiding things2	Hiding2		
Hoarding things2	Hoarding2		
Tearing things or destroying property2	Tearing2		
Performing repetitious mannerisms2	Repetious2		
Making verbal sexual advances2	Vsexual2		
Making physical sexual advances2	Psexual2		

General restlessness2	Restlessness2		
Number of ADL Caregivers	ADL#	####	Nominal
Number of IADL Caregivers	IADL#	####	Nominal
ADL Frequency of contact	ADLFreqcont	#### (Days in a typical30 days month)	Nominal
IADL Frequency of contact	IADLFreqcont	#### (Days in a typical30 days month)	Nominal
Closeness of ADL1	ClosADL1	#### of ADL network at level1)	Nominal
Closeness of ADL2	ClosADL2	#### of ADL network at level2)	Nominal
Closeness of ADL3	ClosADL3	#### of ADL network at level3)	Nominal
Closeness of IADL1	ClosIADL1	#### of IADL network at level1)	Nominal
Closeness of IADL2	ClosIADL2	#### of IADL network at level2)	Nominal
Closeness of IADL3	ClosIADL3	####(% IADL network at level3)	Nominal
Interested1	PInterested1	1=Very slightly or not at all; 2=A little; 3=Moderately; 4=Quite a bit; 5=Extremely	Scale
Distressed1	PDistreesed1		
Excited1	PExcited1		
Upset1	PUpset1		
Strong1	PStrong1		
Guilty1	PGuilty1		
Scared1	PScared1		
Hostile1	PHostile1		
Enthusiastic1	PEnthsiastic1		
Proud1	PProud1		
Irritable1	PIrritable1		
Alert1	PAlert1		
Ashamed1	PAshamed1		
Inspired1	PInspired1		
Nervous1	PNervous1		
Determined1	PDetermined1		
Attentive1	PAttentive1		
Jittery1	PJittery1		
Active1	PActive1		
Afraid1	PAfraid1		
Interested2	PInterested2	1=Very slightly or not at all; 2=A little; 3=Moderately; 4=Quite a bit; 5=Extremely	Scale
Distressed2	PDistreesed2		
Excited2	PExcited2		
Upset2	PUpset2		
Strong2	PStrong2		
Guilty2	PGuilty2		
Scared2	PScared2		
Hostile2	PHostile2		
Enthusiastic2	PEnthsiastic2		
Proud2	PProud2		

THE CORRELATION OF SIZE OF CORE NETWORK AND FREQUENCY OF CONTACTS WITH AGITATION AND POSITIVE AFFECT IN ELDERLY WITH DEMENTIA

by

Amal Al-Ghassani

A Dissertation Submitted in
Partial Fulfillment of the
Requirements for the Degree

Doctor of Philosophy
in Nursing

at

The University of Wisconsin–Milwaukee

December 2017

Irritable2	PIrritable2		
Alert2	PAlert2		
Ashamed2	PAshamed2		
Inspired2	PInspired2		
Nervous2	PNervous2		
Determined2	PDetermined2		
Attentive2	PAttentive2		
Jittery2	PJittery2		
Active2	PActive2		
Afraid2	PAfraid2		
Year	MMSE1	1	Nominal
Season	MMSE2	1	
Date	MMSE3	1	
Day	MMSE4	1	
Month	MMSE5	1	
State	MMSE6	1	
County	MMSE7	1	
Town	MMSE8	1	
Hospital	MMSE9	1	
Floor	MMSE10	1	
Object1	MMSE11	1	
Object2	MMSE12	1	
Object3	MMSE13	1	
Serial seven1	MMSE14	1	
Serial seven2	MMSE15	1	
Serial seven3	MMSE16	1	
Serial seven4	MMSE17	1	
Serial seven5	MMSE18	1	
Recall object1	MMSE19	1	
Recall object2	MMSE20	1	
Recall object3	MMSE21	1	
Name object1	MMSE22	1	
Name object2	MMSE23	1	
Repeat phrase	MMSE24	1	
Command 1	MMSE25	1	
Command 2	MMSE26	1	
Command 3	MMSE27	1	
Read and do	MMSE28	1	
Write a sentence	MMSE29	1	
Copy design	MMSE30	1	
Heart	HEART	**0=**no problem; 1= current mild problem or past significant problem; 2=moderate disability or morbidity/requires "first line" therapy; 3=sever/constant significant disability/"uncontrollable" chronic problems;	Scale
Vascular	VASC		
Hematopoietic	HEMO		
Respiratory	RESP		
Eyes, ears, nose, throat & larynx	EYES		
Upper gastrointestinal tract	UGESTRO		

Lower gastrointestinal tract	LGESTRO	4=extremely severe/immediate treatment required/end organ failure/severe impairment function	
Liver	LIVER		
Renal	RENAL		
Genitourinary	GENO		
Musculoskeletal/Integument	MUSCK		
Neurological	NEURO		
Endocrine/Metabolic	ENDO		

Appendix N

Data Analysis Table

Research Questions/Hypotheses	Unit of Analysis	Variable	Measurement Tool	Level of Measurement	Statistical Test
Descriptive Questions					
1. What is the level of agitation among older adult PWDs in Oman?	People with dementia (PWDs)	DV: level of agitation	- MMSE - CMAI	- Nominal - Interval	Descriptive statistics Means (if no severe skew is present), ranges, and standard deviations.
2. With what frequency do PWDs have contact with their ADL and IADL core networks?	PWDs	IV: dementia DV: frequency of core network contacts	- MMSE - Self-report	- Nominal - Interval	Descriptive statistics (frequency, mean, *SD*, range)
3. Are there differences in the size of ADL and IADL core network between those with early and later stage dementia?	PWDs	IV: dementia DV: size of core network	- MMSE - ADL and IADL checklist	- Nominal - Interval	*t*-test Descriptive statistics Means (if no severe skew is present), ranges, and standard deviations.

Main Hypothesis	Unit of Analysis	Variable	Measurement Tool	Level of Measurement	Statistical Test
1. Controlling for the severity of dementia and comorbid problems, the size (IV) and frequency (IV) of contact with the ADL core network (IV) will predict the agitation (DV) and affect (DV) of PWDs.	PWDs	IV: size and frequency of contacts DV: agitation and affect	- MMSE - ADL and IADL checklist - CMAI - PANAS - CIRS-G	- Nominal - Interval - Interval - Ordinal - Ordinal	- **Mann-Whitney U test to** examine the difference between ADL size of core network/ frequency of contact, and between agitations and affect. - Spearman's rank-order correlation coefficient to identify the strength and direction of the association between the size of ADL core network/ frequency of contact, and agitation and affect.

Secondary Hypothesis	Unit of Analysis	Variable	Measurement Tool	Level of Measurement	Statistical Test
1. Controlling for the severity of dementia and comorbid problems, the size (IV) and frequency (IV) of contact with the IADL core network (IV) will predict the agitation (DV) and affect (DV) of PWDs.	PWDs	IV: size and frequency of contacts DV: agitation and affect	- MMSE - ADL and IADL checklist - CMAI - PANAS - CIRS-G	- Nominal - Interval - Interval - Ordinal - Ordinal	- **Mann-Whitney U test to** examine the difference between IADL size of core network/ frequency of contact, and between agitations and affect. - Spearman's rank-order correlation coefficient to identify the strength and direction of the association between the size of IADL core network/ frequency of contact, and agitation and affect.

Secondary Hypothesis	Unit of Analysis	Variable	Measurement Tool	Level of Measurement	Statistical Test
2. Controlling for the severity of dementia and comorbid problems, the closeness of IADL and ADL caregivers (IV) as well as the size of caregiver core network will predict the density of IADL and ADL care provided (DV).	PWDs	IV: closeness of IADL and ADL caregivers and size of caregiver core network DV: density of IADL and ADL care provided	- MMSE - SCQ - Self-report	- Nominal - Interval - Ordinal	- **Mann-Whitney U test to** examine the difference between closeness of ADL &IADL/ size of core network and ADL &IADL density of care - Spearman's rank-order correlation coefficient to identify the strength and direction of the association between closeness of ADL &IADL/ size of core network and ADL &IADL density of care

Appendix O

Study Results and Characteristics of Selected Research Investigating

Environment: Factors in Home Care and Outcomes

Study: author/year	Study Design & Level of Evidence	Purpose of the Study	Subjects	Interventions/ Control Groups	Validity & Reliability	Outcomes/Significant Results
Zeisel, Silverstein, Hyde, Levkoff, Lawton, & Holmes, 2003	A descriptive study LOE: Level III	To measure the associa- tions between environmental design features of nursing home special care units and the incidence of aggression, agitation, social withdrawal, depression, and psychotic problems among persons living there who have Alzheimer's disease or a related disorder	427 residents in 15 special care units.	Sample included 308 women and 119 men.	Not specifically addressed.	There is an association between each behavioral health measure and particular environmental design features.
Morgan, D. G., & Stewart, N. J. (1997).	Qualitative study. LOE: III	To explore the perception of family and staff caregivers in regard to the relationship between environment and behavior in persons with dementia.	A total of 18 (9 staff and 9 family members).	Semi-structured interview was conducted with open-ended questions. Ethno-graph was used to facilitate coding. Contact summary sheets, summary diagrams, analytic notes, and methodological notes were also completed following each interview.	The instruments have previously demonstrated validity and reliability.	Social environment such as staff-residents interaction, and activity programming was associated with behaviors exhibited by patients with dementia.

Nikmat, A. W., Hawthorne, G., & Al-Mashoor, S. H. (2015).	Cross-sectional survey/ quasi-experimental study LOE: III	To compare the quality of life (QoL) of people with dementia in the nursing home and home care, and identify factors that differentiate their QoL.	A total of 49 people with dementia 60 years old and older.	Consenting participants were assessed on cognitive severity, QoL, (ADLs), (SMMSE), the WHO-8 (the EUROHIS-QOL), Short Assessment of Quality of Life (AQoL-8), Barthel Index (BI), Cornell Scale for Depression (CSDD), and Friendship Scale (FS).	Instruments were tested for validity and reliability.	There were significant differences in QoL, HRQoLs, ADLs, and social connectedness among people with dementia in home care (n1⁄419) and those in nursing homes (n1⁄430) ($p<0.01$).
Garre-Olmo, J., López-Pousa, S., Turon-Estrada, A., Juvinyà, D., Ballester, D., & Vilalta-Franch, J. (2012).	Cross-sectional, observational, analytical. LOE: III	To determine the relationship between quality of life (QOL) and environmental factors of temperature, noise, and lighting in nursing home residents with severe dementia.	Random sample of 160 nursing home residents with severe dementia.	Functional and cognitive impairment, pain, neuropsychiatric disturbances, and QOL were deter- mined using standardized instruments.	Instruments were tested for validity and reliability	QOL of nursing home residents with severe dementia was related to environmental factors such as temperature, noise, and lighting. High temperature, high noise levels, low lighting levels associated with low behavioral signs of social interactions and negative affective mood
Cohen-Mansfield, J., & Werner, P. (1998).	Cross-sectional, descriptive, observational, analytical LOE: III	To assess the effects of an enhanced environment, as a global variable, on the behavior and mood, as well as on the manifestation of pacing and wandering behaviors, of nursing home residents who pace frequently.	27 nursing home residents	Observation: The duration of pacing manifested by each participant was recorded by a trained research assistant using the computer event recorder. Use of Ambulatory Device: Personal Activity Monitor 2 (PAM2) - was used.	Reliability and validity were tested previously	Enhanced environment had a positive effects on the behavior and mood of the nursing home residents

Gitlin, L., Corcoran, M., Winter, L., Boyce, A., & Hauck, W. (2001).	Randomized control trail LOE: I	To determined short-term effects of a home environmental intervention on self-efficacy and upset in caregivers and daily function of dementia patients.	Families (N= 171) of dementia patients	Families were randomized to intervention or usual care control group. The intervention involved 5 90-min home visits by occupational therapists who provided education and physical and social environmental modifications.	Reliability and validity were tested previously	Environmental approach has a positive impact on both the caregiver and the person with dementia such that it may slow the progression of IADL dependence of pa- tients and enhance self-efficacy and reduce upset for select caregivers.
Kostka, T., & Jachimowicz, V. (2010)	Cross-sectional study LOE: III	To describe the relationship of dispositional optimism, health locus of control and self-efficacy to quality of life (QOL) in older subjects differing in level of disability and institutionalisation.	Age > 65 N=110 (healthy community-dwelling elderly) N=102 (independent elders who voluntarily decided to live in veteran home) N=112 (inhabitants of a long-term care home).	Life orientation test—revised (LOT-R), multidimensional health locus of control (MHLC) and generalised self-efficacy scale (GSES) together with a multidimensional assessment were performed with each subject. QOL was assessed using the Euroqol 5D question- naire, the Nottingham health profile and the satisfaction with life scale (SWLS).	Reliability and validity were tested previously	QOL generally decreased with growing level of dependence and institutionalisation. Community-dwelling elderly had the highest physical activity indices and MMSE. Long-term care home inhabitants had the lowest physical activity, and MMSE Internal and external locus of control were the highest in veteran home elders.

Appendix P
Study Results and Characteristics of Selected Research Investigating

Caregivers: Factors in Home Care and Outcomes

Study: author/year	Study Design & Level of Evidence	Purpose of the Study	Subjects	Interventions/ Control Groups	Validity & Reliability	Outcomes/Significant Results
Alvira, M. C., Risco, E., Cabrera, E., Farré, M., Rahm Hallberg, I., Bleijlevens, M. H., & ... Zabalegui, A. (2015).	Association study based on cross-sectional data LOE: Level III	To describe the associations between positive and negative reactions of informal caregivers of people with dementia and health outcomes across eight European Countries	2014 participants of people with dementia and their informal caregivers living at home or in long-term care institutions	Data were collected using the Caregiver Reaction Assessment and associations were sought with informal caregiver burden, quality of life and psychological well-being and with dementia sufferers' neuropsychiatric symptoms, comorbidity and dependency in activities of daily living using correlation coefficients.	The instruments have previously demonstrated validity and reliability. Also, versions were validated in their particular cultural context were used.	Self-esteem and lack of family support correlated with caregiver burden and psychological well-being. Associations were also found between disrupted schedule and caregiver burden, psychological well-being and quality of life.
Jaglal, S, R Cockerill, L Lemieux-Charles, LW Chambers, K Brazil, and C Cohen. (2007).	Multiple comparative case study design LOE: Level III	To examine whether sociodemographic and health characteristics, type of support network, and amount of service use among care recipients and caregivers were associated with experiences with care processes.	Care recipients and caregivers (n=267 dyads)	Health status for caregivers and care recipients were measured according to the core Healthy Days Measures, an integrated set of 4 broad questions about recent perceived health status and activity limitation. Personal support network was measured by using Network Assessment Instrument.	The instruments have previously demonstrated validity and reliability.	If caregivers received home sup- port and the care recipients received emotional support from their social support network, they were more likely to be satisfied with their experiences with health care workers.

Karlsson, S., Bleijlevens, M., Roe, B., Saks, K., Martin, M. S., Stephan, A., & ... Hallberg, I. R. (2015).	Qualitative research (Focus groups) LOE: Level III	To investigate persons with dementia and their informal caregivers' views of inter-sectoral information, communication and collaboration throughout the trajectory of dementia care, in eight European countries	Persons with dementia and their informal caregivers (N = 137)	Focus group interviews. Content analysis generated a tentative model of information, communication and collaboration for people with dementia and their caregivers, which was then tested.	The Categories and sub-categories were formed by the the first author, and categorization was thereafter validated by the last author.	Establishing a trusting relationship with care givers and professionals, professional knowledge and commitment, variation in service and care adapted to needs were identified as important.
Stephan, A., Afram, B., Koskenniemi, J., Verbeek, H., Soto, M., Bleijlevens, M., Sutcliffe, C., Lethin, C., Risco, E., (2015).	Cross-sectional survey LOE: Level III	To explore the perceptions of informal caregivers and healthcare professionals regarding potential reasons for the institutionalization of older PWD in eight European countries.	1160 persons with dementia	Answers were openly coded and categorized. Variation between informal caregivers and healthcare professionals was investigated (agreement on at least one potential reason per case/proportion of maximum attainable kappa).	Two validation procedures were employed. 1. Quality and reliability of translations from the native language to English. 2. Final coding scheme was tested in terms of inter-coder agreement between the two Dutch researchers.	Agreement that caregiver burden, caregiver unable to provide care, neuropsychiatric symptoms, overall deterioration, care dependency were potential reasons for institutionalization of older PWD.

Wang, J., Xiao, L. D., He, G., & Bellis, A. (2014).	Double hermeneutic approach LOE: Level III	To examine socially, culturally and politically constructed factors affecting family caregiver practice in dementia care	23 family caregivers of people with dementia	In-depth semi-structured interviews The interviews were audiotaped, transcribed and analyzed.	Not specifically addressed	Relying on family caregivers to care for people with dementia without the prevision of dementia services by the public healthcare system generates negative health outcomes for both care recipients and caregivers.
Qadir, F., Gulzar, W., Haqqani, S., & Khalid, A. (2013).	Qualitative research (Focus groups) LOE: Level III	To explore **awareness** among **caregivers**, their **attitudes** toward family members suffering from **dementia**, and their experience of **burden**. In-depth interviews were conducted with 12 **caregivers** of **patients** diagnosed with **dementia** in Rizwalpindi/Islamabad, Pakistan.	12 **caregivers** of **patients** diagnosed with **dementia**	In-depth interviews were conducted with participants	Not specifically addressed	Social and financial **burden** of **dementia** on families of **caregivers** in Pakistan may be exacerbated if they do not have support.

Appendix Q
Study Results and Characteristics of Selected Research Investigating

Social : Factors in Home Care and Outcomes

Study: author/year	**Study Design & Level of Evidence**	**Purpose of the study**	**Subjects**	**Interventions/ Control Groups**	**Validity & Reliability**	**Significant Results**
Burgio, LD, FR Butler, DL Roth, JM Hardin, C Hsu, and K Ung. 2000	Descriptive study LOE: Level III	To investigated the relationship among gender of resident, staff social interaction, and agitation	46 (31 male and 15 female) nursing home residents with clinically significant agitation	Direct observations using computer-assisted, real-time observational system	Previously tested tool, Not specifically addressed in this study.	Staff touch and verbal interaction elicit agitation in a significant proportion of residents.
Carpentier, N., Pomey, M., Contreras, R., & Olazabal, I. (2008).	Exploratory study LOE: Level III	To investigates the interface between health care practitioners and caregivers of people with Alzheimer's disease living in the community	20 practitioners drawn from seven urban groups.	The authors interviewed the subjects and analyzed contacts between practitioners and caregivers at the beginning of the care trajectory.	Previously tested tool, Not specifically addressed in this study.	Heterogeneous professional groups and the establishment of contacts in the early stages of dementia seemed beneficial between formal and informal service networks.

Giles, L., Metcalf, P. A., Glonek, G. F. V., Luszcz, M. A. and Andrews, G. R. (2004).	Longitudinal Study LOE: Level III	To investigate the effects of total social networks and specific social net- works with children, relatives, friends, and confidants on disability in mobility and Nagi functional tasks in older adults.	1,477 participants aged 70 years or older	Six waves of data from the Australian Longitudinal Study of Ageing were used. Data were analyzed using binary and multi- nomial logistic regression.	Not specifically addressed in this study.	After controlling for a range of health, environ- mental, and personal factors, social networks with relatives protect against disability in mobility and Nagi tasks.
Nay, R., Bauer, M., Fetherstonhaugh, D., Moyle, W., Tarzia, L., & McAuliffe, L. (2015).	Exploratory study LOE: Level III	To understand what social participation actually means to family carers of people with dementia.	33 family carers (17 spouses and 16 adult children)	Data were collected through semi-structured face-to-face and/or telephone interviews	Not specifically addressed in this study	Carers went through a process whereby the ways in which they had previously participated socially were compromised, which often prompted an exploration of new ways in which to remain socially engaged.

Nicholls, D., Chang, E., Johnson, A., & Edenborough, M. (2013).	Mixed methods approach Implementing the ‘high touch’ intervention and eval- uating results with pre- and post-measurements.LOE: Level I	To improve delivery of palliative care to people with advanced dementia, increase the knowl- edge and skills of care staff and enhance communica- tion between residents, their families and health professionals.	Seven focus groups consisting of 31 participants were conducted separately for each of the study cohorts	Data were derived from focus groups conducted at three residential aged care facilities located in metropolitan and regional areas of NSW, Australia	Not specifically addressed in this study	Social relations contribute to provide life meaning and role satisfaction to the participants, both as providers and as recipients of care
de Vocht, H. M., Hoogeboom, A. M., van Niekerk, B., & den Ouden, M. E. (2015).	Pre-/post-test study LOE: Level III	To assess the **impact** of a one-to-one 30-min **individualized interaction** per day on the behavior and **quality** of **life** of care-**dependent** residents with dementia.	15 care-**dependent** residents with dementia (mean age 88.8 years, 86.7% women) were included. Health care professionals (n = 13) and direct relatives (n = 4)	Resident behavior was measured using video observation and **quality** of **life** using Qualidem. Health care professionals and direct were interviewed about the effect of the intervention.	Not specifically addressed in this study	**Interaction** offered on a one-to-one basis tailored to individual preferences significantly improved positive interactive behavior of care-**dependent** residents with dementia during the intervention.

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