Exploring Experiences of Pain Management among Family Caregivers of Community-Dwelling Older Adults with Dementia: A Qualitative Study

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Abstract

Background: Pain is a significant concern in older adults with dementia. Family caregivers play a crucial role in pain management for their care recipients. However, to date, few studies have examined family caregiver's (FCGs) experiences of pain management for community-dwelling older adults with dementia.

Purpose: To provide a deep understanding of experiences of pain management among FCGs for community-dwelling older adults with dementia.

Methods: This study used a qualitative descriptive design and constant comparison analytic methods. Family caregivers were recruited and participated in semi-structured face-to-face interviews or phone interviews. Inclusion criterion included being an adult providing care to community-dwelling older adults. Recruitment stopped upon reaching thematic saturation. A demographic questionnaire was used to collect additional relevant information.

Results: The study included 25 family caregivers in central Virginia who ranged in age from 29 to 95. Participants were predominantly white, female, married, and had a minimum high school education. Most of them were adult children (52%) or the spouses (28%) of the care recipients. Three themes were identified: 1) Values, 2) Barriers, and 3) Support.

Conclusion: Family caregivers follow their values to make decisions in pain management. Barriers existed for effective pain management. Support is needed for family caregivers in pain management.

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Dedication

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Chapter 1. Introduction

There are an estimated 5.3 million people aged 65 or older with dementia across the United States (Alzheimer's Association [AA], 2017), which represents a significant public health issue. However, the quality of care, particularly in pain management for people with dementia, often falls below standards due to the unique and complex challenges presented by dementia (Corbett et al., 2014).

Pain, as an adverse symptom, is one of the most common medical complaints (McCarberg et al., 2008). The prevalence of pain is strongly associated with age, hitting the oldest population the hardest with prevalence rates of 72% above age 85. Older adults with dementia have even higher prevalence of pain, as high as 80% (Eritz & Hadjistavropoulos, 2011; Hunt et al., 2017).

In addition to high prevalence of pain, studies have indicated that pain in people with dementia is more often under-reported and poorly managed than in those without dementia (Bernabei et al., 1998; Eritz & Hadjistavropoulos, 2011; Morrison & Siu, 2000; Teno, Weitzen, Wetle, & Mor, 2001). Due to the pathologic changes in the brain, persons with dementia have an inability to remember, interpret, and respond to pain (Benedetti et al., 2004). Consequently, despite its prevalence among those with dementia, pain is often under reported and undertreated (Achterberg et al., 2013). Unrelieved pain can affect individual's quality of life, cause profound negative physical and emotional effects, increase healthcare services use and costs, and the burden for caregivers (Covinsky, Lindquist, Dunlop, & Yelin., 2009; Andrew, Cenzer, Yelin, Covinsky, 2013; Shega et al. 2004).

In the United States, nearly 81% of those with dementia live in the community, and family members provide care to approximately 75% of those patients (AA, 2017). In addition, when patients with dementia live in long-term care facilities, family caregivers (FCGs) often spend lots of time with the patients and usually act as decision makers (Lethin, Hallberg, Karlsson, & Janlov, 2015; Tarter et al., 2016). Though FCGs play such an important role in caring for older adults with dementia, existing studies have focused on the formal caregivers' experience in pain management. In addition, most of the studies were conducted in the healthcare settings or long-term care facilities. Little is known about family caregivers' experiences in pain management, particularly in community-dwellings individuals.

Accordingly, the main goal of this study was to gain a deep understanding of FCGs' experiences in pain management for community-dwelling older adults with dementia. The specific aims of this study were: 1) To explore FCGs pain management experiences for their loved ones living in the community-settings; 2) To identify barriers for effective pain management among family caregivers; and 3) To identify ways that help FCGs to improve their quality care for pain.

This study used the qualitative description (QD) method. Qualitative description is the method of choice of choice for describing an unknown phenomena and minimizing inference bias (Sandelowski, 2000). Given the limited knowledge in family caregivers' experiences in pain management for their loved ones, this research method matches the needs for the study.

The analytic process was an iterative process with constant comparison (Corbin & Strauss, 2008). Initially, open coding was done to give higher-level meaning of the statement by labeling them. As coding proceeded, previous coded transcripts were evaluated and recoded. Then the codes were focused into concepts. Finally, themes emerged followed by generated concepts (Corbin & Strauss, 2008). Analytic memos were written throughout the analysis to capture the analytic process. The semi-structured guide was modified to reflect the changes of the process (Emerson, Fretz, & Shaw, 1995).

The theoretical underpinning for the study is the Social Communication Model of Pain ([SCMP], Craig, 2009) that provides a broad framework for understanding of pain management; therefore, it was also used for the development of the interview guide (Craig & Versloot, 2011). This model was originally developed to explore the role of social barriers that limit effective control of pain in infants and children. However, it has also been found useful in understanding pain assessment and care in adults with cognitive impairments (Craig, 2009). The model accepts that infants and children go from a time of full dependence on parents to recognize pain, through a period of partial ability to verbally indicate pain, to a point of having full agency in this regard. People with dementia go through the trajectory in the opposite direction, from having the ability to self-report pain, to eventually losing the ability. The SCMP model facilitates understanding in both cases.

The Social Communication Model of Pain includes biological, psychological, and social perspectives at the level of interaction between the person in pain and the caregivers or observers (Craig, 2009). The multiple levels of factors could play roles as barriers or facilitators for effective pain management. In addition, this model provides a chronological process for pain assessment and pain management, from encoding to decoding to treatment (Craig, 2009). In summary, this model was used to loosely guide the study aimed to explore how family caregivers manage for their loved ones in the community settings.

This dissertation is composed of six chapters summarizing the conclusions of the research. Chapter One is the introduction for the dissertation. Chapter Two is a research proposal. Chapters Three, Four and Five are three manuscripts. Chapter Three is a literature review analyzing the current state of research on pain management for people with dementia. The title is *Pain Management for People with Dementia: An Integrative Literature Review.* The fourth chapter is a concept analysis, titled *Concept Analysis: Pain Management for people with Dementia,* which aimed to examine the unique characteristics of the concept of pain management in people with dementia. Chapter Five reported the results of a qualitative study that aimed to explore how family caregivers manage pain for their loved ones in the community setting. The title of the report is *Exploring Experiences of Pain Management among Family Caregivers of Community-Dwelling Older Adults with Dementia: A Qualitative Study.* The sixth and last chapter provides a conclusive summary of the completed research.

References

Achterberg, W. P., Pieper, M. P., Dalen-Kok, A. H., Waal, M. W. M., Husebo, B. S., Lauenbacher, S….Corbett, A. (2013). Pain management in patients with dementia. *Clinical Interview of Aging, 8*, 1471-1482.

Alzheimer's Association, (2017). Alzheimer's disease facts and figures. Retrieved from http://www.alz.org/facts/

Andrew, J. S., Cenzer, I. S., Yelin, E., Covinsky, K. E. (2013). Pain as a risk factor for disability or death. *J Am Geriatric Soc, 61*, 583-589.

Benedetti, F., Arduino, C., Vighetti, S., Asteggiano, G., Tarenzi, L., Rainero, I. (2004). Pain reactivity in Alzheimer patients with different degrees of cognitive impairment and brain electrical activity deterioration. *Pain, 111*,22-29.Bernabei, R., Gambassi, G., Lapane, K., Landi, F., Gatsonis, C., Dunlop, R., … Mor, V. (1998). Management of pain in elderly patients with cancer: SAGE Study Group: Systematic Assessment of Geriatric Drug Use via Epidemiology. JAMA, 279, 1877-1882.

Corbett, A., Achterberg, B. H., Husebo, B., Lobbezoo, F., DeVet, H., Kunz, M........ Lautenbacher, S. (2014). A international road map to improve pain assessment in people with impaired coggition: the development of the Pain Assessement in Impaired Cognition (PAIC) meta-tool. *BMC Neurology, 14*, 229.

Corbin, J, Strauss, A. L. (2008). *Basics of qualitative research: techniques and procedures for developing grounded theory.* 3rd ed. Thousand Oaks, CA: Sage.

Covinsky, K. E., Lindquist, K., Dunlop, D. D., Yelin, E. (2009). Pain, functional limitations, and aging. *J Am Geriatric Soc 57*, 1556-1561.

Craig, K. D. & Versloot, J. (2011). Psychosocial perspectives on chronic pain. In Lynch, M. E., Craig, K. D., & Peng, W. H. (Eds.) Clinical pain management: A practical guide. Oxford, UK: Blackwell Publishing.

Craig, K. D. (2009). The social communication model of pain. *Canadian Psychology, 50*(1), 22-32. doi:10.1037/a0014772

Emerson, R., Fretz, R., Shaw, L. (1995). Writing ethnographic fieldnotes. Chicago: The University of Chicago Press.

Eritz, H. & Hadjistavropoulos, T. (2011). Do informal caregivers consider nonverbal behavior when they assess pain in people with severe dementia? *Journal of Pain, 12*(3), 331-339.

Hunt, L., Covinsky, K., Yaffe, K., Stephens, C., Miao, Y., Boscardin, W. J., & Smith, A. K. (2017). Pain in community-dwelling older adults with dementia: Results from the National Health and Aging Trends Study. *J Am Geriatr Soc. 63*(8), 1503-1511.

Lethin, C., Hallberg, I. R., Karlsson, S. K., & Janlov, A. C. (2015). Family caregivers experiences of formal care when caring for persons with dementia through the process of the disease. *Scandinavian Journal of Caring Sciences*, *30*(3), 526-534. doi:10.1111/scs.12275.

McCarberg, B. H., Nicholson, B. D., Todd, K. H., Palmer, T., Penles, L. (2008), The impact of pain on quality of life and the unmet needs of pain management: Results from pain suffers and physicians participating in an internet survey.

Morrison, R. S. & Siu, A. L. (2000). A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture. *Journal of Pain Symptom Management, 19*, 240-248.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health, 23*, 334-340.

Shega, J. W., Hougham, G. W., Stocking, C. B., Cox-Hayley, D., & Sachs, G. A. (2004). Pain in community-dwelling persons with dementia: Frequency, intensity, and congruence between patient and caregiver report. *Journal of Pain Symptom Management, 28*(6), 585-592.

Tarter, R., Demiris, G., Pike, K., Washington, K., & Oliver, D. P. (2016). Pain in hospice patients with dementia: The informal caregiver experience. *American Journal of Alzheimer 's disease and Other Dementia, 31*(6), 524-529. doi: 10.1177/1533317516653825

Teno, J. M., Weitzen, S, Wetle, T., & Mor, V. (2001). Persistent pain in nursing home residents. *JAMA, 285*, 2081.

Chapter 2. Research Proposal

SPECIFIC AIMS

Pain is one of the most common medical complaints (McCarberg et al., 2008). Unrelieved pain can affect individual's quality of life, cause profound negative physical and emotional effects, and increase healthcare services use and costs (Covinsky, Lindquist, Dunlop, & Yelin., 2009; Andrew, Cenzer, Yelin, Covinsky, 2013; Shega et al. 2004).

Older adults with dementia experience a high prevalence of pain, reaching about 73-80% (Eritz & Hadjistavropoulos, 2011; Hunt et al., 2015). Despite its prevalence among those with dementia, pain is often under reported and undertreated. Self-report is the golden standard for pain assessment because pain is always subjective (National Pharmaceutical Council [NPC] & The Joint Commission on Accreditation of Healthcare Organizations [JCAHO], 2001). However, the pathologic changes in the brain among persons with dementia alter their ability to remember, interpret, and respond to pain (Benedetti et al., 2004). Consequently, self-reporting pain may not occur in this population, leading to underreported and undertreated pain (Bernabei et al., 1998).

Dementia is a major public health issue, affecting 5.3 million people aged 65 or older (Alzheimer's Association [AA], 2017). In the United States, nearly 81% of those with dementia lives in community, and family members provide care approximately 75% of those patients (AA, 2017). In addition, when patients with dementia live in long-term care facilities, family caregivers (FCGs) often spend lots of time with the patients and usually act as decision makers (Lethin, Hallberg, Karlsson, & Janlov, 2015; Tarter et al., 2016).

Though FCGs play such an important role in caring for older adults with dementia, little is known about their experiences of pain management for community-dwelling older adults with dementia. Existing studies have shown that only formal caregivers in healthcare settings have been trained to use appropriate tools for pain assessment. These tools included observational pain rating scales and behavioral checklists, which have been tested only in clinical settings. Recommendations for effective pain management and guidelines of analgesic administration for pain treatment were developed in clinical settings. No recommendations or guidelines for pain management by FCGs have been developed (Achterberg et al., 2013; Barry, Parsons, Passmore, & Hughes, 2015; Burns & McIlfatrick, 2015; Chow et al., 2016; Eritz & Hadjistavropoulos, 2011; Fuchs-Lacelle, Hadjistavropoulos, & Lix, 2008; Lichtner et al., 2016; Shege et al., 2004). How FCGs manage pain for community-setting older adults remains unclear.

The goal of this study was to develop a deep understanding of FCGs' experiences of pain management for community-setting older adults with dementia. The qualitative descriptive study provided a direct and rich description of how FCGs management pain for their community-setting older adults with dementia. Important knowledge was gained from this project: a deep understanding of experience of pain management among FCGs (**Specific Aim [SA] 1**); barriers affect FCGs' decision-making in pain management (**SA2**); and ways to help FCGs to improve their quality care for pain (**SA 3**).

Twenty-five FCGs of community-setting older adults with dementia were recruited from diverse sites, including University of Virginia Memory and Aging Care Center (UVA MACC), and local area boards on aging in central Virginia such as

Jefferson Area Board on Aging (JABA). Purposive sampling was used to recruit a group of FCGs reflecting diversity in gender, race/ethnicity (i.e., white, African-American, and other Asian or Pacific Islanders), age (variety of age group), and education level. Participants were interviewed once using a semi-structured interview guide.

The specific aims of this study were:

1) To explore FCGs pain management experiences for their loved ones living in the community-setting;

2) To identify barriers for effective pain management among family caregivers; and

3) To identify ways that help FCGs to improve their quality of care for pain.

Potential for a sustained scientific impact: The main premise for this project was to advance the understanding of pain management provided by FCGs of community-setting older adults with dementia. The knowledge obtained from this study is crucial for intervention and policy development in order to promoting quality of life for both community-setting older adults with dementia and their FCGs.

RESEARCH STRATEGIES

Background and significance

Pain and dementia research are priorities of the National Institutes of Health (NIH). Pain, as an adverse symptom, is one of the most common medical complaints, affecting more Americans than diabetes, heart disease and cancer combined. All individuals experience occasional episodes of acute pain (American Pain Society, 1996; McCarberg et al., 2008). A study based on the 2012 National Health Interview Survey (NHIS) reported that more than 25 million Americans (11.2 percent) suffer from daily chronic pain (Nahin, 2015). Unrelieved pain is associated with numerous adverse outcomes, such as anxiety, depression, cardiovascular diseases, high levels of physical disabilities, and mortality, which can lead to profound negative effects on quality of life and increased healthcare services use and cost as well (Covinsky, et al., 2009; Andrew et al., 2013; Shega et al. 2004).

With the respect to the importance of pain management, the National Institute of Nursing Research (NINR) highlights symptom management research, with pain management as one of its research priorities. The NINR also established the Pain Consortium to enhance pain research. In addition to pain research, National Institute of Aging (NIA) is heavily focused on dementia research. This study was designed to advance the knowledge of pain management, especially focused on FCGs' experiences of pain management among community-dwelling older adults with dementia.

Pain is a problem in older adults with dementia. The prevalence of pain is strongly associated with age, hitting the oldest population the hardest with prevalence rates of 72% above age 85. Older adults with dementia have even higher prevalence of pain, as high as 80% (Eritz & Hadjistavropoulos, 2011; Hunt et al., 2015). Based on data from the National Health and Aging Trends Study, Hunt et al. (2015) reported that 63.5% community-dwelling older adults with dementia experienced bothersome pain. The rate was significantly higher than in a cohort of individuals without dementia (54.5%) (Hunt et al., 2015). According to the information supplied by Pinzon et al. (2013), more than half (52.5%) dementia patients suffered pain two days before death.

In addition to high prevalence of pain, studies have indicated that pain in people with dementia is more often under-reported and poorly managed than those without dementia (Bernabei et al., 1998; Eritz & Hadjistavropoulos, 2011; Morrison & Siu, 2000;

Teno, Weitzen, Wetle, & Mor, 2001). It was known that pain is always subjective and self-report is the golden standard for pain assessment (NPC & JCAHO, 2001). However, the pathologic changes in the brain among persons with dementia alter the ability to remember, interpret, and respond to pain (Benedetti et al., 2004). Consequently, self-reporting pain may not be possible in this population, leading to underreport or under-recognition of pain. International epidemiological research reported that elderly persons with dementia received low dosage pain medication and stronger pain medication such as opioids were less frequently prescribed for elderly dementia patients than their cognitively healthy counterparts (Corbett et al., 2013). Evidently, pain management is a persistent issue among older adults with dementia.

Pain is associated with adverse outcomes. Persistent pain leads to increased levels of physical disability, impairments in activities of daily living, sleep disturbances, and decreased appetite (Bosley, Weiner, Ruby, & Granieri., 2004; Cipher, Clifford, & Roper, 2006; Foley, Ancoli-Israel, Britz, & Walsh, 2004). Additionally, uncontrolled pain also causes an increase in behavioral disturbances (agitation, physical or verbal aggression, wandering, or social withdrawal, etc.) and psychological dysfunction (depression, fear, and anxiety, etc.), leading to the use of physical restraints and psychological therapies, rather than adequate pain treatment (Cipher et al., 2006; Whitelock et al., 2017). Psychotropic medications are known to have substantial side effects, including increased mortality, cerebrovascular crisis, and falls, which could highly compromise patients' pain treatment (Ballard et al., 2011; Briesacher et al., 2005). Moreover, a longitudinal cohort study of elders has shown that persistent pain is associated with memory decline and increased probability of dementia (Whitelock et al., 2017).

Family caregivers play a crucial role in pain management in the community. Today, FCGs provide the majority of care for community-dwelling older adults with dementia (Lethin et al., 2015; Tarter et al., 2016). Dementia is a major public health issue and affects mostly older adults because the risk of developing dementia increases with age (Burge et al., 2012; Hebert et al., 2003; United States Department of Health and Human Services, 2016). In the United States, more than five million people 65 years of age or older suffered from dementia (AA, 2017). An estimated 65.7 million Americans function as FCGs for nearly 81% of older adults with dementia (Brodaty & Donkin, 2009; Jones et al., 2011). In 2016, more than 15 million FCGs provided 18.2 billion hours of unpaid care to people living with dementia, a contribution valued at more than $230 billion (AA, 2017). Additionally, when patients with dementia live in long-term care facilities, FCGs often spend substantial time with patients, frequently communicate with healthcare professionals, and act as decision makers. Healthcare providers increasingly turn to FCGs for additional history and insights into the patients' pain experiences (Lethin et al, 2015; Tarter et al., 2016; Shega et al., 2004). Given the level of responsibility in care of FCGs for patients with dementia, FCGs play an important role in pain management for this population.

Pain in older adults with dementia increases caregiver burden. As discussed before, uncontrolled pain can lead to profound physical and psychological impairments in dementia patients, which requires more help from caregivers and result in increased caregiver burden (Shega et al., 2007). Caregivers tend to undergo emotional distress by seeing the suffering of a patient without being able to ease their pain (Rokach, Rosenstreich, Brill, & Aryeh, 2016). Therefore, effective pain management for older adults with dementia is important in maintaining quality of life for FCGs (Cohen-Mansfield, 2002).

Research on pain management focused on formal caregivers. Literature has shown that formal caregivers' pain assessment skills were improved with the recognition of non-verbal cues and the use of observational pain rating scales or behavioral checklists (Achterberg et al., 2013; Burns & McIlfatrick, 2015; Eritz & Hadjistavropoulos, 2011; Fuchs-Lacelle et al., 2008; Lichtner et al., 2016; Shege et al., 2004). Formal caregivers have realized that maintaining communication with FCGs and knowing of individuals' normal state of being with dementia and their baseline behaviors and activity patterns could help healthcare staff in pain detection (Buffum & Haberfelde, 2007; Fall et al., 2004; Herr, 2002; Parke, 1998; Peisah, Weaver, Wong, & Strukovski, 2014; Shega et al., 2004; Soscia, 2003).

Some recommendations have been made in facilitating effective pain management. These recommendations include both pharmacological and non-pharmacological methods for pain treatment; developing guidance of analgesic administration for pain treatment; timely and consistent administrating pain medication; maintaining pain documentation and performing follow-up pain assessment (Barry, Parsons, Passmore, & Hughes, 2015; Barry, Parson, Passmore, & Hughes., 2012; Buffum & Haberfelde, 2007; Burns & McIlfatrick, 2015; Li et al., 2015).

Several barriers for adequate pain assessment and management were also identified. Knowledge deficits among formal caregivers regarding pain, pain treatment, and pain medication and negative beliefs about pain in elders are the most frequently mentioned barriers for adequate pain assessment and treatment (Barry et al., 2012; Burns & McIlfatrick, 2015; Zwakhalen, Hamers, & Berger, 2007). It is clear that existing literature advanced understanding of pain assessment and management among formal caregivers in clinical settings.

Limited research of pain management focused on FCGs. Although FCGs play a crucial role in pain management at community, very limited literature has mentioned FCGs' experience of pain management and particularly focused on pain assessment. Eritz & Hadjistavropoulos (2011) reported that FCGs were either unable to recognize or ignored nonverbal cues when assessing pain for people with dementia due to lack of education or training on how to use observational tools in pain assessment. Li et al. (2015) also noted that modified pain scales for patients with impaired cognition were rarely used by FCGs. In addition, when comparison of pain ratings between FCGs and their care recipients were made, the finding suggested that FCGs assessed pain in concordance with their care recipients (Krulewitch et al., 2000; Murray, Sachs, Stocking, & Shega, 2012; Shega et al., 2004).

Gap identified in literature. With respect to pain assessment and management, family caregivers have largely been overlooked (Hunt et al., 2015), with substantial research focusing on formal caregivers' experiences of pain assessment and management in institutional settings. Only a small number of studies have shed light on FCGs, providing very limited information regarding FCGs experience of pain management. However, this limited evidence fails to address why pain management is a persistent problem among FCGs and their care recipients. In order to resolve the problem, a deeper understanding of experience of pain management among FCGs is necessary.

Impact of the Study

The study addressed gaps in the literature in several ways. First, this study is useful for developing a deep understanding of FCGs' experiences of pain management for community-dwelling older adults with dementia. The qualitative descriptive study provided a direct and rich description of how FCGs manage pain for their community-dwelling older adults with dementia. Important knowledge was gained from this project: a deep understanding experience of pain management among FCGs was explored (**SA 1**); barriers for effective pain management among FCGs were identified (**SA 2**); and ways to help with FCGs to improve their quality care in pain management were also identified (**SA 3**).

In addition, the knowledge obtained from this study is crucial for developing interventions and policies that promoting quality of life for both community-dwelling older adults with dementia and their FCGs. For example, by exploring the experiences of pain assessment and management, FCGs' needs, barriers and/or facilitators for effective pain management will be identified. This knowledge provided first-hand data that can ultimately guide the development of evidence-based interventions in order to meet FCGs' needs in pain management.

Definitions

Family caregiver, also called informal caregiver, is an individual who has a significant personal relationship with an older person or an adult with chronic or disabling condition, involving assistance for activities of daily living and/or medical tasks. The individual could be any relative, partner, friend, or neighbor living with or separately from the care recipient (Family Caregiving Alliance, 2016).

Older adult refers to a person whose chronological age is 55 years or above. As will be discussed, some participants will be recruited from PACE programs, and 55 years is the minimum age requirement for these programs (Center for Medicare & Medicaid Services, n.d.).

Community-setting refers the private residences or non-nursing home residential care settings (Hunt et al., 2015).

Theoretical Underpinning

The Social Communication Model of Pain. The Social Communication Model of Pain ([SCMP], Craig, 2009) was employed as a framework for the study (see Appendix A). This model was originally developed to explore the role of social barriers that limit effective control of pain in infants and children. However, it has also been found useful in understanding pain assessment and care in adults with cognitive impairments (Craig, 2009). The model accepts that infants and children go from a time of full dependence on parents to recognize pain, through a period of partial ability to verbally indicate pain, to a point of having full agency in this regard. People with dementia go through the trajectory in the opposite direction, from having the ability to self-report pain, to eventually losing the ability. The SCMP model facilitates understanding in both cases.

A major novel feature of this framework is the inclusion of persons other than the suffering person in the model. The model specifies that pain should be encoded by patient (person in pain) and expressive behaviors from the patient need to be successfully decoded by observers (caregivers) in order for pain communication expression to occur (Craig, 2015; Eritz & Hadjistavropoulos, 2011). The process from encoding to decoding indicates how the observers assess pain depending upon patients' expression of pain.

The model integrates biological, psychological, and social perspectives at the level of interaction between the person in pain and the observers (Craig, 2009). Multiple factors could act as barrios or facilitators for the accurate pain assessment and consequently affect the pain management.

In summary, the model provides a broad framework for understanding of pain management and can be used to develop interview guide (Craig & Versloot, 2011). For example, the SCMP provides a chronological process for pain management, from pain encoding → pain decoding → pain treatment. Therefore, the interview guide included questions to explore this process. (See Appendix G) The researcher used to interview guide to elicit information regarding the patient's response to pain (encoding) and the caregiver's observation to pain (decoding). In addition, a follow-up question was used to explore the intervention the caregiver uses. However, qualitative description is inductive and aims to explore an under-researched phenomenon; therefore, the semi-structured interview guide provided only loose guidance for the interview.

Approach

Design. The qualitative description (QD) was used in this study. Qualitative description (QD) was used to explore how family caregivers manage pain for their care recipients with dementia. Qualitative description is the method of choice for describing an unknown phenomena and minimizing inference bias (Sandelowski, 2000). Given the limited knowledge in family caregivers' experiences in pain management for their loved ones, this research method matches the needs for the study.

Settings. Family caregivers of older adults with dementia and pain were recruited from a number of communities and facilities in Central Virginia. These sites included JABA, the UVA MACC, AA, and churches. Recruitment was also conducted through community events/health fairs, at-large referral, and snowball recruiting. Snowball recruiting entails asking a current participant for referrals to other potential participants (Biernacki & Waldorf, 1981). The PI also used social media (e.g., Facebook, Twitter, Instagram) for recruiting due to the difficulty recruiting encountered.

Sample. Inclusion criteria included: 1) being age 18 or older; 2) being (or have been within the past 3 years) a caregiver for community-dwelling older adults with dementia who is (or had) experiencing pain; 3) providing (or provided) care at least 14 hours per week.; and, 4) an ability to comprehend and speak English. PI chose 14 hours/week of care as a criterion based on the Family Caregiver Alliance (2016) data suggesting that this is the least average hours of care provided when caregivers are stratified into age groups (i.e., 15-24, etc.). Participants were identified in collaboration with clinical providers and facility staff at research sites, voluntary involvement by respond to the flyers posted at the research sites, and via snowball recruitment.

In keeping with qualitative description methods, recruiting was stopped when thematic saturation was reached; that is, when no new or important themes emerged from the analysis (Ando, Cousins, & Young, 2014; Kools, 1997). In qualitative description, thematic saturation is routinely used as an indication to end data collection and generally occurs with approximately 30 subjects, though the exact number may be more or less (Guest, Bunce, & Johnson, 2006).

Procedure

Recruitment. A purposive sampling strategy was used, with initial participants being chosen using inclusion criteria, and because they were thought to be good informants by personal or clinician referral. As participation was ensured, the participants were purposively included using a maximum variation sampling strategy. Maximum variation aims to reveal important shared patterns that cut across cases and derive their significance from having emerged out of heterogeneity and places greater emphasis on breadth and variation in order to examine differences (Palinkas et al., 2015). Consequently, this approach is useful for identifying and expanding the range of variation or differences in ethnicity, ages, and other education levels among participants. For example, PI recruited family caregivers age 18 years and above, but also selected participants with diverse ethnicities and age ranges to ensure that variations emerged in the reported experiences of pain management (Palinkas et al., 2015; Patton, 2002; Sbaraini, Carter, Evans, & Blinkhorn, 2011).

People willing to participate in the study called or emailed the researcher using the contact information listed on the flyer (see Appendix B). During the call or via email, PI screened (see Appendix C) for eligibility, explained the study, and set up meetings for the face-to-face interview. Once family caregivers were identified as eligible, a face-to-face interview was scheduled afterward. The place chosen most often for the interviews was the participant' home, but senior centers and community and UVA libraries were also used to complete the face-to-face interviews. Along with interviews, PI conducted field observations with field notes written in order to document additional contextual information (Kools et al., 2002).

When a face-to-face interview was not possible, a phone interview was scheduled. A verbal consent (see Appendix J) was used for a phone interview. In this study, 18 out of 25 interviews were conducted face-to-face.

Data Collection. At the beginning of the interview, PI explained the study and consent participants using a teach-back approach. This approach ensured the participants understand the study and are able to consent (Appendix D). Next, participants filled out a demographic questionnaire (Appendix E). All forms were verbally administered to the participants, to minimize participants' burden due to possible low literacy. The expected time to finish the consent form and demographic questionnaire for each individual was between 3-5 minutes.

After the completion of consent form and demographic questionnaire, the semi-structured interview commenced. The interview guide (Appendix F) was initially developed based on the extant literature. The guide was then modified and refined based on input from content and methods experts, such as professors in UVA School of Nursing.

Interviews. Individual interviews varied in length (ranged from 20 minutes to 60 minutes, average 36 minutes), depending on how forthcoming and comfortable the participant was during the interview. All interviews were recorded and transcribed professionally. Transcripts were cross-checked against recordings for accuracy by the PI.

Field Observation. Along with the semi-structured interviews, the PI recorded field observations during the interview. Field notes were also written by the PI during the time of recruitment and interviews. The field notes included the observations of the context for care, descriptions of the participants and their care recipients (e.g., affect, level of rapport, nonverbal communication, and notable interactions between participants and their care recipients) (Kools et al., 2002).

Data Analysis

Constant comparison was used for data analysis. This analytic process wan iterative process. Initially, open coding was done to give higher-level meaning of the statement by labeling them. As coding proceeded, previous coded transcripts were evaluated and recoded. Then the codes were focused into concepts. Finally, themes emerged followed by generated concepts (Corbin & Strauss, 2008). Analytic memos were written throughout the analysis to capture the analytic process. The semi-structured guide was modified to reflect the changes of the process (Emerson, Fretz, & Shaw, 1995).

Throughout the analysis, field notes and analytic memos were written throughout the study to capture the analytic process (Emerson, Fretz, & Shaw, 1995). To facilitate coding and theoretical development, qualitative analysis software NVivo (version 12) was used. Such software allows for easy sorting and structuring of large amounts of text and facilitates the management of the resulting interpretations and evaluations. It makes it easy to organize relevant codes and themes together (Morison & Moir, 1998).

Potential Limitations and Strategies to Ensure Rigor

There were a few limitations of this study. First, this study included some participants (four out of 25) for whom caregiving was in the past. Their memory recall may affect the way they answer questions. On the other hand, participants for whom caregiving was current (21 out of 25) might be influenced by their stress level, which could lead to bias in their responses to questions. To overcome potential bias, data from participants (FCGs) and PI’s field observation were collected. Using two data collecting methods (interviews and observations) allowed the researcher to cross-check data by looking for consistency between what caregivers say and what is observed by the researcher (Morse, 2015).

Second, the researcher included participants' care recipients with dementia. Dementia is not a specific disease but include a wide range of symptoms associated with a decline in memory, judgement, or other thinking skills (AA, 2017). Participants have to deal different types of dementia, such as frontotemporal degeneration, Lewy Body dementia, and vascular dementia. Due to the unique feature of each type of dementia, participants underwent different challenges in caring. To overcome these differences, interviews were conducted with courteous and respectful of all participants.

Third, the study sample was a convenience sample, which may lead to under- or over-representation of the desired population of the study (Bornstein, Jager, & Putnick, 2013). To deal with this disadvantage, recruitment was conducted using multiple sites to enhance the variation of the sample.

Finally, potential bias could be generated from the researcher's personal caregiving experiences in the past. This form of positionality was mitigated through frequent interaction with multiple perspectives. The members of the dissertation committee have expertise in nursing, clinical psychology, community health, dementia, gerontology, and caregiving research, as well as expertise in qualitative methods. The expertise the committee brought to the analytic process enhanced the scientific rigor. In addition, reflexivity was used to be aware of the possibility of existing bias. Reflexivity is an attitude of attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process (Barry et al., 1999).

Implications/Contributions

Improving quality of care for people with dementia. The goals of this study were to increase the understanding of pain management experiences among FCGs of older adults with dementia and to enhance existing knowledge using qualitative description methods. Most existing studies had focused on pain management by formal caregivers (Eritz & Hadjistavropoulos, 2011; Fall et al., 2004; Krulewitch et al., 2000; Murray et al., 2012; Shega et al., 2004). Information regarding how FCGs manage pain for people with dementia in community dwellings is limited. In addition, factors that could influence effective pain management among FCGs caregivers have not been identified. Thus, the results of this study provided important new information to advance the knowledge of FCGs management of pain for their loved ones with dementia.

Future intervention study. The knowledge obtained from this study of FCGs' pain management experiences for older adults with dementia provided a more comprehensive understanding of associated factors and needs. This knowledge will be useful to guide future intervention development to assist FCGs in pain management.

The Social Community Model for Pain was used to underpin the conduct of this study. This model "provides typical chronological sequences/consequences of pain experience and its overt expression, as well as to the caregivers' perception and the process whereby decisions are made concerning delivery of care" (Craig & Versloot, 2011, p58). Based on the theoretical underpinnings that guided the literature review and the development of semi-structured interview, multi-dimensional factors related to FCGs' pain management experience were identified, such as interpersonal, intrapersonal, biological, physical, social-psychological factors. In addition, this study provided important new information regarding FCGs' needs related to effective pain management. Though current studies have revealed a few factors and needs in pain management, knowledge was limited regarding FCGs in community dwellings compared to clinical settings.

Timeline

The total project time was 20 months. The study included five phases (See Appendix H). The design/planning phase which includes IRB approval, preparation of material, orientation for the research study took one month. The empirical phase including recruitment took 13 months. Both the data collection phase and the data analytical phase started one month after the empirical phase began and took13 months, for both tasks. The dissemination phase including completion of drafting the results and preparation of manuscripts started after the empirical phase was done. This phase took four months.

Estimated Budget

This study was developed to improving the quality of life for dementia patients and their family caregivers. Budget for the project included:

Participant costs. Incentives of $25 were provided to each participant and for a maximum of 30 participants. The incentives were given as gift cards. Total cost: $750.

Travel. PI Ms. Zhao, traveled more than 100 miles between UVA and the multiple research sites, including areas in central Virginia. Mileage reimbursement was

0.525 per mile with an estimated 300 miles traveled over the performance period of the project. Total cost: $157.5.

Equipment. Funds to purchase two digital recorders with noise cancelling for the interviews. These are average $50 each. Total supply cost - $100.

Supplies. PI purchased Software, NVivo 12 with student license price $99 for 24 month.

Translation/Transcription. This included the fee for hiring a professional transcription/translation service at the rate of $100/hour with an average of 45 minutes/interview, and a total of 30 interviews. Total cost: 2,250.

Editing. This included the fee for editing grammar at rate of $45/hour and editing final document at the rate of $75/hour for up to 3 hours of each editing task. Total cost: $ 360.

PROTECTION OF HUMAN SUBJECTS

Risk to Human Subjects

Human subjects' involvement, characteristics, and design. In this study, family caregivers' pain management experiences with their care recipients were explored. Selection criteria include: 1) being age 18 or older; 2) being (or have been within the past 2 years) a caregiver for community-dwelling older adults with dementia who is (or had) experiencing pain; 3) provides (or provided) care of an average 14 hours per week; and 4) an ability to comprehend and speak English or Chinese. Participants were identified in collaboration with clinical providers and facility staff at research sites, voluntary involvement by respond to the flyers posted at the research sites, and via snowball recruitment. The PI selected participants who are taking care of patients with various of levels and complexity of pain and stages of dementia (self-reported) in order to ensure that there is variation in participants' experiences in pain management (Sbaraini et al., 2011).

The number of participants recruited for the study was 25. Though 30 was the goal, but the recruitment stopped when the data reaches theoretical saturation. Theoretical saturation is considered achieved as evidenced by the repetition of themes and concepts.

Family caregivers of older adults with dementia were recruited from a number of communities and facilities in Central Virginia. These sites included JABA, the UVA MACC, AA, UVA, geriatrics clinics, and churches. Recruitment was also done through community events/health fairs, at-large referral, and snowball recruiting. Snowball recruiting entails asking a current participant for referrals to other potential participants. If difficulty of recruitment was encountered, social media was adopted (e.g., Facebook, Twitter, Instagram), which could lead to a convenience sampling.

People who were willing to participate in the study simply emailed/called the PI using the contact information listed on the flyer (see Appendix B). If family caregivers decided to participate, the PI conducted a quick and simple screening (see Appendix C) via the phone to confirm the eligibility for the study. If the participant was eligible for the study, they were asked to attend one face-to-face interview. Prior the interview, they were asked to provide written informed consent and to complete a short demographic questionnaire (see Appendix E). During the interview, the researcher asked questions about their caregiving experiences using a semi-structured interview guide (see Appendix F). The completion of the consent and demographic questionnaire and the face-to-face interview took each participant about 3-5 minutes to 20-60 minutes, respectively. The face-to-face interview were audio recorded for data analysis purposes. The PI documented field observation and took field notes during the two interviews.

Sources of materials. Source of materials included protected as well as public sources. Protected sources include participant screening form for eligibility, data from demographic questionnaires, audio and transcribed semi-structured interview data, and field notes. All protected data collected from interview participants were coded with unique identifiers. If a participant used personal information during the interview, PI de-identified the information in the transcripts. For example, if a participant said, “Caring for Sally can be very challenging,” the researcher changed the text to read, “Caring for my mother is very challenging.”

Additionally, identifying information such as participant contact information was kept separate from these data in a locked file drawer. Audio recordings and transcriptions (using a professional transcriptionist) of recorded interviews were locked in a secured file drawer at PI’s home at all times, and only were available to the PI and faculty advisor. When the study is completed, all data and study materials will be destroyed, including audio recordings, transcripts, notes, and memos. In order to protect data from damage, the semi-structured interviews were recorded using two digital voice recorders. The data file was transported in a private car and kept in locked cabinets in PI’s home. The data were also kept on a password-protected computer.

Potential risks. Because the target population of this study was considered vulnerable, there was a potential risk to participating family caregivers that they may experience a psychological burden, fatigue, frustration, or stress from expressing the lack of pain management skills during the interview process.

During the consent process, participants were told that they might withdraw at any time. If they feel fatigued by the interview, the participants were told that they could take a break or reschedule if necessary. The participants were reminded that they could stop participating in the interview at any time and choose not to answer any questions. In the case of participants becoming upset or exhibiting signs of psychological distress, the researcher provided a list of local community resources and assisted with referrals as needed (see Appendix G).

If the participant revealed information leading the researcher to suspect elder abuse or neglect, the researcher should inform the participant that she is obligated to report the abuse or neglect to Adult Protective Services Unit of the Charlottesville/Albemarle Department of Social Services.

Adequacy of Protection against Risk

Informed consent. Approval obtained from UVA Institutional Review Board for Social and Behavioral Sciences (IRB-SBS) at the University of Virginia. The consent documents used IRB-SBS's standard language and standard format (see Appendix D). The PI made sure that subjects could enter the date of signature on the consent document, to permit verification that consent was obtained before the family caregiver began to participate in the study. If the consent was obtained the same day that the family caregiver's involvement in the study began, the case report form documented that consent was obtained prior to participation in the research. A copy of the consent document was provided to the family caregiver and the original signed consent document was retained in the study records. Only one version of the written informed consent was used.

Protection against risk. Protection of confidentiality: All audio recordings and forms with personal information were transported in a personal vehicle from the UVA Memory Clinic or the location of interview to the PI's home in a locked box. Codes for each participant was replaced identifying information on all files with data collected from participants. A document associated with these codes was kept in a locked box in a separate location.

Potential Benefit to Subjects and Others

There were no direct benefits that can be promised to participants of this study. Research findings may contribute to future health-related investments of resources in Charlottesville area, thereby indirectly helping the participants or others in pain relief and improvement of quality of life. Minimal risks to participants included the burden or fatigue from the interviews and the frustration or stress from the feeling of lack of pain management skills. A potential indirect study benefit is expansion of the body of knowledge regarding pain assessment skills and eventually leading optimal pain relief and quality of life improvement for family caregivers of people with dementia. Participants were able to withdraw at any time from the study.

Importance of Knowledge to be Gained

This study is one of the first qualitative study to explore the experiences and strategies of FCGs used in pain management for their care recipients with dementia. It also may guide future intervention studies that aim to improve FCGs' pain assessment and management skills.

Inclusion of Women

Women were included in this study (See Appendix I). Evidences have shown that women are the predominant family caregivers with chronic medical conditions, including older adults with dementia (Sharma, Chakrabarti, & Grover, 2016; Family Caregiver Alliance, 2021).

Inclusion of Minorities (See Appendix I).

The population of Charlottesville is 69% White, 19% Black or African American, 6% Asian, 5% Hispanic, and 1% of other races (Suburban Stats, 2016). Recruitment strategies included recruitment of racial and ethnic minorities, but it may be difficult to access a representative sample in this small population of dementia patients and family caregivers.

Inclusion of Children

No children were included in this study. The study focus was on including adult caregivers who are typically ages 18 and older.

Resource Sharing

The results of this study will be shared at local, regional, and/or national conferences and reported in peer-review journals. However, no data on individual participants will be included in a public forum.

References

Achterberg, W. P., Pieper, M. P., Dalen-Kok, A. H., Waal, M. W. M., Husebo, B. S., Lauenbacher, S….Corbett, A. (2013). Pain management in patients with dementia. *Clinical Interview of Aging, 8*, 1471-1482.

Alzheimer's Association, (2017). Alzheimer's disease facts and figures. Retrieved from http://www.alz.org/facts/

American Pain Society, (1996). Assessment of Pain. Retrieved from http://americanpainsociety.org/uploads/education/section_2.pdf

Ando, H., Cousins, R., & Young, C. (2014). Achieving saturation in thematic analysis: Development and refinement of a codebook. *Comprehensive Psychology, 3*(4).

Andrew, J. S., Cenzer, I. S., Yelin, E., Covinsky, K. E. (2013). Pain as a risk factor for disability or death. *J Am Geriatric Soc, 61*, 583-589.

Ballard, C., Smith, J., Husebo, B., Aarsland, D., Corbett, A. (2011). The role of pain treatment in managing the behavioural and psychological symptoms of dementia (BPSD). *Int J Palliat Nurs.,17*(9), 420–422.

Barry, CA., Britten, N., Barbar, N., Bradley, C. & Stevenson, F. (1999). "Using reflexivity to optimize teamwork in qualitative research." *Qualitative Health Research. 9*(1), 26-44.

Barry, H. E., Parsons, C., Passmore, A. P., & Hughes, C. M. (2012). An exploration of nursing home managers' knowledge of and attitudes towards the management of pain in residents with dementia. *International Journal of Geriatric Psychiatry, 27*(12), 1258-1266.

Barry, H. E., Parsons, C., Passmore, A. P., & Hughes, C. M. (2015). Pain in care home residents with dementia: an exploration of frequency, prescribing and relatives' perspectives. *International Journal of Geriatric Psychiatry, 30*(1), 55-63.

Benedetti, F., Arduino, C., Vighetti, S., Asteggiano, G., Tarenzi, L., Rainero, I. (2004). Pain reactivity in Alzheimer patients with different degrees of cognitive impairment and brain electrical activity deterioration. *Pain, 111*,22-29.

Bernabei, R., Gambassi, G., Lapane, K., Landi, F., Gatsonis, C., Dunlop, R., … Mor, V. (1998). Management of pain in elderly patients with cancer: SAGE Study Group: Systematic Assessment of Geriatric Drug Use via Epidemiology. *JAMA, 279*, 1877-1882.

Biernacki, P., Waldorf, D. (1981). Snowball sampling: problems and techniques of chain referral sampling. Sociological Methods & Research, 10(2), 141-163.

Bornstein, M. H., Jager, J., & Putnick, D. (2013). Sampling in developmental science: Situations, shortcomings, solutions, and standards. *Dev Rev, 33*(4), 357-370.

Bosley, B. N., Weiner, D. K., Rudy, T. E., Granieri, E. (2004). Is chronic nonmalignant pain associated with decreased appetite in older adults? Preliminary evidence. *J Am Geriatr Soc 52*, 247-251.

Briesacher, B. A., Limcangco, M. R., Simoni-Wastila, L., Doshi, J. A., Levens, S. R., Shea, D. G., & Stuart, B. (2005). The quality of antipsychotic drug prescribing in nursing homes. *Arch Intern Med., 165*(11), 1280–1285.

Brodaty, H. & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues of Clinical Neuroscience, 11*(2), 217-228.

Buffum, M. D. & Haberfelde, M. (2007). Moving to new settings: Pilot study of families' perceptions of professional caregivers' pain management in persons with dementia. *Journal of Rehabilitation Research and Development, 44*(2), 295-303.

Burge, E., Kuhne, N., Berchtold, A., Maupetit, C., & Gunten, A. (2012). Impact of physical activities on activity of daily living in moderate to severe dementia: A critical review. *European Rev Aging Act, 9*(1), 27-39.

Burns,M. & McIlfatrick, S. (2015). Nurses' knowledge and attitudes towards pain assessment for people with dementia in a nursing home setting. *International Journal of Palliative Nurses, 21*(10), 479-487.

Center for Medicare & Medicaid Services. Program of all-inclusive care for the elderly. (n.d.) Retrieved from https://www.medicaid.gov/medicaid/ltss/pace/index.html

Chow, S., Chow, R., Lam, M., Rowbottom, L., Hollenberg, D., Friesen, E….Herrmann, N. (2016). Pain assessment tools for older adults with dementia in long-term care facilities: A systematic review. *Neurodegenerative Disease Management, 6*(6). doi:10.2217/nmt-2016-0033

Cipher, D. J., Clifford, P. A., Roper, K. D. (2006). Behavioral manifestations of pain in the demented elderly. *J Am Med Dir Assoc*, *7*, 355-365.

Cohen-Mansfield, J. (2002). Relative's assessment of pain in cognitively impaired nursing home residents. *Journal of Pain and Symptom Management, 24*, 562-571.

Corbett, A., Husebo, B., Malcangio, M., Staniland, A., Cohen-Mansfield, J., Aarsland, D., & Ballard, C. (2013). Assessment and treatment of pain in people with dementia. *Nat Rev Neurol. 8*(5), 264–274.

Corbin, J, Strauss, A. L. (2008). *Basics of qualitative research: techniques and procedures for developing grounded theory.* 3rd ed. Thousand Oaks, CA: Sage.

Covinsky, K. E., Lindquist, K., Dunlop, D. D., Yelin, E. (2009). Pain, functional limitations, and aging. *J Am Geriatric Soc 57*, 1556-1561.

Craig, K. D. & Versloot, J. (2011). Psychosocial perspectives on chronic pain. In Lynch, M. E., Craig, K. D., & Peng, W. H. (Eds.) Clinical pain management: A practical guide. Oxford, UK: Blackwell Publishing.

Craig, K. D. (2009). The social communication model of pain. *Canadian Psychology, 50*(1), 22-32. doi:10.1037/a0014772

Craig, K. D. (2015). Social communication model of pain. *Pain, 156*(7), 1198-1199. doi: 10.1097/j.pain.0000000000000185

Emerson, R., Fretz, R., Shaw, L. (1995). Writing ethnographic fieldnotes. Chicago: The University of Chicago Press.

Eritz, H. & Hadjistavropoulos, T. (2011). Do informal caregivers consider nonverbal behavior when they assess pain in people with severe dementia? *Journal of Pain, 12*(3), 331-339.

Falls, D., Stevens, J., Andersen, M., Collin, S., Dodd, N., Fitzgerald, E…Wilson, V. (2004). Carers' perceptions of pain in people with dementia: a grounded theory approach. *Aust J Holist Nurs.11*(2),4–11

Family Caregiving Alliance, 2016. Caregiver Statistics: Demographics. Retrieved from https://www.caregiver.org/caregiver-statistics-demographics

Family Caregiving Alliance, 2021. Women and Caregiving: Facts and Figures. Retrieved from https://www.caregiver.org/resource/women-and-caregiving-facts-and-figures/

Foley, D., Ancoli-Israel, S., Britz, P., & Walsh, J. (2004). Sleep disturbances and chronic disease in older adults: results of the 2003 National Sleep Foundation Sleep in America Survey. *J Psychosom Res 56*, 497-502.

Fuchs-Lacelle, S., Hadjistavropoulos, T., & Lix, L. (2008). Pain assessment as intervention - A study of older adults with severe dementia. *Clinical Journal of Pain, 24*(8), 697-707.

Guest, G., Bunce, A., Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods,18*, 59–82.

Hebert, L. E., Scherr, P. A., Bienias, J. L., Bennett, D. A., & Evans, D. A. (2003). Alzheimer disease in the US population: Prevalence estimates using the 2000 census. *Archives of Neurology, 60*(8), 1119–1122. doi:10.1001/archneur.60.8.1119

Herr, K. (2002). Pain assessment in cognitively impaired older adults. American Journal of Nursing, 102, 65-67.

Hunt, L., Covinsky, K., Yaffe, K., Stephens, C., Miao, Y., Boscardin, W. J., & Smith, A. K. (2015). Pain in community-dwelling older adults with dementia: Results from the National Health and Aging Trends Study. *J Am Geriatr Soc. 63*(8), 1503-1511.

Jones, S. L., Hadjistavropoulos, H. D., Janzen, J. A., & Hadjistavropoulos, T., (2011). The relation of pain and caregiver burden in informal older adult caregivers. *Pain Medicine, 12*(1), 51-58.

Kools, S. (1997). Adolescent identity development in foster care. *Family Relations, 46*(3), 263-271.

Kools, S., Tong, E., Hughes, R., Jayne, R., Scheibly, K., Laughlin, J., & Gilliss, C. L. (2002). Hospital experiences of young adults with congenital heart disease: divergence in expectations and dissonance in care. *American Journal of Critical Care, 11*(2), 115-127.

Krulewitch, H., London, M., Skakel, V., Lundstedt, G., Thomason, H., & Brummel-Smith, K. (2000). Assessment of pain in cognitively impaired older adults: a comparison of pain assessment tools and their use by nonprofessional caregivers. *Journal of the American Geriatrics Society, 48*(12), 1607 –1611.

Lethin, C., Hallberg, I. R., Karlsson, S. K., & Janlov, A. C. (2015). Family caregivers experiences of formal care when caring for persons with dementia through the process of the disease. *Scandinavian Journal of Caring Sciences*, *30*(3), 526-534. doi:10.1111/scs.12275.

Li, J., Snow, A. L., Wilson, N., Stanley, M. A., Morgan, R. O., Sanbhada, S., & Kunik, M. E., (2015). The Quality of Pain Treatment in Community-Dwelling Persons with Dementia. *Dementia and Geriatric Cognitive Disorders Extra, 5*(3), 470-481.

Lichtner, V., Dowding, D., Allcock, N., Keady, J., Sampson, E. L., Briggs, M…..Closs, S. J. (2016). The assessment and management of pain in patients with dementia in hospital settings: A multi-case exploratory study from a decision making perspective. *BMC Health Services Research, 16*(427), 1-15.

McCarberg, B. H., Nicholson, B. D., Todd, K. H., Palmer, T., Penles, L.(2008), The impact of pain on quality of life and the unmet needs of pain management: Results from pain suffers and physicians participating in an internet survey.

Morison, M. & Moir, J. (1998). The role of computer software in the analysis of qualitative data: efficient clerk, research assistant or Trojan horse? *Journal of Advanced Nursing, 28*(1), 106-116.

Morrison, R. S. & Siu, A. L. (2000). A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture. *Journal of Pain Symptom Management, 19*, 240-248.

Morse, J. M. (2015). Critical analysis of strategies for determine rigor in qualitative inquiry. *Qualitative Health Research, 25*(9), 1212-1222.

Murray, T., Sachs, G., Stocking, C., & Shega, J. (2012). The symptoms experience of community-dwelling persons with dementia: Self and caregiver report and comparison with standardized symptoms assessment measures. *American Journal of Geriatric Psychiatry, 20*(4), 298-305.

Nahin, R. L., (2015). Estimates of Pain Prevalence and Severity in Adults: United States, 2012. *Journal of Pain, 16*(8), 769-780.

National Pharmaceutical Council & Joint Commission on Accreditation of Healthcare Organizations (JCAHO) (2001). *Pain: Current understanding of assessment, management, and treatment.* Retrieved from http://www.npcnow.org/system/files/research/download/Pain-Current-Understanding-of-Assessment-Management-and-Treatments.pdf

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administrative Policy Mental Health, 42*(5), 533-544.

Parke, B. (1998). Gerontological nurses' ways of knowing. Realizing the presence of pain in cognitively impaired older adults. *Journal of Gerontological Nursing, 24*(6), 21–28.

Patton, M. Q. (2002). Qualitative research and evaluation methods. 3rd Sage Publications; Thousand Oaks, CA.

Peisah, C., Weaver, J., Wong, L., & Strukovski, J.-A. (2014). Silent and suffering: a pilot study exploring gaps between theory and practice in pain management for people with severe dementia in residential aged care facilities. *Clinical Interventions in Aging, 9*, 1767-1774.

Pinzon, D. F., Claus, M., Perrar, K. M., Zepf, K. I., Letzel, S., & Weber, M. (2013). Dying with dementia: Symptom burden, quality of care, and place of death. *Dtsch Arztebl Int. 110*(2), 195-202.

Rokach, A., Rosenstreich, E., Brill, S., & Aryeh, I. G. (2016). Caregivers of chronic pain patients: Their loneliness and burden. *Nursing and Palliative Care, 1*(5), 111-117.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health, 23*, 334-340.

Sbaraini, A., Carter, S. M., Evans, R. W., & Blinkhorn, A. (2011). How to do a grounded theory study: a worked example of a study of dental practices. *Medical Research Methodology, 11*(128), 1-10.

Sharma, N., Chakrabarti, S., & Grover, S. (2016). Gender differences in caregiving among family – caregivers of people with mental illnesses. *World J. Psychiatry, 6*(1), 7-17.

Shega, J., Emanuel, L., Vargish, L., Levine, S. K., Brush, H., Herr, K....Weiner, D. K. (2007) Pain in persons with dementia: Complex, common, and challenging. *The Journal of Pain, 8*(5), 373-378.

Shega, J. W., Hougham, G. W., Stocking, C. B., Cox-Hayley, D., & Sachs, G. A. (2004). Pain in community-dwelling persons with dementia: Frequency, intensity, and congruence between patient and caregiver report. *Journal of Pain Symptom Management, 28*(6), 585-592.

Soscia, J. (2003). Assessing pain in cognitively impaired older adults with cancer. *Clinical Journal of Oncology Nursing, 7*, 174-177.

Suburban Stats: Population information and statistics from every city, state, and county in the US: Population Demographics for Charlottesville, Virginia in 2016 and 2015. Retrieved from https://suburbanstats.org/population/virginia/how-many-people-live-in-charlottesville

Tarter, R., Demiris, G., Pike, K., Washington, K., & Oliver, D. P. (2016). Pain in hospice patients with dementia: The informal caregiver experience. *American Journal of Alzheimer 's disease and Other Dementia, 31*(6), 524-529. doi: 10.1177/1533317516653825

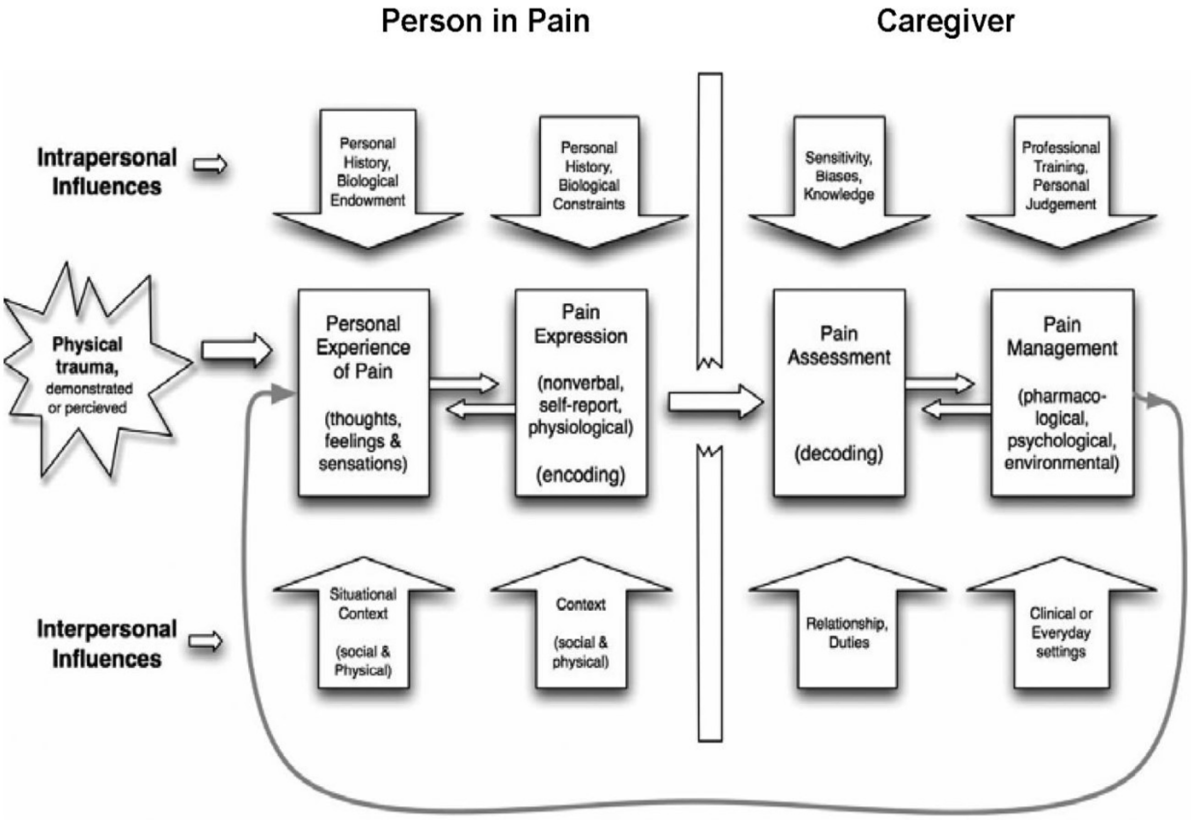
Teno, J. M., Weitzen, S, Wetle, T., & Mor, V. (2001). Persistent pain in nursing home residents. *JAMA, 285*, 2081.

U.S. Department of Health and Human Services. (2016). National plan to address Alzheimer's disease: 2016 updated. Retrieved from https://aspe.hhs.gov/system/files/pdf/205581/NatlPlan2016.pdf

Whitelock, E. L., Diaz-Ramirez, L. G., Glymour, M. M., Boscardin, W. J., Covinsky, K. E., Smith, A. K. (2017). Association between persistent pain and memory decline and dementia in a longitudinal cohort of elders. *JAMA Intern Med. 177*(8), 1146-1153.

Zwakhalen, S. M. G., Hamers, J. P. H., & Berger, M. R.F. (2007). Nursing staff knowledge and beliefs about pain in elderly nursing home residents with dementia. *Pain Research & Management*, *12*(3), 177-184.

Appendix A: The Social Communication Model of Pain (Craig, 2009)



Are you or have you been a family caregiver of an older adult with dementia? Are you 18 years of age or older?

Appendix B: Flyer

Seeking family caregivers of older adults with dementia
to participate in a study exploring your caregiving experiences.
Conducted by Hui Zhao, nursing doctoral student and Pamela Kulbok, Professor Emerita of Nursing, University of Virginia, School of Nursing.

Eligible Participants will be asked to participate in a
face-to-face interview or **phone** interview.

To schedule an interview or for more information,
please contact Hui Zhao at hz3gu@virginia.edu or call 434-466-2285, text 540-603-0396

Prior to the interview, it will take **15 minutes** to obtain your consent
and demographic information.

The interview may last an average of 45 **minutes,** or as little as 15 minutes,
or as long as one hour, to ask about your caregiving experiences.

Compensation for study completion is **$25** gift card.

Principal Investigator: Hui Zhao, PhD (c), MSN, RN

IRB SBS # (2228).

Contact information tear-off flags are optional and good for flyers that will be posted

FCG study Contact: Hui Zhao Call (434) 466-2285 Text (540)603-0396 Hz3gu@virginia.edu	**FCG study Contact: Hui Zhao Call (434) 466-2285 Text (540)603-0396 Hz3gu@virginia.edu**	**FCG study Contact: Hui Zhao Call (434) 466-2285 Text (540)603-0396 Hz3gu@virginia.edu**	**FCG study Contact: Hui Zhao Call (434) 466-2285 Text (540)603-0396 Hz3gu@virginia.edu**	**FCG study Contact: Hui Zhao Call (434) 466-2285 Text (540)603-0396 Hz3gu@virginia.edu**	**FCG study Contact: Hui Zhao Call (434) 466-2285 Text (540)603-0396 Hz3gu@virginia.edu**

Appendix C

Screening Questions

1. How do you know your care recipient has Alzheimer’s disease or related dementia (by clinicians or self-reported)?
2. How long your care recipient has been diagnosed or experienced with Alzheimer’s disease or related dementia?
3. How many hours care you provide per week?

Appendix D

Informed Consent Agreement

Please read this consent agreement carefully before you decide to participate in the study.

Purpose of the research study: The purpose of this study is to explore the experiences of pain management among family caregivers of people with ADRD in home or community settings.

What you will do in the study: In this research study, we are investigating your experiences managing pain for your care recipient. Participants will be recruited from UVa Memory and Aging Care Clinic (MACC) and other community-based settings that serve patients with dementia in Charlottesville. Flyers will be posted in the MACC and in community-based settings. If you decide to participate you will be asked to take part in one interview. Prior to the interview, you will be asked to sign written consent form and to fill out a demographic questionnaire. Then, you participate in a semi-structured interview and the research staff will ask you questions about your caregiving experiences. You can skip any question that makes you uncomfortable and you can stop the interview at any time. The interview will be audio recorded with two digital voice recorders for the purpose of data analysis. In addition, the researcher will take notes during the two interviews.

Time required: The interview of the study will require less than one hour of your time. The interview will be conducted at your home, at the home of your care recipient, or at a community location of your choosing.

Risks: There are potential risks in this study. You may experience fatigue from the interviews and/or frustration or stress from discussing your inability to manage your care recipient's pain during the interview process. You can take a break or reschedule if you feel fatigued by the interview. If you become upset or feel emotional distress, the researcher will provide you with a list of local community resources and assist you with a referral as needed. You can stop participating in the interview at any time and can choose not to answer any questions. You may choose to withdraw at any time from the study. If elder abuse or neglect is reported or observed, the researcher will inform the participant that she is obligated to report the abuse or neglect to the Adult Protective Services Unit of the Charlottesville/Albemarle Department of Social Services.

Benefits: There are no known direct benefits that to you as a participant in this study. Research findings may contribute to future investment in health resources in the Charlottesville area for persons with dementia or their family caregivers, thereby indirectly helping family caregivers or others in pain relief and improvement of quality of life.

Confidentiality: The information that you give in the study will be handled confidentially. Your information will be assigned a code number. The list connecting your name to this code will be kept in a locked file. When the study is completed and the data have been analyzed, this list will be destroyed. The audio tape used in the study will be destroyed after manuscripts are published. In addition, your name or your care recipient's name will not be used in any report. Only the research team will have access to data we collect. Because of the nature of the data, it may be possible to determine your identity; however, there will be no attempt to do so and your data will be reported in a way that will not identify you or your care recipient.

Voluntary participation: Your participation in the study is completely voluntary. The treatment or services you and your care recipients received from UVA Memory and Aging Care Clinic or other community-based settings will not be affected by your participation in the study.

Right to withdraw from the study: You have the right to withdraw from the study at any time without penalty. If you have already been audio taped at the time of deciding to withdraw, the audio tape will be destroyed.

How to withdraw from the study: There is no penalty for withdrawing. While the study has been conducted, if you want to withdraw from the study, you just need to tell the researcher/interviewer to stop the interview. If you would like to withdraw after the study has been completed or your materials have been submitted, please contact Hui Zhao by email hz3gu@virginia.edu or call 434-466-2285.

Incentives: You will receive a $25 gift card for participating in the study.

If you have questions about the study, contact:
Hui Zhao, MSN, RN
Doctoral student, University of Virginia School of Nursing
225 Jeanette Lancaster Way
Charlottesville, VA 22903.
Telephone: (434) 466-2285
Email address: hz3gu@virginia.edu

Pamela Kulbok, DNSc, RN
Professor of Nursing, University of Virginia School of Nursing
225 Jeanette Lancaster Way
Charlottesville, VA 22903.

Telephone: (434) 924-0128
Email address: pk6c@virginia.edu

If you have questions about your rights in the study, contact:

Tonya R. Moon, Ph.D.
Chair, Institutional Review Board for the Social and Behavioral Sciences
One Morton Dr Suite 500
University of Virginia, P.O. Box 800392
Charlottesville, VA 22908-0392
Telephone: (434) 924-5999
Email: irbsbshelp@virginia.edu
Website: www.virginia.edu/vpr/irb/sbs

Agreement:

I agree to participate in the research study described above.

Signature: ____ **Date:** _____________

You will receive a copy of this form for your records.

If you have questions about your rights in the study, contact:

Tonya R. Moon, Ph.D.
Chair, Institutional Review Board for the Social and Behavioral Sciences
One Morton Dr Suite 500
University of Virginia, P.O. Box 800392
Charlottesville, VA 22908-0392
Telephone: (434) 924-5999
Email: irbsbshelp@virginia.edu
Website: www.virginia.edu/vpr/irb/sbs

Agreement:

I agree to participate in the research study described above.

Signature: ____ **Date:** _____________

You will receive a copy of this form for your records.

Appendix E

Demographic Questionnaire

Instructions: Please provide background information about yourself by circling your response. If you do not want to answer a question, please leave it blank.

1. What is your age? ______________

2. What is your gender/sex?

   (0) Male (1) Female

3. What is your relationship with your care recipient?

   (0) Spouse (1) Child (2) Parent (3) Other type of relative (4) Friend

   (5) Other, please be specific _________

4. What is your marital status?

   (0) Single (1) Married (2) Widowed (3)Divorced (4) Partnered

5. What is your race/ethnicity?

   (0) White (1) African American (2) Hispanic (3) Asian (4) Native American (5) Other

6. What is your education level?

   (1) Did not complete high school education (2) High school

   (3) Vocational school after high school (4) Some college/Associate degree

   (5) Bachelor's degree (6) Graduate school

7. What is your range of annual income?

   (0) <$ 5,000 (1) $5,000 - & 9,999 (2) $ 10,000 – 19,999

   (3) $20,000 – 29,000 (5) $ 30,000 or more

8. Are you currently employed?

   (0) No (1) Yes, part-time (2) Yes, full-time (3) Retired (4) N/A

Appendix F

Semi-Structured Interview Questions

1. What is the name of your care recipient? May I refer to him/her by name?
2. Describe a typical day taking care of your care recipient (use name)?
3. How do you feel about your caregiving experience?
4. Does your care recipient (use name) experience any pain? If yes, please describe the pain. If not, does he/she experience discomfort? Any physical limitation?

[If the participant answers NO to above questions, interviewer may go to question 11 directly].

5. How do you recognize your care recipient (use name) is suffering from pain?
6. What types of pain medication have been prescribed for your care recipient (use name)?
7. What do you think about giving narcotic to your care recipient (use name)?
8. What other alternative methods have you tried to manage pain for your care recipient (use name) beside pharmacological methods?
8. Do you have any concerns about pain assessment and management? If yes, please explain it.
9. What kind of resources have you been using to help you with pain management for your care recipient (use name)?
10. What is important for you to think about when making decisions about administration of prescribed “as needed” pain medication?
11. What does pain management mean to you?
12. What other questions should I ask that I haven’t asked?

13. Is there anything else you would like to add?

Appendix G: A List of Resources for Caregivers

The PI or the research staff will provide the following resources for caregivers if needed:

Organizations/Resources	Contact Information
Jefferson Area Board for Aging (JABA)	Address: 674 Hillsdale Dr # 9, Charlottesville, VA 22901 Phone: (434) 817-5222
Alzheimer's Association in Charlottesville (AA)	Address: 1160 Pepsi Pl, Charlottesville, VA 22901 Phone: (434) 973-6122
Program of All-Inclusive Care for the Elderly (PACE)	Address: 1335 Carlton Ave, Charlottesville, VA 22902 Phone: (434) 529-1300
Charlottesville Health Department	Address: 1138 Rose Hill Dr #108, Charlottesville, VA 22903 Hours: Closing soon · 8AM–4:30PM Phone: (434) 972-6200
Charlottesville Department of Social Services	Address: 120 7th St NE, Charlottesville, VA 22903 Phone: (434) 970-3400
Albemarle County Department of Social Services	Address: Suite A, 1600 5th St, Charlottesville, VA 22902 Phone: (434) 972-4010

Appendix H: Timeline

Phase	Tasks	2018				2019												2020			
		09	10	11	12	01	02	03	04	05	06	07	08	09	10	11	12	01	02	03	04
1	IRB approval, determination of content elements, presentation of study material, & orientation (1 mon)	🟨																			
2	Recruitment & consent collection (15 mons)		🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩						
3	Data collection (15 mons)			🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪					
4	Data analysis (15mons)				🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧				
5	Completion of writing/Preparing submission for manuscript (4 mons)																	🟦	🟦	🟦	🟦

Appendix I: Targeted/Planned Enrollment Table

Ethnic Category	Gender		
	Females	Males	Total
White	11	10	21
African American	3	3	6
Asian	1	1	2
Hispanic	1	0	1
Other Races	0	0	0
Total of All Subjects	16	14	30

(Suburban Stats, 2016)

Appendix J: Verbal Consent

As you know, I am a nursing doctoral student from the University of Virginia. I am conducting a study on the experiences of pain management among family caregivers of people with dementia at community settings, and I would like to ask you some questions about that. I would like to tape record our conversation, so that I can get your words accurately. If at any time during our talk you feel uncomfortable answering a question please let me know, and you don't have to answer it. Or, if you want to answer a question but do not want it tape recorded, please let me know and I will turn off the machine. If at any time you want to withdraw from this study please tell me and I will erase the tape of our conversation. Audio recordings and transcriptions of recorded interviews will be locked in a secured file drawer at all times, and will only be available to the PI and faculty advisor. When the study is completed and the data have been analyzed, this list will be destroyed. The audio tape used in the study will be destroyed after manuscripts are published. I will do everything I can to protect your privacy, but there is always a slight chance that someone could find out about our conversation. After the completion of the interview, you will be paid with a $25 E-gift card. If you have any questions regarding this protocol, please email me hz3gu@virginia.edu or call 434-466-2285 or text me 540-603-0396. To ask questions regarding research subjects' rights, please contact Tonya R. Moon, the chair of Institutional Review Board for the Social and Behavioral Sciences, via phone 434-924-5999 or by email irbsbshelp@virginia.edu

Now I would like to ask you if you agree to participate in this study, and to talk to me about your experiences of pain management for your care recipients. Do you agree participate, and to allow me to tape record our conversation?

Chapter 3. Manuscript 1 - Pain Management for People with Dementia: An Integrative Literature Review

To be submitted to The Journal of Gerontological Nursing

Hui Zhao, PhD(c), MSN, RN

Committee Members:

Pamela Kulbok, DNSc, RN, FAAN, Committee Chair

Rafael Romo, PhD, RN, PHN

Ishan Williams, PhD, FGSA

Carol Manning, PhD, ABPP-CN

University of Virginia School of Nursing

Introduction

The population of older adults aged 64 and above is expected to increase from 40 million in 2010 to 80 million in 2030 and the number of individuals with dementia will increase accordingly (Administration on Aging, 2010). By the end of 2050, older adults with dementia will grow from 4 million to 17 million in the United States (U.S.) (Alzheimer's Association [AA], 2009; Hebert et al., 2003). Approximately, one in ten older adults has dementia (AA, 2018). An increasing number of illnesses and conditions associated with pain, such as cancer, inflammatory diseases, and neurologic diseases come with increasing age. In some studies, pain prevalence among older adult with dementia is as high as 80 percent. Therefore, pain is likely a common concern among family members of older adults with dementia (Eritz & Hadjistavropoulos, 2011; Jones, Hadjistavropoulos, H. D., Janzen, & Hadjistavropoulos, T.; Mobily, Herr, Clark, & Wallace 1994).

McCaffery's (1968) definition, "Pain is whatever the experiencing person says it is, existing whenever he says it does," highlights the subjective nature of pain. Published guidance recommends that the pain reports should be obtained directly from a patient if possible (Eritz & Hadjistavropoulos, 2011). However, older adults with moderate to severe dementia usually experience memory and cognitive disturbance, accompanied by neuropsychiatric symptoms such as agitation and aggression, depression and apathy, and sleeping disorders (Cummings et al., 1994; Lyketsos et al., 2002). One of the possible triggers for these symptoms may be untreated pain. In this situation, people are no longer able to describe their suffering or give precise self-reports regarding the intensity, location, and duration of the pain (Corbett et al., 2012). Additionally, they are not able to report appropriate pain-relieving effects or side effects of pain treatment (Flo et al., 2014). Consequently, pain in older adults with dementia usually is under reported and mistreated treated.

Pain that is not adequately controlled can lead to adverse physical, emotional, and psychological patient outcomes for older adults with dementia and their caregivers (Cheng, Foster, & Huang, 2002). For example, unrelieved pain limits patients' mobility, resulting in complications such as deep vein thrombosis. In addition, unrelieved pain also affects the psychological state of patients and their caregivers. Common psychological responses to pain include anxiety and depression. Pain is frequently the underlying cause of behavioral symptoms, which can lead to inappropriate treatment with antipsychotic medications (Wells, Pasero, & McCaffery, 2008). In summary, it is necessary to find ways to improve pain assessment and pain management skills of caregivers for people with dementia.

Recently, observational and behavioral pain assessment tools were developed and increasing studies have reported good outcomes for pain assessment in the general patient population. In addition, pain management protocols designed for use with nonverbal individuals were developed (Achterberg et al., 2013; Kaasalainen, 2007). Although more than one decade has passed, the issues of underreported pain and inappropriate pain management in dementia patients have not been resolved. This review examined available studies that focused on pain management for older adults with dementia since 1996 and aims to explore the current situation in pain management for dementia patients, while providing implications for future research. The specific aims included: 1) To identify the factors that may influence caregivers' attitudes towards decision making on pain management; 2) To explore the effective strategies for pain management; and, 3) To explore the perceived barriers of effective pain management.

Methods

A systematic search was conducted in December 2017, including database CINAHL, PsychINFO, OVID, and Web of Science. Key words and MESH terms for "pain", "pain assessment", "pain management", and "dementia" were combined to identify relevant studies. Duplicates were removed and subsequently, a two-step inclusion process was used: 1) screening on the basis of title and abstracts, and 2) screening based on full-text papers.

The inclusion criteria included: 1) studies written in English language, 2) articles published in a peer-reviewed journal, and 3) articles published between January 2005 and December 2017. Articles were excluded if the study was: 1) a review article, 2) an expert opinion, 3) a study protocol, 4) a recommendation, 5) an editorial, 6) an instrument development study, and or, 7) only focused on pharmacological treatment. The methodological quality of all included studies was assessed using Mixed Methods Appraisal Tool (MMAT) (Pluye et al., 2011) (see Appendix B). The scores using the MMAT were the number of the criteria met, divided by the total number of criteria.

Results

Search and Quality Assessment

The initial search yielded a total of 3,813 unique hits: 2,587 from CINAHL, four from PsychINFO, 650 from OVID, and 572 from Web of Science. After removing duplicates, there were 3,793 hits. Evaluation of titles and abstracts resulted in 150 articles for full-text analysis. Finally, 19 studies met the inclusion or exclusion criteria and were included for the review (see Appendix A).

There were 13 quantitative and six qualitative studies. Of the quantitative studies, a majority of them were conducted in other countries rather than in U.S. (9 out of 13) and in a long-term care facility. Though the search included year range from 1996 to 2017, the first study was conducted 2004 and majority of the studies were conducted in 2015. No randomized control trial was found for this search and all of the 13 studies were observational studies. Of the 13 quantitative studies, nine studies were analytical studies (eight cross-sectional studies and one cohort study) and five were descriptive studies (survey studies). Based upon the MMAT, the quality scores varied from 25% (one criterion met) to 75% (three criteria met) (see Appendix C). Overall, the analytical studies had higher methodological quality than the descriptive studies: Of the nine analytical studies, five studies were scored 75% (Nygaard & Jarland, 2005; Zwakhalen,et al., 2007; Eritz & Hadjistavropoulos, 2011; Hunt et al., 2015; Tang et al., 2016); two studies were scored 50% (Shege et al., 2004; Fuchs-Lacelle et al., 2008); and one study was scored 25% (Barry et al., 2015). Of the five descriptive studies, only one study was scored 75% (Li et al., 2015); two were scored 50% (Buffum et al., 2007; Burns & McIlfatrick, 2015) and two were scored 25% (Barry et al., 2012; Peisah et al., 2014). The main issues that existed with the methodology included: 1) low response rate, and 2) measures used lacked reliability and validity examination. More detailed information regarding studies is presented in matrix table (see Appendix D).

Of the six qualitative studies, only one, out of the six studies, was conducted in the US (Tarter et al., 2016). Overall, all these studies met the four criteria based on

MMAT. One of the six studies used content analysis (Martin et al., 2005) and the rest of them employed thematic analysis to analyze the data (see Appendix D). The limitations from these studies were mainly due to the sample or sampling issues, such as convenient sample (Jansen et al., 2017a; Tarter et al., 2016), small sample size (Martin et al., 2005; Lichtner et al., 2016), skewed samples (Jansen et al., 2017b), and limited geographic area of the sample (Fry, Chenoweth, & Arendts, 2016).

Factors Impact on Decision Making in Pain Management

Reviewed studies examined factors influencing caregivers' decision-making in pain management (Barry et al., 2012; Eritz & Hadjistavropoulos, 2011; Nygaard & Jarland, 2005; Peisah, Weaver, Wong, & Strukovski, 2014; Shege et al., 2004; Zwakhalen et al., 2007). Shege et al. (2004) examined the congruence of pain assessment between the patients and their family caregivers. The results of study revealed that patients' gender and level of agitation were associated with the dyadic congruence in pain reports. Being a male patient and having a decreased level of agitation increased the odds of congruence of pain report. In Fry et al. (2016) and Nygaard & Jarland's (2005) studies, nurses' opinion was a significant factor for administering analgesic drugs. Staff educational level was found to influence their beliefs and knowledge about pain in elderly dementia patients (Zwakhalen et al., 2007). The authors compared nursing staff with different educational levels and clinical work experiences to examine if there were any differences in pain management activities. The results confirmed that higher education and efficient knowledge would contribute to more adequate pain assessment, treatment, and management.

Barry and colleagues (2012) reported that nurse managers' beliefs about painkillers were largely ambivalent and were influenced by the country in which they had received their nursing education. This report was confirmed by Peisah et al. (2014): patient factors, staff and system factors, and attitudinal factors can influence pain treatment decisions.

However, Eritz & Hadjistavropoulos (2011) reported informal caregivers' empathy, mood/psychological health status (stress and depression), gender or other demographics were not predictive of their rating for pain. Instead, informal caregivers relied on the social or environmental context in making the pain determination. Their results have shown that the longer the time caregivers spent with patients, the more accurate assessments of pain detection were made.

Barriers Contributed to Pain Management

From the literature review, several barriers for adequate pain assessment and management were identified. Knowledge deficits, lack of pain assessment tools, and lack of support and guidance/policy were frequently mentioned (Barry et al., 2012; Burns & McIlfatrick, 2015; Fry et al., 2016; Jansen et al., 2017a; Jansen et al., 2017b; Martin et al., 2005; Tarter et al., 2016; Zwakhalen et al., 2007).

Knowledge deficits. The Knowledge deficits have shown in two categories: in pain medication and in etiology of pain. Barry et al. (2012) found that nursing managers in nursing homes demonstrated concern that they were uncertain about how to manage pain in residents with dementia and the safety of use of analgesics. Jansen et al. (2017a) and Jansen et al., (2017 b) reported that nurses felt challenges when administer intravenous drugs. The results of the studies indicated that nursing managers who had received recent training on pain management were less likely to have concerns about the use of opioid analgesia than those who had not received training. Similarly, Burns & McIlfatrick (2015) conducted a pilot survey study on nurses who work at nursing homes to investigate the barriers to pain management. The results of the study emphasized uncertainty among nurses over analgesic choice and the safety of opioid use in patients with dementia.

The deficits in etiology of pain were reported by family caregivers. Studies have shown that healthcare professionals have been trained to assess pain based on the symptoms and treat pain consequently, but the family caregivers have rarely been educated about the approach. Family caregivers reported that they had hard time to tell the differences between “real” and “imagined” pain among the patients with dementia. Uncertainty about the etiology of pain and pain treatment caused great amount of anxiety among family caregivers (Tarter et al., 2016).

Unable to select appropriate pain assessment tools. When self-report pain is not possible, tracing nonverbal cues is a valuable approach to identify pain in people with dementia (Achterberg et al., 2013). Selecting appropriate pain assessment tools could contribute to effective pain management. Several studies have identified that using inappropriate pain assessment tools could compromise the quality of pain management (Burns & McIlfatrick, 2015; Fry et al., 2016; Lichtner et al., 2016; Martin et al., 2005; Jansen et al., 2017 b). This was a barrier frequently mentioned in the reviewed literature.

Difficult relationships. In the reviewed studies, it has been noted that there were difficult relationship dynamics between nurses and physicians in acute care or nursing home settings. Some nurses felt that there was lack of support from doctors due to the reluctance to conduct patients' assessments for help with complex cases (Jansen et al., 2017a; Lichtner et al., 2016). In addition, Tarter et al. (2016) reported that family caregivers felt the lack of support from healthcare professionals in what to anticipate during the end of life care trajectory. Workload pressure, poor staffing, and lack of policy were also contributors to inadequate pain assessment and treatment (Burns & McIlfatrick, 2015; Fry et al., 2016; Lichtner et al., 2016).

Facilitators for Pain Management

Besides the barriers for pain management, there were positive and effective strategies for pain management. The fluently mentioned ones in the literature included: interactive learning, professional development opportunities, and knowing patients and the process of aging and dementia.

Interactive learning and professional development. Nurses perceived challenges when assessing pain due to the patients' cognitive impairment and understood that the pain assessment should heavily rely on experiences and clinical judgement. Some hospice nurses felt interactive group discussions for patients' cases were very helpful in improving pain management among people with dementia (Jansen et al., 2017a; Martin et al., 2005). Even physicians agreed that programs that improve knowledge and skills were required for effective pain management (Jansen et al., 2017b). Therefore, having interactive learning and professional development programs available is important.

Knowing patients and the process of the dementia and aging. Selection of pain medication often accompanied with aging restriction. Many times, how the patient responded to the analgesic can be uncertain. Therefore, knowing patients' medical history and understanding the relationship between pain analgesic and the process of the dementia and aging are important for effective pain management (Fry et al., 2016). Many nurses strongly believed that pain management among people with dementia required input from family caregivers. Shared knowledge from family caregivers was a facilitator for healthcare providers to provide optimal care in pain management (Buffum & Haberfelde, 2007; Jansen et al., 2017b; Lichtner et al., 2016).

Strategies Recommended in Pain Management

The recommendation for effective pain management were mentioned. These strategies may be categorized into two subgroups: 1) strategies for pain assessment and detection (Barry et al., 2012; Burns & McIlfatrick, 2015; Buffum & Haberfelde, 2007; Eritz & Hadjistavropoulos, 2011; Fuchs-Lacelle et al., 2008; Peisah et al., 2014; Shege et al., 2004); and, 2) strategies for pain treatment (Barry et al., 2012; Burns & McIlfatrick, 2015; Buffum & Haberfelde, 2007; Hunt et al., 2015; Li et al., 2012; Nygaard & Jarland, 2005; Zwakhalen et al., 2007).

Recommendations for Pain Assessment and Detection. Buffum & Haberfelde (2007) emphasized that communication between family caregivers and healthcare staff would be helpful in pain detection. Family members can guide staff to detect indicators of pain (Peisah et al., 2014) because family caregivers spend considerable time with care recipients and they can detect more pain indicators than nursing staff (Shege et al., 2004). In addition, regular observation and assessment, verbal pain report, behavioral change, and non-verbal cues were helpful strategies for pain assessment (Burns & McIlfatrick, 2015).

Appropriate pain assessment tools and training were the remaining strategies (Eritz & Hadjistavropoulos, 2011; Fuchs-Lacelle et al., 2008; Shege et al., 2004). Pain assessment should always be initiated with self-report method (Eritz & Hadjistavropoulos, 2011; Shege et al., 2004). If patients have moderate to severe dementia and are unable to self-report their pain, alternative assessment methods should be considered. To evaluate the level of cognitive impairment, the Mini-Mental State Examination (MMSE) was used in several studies (Eritz & Hadjistavropoulos, 2011; Shege et al., 2004; Tang et al., 2016). If the MMSE score is <23, it indicates the moderate to severe dementia (Folstein, M., Folstein, S., & McHugh, 1975). Consequently, modified pain assessment tools such as the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC) (Fuchs-Lacelle et al., 2004) should be considered (Burns & McIlfatrick, 2015; Fuchs-Lacelle et al., 2004; Li et al., 2012). Training regarding how to use the modified pain assessment tools is necessary to perform accurate assessment for caregivers (Barry et al., 2012; Burns & McIlfatrick, 2015).

Recommendations for Pain Treatment. Two categories of pain treatment were discussed in the reviewed studies: pharmacological and non-pharmacological methods. For pharmacological methods, antipsychotic drugs were used for pain treatment in dementia patients (Barry et al., 2015). Developing guidance for analgesic administration for pain treatment and following the guidelines was recommended (Barry et al., 2012; Burns & McIlfatrick, 2015). Timely and consistent pain medication administration was recommended as useful pain management strategies (Buffum & Haberfelde, 2007; Barry et al., 2012; Burns & McIlfatrick, 2015).

In addition, maintaining pain documentation and performing follow-up pain assessment are good strategies for pain treatment evaluation (Li et al., 2015). Since lack of knowledge of pain, pain medication, and pain treatment were presented in several studies, education for improving knowledge is necessary (Barry et al., 2012; Burns & McIlfatrick, 2015; Zwakhalen et al., 2007).

Non-pharmacological interventions and alternative methods were underused (Li et al., 2015). Creative interventions such as combination of pharmacological and non-pharmacological methods are needed (Hunt et al., 2015; Martin et al., 2005).

Discussion

The literature review highlighted the fact that pain is a major issue for older adults with dementia. Pain assessment and management in older adults with dementia are particularly challenging due to the difficulty for the patients reporting their pain. Though pain assessment skills among healthcare workers were improved with the recognition of non-verbal cues and the increasing use of observational pain rating scales (Achterberg et al., 2013; Burns & McIlfatrick, 2015; Eritz & Hadjistavropoulos, 2011; Fuchs-Lacelle et al., 2008; Lichtner et al., 2016; Shege et al., 2004), healthcare workers still felt unconfident to assess pain and administer analgesic medication. At the time, healthcare workers tended to undergo emotional distress. Many barriers such as limited resources, lack of training, and negative beliefs could influence the decision-making on pain assessment and management. Therefore, continuous education and available resources for healthcare workers remains important as staff development tasks in healthcare organizations.

Based on this literature review of 19 studies, many recommendations were made in facilitating effective pain management. The need for guidance in analgesic administration for pain treatment was identified (Barry et al., 2012; Burns & McIlfatrick, 2015). Timely and consistent administrating of pain medication and maintaining pain documentation and performing follow-up pain assessment were considered effective strategies for pain assessment and management. Pain treatment should involve both pharmacological and non-pharmacological methods. However, only one of the 13 studies addressed the use of alternative or non-pharmacological methods for pain management (Buffum & Haberfelde, 2007). Future studies need to focus on developing combined interventions (pharmacological and non-pharmacological methods) for pain management for dementia patients.

Today, family caregivers (FCGs) provide the majority of care for community-dwelling older adults with dementia (Lethin et al., 2015; Tarter et al., 2016). An estimated 65.7 million Americans function as FCGs for nearly 81% of older adults with dementia (Brodaty & Donkin, 2009; Jones et al., 2011). In 2016, more than 15 million FCGs provided 18.2 billion hours of unpaid care to people living with dementia, a contribution valued at more than $230 billion (AA, 2017). This literature review has shown that FCGs played a crucial role in pain management for patients living in the healthcare settings. When patients with dementia live in long-term care facilities, FCGs often spend substantial time with patients, frequently communicate with healthcare professionals, and act as decision makers. Healthcare workers realized that maintaining communication with family caregivers in order to know dementia patients' baseline behaviors and activity patterns could help healthcare staff in pain detection. Therefore, healthcare providers increasingly turn to FCGs for additional history and insights into the patients' pain experiences (Lethin et al, 2015; Tarter et al., 2016; Shega et al., 2004).

Several limitations related to quality and methodology existed in this literature review. First, none of the studies included in this review were randomized control trials or experimental studies. Therefore, the generalizability of the studies is limited. Second, several measures used in the reviewed studies lacked reliability and validity testing. Third, the majority of the studies had small sample size and did not sufficiently describe management of dropouts. Possible lack of statistical power and selection bias suggested that the studies in this review may have methodological and statistical biases. Consequently, conclusive recommendations based on aggregated evidence are difficult to provide.

Besides the methodological limitations, the definition of pain management was not consistently provided. Only one of the 13 studies described pain management as including "...assessment; development, implementation, and evaluation of a treatment plan; and ongoing reassessment of pain" (Buffum & Haberfelde, 2007, p 296). Based on this definition, pain management should include three steps: initial assessment, ongoing treatment, and follow-up assessment (reassessment). However, the majority of the studies discussed the first two steps, and only one study recommended that follow-up pain assessment is a good strategy for pain treatment evaluation (Li et al., 2015). For future research, development of the concept of pain management is necessary.

It was also found that only few studies involved community-based settings and focused on family caregivers' viewpoint related to pain management. These studies only examined how the family caregivers perceived the pain management by healthcare professionals or compared with health professionals, how family caregivers rated pain. Unfortunately, no studies have examined family caregivers' experiences of pain assessment and management for people with dementia. Since family caregivers play an important role as the decision maker in pain management, researchers should conduct studies to explore family caregiver’s experiences of pain assessment and management for older adults living in community settings.

Implications for Practice

The specific aims of this literature review aimed to identify the factors that may influence caregivers’ attitudes towards decision making on pain management; explore the effective strategies for pain management; and, explore the perceived barriers of effective pain management. The ultimate goal was to demonstrate the need to improve the quality of pain assessment and management for older adults with dementia. The review has shown substantial implications for optimal pain management at the individual, organizational, and the systemic levels.

The review identified knowledge deficits among individual healthcare workers in pain assessment and management including administer pain medication for patients with dementia. Therefore, education and training programs regarding pain assessment and management for individual staff are important. In addition, the healthcare organizations need to secure the accessibility of the programs for their staff. The lack of resources and staffing issue were also noticed as barriers for adequate pain assessment and management. The organizations should pay attention to the issues in order to support their staff to improve their quality of care in patients with dementia and pain. Developing guidelines of pain assessment and management for older adults with dementia is also important for the healthcare sectors. At the systemic level, developing policy to secure the implementation or efforts related to pain management is the key to success. Research is required to focus on the evaluation of the current or developing programs for healthcare staff in relation to the care of older adults with dementia.

As previously mentioned, information regarding FCGs in pain management for older adults with dementia in community dwellings is very limited. In addition, factors that could influence effective pain management among FCGs caregivers remain unrevealed. Thus, the results of this review will provide direction for future research to help FCGs in management of pain for their loved ones with dementia.

Conclusion

It is clear that existing literature advanced an understanding of pain assessment and management among formal caregivers in clinical settings. Pain assessment and management are challenging among older adults with dementia due to their inability to self-report pain. Though healthcare workers' pain assessment skills were improved with the recognition of non-verbal cues and the use of newly developed screening tools, barriers contribute to inadequate pain treatment were identified. To overcome these barriers to improve quality of care in pain, efforts are needed at individual, organizational, and system levels. In addition, family caregivers should be included in the consideration of training and education programs because they play a crucial role in care of older adults with dementia and pain in both clinical and community settings.

References

Achterberg, W. P., Pieper, M. P., Dalen-Kok, A. H., Waal, M. W. M., Husebo, B. S., Lauenbacher, S.,…Corbett, A. (2013). Pain management in patients with dementia. *Clinical Interview of Aging, 8*, 1471-1482.

Administration on Aging (2010). Projected future growth of older population. Retrieved from http://www.aoa.gov/aoaroot/aging_statistics/future_growth/future_growth.aspx.

Alzheimer's Association (2009). Alzheimer's disease facts and figures. Retrieved from http://www.alz.org/national/documents/report_alzfactsfigures2009.pdf.

Alzheimer's Association (2018). 2018 Alzheimer’s disease facts and figures. Retrieved from https://www.alz.org/media/homeoffice/facts%20and%20figures/facts-and-figures.pdf

Barry, H. E., Parsons, C., Passmore, A. P., & Hughes, C. M. (2012). An exploration of nursing home managers' knowledge of and attitudes towards the management of pain in residents with dementia. *International Journal of Geriatric Psychiatry, 27*(12), 1258-1266.

Barry, H. E., Parsons, C., Passmore, A. P., & Hughes, C. M. (2015). Pain in care home residents with dementia: an exploration of frequency, prescribing and relatives' perspectives. *International Journal of Geriatric Psychiatry, 30*(1), 55-63.

Brodaty, H. & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues of Clinical Neuroscience, 11*(2), 217-228.

Buffum, M. D. & Haberfelde, M. (2007). Moving to new settings: Pilot study of families' perceptions of professional caregivers' pain management in persons with dementia. *Journal of Rehabilitation Research and Development, 44*(2), 295-303.

Burns, M. & McIlfatrick, S. (2015). Nurses' knowledge and attitudes towards pain assessment for people with dementia in a nursing home setting. *International Journal of Palliative Nurses, 21*(10), 479-487.

Cheng, S, Foster, R. L., & Huang, C., (2003). Concept analysis of pain. *Tzu Chi Nursing Journal, 2*(3), 20-28.

Corbett, A., Husebo, B. S., Malcangio, M., Staniland, A., Cohen-Mansfield, J., Aarsland, D., & Ballard, C. (2012). Assessment and treatment of pain in people with dementia. *Nature Reviews Neurology, 8*(5), 264–74.

Cummings, J. L., Mega, M, Gray, K., Rosenberg-Thompson, S., Carusi, D. A., & Gornbein, J. (1994). The Neuropsychiatric Inventory: Comprehensive assessment of psychopathology in dementia. *Neurology, 44*(12), 2308–2314.

Eritz, H. & Hadjistavropoulos, T. (2011). Do informal caregivers consider nonverbal behavior when they assess pain in people with severe dementia? *Journal of Pain, 12*(3), 331-339.

Flo, E., Gulla, C., & Husebo, B. S. (2014). Effective pain management in patients with dementia: Benefits beyond pain? *Drugs Aging, 31*(12), 863–71.

Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research. 12* (3), 189–98.

Fry, M., Chenoweth, L., & Arendts, G. (2016). Assessment and management of acute pain in the older person with cognitive impairment: A qualitative study. *Int Emerg Nurs., 24* (54-60).

Fuchs-Lacelle, S., Hadjistavropoulos, T., & Lix, L. (2004). Pain assessment as intervention - A study of older adults with severe dementia. *Clinical Journal of Pain, 24*(8), 697-707.

Hebert, L. E., Scherr, P. A., Bienias, J. L., Bennett, D. A., & Evans, D. A. (2003). Alzheimer disease in the US population: Prevalence estimates using the 2000 census. *Archives of Neurology, 60*(8), 1119–1122.

Hunt, L. J., Covinsky, K. E., Yaffe, K., Stephens, C. E., Miao, Y., Boscardin, W. J., & Smith, A. K. (2015). Pain in Community-Dwelling Older Adults with Dementia: Results from the National Health and Aging Trends Study. *Journal of American Geriatric Society, 63*(8), 1503-1511.

Jansen, B. D. W. K., Brazil, P., Passmore, H., Buchanan, D., Maxwell, SJ., McIlfactrick, SM., ……, Parsons, C. (2017a). Nurses' experiences of pain management for people with advanced dementia approaching the end of life: a qualitative study. *J Clin Nurs.26* (9-10),1234-1244. doi: 10.1111/jocn.13442.

Jansen, B. D. W. K., Brazil, P., Passmore, H., Buchanan, D., Maxwell, SJ., McIlfactrick, SM.,…Parsons, C. (2017b). 'There's a Catch-22' - The complexities of pain management for people with advanced dementia nearing the end of life: A qualitative exploration of physicians' perspectives. *Palliat Med., 31*(8),734-742. doi: 10.1177/0269216316673549.

Jones, S. L., Hadjistavropoulos, H. D., Janzen, J. A., & Hadjistavropoulos, T., (2011). The relation of pain and caregiver burden in informal older adult caregivers. *Pain Medicine, 12*(1), 51-58.

Kaasalainen, S. (2007). Pain assessment in older adults with dementia: using behavioral observation methods in clinical practice. *Journal of Gerontology Nurse, 33*(6), 6-10.

Lethin, C., Hallberg, I. R., Karlsson, S. K., & Janlov, A. C. (2015). Family caregivers experiences of formal care when caring for persons with dementia through the process of the disease. *Scandinavian Journal of Caring Sciences*, *30*(3), 526-534. doi:10.1111/scs.12275.

Li, J., Snow, A. L., Wilson, N., Stanley, M. A., Morgan, R. O., Sanbhada, S., & Kunik, M. E., (2015). The Quality of Pain Treatment in Community-Dwelling Persons with Dementia. Dementia and Geriatric Cognitive Disorders Extra, 5(3), 470-481.

Lichtner, V., Dowding, D., Allcock, N., Keady, J., Sampson, E. L., Briggs, M.,…Closs, S. J. (2016). The assessment and management of pain in patients with dementia in hospital settings: A multi-case exploratory study from a decision making perspective. *BMC Health Services Research,16*(427), 1-5.

Lyketsos, C. G., Lopez, O., Jones, B., Fitzpatrick, A. L., Breitner, J., & DeKosky, S. (2002). Prevalence of neuropsychiatric symptoms in dementia and mild cognitive impairment: Results from the cardiovascular health study. *JAMA, 288*(12), 1475–1483.

Martin, R., Williams, J., Hadjistavropoulos, T., Hadjistavropoulos, H. D., & MacLean, M. (2005).A qualitative investigation of seniors' and caregivers' views on pain assessment and management. *Can J Nurs Res., 37*(2):142-164.

McCaffery, M. (1968). Nursing practice theories related to cognition, bodily pain, and man-environment interactions. Los Angeles (CA): UCLA Students' Store.

Mobily, P. R., Herr, K. A., Clark, M. K., & Wallace, R. B. (1994). An epidemiological analysis of pain in the elderly: The Iowa 65+ Rural Health Study. *Journal of Aging and Health, 62*, 139-154.

Nygaard, H. A. & Jarland, M. (2005). Are nursing home patients with dementia diagnosis at increased risk for inadequate pain treatment? *International Journal of Geriatric Psychiatry, 20* (8), 730-737.

Peisah, C., Weaver, J., Wong, L., & Strukovski, J.-A. (2014). Silent and suffering: A pilot study exploring gaps between theory and practice in pain management for people with severe dementia in residential aged care facilities. *Clinical Interventions in Aging, 9*, 1767-1774.

Pluye, P., Robert, E., Cargo, M., Bartlett, G., O'Cathain, A., Griffiths, F. …& Rousseau, M.C. (2011). Proposal: A mixed methods appraisal tool for systematic mixed studies reviews. Retrieved on Jan 2017 from http://mixedmethodsappraisaltoolpublic.pbworks.com.

Shege, J. W., Hougham, G. W.; Stocking, C. B., Cox-Hayley, D.; & Sachs, G. A. (2004). Pain in community-dwelling persons with dementia: Frequency, intensity, and congruence between patient and caregiver report. *Journal of Pain Symptom Management, 28*(6), 585-592.

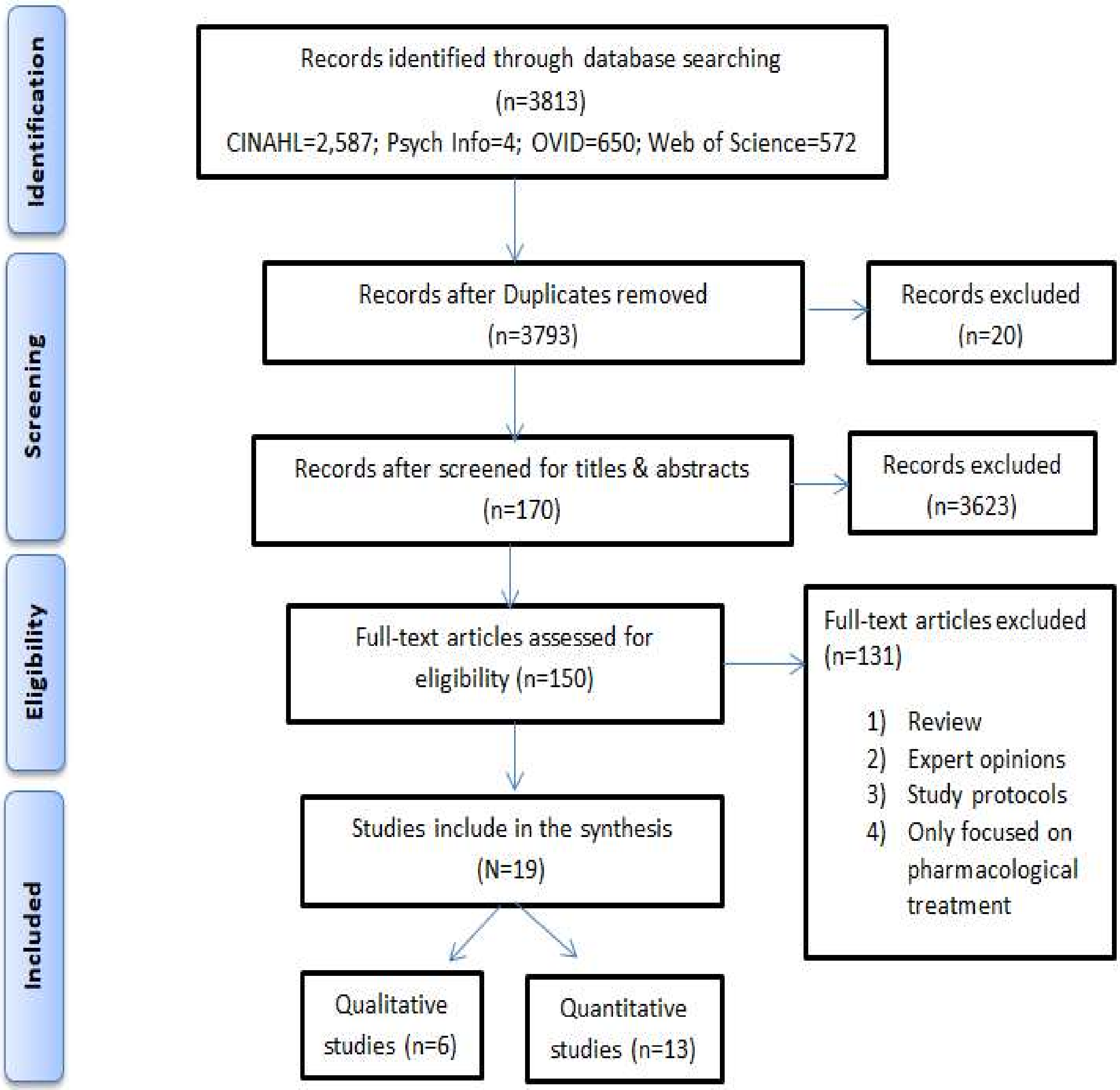
Tang, M. M., Wollsen, M. G., & Aafaard, L. (2016). Pain monitoring and medication assessment in elderly nursing home residents with dementia. *Journal of Research in Pharmacy Practice, 5*(2), 126-131.

Tarter, R., Demiris, G., Pike, K., Washington, K., & Oliver, D. P. (2016). Pain in hospice patients with dementia: The informal caregiver experience. *American Journal of Alzheimer 's disease and Other Dementia, 31*(6), 524-529. doi: 10.1177/1533317516653825

Wells, N., Pasero,C., & McCaffery, M. (2008). Improving the quality of care through pain assessment and management. Rockville: MD.

Zwakhalen, S. M. G., Hamers, J. P. H., & Berger, M. R.F. (2007). Nursing staff knowledge and beliefs about pain in elderly nursing home residents with dementia. *Pain Research & Management, 12*(3), 177-184.

Appendix A. PRISMA



Appendix B: Criteria Mixed Methods Appraisal Tool (MMAT) (Pluye et al., 2011)

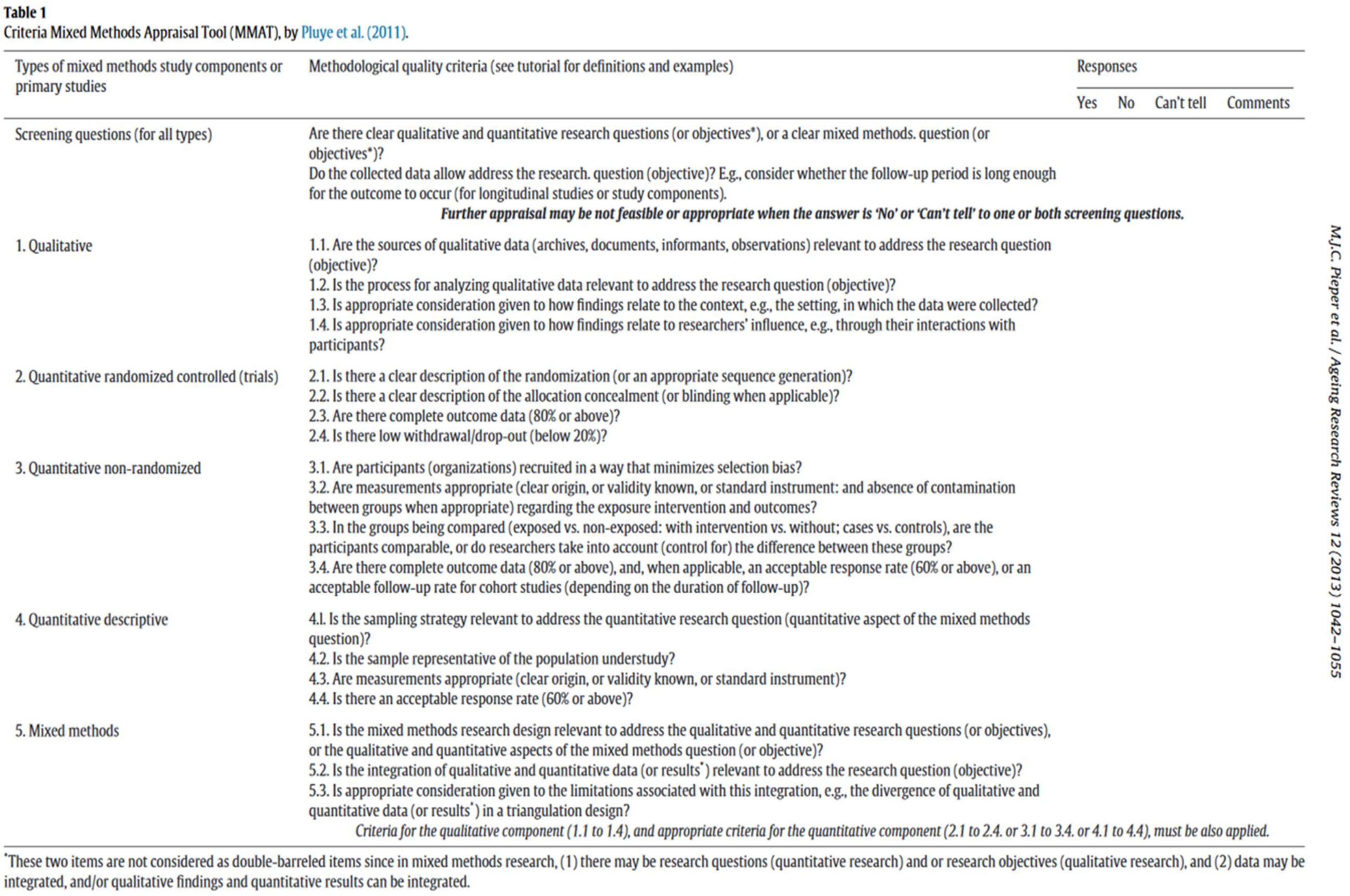


Table 1
Criteria Mixed Methods Appraisal Tool (MMAT), by Pluye et al. (2011).

Types of mixed methods study components or primary studies	Methodological quality criteria (see tutorial for definitions and examples)	Responses			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods. question (or objectives*)? Do the collected data allow address the research. question (objective)? E.g., consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components). ***Further appraisal may be not feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.***				
1. Qualitative	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)? 1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)? 1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected? 1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?				
2. Quantitative randomized controlled (trials)	2.1. Is there a clear description of the randomization (or an appropriate sequence generation)? 2.2. Is there a clear description of the allocation concealment (or blinding when applicable)? 2.3. Are there complete outcome data (80% or above)? 2.4. Is there low withdrawal/drop-out (below 20%)?				
3. Quantitative non-randomized	3.1. Are participants (organizations) recruited in a way that minimizes selection bias? 3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument: and absence of contamination between groups when appropriate) regarding the exposure intervention and outcomes? 3.3. In the groups being compared (exposed vs. non-exposed: with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups? 3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)? 4.2. Is the sample representative of the population understudy? 4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)? 4.4. Is there an acceptable response rate (60% or above)?				
5. Mixed methods	5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)? 5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)? 5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design? *Criteria for the qualitative component (1.1 to 1.4), and appropriate criteria for the quantitative component (2.1 to 2.4. or 3.1 to 3.4. or 4.1 to 4.4), must be also applied.*				

*These two items are not considered as double-barreled items since in mixed methods research, (1) there may be research questions (quantitative research) and or research objectives (qualitative research), and (2) data may be integrated, and/or qualitative findings and quantitative results can be integrated.

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Appendix C. The Quality of the Studies

Quantitative Studies (N=13)					
Analytical study			**Descriptive**		
Studies	**Methodology**	**MMAT Score**	**Studies**	**Methodology**	**MMAT Score**
Shege et al., 2004.	cross-sectional	50%	Buffum et al., 2007	Survey	50%
Nygaard & Jarland, 2005.	cross-sectional	75%	Barry et al., 2012	Survey	25%
Zwakhalen,et al., 2007	Cross-sectional	75%	Peisah et al., 2014	Survey	25%
Fuchs-Lacelle et al., 2008	Cohort (longitudinal)	50%	Burns & McIlfatrick, 2015	cross-sectional survey	50%
Eritz & Hadjistavropoulos, 2011	Cross-sectional	75%	Li et al., 2015	Survey	75%
Barry et al., 2015	Cross-sectional	25%			
Hunt et al., 2015	Secondary data analysis of a cross-sectional study	75%			
Tang et al., 2016	Cross-sectional	75%			
Qualitative Studies (N=6)					
Jansen et al., 2017a	Qualitative + thematic analysis	100%			
Fry et al, 2016	Qualitative + thematic analysis	100%			
Jansen et al., 2017b	Qualitative + thematic analysis	100%			
Tarter et al., 2016	Qualitative + thematic analysis	100%			
Martin et al., 2005	Qualitative + thematic content analysis	100%			
Lichtner et al., 2016	Qualitative + multi cases	100%			

Appendix D. Matrix Table

Author, Title, Journal	**Aim**	**Measures**	**Methods /Setting**	**Sample**	**Results**	**Conclusion**	**Limitation**
1. Shege, J. W., Hougham, G. W.; Stocking, C. B., Cox-Hayley, D.; & Sachs, G. A. (2004). Pain in community-dwelling persons with dementia: Frequency, intensity, and congruence between patient and caregiver report. Journal of Pain Symptom Management, 28, (6), 585-592.	To better understand the pain experience of persons with dementia and to describe what factors are related to congruence of pain reports within patient-caregiver dyads.	MMSE/Geriatric Depression Scale (GDS)/ the Beck Depression Inventory/ Caregiver Strain Index (CSI)/ the Cohen Mansfield Agitation Index (CMAI) /the Verbal Descriptor Scale (VDS) for pain.	Quantitative cross-sectional study/ Community dwelling	N=150 dyads of patients and family caregivers	Caregivers more frequently report patients to be in pain, and at a higher intensity of pain, than did the PwD. The odds of congruence of pain reports increase 3.7 (1.2-12.3) if the patient is male & decrease 0.938 (0.93-0.99) as patients more agitated.	Community-dwelling persons with dementia report less pain than those in the nursing home and caregivers do a fair job of predicting patient pain. Gender (male) and level of agitation are associated with the dyadic congruence. Caregivers' psychological health status (stress and depression) don't interfere with the reliability of pain report.	African American only; one-time point report of pain, short-term or long-term memory of pain not involved.

Author, Title, Journal	Aim	Measures	Methods /Setting	Sample	Results	Conclusion	Limitation
2. Nygaard, H. A.& Jarland, M. (2005). Are nursing home patients with dementia diagnosis at increased risk for inadequate pain treatment? International Journal of Geriatric Psychiatry, 20 (8), 730-737.	To examine pain assessment and complaints and pain treatment in nursing home according to mental state, and with special regard to treatment of PwD diagnosis and cognitively impaired patients who did not have a dementia diagnosis.	Abbreviated Mental Test/ask if experiencing pain	Cross-sectional study, Norway.	N= 125, age=84, dementia patients, nursing home.	Patients with dementia diagnosis were less likely to receive PRN medication [Adjusted odds ratio (AOR) 0.22 95% confidence interval (CI) 0.06–0.76] compared to mentally impaired patients. Regarding scheduled medication there was no difference between the groups. Nurses' opinion of pain was a significant factor for receiving analgesic drugs, scheduled AOR 3.95 95% CI 1.48–10.5, PRN 3.80–95% CI 1.28–11.3).	A label of dementia may bias the interpretation of pain cues of demented patients, while complaints from cognitively impaired patients may be taken for granted. This may contribute to lower use of PRN medication in demented patients compared to cognitively impaired patients.	Pain assessment relies on verbal assessment using “yes/no” to assess pain. But not for severe dementia. So the prevalence may be lower than the accurate.

Author, Title, Journal	Aim	Measures	Methods /Setting	Sample	Results	Conclusion	Limitation
3. Buffum, M. D. & Haberfelde, M. (2007). Moving to new settings: Pilot study of families' perceptions of professional caregivers' pain management in persons with dementia. Journal of Rehabilitation Research and Development, 44(2), 295-303.	To determine from family caregivers whether pain was problematic when their family members with dementia moved to different care settings (e.g., admission or transfer).	Unable to report pain. Severe and advanced dementia. Survey,	Pilot study survey. Transition between settings.	N=34 FCGs Response rate 50%.	A total of 34 family caregivers responded to an anonymous survey; 50% reported that pain was not discussed at admission or after entry into a new care setting, and 67% were not confident that staff could detect pain. From the caregivers' perspectives, pain Information is not communicated between family caregivers and staff at new care settings. Defined pain management.	Respondents' recommendations for improving pain management included regular observation and assessment, timely and consistent pain medication administration, communication with family caregivers, and staff education, alternative methods, & psychosocial supp.	Convenient sample, no validation for the survey

Author, Title, Journal	Aim	Measures	Methods /Setting	Sample	Results	Conclusion	Limitation
4. Zwakhalen, S. M. G., Hamers, J. P. H., & Berger, M. R.F. (2007). Nursing staff knowledge and beliefs about pain in elderly nursing home residents with dementia. Pain Research & Management, 12(3), 177-184.	To develop a questionnaire and to gather info about knowledge/ beliefs of nursing staff regarding aspects of pain in elderly PwD.	Unable to report pain. /Severe and advanced dementia. Pain Assessment Checklist for Seniors with Limited Ability to Communicate; Pain Assessment in Advanced Dementia.	Quantitative Cross-sectional study, nursing home in the Netherlands	N=123 nursing staff,	Knowledge deficits about aspects of pain, though satisfied about the way pain was assessed and treated at their wards. Specific knowledge deficits were found regarding pain treatment and medication in nursing home residents. Staff educational level influenced their beliefs and knowledge about pain in elderly nursing home patients. The differences in categories of nurses with respect to beliefs about pain were investigated.	Besides factors contributing to adequate pain treatment, nursing home staff still show knowledge gaps or negative beliefs about pain in PwD (contribute to inadequate assessment and treatment). Educational level is a factor.	Lack of validity of measures.
5. Fuchs-Lacelle, S., Hadjistavropoulos, T., & Lix, L. (2008). Pain assessment as intervention - A study of older adults with severe dementia. Clinical J. of Pain, 24(8), 697-707.	To see whether systematic pain assessment can improve pain management and decreases nursing stress in comparison with a control condition.	informant-administered Present Functioning Questionnaire & Maslach Burnout Inventory/ PACSLAC; Medication Quantification Scale.	Quantitative Longitudinal (Cohort) design, Canada	N=61 RN, LPN, SCAs. N=89 patients in IG, N=84 in CG. Long-term care.	Use of the PACSLAC improved pain management as reflected in increased usage of analgesic medications “as needed” in comparison with the control group. As pain interventions increased, a corresponding decrease in PACSLAC assessments was observed. In addition, nurses who used the PACSLAC reported decreased distress and burnout over time.	Pain type was reported.	High dropout rate. Only 32.8% completed.

Author, Title, Journal	Aim	Measures	Methods /Setting	Sample	Results	Conclusion	Limitation
6. Eritz, H. & Hadjistavropoulos, T. (2011). Do informal caregivers consider nonverbal behavior when they assess pain in people with severe dementia? Journal of Pain, 12(3), 331-339.	To determine the types of nonverbal cues that ICGs use to evaluate pain in loved ones with dementia. To determine the extent to which caregiver characteristics (mood, empathy, and sex) are associated with CGs rating of pain.	MMSE; CES-D; The Interpersonal Reactivity Index (IRI)/Colored Analogue Scale (CAS); PACSLAC (validity & reliability)	Quantitative / Long-term care. Canada	N=81 dyads of patients and ICGs	CGs ratings of pain were not related to specific pain behaviors, indicated that nonverbal pain cues were either disregarded or not noticed by the caregivers. The total number of pain behaviors expressed by patients was related to caregiver ratings of pain intensity only among caregivers who spent relatively more time with the patient each week. CG empathy, mood, sex or other demographics were not predictive of caregiver ratings. Instead, CGs relied on context in making the pain determinations.	Same as results.	Not RCT.

Author, Title, Journal	Aim	Measures	Methods /Setting	Sample	Results	Conclusion	Limitation
7. Barry, H. E., Parsons, C., Passmore, A. P., & Hughes, C. M. (2012). An exploration of nursing home managers' knowledge of and attitudes towards the management of pain in residents with dementia. International Journal of Geriatric Psychiatry, 27(12), 1258-1266.	To explore the knowledge, attitudes & beliefs that nursing home managers hold with regard to the assessment and management of pain in residents with dementia and to determine how these may be affected by the demographic characteristics of the respondents.	Questionnaires; no reliability 25%	Quantitative survey study. / nursing home; Northern Ireland.	N=244 nursing managers Response rate 33%	60% of managers claimed to use pain treatment guidelines within their nursing home. Respondents demonstrated good knowledge about pain in residents with dementia and acknowledged the difficulties surrounding accurate pain assessment. Nursing home managers were uncertain about how to manage pain in residents with dementia, demonstrating similar concerns about the use of opioid analgesics to those reported in previous studies about pain in older people. Managers who had received recent training (p = 0.044) were less likely to have concerns about the use of opioid analgesia than those who had not received training. Respondents' beliefs about painkillers were largely ambivalent and were influenced by the country in which they had received their nursing education.	It revealed that accurate pain assessment, training of nursing staff and a standardized approach to pain management (the use of pain management guidelines) within nursing homes all have a significant part to play in the successful management of pain in residents with dementia.	L: low response rate (33%) and lack of validated test for measures. I: to explore the formulations of analgesics regularly prescribed for people with dementia.

Author, Title, Journal	Aim	Measures	Methods /Setting	Sample	Results	Conclusion	Limitation
8. Peisah, C., Weaver, J., Wong, L., & Strukovski, J.-A. (2014). Silent and suffering: a pilot study exploring gaps between theory and practice in pain management for people with severe dementia in residential aged care facilities. Clinical Interventions in Aging, 9, 1767-1774.	To explore attitudes and processes relating to pain assessment and management for people with severe dementia in residential aged care facilities.	Abbey Pain Charts; Pain Assessment in Advanced Dementia scale	survey/Austrilia, residential aged care facilities	N=15 residential aged care facilities.	Pain charts were not used to monitor the efficacy of pain management. Calling out in pain, behavioral change and nonverbal cues were used to assess pain. Family members guide staff to pick up indicators. Circumstances under which pain medications are not given can be classified according to patient factors, staff and system factors, and attitudinal factors. Pain education from a variety of sources. Pharmacological and non-pharmacological management of pain.	Interactions with medical staff were very variable, although problems were noted in communication between junior staff, assistants in nursing/certificate III care workers, and medical staff, which usually involved the registered nurse as a conduit.	Small sample size. not measure knowledge about pain among either nursing or medical staff.

Author, Title, Journal	Aim	Measures	Methods /Setting	Sample	Results	Conclusion	Limitation
9. Barry, H. E., Parsons, C., Passmore, A. P., & Hughes, C. M. (2015). Pain in care home residents with dementia: an exploration of frequency, prescribing and relatives' perspectives. International Journal of Geriatric Psychiatry, 30(1), 55-63.	To determine pain frequency in care home residents with dementia, to investigate variables related to pain, to explore analgesic use and to seek residents' relatives' views on provision of care and management of pain by the care home.	Neuropsychiatric tests / self-report pain; Clinical Dementia Rating scale. 33%	Nursing home Ireland/Quantitative study cross-sectional	N=42 residents, 16 nurses/ care assistants and 35 relatives	A significantly higher proportion of relatives (57.1%) deemed residents to be experiencing pain at the time of the interview, compared with residents (23.8%, $p = 0.005$) and nurses/care assistants (42.9%, $p = 0.035$). Most residents (88.1%) were prescribed with analgesia; non-opioid analgesics were most commonly prescribed. High proportions of residents were prescribed with psychoactive medications. Antipsychotic drug use was associated with presence of pain ($p = 0.046$).	Reinforced the challenge of assessing and managing pain in population and highlighted issues to be addressed by long-term care providers. Participation of people with dementia, and their families, in healthcare research needs to be improved.	Small sample size for nurses

Author, Title, Journal	Aim	Measures	Methods /Setting	Sample	Results	Conclusion	Limitation
10.Burns, M. & McIlfatrick, S. (2015). Nurses' knowledge and attitudes towards pain assessment for people with dementia in a nursing home setting. International Journal of Palliative Nurses, 21(10), 479-487.	To determine nurses' knowledge and attitudes towards pain assessment for people with dementia in a nursing home setting.	Checklist of non-verbal pain indicatiors-Doloplus-2 (Helen et al, 2007). PACSLAC (Fuchs-Lacelle et al., 2004). Abbey pain scale (Abbey et al., 2004). Pain assessment in advanced dementia painad (Warden et al., 2003). Validity and reliability done.	A cross-sectional survey design/ nursing home in UK.	N=32 (Response rate=33 %) nurses	The majority of nurses had a good knowledge in relation to the assessment and management of pain in residents with dementia. There was, however, some uncertainty among nurses over analgesic choice, the safety of opioid use in dementia, and the use of dementia-specific pain assessment tools for residents with no cognitive impairment. The main barriers to effective pain assessment for older people with dementia were workload pressures, poor staffing and lack of medical support.	Highlights the need to develop pain education programs and clear guidance specifically designed for nurses caring for older people with dementia. It also emphasizes the need for better communication and co-ordination of pain treatment for nursing home residents with dementia.	Pilot study. Reflects best practice rather than they actually do. Questionnaire is not texted for reliability.

Author, Title, Journal	Aim	Measures	Methods /Setting	Sample	Results	Conclusion	Limitation
11. Hunt, L. J., Covinsky,K. E., Yaffe, K., Stephens, C. E., Miao,Y., Boscardin,W. J., & Smith, A. K. (2015). Pain in Community-Dwelling Older Adults with Dementia: Results from the National Health and Aging Trends Study. Journal of American Geriatric Society, 63(8), 1503-1511.	To report prevalence, correlates, and medication management of pain in community-dwelling older adults with dementia.	a two-question verbal descriptor scale (VDS); General Anxiety Disorder (GAD)-2; Patient Health Questionnaire (PHQ)-2. Validity of the measure.	Secondary data analysis using a Cross-sectional.	N= 802	670 (63.5%) experienced pain, and 347 (43.3%) had pain that limited activities. The rates were significantly higher than a cohort without dementia (54.5% pain, P < .001, 27.2% pain that limited activity, P < .001). Proxies reported slightly higher rates of pain than self-respondents, but differences were statistically significant only for activity-limiting pain (46.6% proxy vs 40.1% self, P = .03). Correlates of bothersome pain included arthritis, heart and lung disease, > high school education, ADL disability, depressive and anxiety symptoms, and low energy. Of those reporting pain, 30.3% stated that they rarely or never took any pain meds.	Community-living older adults with dementia are at high risk of having pain. Creative interventions and programs are needed to manage pain adequately in this vulnerable population.	Data was collected in 2010 and may not reflect the updated facts.

Author, Title, Journal	Aim	Measures	Methods /Setting	Sample	Results	Conclusion	Limitation
12. Li, J., Snow, A. L., Wilson, N., Stanley, M. A., Morgan, R. O., Sanbhada, S., & Kunik, M. E., (2015). The Quality of Pain Treatment in Community-Dwelling Persons with Dementia. Dementia and Geriatric Cognitive Disorders Extra, 5(3), 470-481.	To assess the quality of pain care for community-dwelling elderly patients with dementia.	A standardized self-report-based pain assessment scale; Pain scales modified (e.g. measure behavioral characteristics) for cognitive impairment	Interview and review medical record.	N=203 community dwelling elders	Pain assessment was documented for 98%, and a standard pain scale was used for 94%. Modified pain scales were rarely used. Though 70% self-reported pain of ‘quite bad’ or worse, charts documented no pain in 64%. When pain was identified, treatment was offered to 80%; but only 59% had a follow-up assessment within 6 months. Nonpharmacological interventions were underused	Community-dwelling elders with dementia are underdiagnosed and undertreated for pain.	Participants are military men, number of quality indicators for pain management is small

Author, Title, Journal	Aim	Measures	Methods /Setting	Sample	Results	Conclusion	Limitation
13. Tang, M. M., Wollsen, M. G., & Aafaard, L. (2016). Pain monitoring and medication assessment in elderly nursing home residents with dementia. Journal of Research in Pharmacy Practice, 5(2), 126-131.	To monitor pain intensity, pain symptoms, and medication use in elderly with dementia.	MMSE/the Mobilization-Observation-Behaviour-Intensity-Dementia-2 (MOBID-2) pain scale. observations on the numeric pain rating scale (NRS)	Nursing home in Denmark /cross-sectional	N=61 resident-s	Sixty-one nursing home residents diagnosed with dementia, 15 of these fulfilled the inclusion criteria, and 12 agreed to participate in the study. The mean age was 87 years of age (range: 77-96), and 42% of the residents were males. The patients' overall pain intensity was 83% for observations on the numeric pain rating scale (NRS) >0 and 67% for NRS ≥3. Most painful were the situations in which the residents were to mobilize their legs, turn around to both sides of the bed, and when sitting on the bed. The medication reviews identified a total of 95 individual prescriptions, and 33% of these were for nervous system medications, followed by medicines for the treatment of alimentary tract and metabolism disorders (31% of total). Eleven prescriptions for pain medicine were identified; the majority of these were for paracetamol and opioids. Seventeen proposals to patients' medication use were suggested, but the general practitioners accepted only 6% of these.	This study indicates that the MOBID-2 pain scale in combination with medication reviews can be used as a tool for optimization of patients' medication use. However, we recommend the conduction of a larger-scale study in multiple settings, to validate our results and the generalizability of the findings.	Observation of pain. Small sample size,

Author, Year, &Title,	Aim	Measures	Methods /Setting	Sample	Results	Conclusion	Limitation
14.Jansen et al., 2017a. Nurses' experiences of pain management for people with advanced dementia approaching the end of life: a qualitative study. J Clin Nurs.26(9-10), 1234-1244.	To explore hospice, acute care & nursing home nurses' experiences of pain management for PwD at the end of life. To identify the challenges, facilitators & practice areas requiring further support.	Semi-structured interview guide	Thematic analysis; hospice, acute care and nursing home UK	N=24 RNs in UK	Three themes: challenges administering analgesia, the nurse-physician relationship, and interactive learning and practice development.	Effective pain management is challenging and barriers were identified.	Self selecting sample; nursing home nurses were 50%.
15.Fry et al, 2016. Assessment and management of acute pain in the older person with cognitive impairment: A qualitative study. Int Emerg Nurs., 24, 54-60.	To understand emergency nurses' perceptions of the management of pain for older persons with cognitive impairment and presenting with a long bone fracture.	Focused group interviews .	Thematic analysis; ED Australia	N=80 ED nurses.	Five themes emerged from data analysis and included: 1) Belief in championing pain management; 2) Pain management and the ageing processes; 3) Lack of pain assessment tools for the cognitively impaired older person; 4) Delivering analgesia--a balancing act; and 5) Policy barriers to nurse initiated pain management.	ED clinicians faced challenges in pain management for elderly with cognitive impairment facing greater obstacles in receiving effective pain relief given the lack of pain assessment tool.	Quiet participants from the focus group. Different perspectives from nursed from different sites. ED is specific unable to generalize.

Author, Year, &Title,	Aim	Measures	Methods /Setting	Sample	Results	Conclusion	Limitation
16.Jansen et al., 2017b. 'There's a Catch-22' - The complexities of pain management for people with advanced dementia nearing the end of life: A qualitative exploration of physicians' perspectives. Palliat Med., 31(8),734-742.	To explore physicians' experiences of pain management for patients nearing the end of life, the impact of these on prescribing and treatment approaches, and the methods employed to overcome these challenges.	Semi-structured interviews	Thematic analysis; hospice, primary care and Psychiatry. UK	N=23 end-of life physicians	Six themes emerged diagnosing pain, complex prescribing and treatment approaches, side-effects and adverse events, route of administration, importance of sharing knowledge and training needs. Knowledge exchange was often practiced through liaison with physicians from other specialties.	Pain management in end-stage dementia is complex, requiring cross-population of knowledge between palliative care specialists and non-specialists, in addition to collateral information provided by other health professionals and patients' families. Regular, cost- and time-effective mentoring and ongoing professional development are perceived to be essential in empowering physicians to meet clinical challenges.	Skewed sampling-low participated in psychiatry.

Author, Year, &Title,	Aim	Measures	Methods /Setting	Sample	Results	Conclusion	Limitation
17. Tarter et al., 2016. Pain in Hospice Patients With Dementia: The Informal Caregiver Experience. American Journal of Alzheimer 's disease and Other Dementia, 31(6), 524-529.	To describe informal caregivers' experience managing pain in hospice patients with dementia.	Semi-structured interviews	Thematic analysis; Hospice care. USA	N=51 informal caregivers from hospice care	Four themes: difficulty in communicating with patients, lack of consistent guidance from health-care professionals, perceived uncertainty about the etiology of pain, and secondary suffering.	Possible need for increased support for caregivers, including educational interventions targeting pain etiology and assessment, and improved communication with health-care professionals.	Only focused on one geographic setting, convenient sample.
18. Martin et al., 2005. A qualitative investigation of seniors' and caregivers' views on pain assessment and management. Can J Nurs Res., 37(2),142-164.	To explore both pain assessment and management separately for seniors with and without dementia.	Open-ended questionnaire	Content analysis; Community, nursing home, Canada	N=6 focus groups of seniors with dementia; informal caregivers; health professionals	Four topics were identified: pain assessment among seniors, pain treatment among seniors, effects of pain on seniors' quality of life, and concerns specific to seniors with dementia.	Needs a multidimensional approach to the assessment and treatment of pain in seniors.	Small sample size, limited generalization due to the recruiting types of participants.

Author, Year, &Title,	Aim	Measures	Methods /Setting	Sample	Results	Conclusion	Limitation
19. Lichtner et al., 2016. The assessment and management of pain in patients with dementia in hospital settings: A multi-case exploratory study from a decision making perspective. BMC Health Services Research,16 (427), 1-5.	To investigate how pain is recognized, assessed and managed in patients with dementia in a range of acute hospital wards, to inform the development of a decision support tool to improve pain management for this group.	Semi-structured interviews	Observation, audits, interviews of four case Sites England & Scotland	Four case sites reviewing documentations	Four themes: communicating pain with dementia, carer-clinician communication, trials with therapy, and putting a picture together.	A need for an efficient method of eliciting and centralizing all pain-related information for patients with dementia,	Small sample, not all sites have paper documentation available.

Chapter 4. Manuscript 2- Concept Analysis: Pain Management for people with Dementia

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Abstract

Background: Pain is a common comorbid condition in older adults with dementia. However, despite 20 years of discourse on pain and dementia, effective pain management approaches for this population remains inadequate. The less well-examined concept of pain management for dementia patients may contribute to this issue.

Purpose: To examine the unique characteristics of the concept of pain management in people with dementia.

Methods: A literature review and guided by Walker and Avant's method of concept analysis.

Data Sources: Databases used include CIINAHL, OVID, Web of Science and Psych Info. The search included these key words: "pain management" and "people with dementia." After screening for inclusion criteria, seventeen articles out of 432 were included in the analysis. Grey literature and dictionaries were also considered in order to identify various uses of the concepts.

Results: Six attributes were synthesized: 1) knowing non-verbal cues of pain and relationships between pain and psychological symptoms of dementia; 2) applying multimodal approaches for pain; 3) communication between professionals and family caregivers; 4) selecting appropriate instruments for pain assessment among patients with dementia; 5) categorizing people with various abilities to self-report pain by considering different stages of dementia; and, 6) pain relief for people with dementia. The consequences of pain management included achieving patients' maximized function and improved quality of life regardless the population of interest. Empirical referents,

including developing protocols for pain medication administration and surveys for evaluation of effectiveness in communication, were also identified.

Conclusion: This analysis offered a better understanding of the concept of pain management. It also contributed to quality improvement in pain management for people with dementia.

Introduction

In the United States, there was an estimated 5.4 million people with dementia in 2016 and one in nine of those were individuals aged 65 and older (Alzheimer's Association [AA], 2016). Pain is a common comorbid condition in older adults with dementia. Recent studies have reported that 80% of the older adults with dementia suffer from acute or chronic pain (Achterberg et al., 2013; Chandler et al., 2014). Unrelieved pain can cause physical, psychological, and emotional distress (Cheng, Foster, & Huang, 2003; Davis, 1992). In addition, pain is frequently the underlying cause of behavioral symptoms, which can lead to inappropriate treatment with antipsychotic medications. Pain also can contribute to further complications in treatment and care. However, despite of 20 years of discourse on research of pain and dementia, effective pain management approaches for this population remains inadequate. The less well-examined concept of pain management for dementia patients may contribute to this issue.

The gold standard for pain assessment is self-report because pain is "Whatever the experiencing person says it is" (Blalock, 1982, p11). However, the gold standard could not be used in cognitive-impaired patients such as people with dementia, due to their limited verbalization ability. Alternative methods such as observation could be considered for use with this population. Consequently, special tools for measuring pain for dementia patients also need to be selected. Based on these different features of pain management, the meaning of the concept of pain management in this case should not be the same as the one for general use. In fact, even though the concept of pain management has been intensively used in healthcare field, the meaning of this concept for dementia patients has not been differentiated from the one for the general population of patients.

The main purpose of this concept analysis is to examine the unique characteristics of the concept of pain management in people with dementia. In addition, this concept analysis will identify the attributes, consequences, and empirical referents. A better understanding of these defining attributes, consequences, and empirical referents will contribute to quality improvement and better understanding in pain management for people with dementia.

Data Collection

The method of data collection for this analysis was literature review. Four major databases, including CIINAHL, OVID, Web of Science, and Psych Info were searched using key words “pain management” and “people with dementia.” The inclusion criteria were English language, peer review articles, and year 1970 to current (see Appendix A). A total of 432 articles were generated in the first step of the search. The next step of selection, screening the titles and abstracts, yielded thirty-four articles. Finally, after the full texts of 34 articles were read, a total of 17 articles were included for concept analysis (see Appendix B). In addition, sources other than published literature, including grey literature and dictionaries, were also considered in order to identify various uses of the concepts, but no new emerging publications was included in the reviewed literature.

Methodological Approach for Analysis

The Walker and Avant (2010) concept analysis method was used to direct this analysis. This method was originally adapted from Wilson (1996). According to Walker and Avant (2010), concept analysis allows researchers to clarify a vague concept and enable the consistent use of the term, in this case “pain management,” in practice and research. In addition, the method allows the researcher to distinguish defining attributes of a concept from its irrelevant attributes. Furthermore, the development of case studies contributes to understanding of the application and critical analysis of the concept. The effort of identifying consequences is useful in determining factors that are often missed or neglected by researchers and practitioners (Davis, 1992; Walker & Avant, 2010). Finally, the Walker and Avant (2010) method identifies empirical referents, which are useful in determining the barriers in pain management (Larsen, 2007). There are seven steps for concept analysis procedures, including (a) select a concept; (b) determine the purposes of the analysis; (c) identify all uses of the concept; (d) define attributes; (e) identify a model case of the concept; (f) identify antecedents and consequences of the concept; (g) define empirical referents of the concept.

Results

The concept of pain management is associated with the development of the concept of pain. Aristotle and other ancient Greek philosophers proposed the concept of pain, defined as a passion of the soul. For a century after the scientific study of pain began, several theories and various therapeutic modalities were proposed, which prompted the development of principles of pain management (Bonica, 1991).

In the 1970s and 1980s, research on pain management focused on theoretical knowledge of the physiological, psychological, and social aspects of improved quality of life associated with pain relief. Some concepts have been integrated into practice to enhance effectiveness of pain management. However, both implementation of research findings on the practice of pain management and application of the concepts in the pain management have slowly evolved (Wells, Pasero, & McCaffery, 2008). However, the concept of pain management, although used frequently in practice and research, has not been consistently defined (Davis, 1992; Larsen, 2007).

In 1992, Davis recognized the need for conceptual clarity of pain management. Davis (1992) emphasized that understanding the concept of pain management would be the key leading to improved patient outcomes. He described that pain management is derived from the individual's perception and experience because pain is "whatever the experiencing person says it is" (Blalock, 1982, p11). Larsen (2007) has offered an operational definition of pain management as "...the intention to modulate the patient's pain or the response to it, using a multi-professional and multimodal approach to pain, in a participatory relationship with the patient in pain, with the aim of self-efficacy of the patient in pain" (para. 38).

Identify All Uses of the Concept

Definition of pain from dictionary. The Collin dictionary and Thesaurus (2004) defined the terms pain and management separately. In this dictionary, pain refers to (a) sensation of acute hurt or discomfort caused by injury; (b) emotional suffering or mental distress; (c) hurt, grief, anxiety; (d) annoy, irritate. Management is defined as (a) to be in charge of; (2) to succeed in being able (to do something); (c) to exercise control or domination over. The combination of these definitions gives a general definition of pain management. The Mosby's Dictionary of Medicine, Nursing & Health Professions (2017) was used to explore the definition in healthcare field. In this dictionary, pain management is defined as "the alleviation of pain or a reduction in pain to a level that is acceptable to the patient." From the Webster's New World Medical dictionary (2009), pain management "encompasses pharmacological, nonpharmacological, and other approaches to prevent, reduce, or stop pain sensations."

Definition from a patient. A patient with a chronic orthopedic disease stated, "Pain management to me means two things both equally important: Intervention to reduce the pain using medication and other skills, e.g. operation, physiotherapy, meditation etc.; helping, teaching, showing, counseling me to help me have a high quality life while I live with the pain" (Larsen, 2007, para 38).

Uses of the concept in professional fields. The term "pain management" originated in practice of medicine and has referred to healthcare providers' treatment to "manage" their patients' pain (Davis, 1992). A pharmacist proposed, "Pain management meant giving analgesia and making the patient comfortable" (Barry et al., 2013).

Relevance to nursing. The concept of pain management has many meanings from diverse nursing professionals. From a nursing educator, pain management meant, "Success in taking care of or handling the pain by using certain actions and by directing and controlling one's own use of these actions" (Davis, 1992, p78). From a rheumatology specialist nurse, pain management was described as, "The application of pharmacological and non-pharmacological strategies that relieves pain or reduces pain to a manageable level of severity and to enable the patient to use these strategies so that they are enabled to effectively manage their pain to maintain optimum levels of independence" (Larsen, 2007, para. 38). One operational definition from a pain specialist nurse was, "The intention to modulate the patient's pain or the response to it, using a multi-professional and multimodal approach to pain, in a participatory relationship with the patient in pain, with the aim of self-efficacy of the patient in pain" (Larsen, 2007, para. 38).

Pain is one of the most frequently used diagnoses in nursing practice (Cheng et al., 2002). Nurses are constantly faced with managing pain. Oncology nurses working with physicians need to be experts in both acute and chronic pain management. Nurses who work with trauma patients or post-surgical patients always face pain management for acute pain. When patients suffer from arthritis or migraine, nurses need to manage chronic pain. Regardless of the variety of pain types, nurses are responsible for assessment, diagnosis, intervention, and evaluation when caring for these individuals in pain (Wood, 2002). In addition, nurses need to grasp sufficient knowledge about pain and hold appropriate beliefs and attitudes towards pain management, which can affect providing interventions for pain relief (Mahon, 1994).

In addition to nursing practice, pain management has been studied in nursing research. A recent study (Glowacki, 2015) identified five dimensions that contribute to pain management. The five dimensions included physiological, sensory, affective, cognitive, and sociocultural components. The researcher suggested applying this finding to the practice of pain relief, which could contribute to the goal of improving quality of life of people in pain. In addition, a transdisciplinary team approach to pain management emphasizes mutual learning, training, and education, and the flexible exchange of discipline-specific roles (Gordon et al., 2013).

Relevance to dementia patients. Pain is not always effectively managed, particularly for people with dementia. Since pain is “whatever the experiencing person says it is” (Blalock, 1982, p11), this suggests that self-report is the gold-standard method for pain assessment. People with dementia are often cognitively impaired and have a limited ability to verbalize their pain experience, especially as the disease progresses

(Eritz & Hadjistavropoulos, 2011). The inability of reporting pain is a barrier for appropriate pain assessment and leads to a high risk of inappropriate treatment for pain in this population.

In order to have accurate pain assessment, many pain assessment instruments have been developed for general use or for use with dementia patients or others with cognitive impairment. The instruments include the Pain Assessment Checklist for seniors with Limited Ability to Communicate (PACSLAC), the Pain Assessment in Advanced Dementia (PAINAD), and the Non-Communicative Patient's Pain Assessment Instrument (NOPPAIN). Most of the instruments address the key points of pain management in terms of ability to differentiate pain from non-pain conditions, ability to show change in response to treatment, comparison with self-report pain indices (Gibson, 2016), which are challenging in the case of dementia. These instruments enhance the possibility of high quality of pain management in this vulnerable population. Systematic reviews and randomized control trials show a high level of agreement around the value of treatment with the pain reliever, paracetamol (acetaminophen), as a first-line approach. However, official guidelines for pain assessment and treatment for people with dementia are lacking (Corbett et al., 2014).

Defining Attributes

Defining attributes are characteristics that are associated with a concept, which assists the analyst to label a specific phenomenon as differentiated from another similar or related one (Rodger & Knafl, 2000). A concept analysis usually consists of more than one defining attribute. The analyst needs to determine which attributes are appropriate for the purpose of exploration of the concept and refine the fewest number that still allow the analyst to differentiate the selected concept from similar ones (Walker & Avant, 2010).

Based on this principle, the 17 reviewed articles (see Appendix B) were examined to determine relevant attributes of the concept of pain management for patients with dementia (see Appendix B). The major components as evidenced by the literature review were recognition of non-verbal cues for pain assessment among people with dementia and the use of multimodality methods for pain management. Communication was another component that was frequently discussed in the literature. Selecting an appropriate instrument and pain relief were also attributes identified from the reviewed literature.

Recognizing non-verbal cues of pain and relationships between pain and psychological symptoms of dementia. When patients with dementia cannot self-report their pain, non-verbal cues for pain is an import factor for pain identification and pain management. In addition, caregivers, sometimes, may misinterpret the psychological behaviors as the manifestation of pain, or vice versa; consequently, the treatment for the misinterpretation of the symptoms will be inappropriate. Therefore, Recognizing the non-verbal cues and the differences between psychological symptoms and pain is the most component of pain management evidenced by all the reviewed literature (Achterberg et al., 2013; Barry, Parson, & Passmore, 2013; Chadler & Bruneau, 2014; Corbett et al., 2014; Corbett et al., 2016; Dowding et al., 2016; Frampton, 2003; Guerriero et al., 2016; Horgas & Elliot, 2004; Lichtner, Dowding, & Closs, 2015; Liu & Lai, 2014; Peisah, Weaver, Wong, & Strukovski, 2014; Reynold et al., 2008; Scherder & Plooij, 2012; Shega et. al., 2006; Tarter et al., 2016).

Implementing multimodal approach for pain. Research studies have shown that two categories of pain treatment were available: pharmacological and non-pharmacological methods. Non-pharmacological interventions and alternative methods were underused. Creative interventions such as combination of pharmacological and non-pharmacological methods are needed (Barry et al., 2015; Hunt et al., 2015; Li et al., 2015). This is the other very important component confirmed by several reviewed literature (Chadler & Bruneau, 2014; Corbett et al., 2016; Guerriero et al., 2016; Horgas & Elliot, 2004; Liu & Lai, 2014; Reynold et al., 2008; Scherder & Plooij, 2012; Shega et. al., 2006; Tarter et al., 2016).

Communicating between professionals and family caregivers. To communicate with people with dementia is challenging due to the receptive and expressive deficits, especially reported by healthcare providers that they had hard time to gather information about the patient's health history, including pain (Tarter et al., 2016). Today, family caregivers provide the majority of care for community-dwelling older adults with dementia and spend more time with the patients (Lethin et al., 2015; Tarter et al., 2016). Healthcare providers have realized that maintaining communication with family caregivers can help their with knowing of patients' normal state of being with dementia and their baseline behaviors and activity patterns, and further help healthcare providers in pain management. Therefore, communication between professionals and family caregivers are crucial in pain management (Buffum & Haberfelde, 2007; Fall et al., 2004; Herr, 2002; Peisah et al., 2014; Shega et al., 2004; Soscia, 2003). It was another component that was frequently discussed in the reviewed literature (Achterberg et al., 2013; Corbett et al., 2016; Dowding et al., 2016; Lichtner et al., 2015; Peisah et al., 2014; Tarter et al., 2016).

Categorizing patients with various ability to self-report pain by considering different stages of dementia. In the early stages of dementia, communication ability is mostly reserved due to the limited cognitive impairment. At this stage, people with dementia are still able to self-report pain. However, along with the progress of the disease, communication ability will decrease. Eventually, people with advanced dementia are often no long able to communicate (Achterberg et al., 2013). Based on this fact, healthcare providers or any caregivers need to take considerations in terms of the change in communication ability while performing pain assessment and management. Some of the reviewed literature has mentioned this component (Achterberg et al., 2013; Frampton, 2003; Horgas & Elliot, 2004)

Selecting appropriate instruments for pain assessment for cognition impaired patients. When self-report pain is not possible, tracing nonverbal cues is a valuable approach to identify pain in people with dementia. A guidance outlining the various nonverbal cues such as facial and behavioral expressions was published by the American Geriatrics Society expert panel. Consequently, many assessment instruments for dementia were developed. It is important to select appropriate tools for the particular person with dementia (Achterberg et al., 2013; Frampton, 2003).

Pain relief. The goal for pain management is achieving pain relief, therefore, it is a component mentioned by two literatures (Corbett et al., 2014; Frampton, 2003).

These six attributes appeared repeatedly in the reviewed literature and are appropriate for the purpose of exploration of the concept. Also, they influence each other and work together to provide a concrete component in the concept of pain management for people with dementia.

Constructing Cases

A model case should include all attributes of the concept and should be a paradigmatic example. It also illustrates the attributes of the concept (Walker & Avant, 2010). The following example created by the author presents a model case for the concept of pain management.

A model case. Mrs. X has dementia and is experiencing a lot of pain including neck pain, back pain, and neuropathy pain. Her daughter, Mrs. Y, is the primary caregiver taking care of her at home. Since Mrs. X was diagnosed with Alzheimer's disease two years ago, she is still in an early stage and is able to tell the daughter when her pain presents. The daughter often asks her mom: "How bad is your pain?" and "Where is your pain?" The daughter uses a numerical pain assessment tool to rate Mrs. X's pain. The daughter often gives Mrs. X oral pain meds such as Gabapentin and baclofen if the pain is mild or moderate. If the pain is severe, she may give her Hydrocodone prescribed as PRN by her primary doctor. In addition to the pharmacological interventions, the daughter also tried non-pharmacological methods such as physical therapy, ice, heat, and massage. Mrs. X also gets injections for some of the pain every three months. Sometimes her pain is uncontrolled. At those times, the daughter will take Mrs. X to the pain clinic. The healthcare team will interview the family caregiver and ask about previous pain experiences of the patient and the modulation or change in pain after treatment. After the holistic assessment, the healthcare team develops a plan to give an additional injection for severe pain. The daughter does follow-up assessment for her mother by asking Mrs. X how she feels after the pain medication given.

***Case analysis*.** This case illustrates all six attributes of the concept of pain management. Mrs. X was a patient suffering early stage dementia and able to self-report her pain. The daughter uses appropriate tool for pain assessment. Then, the level of pain was identified and a multimodal method for pain management was implemented, including pharmacological and non-pharmacological methods. If the pain was still not relieved, the daughter communicated with healthcare professionals to develop an advanced care plan for pain control. The daughter did reassessment for pain treatment. Finally, patient's pain was well controlled.

To be noted that knowing of the stages of the disease is very important because the way that patients communicated with caregivers about their pain could be changed, which then may lead to using different approaches in pain treatment.

A borderline case. Walker and Avant (2010) suggested that identifying additional cases can contribute to the enhanced clarify of the concept. The additional cases may not involve all the attributes of the concept as the model case does; or, these cases may not present the concept of interest at all. The following example is a borderline case created by the author and contains partial attributes of the concept.

Mr. X is in his 90s and was diagnosed with Alzheimer's disease about five years ago. He had a recent fall with fractured ribs and was hospitalized for one week. Since he was recovering nicely, his wife Y and daughter Z began taking care of him at home. The patient was on oxycodone for two weeks and was weaned off. He currently takes Ibuprofen and Tylenol because the patient reports pain only upon his movement. Though the patient is able to report his pain most of the time, he needs to be watched/observed for pain as well. For example, one morning, his wife helped him with a shower and noticed some tissue paper between his toes. When his wife asked why the tissues were there, he said his toes hurt. After his wife told the daughter about the patient's pain, the daughter assessed the pain level using a numeric pain assessment tool and administered Tylenol. Later the daughter reassessed her dad's pain and saw that the tissues were not there and her dad said "No, nothing wrong with my feet."

Case analysis. This case illustrates five out of six attributes of the concept. Mr. X was a patient suffering dementia and able to self-report his pain in certain degree. The family caregivers recognized the non-verbal cues of pain (tissue paper between the toes) based on their knowledge. The appropriate tool for pain assessment (numeric pain assessment tool) was selected and used. Then, moderate pain was identified and pain medicine was administered. Finally, patient's pain was relieved. In this case, family caregivers did not use multimodal method to treat the pain. In addition, the family caregivers didn't communicate with healthcare professionals.

A contrary case. A contrary case is an example that is "not the concept" (Walker & Avant, 2010). People can easily differentiate this concept from the one of interest. The following is an example of contrary case that originated from an article (Cheng et al., 2003) and has been modified by the author.

Mrs. X is in her 70s and was diagnosed with dementia in 2017. She also has an extensive history of mental health issues. One night, she was screaming and complained that her legs were so swollen with blood that she thought it was going to burst open. The son, her caregiver, was staying with her and did a physical examination of her legs. There was no observable sign of what Mrs. X reported. In addition, based upon the physical examination, her son found out she didn't have any difficulty using her legs. Since her son knew her well, he administered medicine for anxiety, Mrs. X then calmed down.

***Case analysis*.** All the defining attributes of pain management for patient with dementia are missing from this case. It presents the concept of confabulation in a person with dementia. Confabulation is the creation of false memories in the absence of intentions of deception. Person who confabulates will not recognize that the information being relayed to others is fabricated. This confabulating individual is not intentionally being deceptive and believes the information they are communicating to be accurate and true (Brown et al., 2017). In this case, Mrs. X did not distinguish between her internal landscape and an external reality that the rest of us might agree on. She was not really conscious of what she's doing. Her son was vigilant about this situation and took the appropriate action to treat Mrs. X. The situation may be associated with pain; however, none of the defining attributes for concept of pain management for people with dementia were applicable.

Identifying Antecedents and Consequences

Antecedents. According to Walker and Avant (2010), antecedents are the incidents that occur before the existence of the concept. Therefore, antecedents facilitate the occurrence of pain management (Larson, 2007). Antecedents usually highlight social contexts. In this concept analysis, based on the literature reviewed, expression of pain, caregiver's belief and attitude, organizational culture, and resources are the identified antecedents.

Before the action of pain management occurs, patient must express their pain. The expression of pain could be the self-report, observed non-verbal cues, and the combination of self-report and observation of non-verbal cues. When pain is expressed via non-verbal cues, caregivers' interpretation of pain is essential to inform decision-making related to pain management. Caregivers' personal beliefs and attitudes determine how they interpret and react to pain, and thus inform decision-making (Barry et al., 2013; Dowding et al., 2016; Lichtner et al., 2015). Organizational culture or climate will impact decision making for pain management. If an organization or a healthcare facility can establish a multidisciplinary environment and facilitate an interpersonal communication, effective pain management is more likely to happen (Dowding et al., 2016).

Several studies have shown that healthcare professionals at all levels and family caregivers often lack sufficient training and education in pain assessment for cognition impaired patients (Corbett et al., 2016; Frampton, 2003; Reynolds et al., 2008; Tarter et al., 2016). Members of the caregiving team must be educated in pain management. Using adequate pain assessment skills can help to address physical, psychological, and social difficulties and result in improved pain management strategies overall. In addition, whether a healthcare facility has well-established protocols or guidelines for pain management could affect the quality of outcomes for pain management. In sum, resources are important and should be available to healthcare professionals and family caregivers.

Consequences. Consequences are the outcomes of the concept and can assist in determine often-neglected factors that may generate new research directions (Walker &

Avant, 2010). In this concept analysis, the consequences may help develop a hypothesis in terms of the quality of pain management.

Generally, the consequences of pain management should be defined by the patient's own measurement of their physical, emotional, and social wellbeing, due to the subjective nature of pain (Larsen, 2007). However, the population of interest is patients with dementia; the impaired cognition limits their ability to accomplish self-measurement of their physical, emotional, and social wellbeing. Therefore, in this case, the consequences of self-determination may not be applicable.

On the other hand, pain management for people with dementia usually involves pain assessment, pain identification, pain modulation, and pain relief evaluation from people other than the patients themselves. A consequence of achieving pain management should be defined by the caregivers' measurement of patients' physical, emotional, and social wellbeing. Determining how and what to evaluate for the quality of pain management is a decision making process. Thus, decision-making is one consequence of the concept. Patients perceive pain and react to pain treatment differently, which results in various pain modulations. Because of this fact, another consequence of pain management could be that the meaning of pain management is developed for both caregivers and patients.

Pain is an unpleasant and discomforting experience for patients and can compromise other functions of the patients. Therefore, the consequence of pain management should include achieving patients' maximized function regardless the population of interest. Once patients reach maximized function, their quality of life will also be improved. As a result, improved quality of life should be one of the consequences of the concept.

Defining Empirical Referents

The final step of Walker and Avant's method of concept analysis is empirical references that indicate the occurrence of the concept demonstrated by the existence of actual phenomena and how the concept is measured (Walker & Avant, 2010). Empirical references are useful because they deliver clinicians and researchers the observed actual phenomena by which to determine the existence of the concept in particular patients (Larsen, 2007).

As discussed before, six attributes were identified. These attributes are the heart of the concept (Walker & Avant, 2010). Measuring of the concept can be achieved by measuring each individual attribute. Measures used for these attributes will be the empirical referents. To measure the different stages of dementia, the Mini-Mental State Examination (MMSE) was used (Lichtner et al., 2015; Reynolds et al., 2008). For patients with mild cognition deterioration, caregivers can still ask the patients and also use observational methods. For people with severe dementia, evaluation of pain should rely largely on observational methods (Achterberg et al., 2013; Scherder & Plooij, 2012). A large number of tools are available that can be used for pain evaluation when observational methods are used. These tools include Visual Analog Scale, Pain Observation Scale; Horizontal Visual Analogue Scale, and the Faces Pain Scale (Achterberg et al., 2013; Corbett et al., 2014; Horgas & Elliott, 2004; Liu et al., 2014; Scherder & Plooij, 2012). However, researchers and clinicians need to note that when selecting the tools for pain evaluation, they should consider the psychometric quality and clinical utility of these tools. By checking the validity and reliability of the tools, one can determine whether the tools are validated or not (Frampton, 2003). To measure the effectiveness of communication between professionals and family caregivers, a survey can be conducted. The reviewed literature consistently recommended that protocols should be established to ensure the appropriate use of pain medication and other alternative methods for pain relief (Frampton, 2003; Horgas & Elliott, 2004; Peisah et al., 2014; Guerriero et al., 2016). The measure used to assess pain relief could be the same as the pain assessment measure.

In summary, the major components regarding to the concept of pain management for people with dementia were consistent with the structure of the Revised Model for Decision-Making. The concept map was created based on the model (see Appendix C). The attributes are the core of the concept analysis. The antecedents are the factors that will facilitate the occurrence of attributes. The consequences are the outcomes that could result from the implementations. This map demonstrates that performing pain management is assumed to follow a sequential linear process. The process of pain management is similar to the process of how people make a decision. In addition, this map indicates that pain management is not an individual's activity; it is more likely that a group of people within certain organizational culture will complete the task. The task is shaped by individuals' beliefs and attitudes (Dowding et al., 2016).

Discussion

The purpose of this concept analysis was to examine the unique characteristics of the concept of pain management in people with dementia. From the analysis, attributes, antecedents, consequences, and its' empirical referents for the concept of pain management for people with dementia were identified. The study results assisted the better understanding of the concept and its implications provided direction for future research in advancing the quality of pain management and quality of life in people with dementia.

Conceptual, Theoretical, and Empirical Applications

Evidence of the exploration of pain management can be found in both theoretical and empirical sources. The Gate Control Theory of Pain (Melzack & Wall, 1965) provides a framework that allows researchers to view pain management from a broad perspective. In this theory, pain is interpreted as a phenomenon that results from the interaction of motivational, cognitive, and sensory processes. Consequently, pain management involving various approaches, including pharmacological, psychological, and physical methods, has developed and the concept of pain management has been used in various scientific disciplines including nursing, medicine, and psychology (Davis, 1992).

Dowding and other research team members (2016) examined existing models of pain assessment and management and concluded that pain management in people with dementia could be viewed as a process of decision-making. The social contexts such as personal belief and organizational culture could shape decision-making related to pain management.

The concept of pain management could be used to guide empirical studies. For example, the Pain Management Inventory (PMI) is an instrument developed and used for patients with rheumatic disease. This instrument lists 17 pain management strategies. High content validity and moderate construct validity have been demonstrated (Davis &

Atwood 1996). As discussed before, one of the empirical referents is the well-established protocols for the appropriate use of pain medication and other alternative methods for pain relief (Frampton, 2003; Horgas & Elliott, 2004; Peisah et al., 2014; Guerriero et al., 2016). Future research that examines the applicability and utility of the PMI in the population of dementia patients is warranted.

Limitations

Limitations for the concept analysis were noticed. First, of the 17 articles, only one article was a randomized control trial; eight were non-experimental studies (three pilot studies, two qualitative studies, three cross-sectional studies); and eight were review articles. The quality of the studies may compromise the accuracy of the analysis regarding the concept. Second, the bias could exist because the identification of attributes of the concept from the literature review was done by the researcher and not cross-checked by the second researcher (Walker & Avant, 2005). Though the limitations exist, this analysis is the first concept analysis of pain management for people with dementia. It offered a better understanding of the concept of pain management and contributed to the quality improvement in pain management for people with dementia.

Implications for Nursing

Because pain management is an inevitable nursing task, it has significant implications for the care of dementia patients. To manage pain for people with dementia, nurses need to understand each of the defining attributes and consequences. These attributes and consequences provide a basis for developing a research hypothesis to test the quality of pain management in the practice of pain management for dementia patients. The antecedents give clear indicators for what needs to be in place before pain management can be achieved. Nurses' beliefs and attitudes will inform decision-making on pain management. Given a multidisciplinary environment, nurses play an important role on facilitating communications between patients, family caregivers, and other healthcare professionals. In sum, shared understanding of pain management is important in nursing to aid effective communication, develop knowledge, and enable the development of tools to evaluate the quality of pain management in practice. Moreover, shared understanding of pain management is necessary if all healthcare professionals involved with family caregivers and patients with dementia are to resolve problems associated with acute and chronic pain (Larson, 2007). Eventually, it will contribute to the improvement of pain management among people with dementia.

References

Achterberg, W. P., Pieper, M. J. C., Dalen-Kok, A. H., Waal, M. W. M., Husebo, B. S., Lautenbacher, S., Kunz, M.,… Corbett, A. (2013). Pain management in patients with dementia. *Journal of Clinical Intervention in Aging, 8*, 1471–1482.

Alzheimer's Association, (2016). 2016 Alzheimer's disease facts and figures: Prevalence. Retrieved from http://www.alz.org/facts/

Barry, H. E., Parsons, C., & Passmore, A. P. (2013). Community pharmacists and people with dementia: A cross-sectional survey exploring experiences, attitudes, and knowledge of pain and its management. *International Journal of Geriatric Psychiatry, 28*(10), 1077-1085.

Barry, H. E., Parsons, C., Passmore, A. P., & Hughes, C. M. (2015). Pain in care home residents with dementia: an exploration of frequency, prescribing and relatives' perspectives. *International Journal of Geriatric Psychiatry, 30*(1), 55-63.

Blalock, H. M. (1992). *Conceptualization and measurement in the social sciences*. Beverly Hills, Clif: Sage.

Bonica, J. J. (1991). History of pain concepts and pain therapy. *Mount Sinai Journal of Medicine, 58*(3), 191-202.

Brown, J., Huntley, D., Morgan, S., Dodson, K. D., & Cich, J. (2017). Confabulation: A guide for mental health professionals. *International Journal of Neurology and Nueurotherapy*. *4*(2). doi.org/10.23937/2378-3001/1410070

Buffum, M. D. & Haberfelde, M. (2007). Moving to new settings: Pilot study of families' perceptions of professional caregivers' pain management in persons with dementia. *Journal of Rehabilitation Research and Development, 44*(2), 295-303.

Chandler, R. & Bruneau, B. (2014). Barriers to the management of pain in dementia care. Nursing times, 110(28), 12-16.

Cheng, S, Foster, R. L., & Huang, C., (2003). Concept analysis of pain. *Tzu Chi Nursing Journal, 2*(3), 20-28.

Corbett, A., Husebo, B. S., Achterberg, W. P., Aarsland, D., Erdal, A., & Flo, E. (2014). *The importance of pain management in older people with dementia. British Medical Bulletin, 111*(1), 139-148.

Corbett, A., Husebo, B. S., Achterberg, W. P., Aarsland, D., Erdal, A., & Flo, E. (2014). The importance of pain management in older people with dementia. *British Medical Bulletin, 111*(1), 139-148.

Corbett, A., Nunez, K.-M., Smeaton, E., Testad, I., Thomas, A., Closs, J., Briggs, M., …Lawrence, V. (2016). The landscape of pain management in people with dementia living in care homes: A mixed methods study. *International Journal of Geriatric Psychiatry, 31*(12), 1354-1370. doi: 10.1002/gps.4445

Davis, G. (1992). The meaning of pain management: A concept analysis. *Advances in Nursing Science, 15*(1), 77-86.

Davis, G. C., & Atwood, J. R. (1996). The development of the Pain Management Inventory for patients with arthritis. *Journal of Advanced Nursing, 24*(2), 236-243.

Dowding, D., Lichtner, V., Allcock, N., Briggs, M.,… James, K., Keady, J., … Closs, S. J. (2016). Using sense-making theory to aid understanding of the recognition, assessment and management of pain in patients with dementia in acute hospital settings. *International Journal of Nursing Studies, 53*, 152-162. doi: 10.1016/j.ijnurstu.2015.08.009

Eritz, H. & Hadjistavropoulos, T. (2011). Do informal caregivers consider nonverbal behavior when they assess pain in people with severe dementia? *American Pain Society, 12*(3), 331-339.

Falls, D., Stevens, J., Andersen, M., Collin, S., Dodd, N., Fitzgerald, E…Wilson, V. (2004). Carers' perceptions of pain in people with dementia: A grounded theory approach. *Aust J Holist Nurs., 11*(2),4–11.

Frampton, M., (2003). Experience assessment and management of pain in people with dementia. *Age and Aging, 32*(3), 248-251.

Gibson, S. J. (2016). Pain in persons with dementia. *16TH World Congress on Pain*, Washington, D.C.: IASP Press.

Glowacki, D. (2015). Effective pain management and improvements in patients' outcomes and satisfaction. *Critical Care Nurse, 35*(3), 33-43.

Gordon, R. M., Corcoran, J. R., Bartley-Daniele, P., Sklenar, D., Sutton, P. R., & Cartwright, F. (2013). A transdisciplinary team approach to pain management in inpatient health care setting. *Pain Management Nursing, 15*(1), 426–435. doi:10.1016/j.pmn.2013.01.004

Guerriero, F., Sgarlata, C., Maurizi, N., Francis, M., Rollone, M., Carbone, M., Rondanelli, M., ... Ricevuti, G. (2016). Pain manamgement in dementia: so far, not so good. *Geriatrics and Gerontology Elsewhere, 64*, 31-39.

Herr, K. (2002). Pain assessment in cognitively impaired older adults. American Journal of Nursing, 102, 65-67.

Horgas, A. L., Elliott, A. F. (2004). Pain assessment and management in persons with dementia. *Nursing Clinics of North Amercia,39*(3), 593-606.

Hunt, L. J., Covinsky, K. E., Yaffe, K., Stephens, C. E., Miao, Y., Boscardin, W. J., & Smith, A. K. (2015). Pain in Community-Dwelling Older Adults with Dementia: Results from the National Health and Aging Trends Study. *Journal of American Geriatric Society, 63*(8), 1503-1511.

Larsen, D. (2007). Pain management in nursing: what does it mean? *The national discussion forum and community for UK healthcare professionals with an interest in acute, chronic, or palliative pain management: pain-talk.org.edu*. Retrieved from http://www.gb42.com/ynot_what_does_it_mean.html

Li, J., Snow, A. L., Wilson, N., Stanley, M. A., Morgan, R. O., Sanbhada, S., & Kunik, M. E., (2015). The Quality of Pain Treatment in Community-Dwelling Persons with Dementia. *Dementia and Geriatric Cognitive Disorders Extra, 5*(3), 470-481.

Lichtner, V., Dowding, D., Closs, S. J. (2015). The relative meaning of absolute numbers: The case of pain intensity scores as decision support systems for pain management of patients with dementia. *BMC Medical Informatics and Decision Making, 15*(111). doi: 10.1186/s12911-015-0233-8

Liu, J. Y. W. & Lai, C. (2014). Implementation of observational pain management protocol to improve pain management for long-term institutionalized older care residents with dementia: study protocol for a cluster-randomized controlled trial. *Trials, 15*. doi: 10.1186/1745-6215-15-78.

Mahon, S. M. (1994). Concept analysis of Pain: Implications related to nursing diagnoses. *Nurses Diagnoses, 5*(1), 14-25.

Melzack, R., & Wall, P. (1965). Pain mechanisms: A new theory. *Science, 150*(3699), 971-979.

Pain. (2004). In *Collin dictionary and Thesaurus: Two books in one* (3rd ed.) Collins. Retrieved from https://www.collinsdictionary.com/us/dictionary/english-thesaurus/pain

Pain. (2017). In *Mosby's Dictionary of Medicine, Nursing & Health Professions (*20th ed.) St. Louis, Missouri: Elsevier. Retrieved from https://www.amazon.com/Mosbys-Dictionary-Medicine-Nursing-Professions/dp/0323222056

Pain. (2009). In Webster's New World Medical Dictionary (3rd ed.) Hoboken, New Jersey: Wiley. Retrieved frhttps://play.google.com/books/reader?id=t8UfI3BH78wC&hl=en_US&pg=GBS.PP6

Peisah, C., Weaver, J., Wong, L., & Strukovski, J. (2014). Silent and suffering: a pilot study exploring gaps between theory and practice in pain management for people with dementia in residential aged care facilities. *Clinical Interventions in Aging, 9*, 1767-1774.

Reynolds, K. S., Hanson, L. C., DeVellis, R. F., Henderson, M., & Steinhauser, K. E. (2008). Disparities in pain management between cognitively intact and cognitively impaired nursing home residents. *Journal of Pain and Symptom Management, 35*(4), 388-396.

Rodger, B. L. & Knafl, K. A. (2000). Concept development in nursing: Foundations, techniques, and applications (2nd Ed.). Philadelphia, PA: W. B. Saunders Company.

Scherder, E. J. A. & Plooij, B. (2012). Assessment and Management of Pain, with Particular Emphasis on Central Neuropathic Pain, in Moderate to Severe Dementia. *Drugs & Aging, 29*(9), 701-706.

Shega, J. W., Hougham, G. W.; Stocking, C. B., Cox-Hayley, D., & Sachs, G. A. (2006). Management of noncancer pain in community-dwelling persons with dementia. *Journal of the American Geriatrics Society, 54*(12), 1892-1897.

Shega, J. W., Hougham, G. W., Stocking, C. B., Cox-Hayley, D., & Sachs, G. A. (2004). Pain in community-dwelling persons with dementia: Frequency, intensity, and congruence between patient and caregiver report. *Journal of Pain Symptom Management, 28*(6), 585-592.

Soscia, J. (2003). Assessing pain in cognitively impaired older adults with cancer. *Clinical Journal of Oncology Nursing, 7*, 174-177.

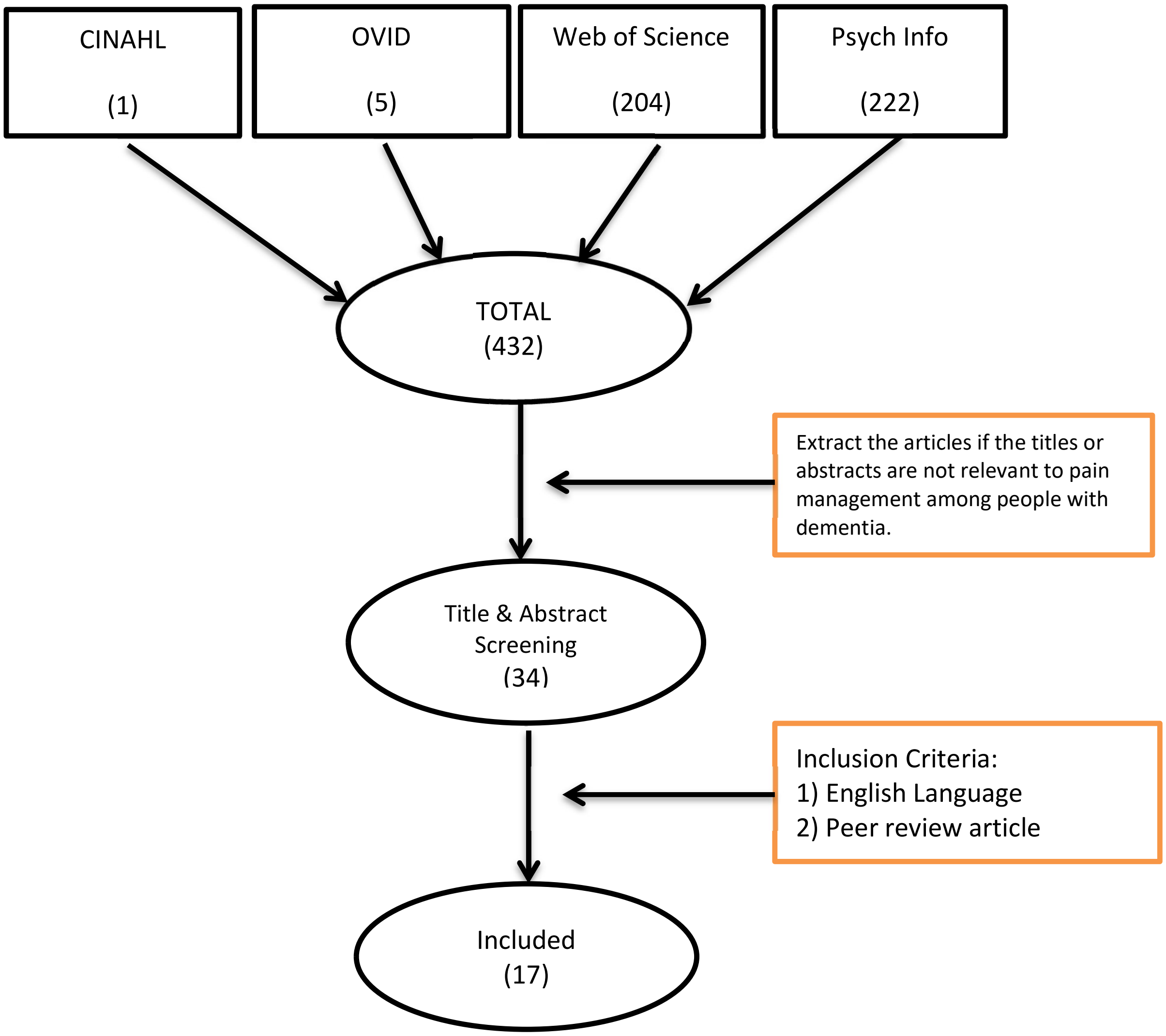
Tarter, R., Demiris, G., Pike, K., & Oliver, D. P. (2016). Pain in hospice patients with dementia: The informal caregiver experience. *American Journal of Alzheimer's Disease & Other Dementias, 31*(6), 524-529. doi: 10.1177/1533317516653825

Walker L.O. & Avant K.C. (2010). *Strategies for Theory Construction in Nursing*, 5th edn. Pearson Prentice Hall, Upper Saddle River, NJ.

Wells, N., Pasero, C., & McCaffery, M. (2008). *Improving the quality of care through pain assessment and management.* In: Hughes RG, ed. Patient Safety and Quality: An Evidence-Based Handbook for Nurses. Rockville, MD: US Agency for

Healthcare Research and Quality, 469-497.Wood, S. (2002). Pain management: assessment and diagnosis. *Nursing Times, 98*(39), 43.

Appendix A: CONSORT



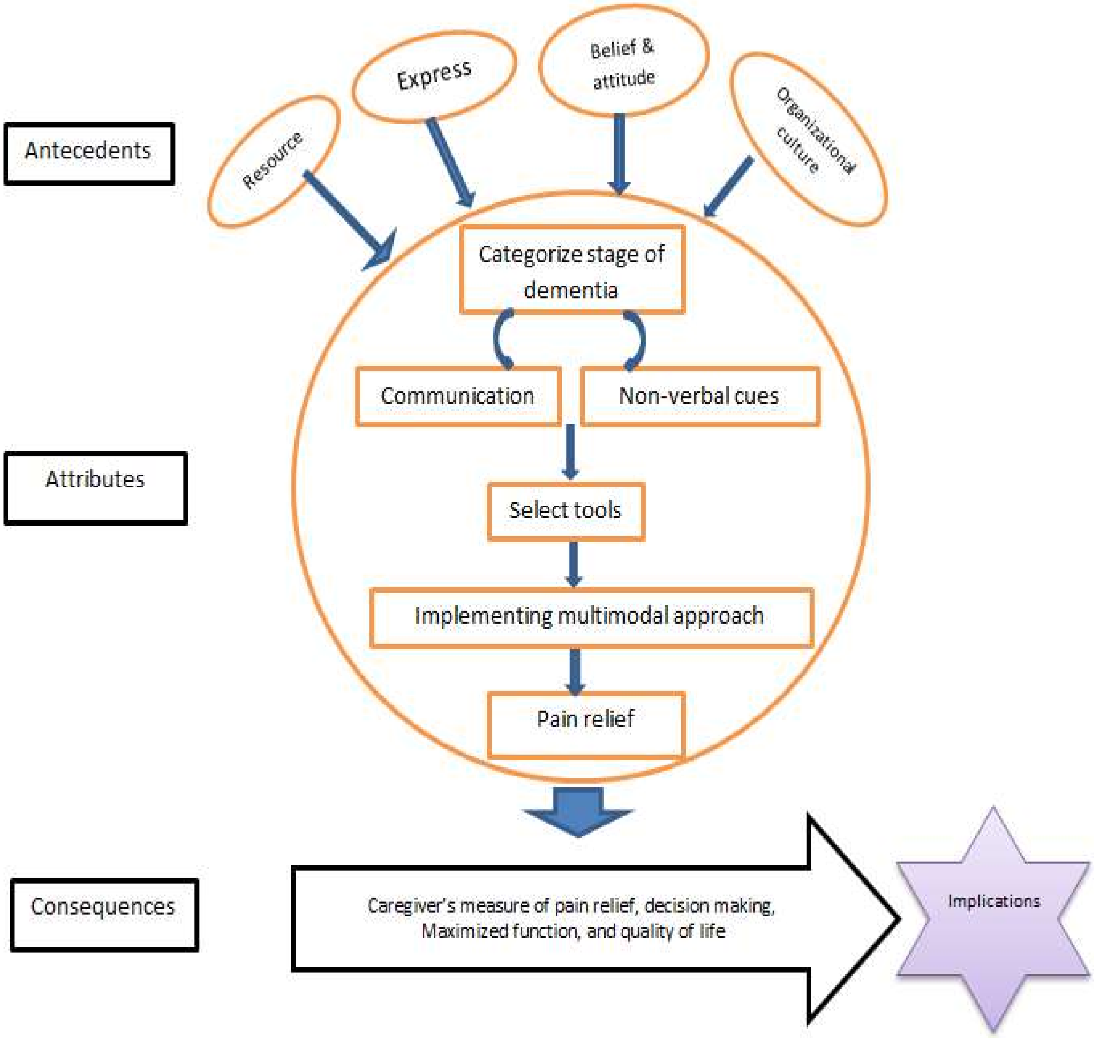
Appendix B: Literature Review Table

Author & Year	Purpose	Concept attributes	Empirical Referents	Limitations
1.Frampton, 2003	To make recommendation for poor pain management in patient with dementia.	Stage of dementia; relationships between pain & psychological symptom; pain relief; Select appropriate instrument.	MMSE; Evaluation psychometric properties test; observational tools.	Limitation of generalizability
2. Horgas & Elliott, 2004	To make recommendation for poor pain management by focusing on the issues in assessing pain.	Recognition of non-verbal cues of pain; Stage of dementia; Multi-dimensional approach;	MMSE; protocol; Pain assessment tools for cognition impaired.	Review, not experimental study.
3. Shega et al., 2006	To explore the pharmacological treatment of non-CA pain in PwD and identify predictors associated with insufficient analgesia.	Recognition of non-verbal cues of pain; Implementing multimodal approach.	WHO Class I – III, assessment tools for cognition impaired	Convenient sample
4. Reynolds et al., 2008	To test the association between residents' cognitive impairment and nursing homes' pain management practices.	Recognition of non-verbal cues of pain; Multimodal approach.	Protocol, Tools for observational methods	Small sample size
5. Scherder & Plooij, 2012	To address assessment and management of pain, with particular emphasis on central neuropathic pain, in moderate to severe dementia.	Recognition relationships between pain and psychological symptoms of dementia; Implementing multimodal approach.	Pain assessment scales for cognation impaired; Protocol.	Imitated generalizability
6. Achterberg et al., 2013	To explore the key perspectives of pain management in dementia and make recommendation to research and practice.	Recognition relationships between pain and psychological symptoms of dementia; communication; Select appropriate instruments.	Psychometric properties; Survey.	Review, not experimental study.

Author & Year	Purpose	Concept attributes	Empirical Referents	Limitations
7.Barry et al., 2013	To explore community pharmacists' experiences with and attitudes towards people with dementia and to determine the knowledge they have about pain and management in PwD.	Recognition relationships between pain and psychological symptoms of dementia;	Tools for observational methods	Low response rate; limited generalizability, small sample size
8. Chandler & Bruneau, 2014	To discuss the barriers, strategies to overcome barriers, implications of pain management in demented population.	Recognition of non-verbal cues of pain; Multimodal approach.	Tools for observational methods; Protocol.	Lack of RCT
9. Corbett et al., 2014	To fill the gaps in evidence to support pain assessment and treatment	Recognition of non-verbal cues of pain; Pain relief.	Tools for observational methods; Protocol.	Review, not experimental study.
10. Flo et al., 2014	To provide a literature overview of the associations between pain & neuropsychiatric symptoms and the efficacy of pain management for both pain and neuropsychiatric symptoms.	Recognition relationships between pain and psychological symptoms of dementia.	Tools for observational methods	methodological predicament
11. Liu et al., 2014	To investigate the extent to which the implementation of this protocol can improve pain management	Recognition of non-verbal cues of pain; Multimodal approach.	Tools for observational methods; Protocol	Small sample size
12. Peisah et al., 2014	To develop the interventions that could improve nursing staff & FCG's skills of pain management.	Recognition of non-verbal cues of pain; Communication	Tools for observational methods; Survey.	Small sample size
13. Lichtner et al., 2015	To understand current pain assessment practices, in order to inform the development of a decision support tool designed to improve management of pain.	Recognition of non-verbal cues of pain; Communication	Tools for observational methods; Survey.	Small sample size.

Author & Year	Purpose	Concept attributes	Empirical Referents	Limitations
14. Corbett et al., 2016	To explore the current landscape of pain management in people with dementia.	Recognition of non-verbal cues of pain; Communication; Multimodal approach.	Tools for observational methods; Survey; Protocol.	Small sample size
15. Tarter et al., 2016	To describe informal caregivers' experiences managing pain in hospice patients with dementia.	Recognition of non-verbal cues of pain; Communication; Multimodal approach.	Tools for observational methods; Survey; Protocol.	Limited diverse in geographical, racial factors
16. Dowding et al., 2016	To provide a revised conceptual model of pain recognition, assessment and management based on sense-making theories of decision making.	Recognition of non-verbal cues of pain; Communication.	Tools for observational methods; Survey.	Limited generalizability to other settings
17. Guerriero et al., 2016	To summarize the best-available evidence regarding the etiology, assessment and Treatment of pain in people with dementia.	Recognition of non-verbal cues of pain; Multimodal approach.	Tools for observational method; Protocol.	Lack of large-scale randomized control trials.

Appendix C: Concept Map



Chapter 5. Manuscript 3 - *Exploring Experiences of Pain Management among Family Caregivers of Community-Dwelling Older Adults with Dementia: A Qualitative Study*

To be submitted to Innovation in Aging

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Abstract

Background: Pain is a significant concern in older adults with dementia. Family caregivers play a crucial role in pain management for their care recipients. However, to date, few studies have examined family caregiver's (FCGs) experiences of pain management for community-dwelling older adults with dementia.

Purpose: To provide a deep understanding of experience of pain management among FCGs for community-dwelling older adults with dementia.

Methods: This study used a qualitative descriptive design and constant comparison analytic methods. Family caregivers were recruited and participated in semi-structured face-to-face interviews or phone interviews. Inclusion criterion included being an adult providing care to community-dwelling older adults. Recruitment stopped upon reaching thematic saturation. A demographic questionnaire was used to collect additional relevant information.

Results: The study included 25 family caregivers in central Virginia who ranged in age from 29 to 95. Participants were predominantly white, female, married, and had a minimum high school education. Most of them were adult children (52%) or the spouses (28%) of the care recipients. Three themes were identified: 1) Values, 2) Barriers, and, 3) Support.

Conclusion: Family caregivers follow their values to make decisions in pain management. Barriers existed for effective pain management. Support is needed for family caregivers in pain management.

Introduction

Pain, as the fifth vital sign, is one of the most common medical complaints (McCarberg et al., 2008). The 2012 National Health Interview Survey reported that more than 25 million Americans (11.2%) suffer from daily chronic pain (Nahin, 2015). The prevalence of pain is strongly associated with age, hitting the oldest population the hardest with prevalence rates of 72% above age 85.

Older adults with dementia have even higher prevalence of pain, as high as 80% (Eritz & Hadjistavropoulos, 2011; Hunt et al., 2017). Based on data from the National Health and Aging Trends Study, Hunt et al. (2017) reported that 63.5% community-dwelling older adults with dementia experienced bothersome pain. The rate was significantly higher than in a cohort of individuals without dementia (54.5%) (Hunt et al., 2017). According to the information supplied by Pinzon et al. (2013), more than half (52.5%) dementia patients suffered pain within two days of death. Currently, there are an estimated 5.3 million people aged 65 or older with dementia across the United States (Alzheimer's Association [AA], 2017), which represents a significant public health issue.

In addition to the high prevalence of pain, studies have indicated that pain in people with dementia is more often underreported and poorly managed than in those without dementia due to the complex challenges presented by dementia (Bernabei et al., 1998; Corbett et al., 2014; Eritz & Hadjistavropoulos, 2011; Morrison & Siu, 2000; Teno, Weitzen, Wetle, & Mor, 2001). Moreover, pain is always subjective and self-report is the golden standard for pain assessment (The National Pharmaceutical Council [NPC] & The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) 2001). However, the pathologic changes in the brain among persons with dementia alter the ability to remember, interpret, and respond to pain (Benedetti et al., 2004). Consequently, self-reporting pain may not be possible in this population, leading to underreport or under-recognition of pain. International epidemiological research reported that older adults with dementia received lower dosages of pain medication, and stronger pain medications, such as opioids, were less frequently prescribed for dementia patients than for their cognitively healthy counterparts (Corbett et al., 2013). Consequently, pain management is a persistent concern among older adults with dementia.

Unrelieved pain can affect individual's quality of life and cause profound negative effects on the body (Covinsky, Lindquist, Dunlop, & Yelin., 2009; Andrew, Cenzer, Yelin, Covinsky, 2013; Shega et al. 2004). For example, persistent pain leads to increased levels of physical disability, impairments in activities of daily living, sleep disturbances, and decreased appetite (Bosley, Weiner, Ruby, & Granieri., 2004; Cipher, Clifford, & Roper, 2006; Foley, Ancoli-Israel, Britz, & Walsh, 2004). Additionally, uncontrolled pain also causes an increase in behavioral disturbances (agitation, physical or verbal aggression, wandering, or social withdrawal, etc.) and psychological dysfunction (depression, fear, and anxiety, etc.), leading to the use of physical restraints and psychological therapies, rather than adequate pain treatment (Cipher et al., 2006; Whitelock et al., 2017). Psychotropic medications are known to have substantial side effects, including increased mortality, cerebrovascular crisis, and falls, which could highly compromise patients' pain treatment (Ballard et al., 2011; Briesacher et al., 2005). Moreover, a longitudinal cohort study of older adults has shown that persistent pain is associated with memory decline and increased probability of dementia (Whitelock et al., 2017). Therefore, in order to minimize using psychotropic therapies, accurately assessing pain and differentiating pain from behavioral problems are important.

Dementia, as a public health issue, affects mostly older adults because the risk of developing dementia increases with age (Burge et al., 2012; Hebert et al., 2003; United States Department of Health and Human Services, 2016). In the United States (U.S.), more than five million people 65 years of age or older suffered from dementia (AA, 2017). In the U.S., an estimated 65.7 million Americans function as FCGs for nearly 81% of older adults with dementia (Brodaty & Donkin, 2009; Jones et al., 2011). FCGs spend an average of 24.4 hours providing care per week and nearly one in four of them provide more than 40 hours of care per week for older adults with dementia living in community-dwellings (Family Caregiver Alliance, 2015). In 2016, more than 15 million FCGs provided 18.2 billion hours of unpaid care to people living with dementia, a contribution valued at more than $230 billion (AA, 2017). Additionally, when patients with dementia live in long-term care facilities, FCGs often spend substantial time with patients. Healthcare providers increasingly turn to FCGs for additional history and insights into the patients' pain experiences (Lethin et al, 2015; Tarter et al., 2016; Shega et al., 2004).

Given the key role in taking care of loved ones with dementia in the community-settings, research should focus on providing a deep understanding of the FCGs' experience in pain management. However, with substantial research focusing on formal caregivers' experiences of pain assessment and management in institutional settings, FCGs have largely been overlooked (Hunt et al., 2017).

Existing studies have shown improvement in pain assessment and pain management among formal caregivers in the clinical setting. Research has shown that formal caregivers' pain assessment skills were improved with the recognition of non-verbal cues and the use of observational pain rating scales or behavioral checklists (Achterberg et al., 2013; Burns & McIlfatrick, 2015; Chow et. al., 2016; Eritz & Hadjistavropoulos, 2011; Fuchs-Lacelle et al., 2008; Lichtner et al., 2016; Shege et al., 2004). Another improvement was that recommendations for using pharmacological and non-pharmacological methods for pain treatment and guidance for analgesic administration have been made in the clinical setting for formal caregivers (Barry, Parsons, Passmore, & Hughes, 2015; Barry et al., 2012; Buffum & Haberfelde, 2007; ; Burns & McIlfatrick, 2015; Li et al., 2007). However, selecting appropriate pain assessment tools remains challenging for formal caregivers (Achterberg et al., 2013).

Some studies examined factors that could affect pain management (Fry et al., 2016; Nygaard & Jarland, 2005; Jansen et al., 2017a; Lichtner et al., 2016; Martin et al., 2005). Clinicians' beliefs about painkillers, staff education level, and clinical experiences were factors that could influence decision-making in pain management (Fry et al., 2016; Nygaard & Jarland, 2005). The relationship between nurses and doctors could affect the quality of care for pain (Jansen et al., 2017a; Lichtner et al., 2016). Programs for professional development can help with pain management (Jansen et al., 2017a; Jansen et al., 2017b; Martin et al., 2005).

Furthermore, knowledge deficits regarding pain, pain treatment, and pain medication and negative beliefs about pain in elders are the most frequently mentioned barriers among formal caregivers (Barry et. al., 2012; Burns & McIlfatrick, 2015; Zwakhalen, Hamers, & Berger, 2007). It is clear that existing literature advanced understanding of experience of pain management among formal caregivers in the clinical setting.

Compared to the large body of literature focused on formal caregivers in the clinical setting, very few studies have shed light on FCGs, and the studies were not necessarily conducted in the community setting. Eritz & Hadjistavropoulos (2009) reported that FCGs were either unable to recognize or ignored nonverbal cues when assessing pain for people with dementia due to lack of education or training on how to use observational tools in pain assessment. Li et al. (2015) also noted that modified pain scales for patients with impaired cognition were rarely used by FCGs. In addition, when comparison of pain ratings between FCGs and their care recipients were made, the finding suggested that FCGs assessed pain in concordance with their care recipients (Krulewitch et al., 2000; Murray, Sachs, Stocking, & Shega, 2012; Shega et al., 2004). Tarter et al. (2016) reported that FCGs felt lack of support from healthcare professionals in what to anticipate during the end of life care trajectory. This limited evidence failed to describe the experience of pain management and is unable to explain why pain management is a persistent problem among FCGs and their care recipients.

In order to resolve the problem, research focusing on exploring the experience of pain management among FCGs is necessary. The goals of the study included: 1) exploring experience of pain management among family caregivers; 2) identifying barriers for effective pain management; and, 3) identifying ways that help FCGs to improve their quality care for pain.

Theoretical Underpinning

The Social Communication Model of Pain ([SCMP], Craig, 2009) was employed as a framework for the study (see Appendix A). This model was originally developed to explore the role of social barriers that limit effective control of pain in infants and children. However, it has also been found useful in understanding pain assessment and care in adults with cognitive impairments (Craig, 2009). The model accepts that infants and children go from a time of full dependence on parents to recognize pain, through a period of partial ability to verbally indicate pain, to a point of having full agency in this regard. People with dementia go through the trajectory in the opposite direction, from having the ability to self-report pain, to eventually losing the ability. The SCMP model facilitates understanding in both cases.

A major novel feature is the inclusion of persons other than the suffering person in the model. The model specifies that pain is encoded by the patient (person in pain) and expressive behaviors from the patient are decoded by observers (caregivers). in order for pain communication expression to occur, caregivers must successfully accomplish the decoding (Craig, 2015; Eritz & Hadjistavropoulos, 2011). The process from encoding to decoding indicates how the observers assess pain depending, in part, upon patients' non-verbal expression of pain that is central to the FCGs ability to recognize pain in dementia patients.

The model integrates biological, psychological, and social perspectives at the level of interaction between the person in pain and their caregivers, with specific constructs related to non-verbal indicators that FCGs use as observers (Craig, 2009). Multiple factors could act as barriers or facilitators for the accurate pain assessment and consequently affect the pain management.

The model provides a broad framework for understanding of pain management and was used in the study reported here to develop an interview guide. For example, the SCMP provides a chronological process for pain management, from pain encoding → pain decoding → pain treatment. Therefore, the interview guide included questions to explore this process (See Appendix A). I anticipated eliciting information regarding the patient's response to pain (encoding) and the caregiver's observation to pain (decoding). So, a follow-up question explored the intervention the caregiver used. However, qualitative description is inductive and aims to explore an under-researched phenomenon; therefore, the semi-structured interview guide provided only loose guidance for the interview.

Methods

Design

Qualitative description (QD) was used to explore how family caregivers manage pain for their care recipients with dementia. Qualitative description is the method of choice for describing an unknown phenomena and minimizing inference bias (Sandelowski, 2000). Given the limited knowledge in family caregivers' experiences in pain management for their loved ones, this research method matches the needs for the study.

Sites and Sample

The sites for recruitment include the University of Virginia (UVA) Memory Aging Care Center (MACC), the Jefferson Area Board for Aging (JABA) Community Senior Center, Alzheimer's Association, and churches. In addition, social media and community events/health fairs were also the sites for recruitment.

Inclusion criteria included: 1) being age 18 or older; 2) being (or have been within the past 3 years) a caregiver for community-dwelling older adults with dementia who is (or had) experiencing pain; 3) providing (or provided) care at least 14 hours per week.; and, 4) an ability to comprehend and speak English. Family caregiver was defined as someone who provided at least 14 hours/week of care. This definition was based on the Family Caregiver Alliance (2015) data suggesting that this is the least average hours of care provided when caregivers are stratified into age groups (i.e., 15-24, etc.).

Recruitment and Sampling

A purposive sampling strategy was used. Participants were first recruited from UVA MACC. Clinicians made referrals. In order to expand the diversity of the sample, the researcher another site was added, the Jefferson Area Board for Aging (JABA) Community Senior Center. Direct referrals were received from JABA staff members. JABA also connected with Alzheimer's Association of Charlottesville to further increase sample size. Churches were included in sampling with either personal connections or through the snowball sampling where participants made referrals. Additionally, recruitment through community events/health fairs and social media were adopted to recruit participants.

Data Collection and Analysis

Potential participants were contacted by phone or email based on either the referral or recruitment source. During the initial contact, I explained the study and its purpose. Potential participants were also screened for eligibility at this time. Once eligibility was confirmed, either a face-to-face or a phone interview was scheduled. The place and/or time of the interviews were chosen by mutual agreement of the participant and myself. The only requirement was that the interview be conducted so as to preserve the participants confidentiality.

At the beginning of the interview, the study was described and informed consent was obtained using a teach-back approach (Sudore et al., 2006). This approach ensured that the participants understood the study and were able to consent. Next, participants filled out a demographic questionnaire that was developed for this study. The consent process and demographic survey were administered verbally to minimize possible issues related to low literacy.

The interview then commenced and was audio recorded. A semi-structured interview guide was used to explore the specific aims. The guide was initially developed based on the SCMP and extant literature, then modified and refined based on input from content and methods experts (gerontological nurses, clinical psychologists, experts in qualitative methods).

The field notes included the observations of the context for care, descriptions of the participants and their care recipients (e.g., affect, level of rapport, nonverbal communication, and notable interactions between participants and their care recipients; [Kools et al., 2002]).

Interviews were transcribed professionally and cross-checked against recordings for accuracy by me. Verified transcripts were uploaded into NVivo (Versin12) [QSR International], which assisted in managing, analyzing, and presenting qualitative data. This study was approved by University of Virginia Institutional Review Board-Social and Behavioral Science (IRB SBS #2228).

The analytic process was an iterative process with constant comparison (Corbin & Strauss, 2008). Initially, open coding was done to give higher-level meaning of the statement by labeling them. As coding proceeded, previous coded transcripts were evaluated and recoded. Then the codes were focused into concepts. Finally, themes emerged followed by generated concepts (Corbin & Strauss, 2008). Analytic memos were written throughout the analysis to capture the analytic process. The semi-structured guide was modified to reflect changes in the process (Emerson, Fretz, & Shaw, 1995).

As the study was a qualitative study, potential bias was possibly generated from researcher's personal caregiving experiences in the past. This form of positionality was mitigated through frequent interaction with multiple perspectives. To avoid potential bias, the researcher shared the coding and categorizing processes with experts in nursing, clinical psychology, community health, dementia, gerontology, and caregiving research, as well as experts in qualitative methods. The use of experts in the analytic process enhanced the scientific rigor. In addition, the researcher engaged in reflexivity to be aware of the possibility of existing bias. Reflexivity is an attitude of attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process (Barry et al., 2012).

Results

Twenty-five family caregivers were recruited and included in the analysis. In QD, the thematic saturation routinely occurs at the sample size of 30 (Guest, Bunce, & Johnson, 2006). However, in this study, thematic saturation was reached at the sample size of 25; that is, when no new or important themes emerged from the analysis (Ando, Cousins, & Young, 2014; Kools, 1997).

The participants ranged in age from 29 to 95, were predominantly white, female, and married, and had a minimum of a high school education. Most participants were adult children (52%) or the spouses (28%) of the care recipients (see Table 1). All the caregiving spouses were living with their care recipients and provided 24/7 care. However, not all the caregiving adult children lived with their parents (72%) and the other 28% provided some hours of the care each week. This fact is consistent with the existing evidence that caregiving spouses are more likely to live with the care recipient and tend to provide more hours of care than caregiving adult children (Tennstedt, Crawford, & McKinlay, 1993). However, there were no differences associated with pain management performance.

Of the 25 participants, four did not play the caregiver's roles at the time of interviews because their care recipients had died in the three years prior to the interviews. Three of the four deceased recipients lived alone (either in their homes or independent living housing) and one lived with her caregiver while they were alive. All of the four deceased care recipients were transferred to an assistant living facility in the three months prior to their deaths (See table 2). The purpose of including the participants with deceased care recipients was to include as many caregivers who were interested in the study, due to low number of accruals of participants.

Of the 21 participants who were caregivers at the time of interviews, most of them lived with the care recipients and provide 24/7 cares. Only four out of 21 participants' care recipients lived alone in their own homes, but the participants provided more than 14 hours care per week (See table 1).

Most of the interviews (18 out of 25 interviews) were conducted face-to-face. Seven interviews were conducted by phone. Individual interviews varied in length (ranged from 20 minutes to 60 minutes, average 36 minutes), depending on how forthcoming and comfortable the participant was during the interview. Along with the face-to-face interviews, field observations were conducted during the interview, and field notes were written immediately following the interviews.

Three themes emerged around exploring how FCGs manage pain for their loved ones. These themes included: 1) Values, 2) Barriers, and 3) Support. Values indicate the caregivers' personal beliefs that influence decisions in pain management. Barriers are obstacles for achieving effective pain management. Support included means that would help with FCGs in improving pain management.

Theme 1: Values.

Family caregivers hold diverse values in their experiences of pain management and demonstrated values-based decision making in pain management. These values included goals for pain management, views towards opioids, and views towards alternative medicine. The goal for pain management is the FCGs' perception of the outcomes for pain relief and their loved ones' ability to perform routine activities. The expected outcomes for pain relief would directly or indirectly impact FCGs' decisions in choosing pain medication. Views towards opioids and alternative medicine influenced FCGs' decision in whether or not these types of medications would be considered. In turn, the decisions for selection of pain medication would affect the outcomes of pain relief.

Goals for pain management. Family caregivers' perception of the outcome for pain relief drove their actions in pain management. A participant thought maintaining the comfort level to enable routine activities is their goal for pain management, "*The goal for pain management I think is maintaining comfort, not necessarily being pain-free, but managing your pain in a way that you can still maintain your daily life, do things you like to do, continuing doing the activities that you enjoy.*" She emphasized the priority for her loved one was the quality of life.

Another participant added, "*I see it in terms of quality of life. I see it in terms of her being able to be involved and engaged in things at the level that she wants to, so in the sense of, you know, she wants to be up and going for a walk and, you know, driving. Like we have to drive for a couple of hours to go see a family member, you know, if she was in too much pain to not - like if she couldn't do the things that she was wanting to do then that' s part - I see more the functional things or in terms of quality of life, so if the pain is interfering with her doing something she would enjoy or want to do then that' s when it would seem like, you know. I don't see it necessarily as pain zero. I see it as being able to engage in the things you enjoy and enjoy them."* This caregiver's goal for pain management was that her loved one was able to do what he enjoyed or wanted to do.

One participant even gave a reason why she did not expect her care recipient to be pain-free, saying, "*I don't know if there's anything, like when you reach a certain age about being pain-free without being depending on, you know, something really strong, some strong narcotic but there' s a level of comfort where, you know, you can reach where it' s okay, you know. My back hurts but it's not killing me."* It was clear that the participant was making judgements about what constitutes expected outcomes for pain management, which is undergirded by their personal opinions and values.

Views towards stronger pain medication. During the interviews, participants often had no concerns about the pain medications that were commonly used, such as Acetaminophen or Ibuprofen that are considered as non-opioid medication. However, many participants showed concerns regarding the use of opioids or narcotics. This type of medication also could be called by participants as stronger pain medications. When caregivers focused on the quality of life – where the priority for the patient is comfort, they tended to administer stronger pain meds with less concern for side effects: "*If she was really hurting I would hope that the medical field would give her something to manage the pain, period. That would be it.*" This attitude was especially supported by caregivers who took care of the patient when under hospice care or at the end-of-life care stage. "*I don't want her to be in pain, and everybody I talked to I said, 'My priority for her is no pain. She's [85] and going to die and I don't want her to be afraid and I don't want her to be in pain.' So I know she has sensitivity to narcotic painkillers. I don't care.*" This participant may not care if her care recipient died addicted to the pain medication and this view reflects the value of quality of life.

However, the opposite view towards stronger medications from caregivers also exists. Caregivers' perception of opioids as addictive or harmful influenced some caregiver's willingness to use these drugs, making them less likely to give the stronger pain medication to loved ones. One participant said, *"…if you give him that pain medicine[opioids], if I give it to him he would take it and if it makes him feel good he will want more, and I'm not gonna give it to him, like it' s best not to start. Like when his pain gets so bad that we can't control it I take him to his family doctor. We'll go to our family doctor, our primary care doctor and because I don't believe in taking that strong* *medicine .....”* We can see the caregiver’s personal belief towards stronger pain medications drove her actions in pain management.

There were participants who stood in the middle: they would give stronger pain medications if it were necessary. For example, “*I guess it depends on the day because some days she seems to be in more pain than others, but if I was managing it and it seemed to be a really bad day then I would probably try to help by treating her [with opioid] before the pain really started coming back....”* Evidently, the varieties of views towards stronger pain medications are personal beliefs and values that drove the decision in pain management.

Views towards alternative methods. Some of the participants thought the alternative medicine was not useful. One participant integrated her own experience with alternative medicine to form the personal belief regarding this type of medicine, *“I have back issues myself and my thought is if I go there they're gonna mess me up worse than what I am so I know I don't want them to work on him. I don't know, it might be better, I don't know but no, I have not given it any thought.”* Some of the participants had their personal preferences for alternative medicine, either from their previous experiences or from the care recipients’ condition. Another participant said, *“Because it was just like somebody having an ache or a pain somewhere and we never thought about that (alternative methods), you know, it was just a really minor pain. And I don't know, she wouldn't have taken to the ice, that's for darn sure. Momma was at the end, towards the end she was a cold natured person.”* Personal values influence the caregivers to take different approaches in pain management.

In this theme, family caregivers considered quality of life for their loved ones.

While adherent to this value, family caregivers intended to use stronger pain medication, such as opioids, to keep a high quality of life for their loved ones. However, opposite views towards opioids were also noticed. These FCGs were worried about the addiction effect or other side effects caused by opioids. Moreover, some FCGs had a neutral view towards stronger pain medication – stronger pain medication would be given only if it were necessary. Family caregivers also realized that instead of being pain-free, maintaining a comfort level was a more realistic goal for their loved ones in pain management.

Theme 2: Barriers

Managing pain for people with dementia is challenging. Family caregivers often encountered obstacles to achieving effective pain management. Older adults with dementia often have more than one health problem. Having multiple health issues increased the complexity of care. Therefore, comorbidity and complexity of care were the key barriers for a high quality of pain management. Further, due to the comorbidity and complexity of care, family caregivers were expected to have higher level of skills and knowledge to do their caregiver roles. Adequate knowledge was also needed for the care. Lack of assessment skills, lack of formal resources, and lack of expertise in using existing resources were additional identified barriers in pain management.

Comorbidity. Older adults with dementia often had multiple health issues that influence the selection of pain medication, further leading to limited options for pain management. Many times, the doctor had to change the pain medication due to new medical issues. For example, one participant said, *"She [my mom] had a stroke this spring and they put her on blood thinners and had to take her off of her NSAID* *medications for pain management."* Then, the participant had to use a new pain medication to treat her mom's pain and she needed to evaluate the effectiveness of the new medication. Another example indicated that the participant was concerned about interactions between the stronger pain medication the pre-existing health problems, "*And part of it has to do with we want to avoid getting addicted and also - and I'm the same way, I would rather work through the pain or use a milder form because we get gastrointestinal disturbances too and it just makes us all cloudy and we don't like that feeling. I think part of that is because you lose control and both of us are control people...(both laugh)*"

Complexity of care. As the nature of dementia, patients either could not express pain or could report pain but not effectively or accurately. Given this fact, family caregivers could get confused when they received report of pain from their loved ones. For example, "*They know there's pain but just couldn't, like you said, they point to the stomach but she said it's a headache…*" The patient was able to report the pain, but expressed in a wrong way. Another participant reported, "*He told my mom he had pain between his toes, but then when I looked and investigated and I moved all the toes, there was nothing so you know, that' s a tough one to figure out so we'll probably have to visit that again this evening or tomorrow*." In this case, there was an expression of pain but no actual pain or didn't know where pain was. Evidently, the caregivers could not rely on the self-report from the recipients and needed further assessment for the pain.

Lack of pain assessment skills. Because of the comorbidity and complexity of care, family caregivers need adequate skills and knowledge in pain assessment and management. However, unlike formal caregivers, using valid tools for pain assessment, family caregivers did not use an appropriate pain assessment tool. For example, one participant said, "*I don't do that [not using pain scales]. I just ask him how he' s doing*." Many caregivers reported that they were not sure if their assessment for pain was accurate when the care recipient was unable to report pain or an inconsistency appeared between the recipient's self-report of pain and the caregiver's observation for pain. Another participant said, "*Yeah, he always say he's in pain but I don't know that he's always in pain." Another participant said, "Probably more behavioral than pain to be honest, but it was hard to tell. At the end, he did look like he was uncomfortable."* Obviously, this caregiver could not tell if the care recipient was in pain or whether there were behavioral problems due to the dementia.

In addition, caregivers found that follow-up assessments were challenging due to care recipients' forgetfulness. "*If you ask her one day, 'Are you in pain?' and she said 'Yes' ….and the next day you say, 'How is your pain?' and she'll say, 'I'm not in pain. What pain?' She may not remember. She might have been in pain the day before. So trying to track anything was almost impossible. You couldn't piece it together*." This participant was unable to determine if her pain management strategies were effective. Overall, caregivers experienced challenges in pain assessment and management due to lack of assessment skills and knowledge on medication.

Lack of formal resources. Lack of resources was an important barrier for family caregivers. One participant reported, "*Well, I mean we went to see a rheumatologist and he actually cancelled her last appointment because he said that he had exhausted all of his options*." This patient has problems with Rheumatoid arthritis, but the caregiver didn't get adequate support from healthcare provider because the rheumatologist ran out of options for the treatment.

Lack of expertise in using existing resources. Rather than lack of resources, participants reported that they were unable to use the existing resources because the level of knowledge is too high that required greater level of education to utilize the resources. One participant said, "*For me I think the biggest barrier has been access to resources or feeling like you almost have to be a professional in the game to understand what you qualify for and what you don't.*" She addressed the big issue is that you do not know how to use the resources around you. Caregivers many times won't administer stronger pain meds because they were concerned about the side effects, such as falls or delirium. For example, "*I don't want him to have anything that's cause him to stumble and fall. He already has problems sometimes walking so if you give him something stronger it could have him sleep, could have him get off as far as the way he's walking so no, I don't want to give him anything stronger than that.*" Obviously, the caregiver had the opioid medication on hands, but she didn't know how to take care of the side effects and balance the benefit and the risk of opioids.

Comorbidity and complexity of care were barriers from patients' perspective. These two factors directly increased demanding on high-level of skills and adequate knowledge to perform pain management. Lack of assessment skills, lack of formal resources, and lack of expertise in using existing resources were barriers from the FCGs' perspective. These five barriers intensified the difficulties for a better outcomes of pain management.

Theme 3. Support

Support includes means that would help with family caregivers in improving pain management. The support could be available from external resources or internal (family caregivers). Three subthemes indicated two types of support: support from professionals such as doctors, social workers, and family members are the external support; family caregivers developed strategies to support themselves to sense of accomplishment in pain management. These strategies also can be helpful for professionals to deliver efficient and better care for the patients. These strategies are internal resources that include self-efficacy and adaptation.

External support from professionals. When people with dementia live in the community settings, the primary doctor is the main resource for the patient to seek medical advice, treatment, and referral. With adequate support for the primary doctors, family caregivers would feel more comfortable to provide pain management. Other professionals such as social services also can be supportive. One participant said*, "A thing that has really helped is to be able to email when I have concerns. They do respond very quickly so that's why I don't have any issues, but encourage people to email their doctors or their nurse practitioner or their social worker when an issue comes up because they can help. If they can't fix the problem, at least they can alleviate the stress that you're having by answering some questions or for me, I always thank them just for listening cause that helps more than anything in the world. They can't fix it but by listening it helps the caregiver. The sympathetic and the empathetic."* From this case, we can see how the professionals, not just healthcare providers, but also including other professionals, such as social services in the community, supported the caregiver by communicate with them or respond to them quicker.

Caregivers also mentioned that if the family member worked in the medical field, it was very helpful for the task of pain management. Another participant said, "*You see, the thing is it was helpful, it was very helpful that I was a medical person, you know, that I was in healthcare because I could see that and I could see, okay, we need to go back to the other dose whereas like someone who wasn't in healthcare might not realize that' s what caused his paranoia. …So I knew I could adjust it [the dosage of pain meds] cause like I said, well, my husband was the one who prescribed it [pain meds] so it was no problem. And we would discuss, you know, 'Okay, what should we do here?' That's why we never upped it in the beginning because we didn't want to mess up his kidneys any more than they already were."* This participant was also confident in pain assessment and management due to training received from medical school. However, not all FCGs had adequate external resources. Lack of formal resources is an identified barrier mentioned in theme two.

Self-efficacy. Though encountering barriers in pain management, FCGs perceived confidence to do a better care of pain by engaging in learning, utilizing resources, and seeking external help. One participant said *"I'm always looking at what's new - new trials they're doing, new meds, or whatever, to try to stay as abreast on this as I can."* "*Just my own personal research. Web MD, I always look on there and see what's new."* Another participant said, "*I've reached out to a lot of those places…whatever the study is they're doing at the memory clinic seemed really helpful, also having the hotline number …has made a big difference, like there's been a couple times where I've had really, really bad days and having a hotline number just to call and speak to somebody has made a huge difference."* This participant used the hotline as a useful resource to reduce her stress level and boost a positive mood, which can create a belief in self-efficacy. Building self-efficacy contributes to the belief in her capabilities to achieve a goal in caregiving, such as effective pain management.

Adaptation. Adaptation is one strategy developed by FCGs during their long-hour of caregiving. The long-hour of care allowed FCGs to know patients better, which helped FCGs to recognize the changes or problems quicker. *"Then on the other flip side if they're not able to articulate their pain and you can't read their body motion, then maybe they could suffer by not having something. It's a tough call. If you know the person, like you do 24-7, it helps to…."* In addition, by providing long hours of care, FCGs were able to record the change and trace the pain. One participant said, "*Making notes takes the burden off of having to memorize it and sometimes we take those notebooks to doctor's appointments so when they say, 'Well, when did this start?' Or, 'How many times did this happen?' Or, 'What was her blood sugar trend while she was having pain? Is she having more pain when she's having higher sugars?' All those things."* By sharing the note with the doctor, it was easier for doctor to develop an effective care plan for the patient. By using self-efficacy and adaptation strategies, family caregivers believed that they could do a better job for care of pain.

Overall, theme one, values, explained that FCGs' personal views that strongly influenced FCGs decision-making in pain management. Theme two, barriers, were the obstacles for effective pain management. Theme three, support, are the key features that can assist FCGs in improving quality of pain management. Three themes work together to provide a deep understanding of experiences in pain management among family caregivers. Each of the themes included several subthemes.

Discussion

This study explored the experiences of pain management among family caregivers for their loved ones with dementia living in the community setting. Three themes including values, barriers, and support were developed as key aspects to describe how FCGs manage pain for their loved ones. The family caregivers' values toward goals in pain management, opioids, and alternative medicine strongly influenced their decisions in pain management. Significant barriers for effective pain management were identified including comorbidity, complexity of care, lack of pain assessment skills, lack of formal resources, and lack of expertise in using existing resources. Finally, the study findings also revealed ways to assist FCGs in pain management. These means included external support from professional and internal elements such as self-efficacy and adaptation.

This research is the first study that provided a deep understanding of experiences of pain management among FCGs in the community setting. New knowledge related to FCGs' experiences in pain management was obtained. Existing literature has shown that clinician's' personal values are important factors that affect decision-making in pain management (Zwakhalen, Hamers, & Berger, 2007). The findings of the study reported here are consistent with the report by Zwakhalen and others. The current study suggests that FCGs performed values-based decision-making in pain management. Family caregivers value quality of life more than quantity of life. With respect to this value, family caregivers tend to administer pain medication to keep their loved one comfortable. This value reflects their personal views towards opioids, that is, FCGs do not care about the side effects or the risk of addiction in order to maintain the comfort level for their loved ones. However, family caregivers also acknowledged that it was nearly impossible for their loved ones to be pain-free. Their goal for pain relief was being able to maintain routine functions. While balancing the quality of life and being realistic in pain relief, family caregivers made decisions to manage pain. These FCGs often held a neutral view towards opioids. They would give opioids to their loved ones if it were necessary.

Furthermore, it was noted that an opposite view towards stronger pain medications also existed among family caregivers. Some FCGs do not want to give opioids to patients because they do not trust opioids due the harm from side effects or the risk of addiction. When family caregivers fear addiction or the side effects from opioids, they are less like to administer stronger pain medication. Potentially, this approach can compromise pain treatment (Ballard et al., 2011; Briesacher et al., 2005). This finding is consistent with research reported by Corbett and colleagues (2013) that older adults persons with dementia received low dosage pain medication and stronger pain medication such as opioids were less frequently prescribed for elderly dementia patients than for their cognitively healthy counterparts. It is clear that divergent views towards opioids among FCGs lead to different outcomes of pain management.

In the study reported here, several barriers were identified. The presence of barriers helped to explain why FCGs had persistent issues in pain management. Older adults with dementia often live with three or more health problems (Caughey et al., 2008). Multiple comorbidities can contribute to the complexity of care, including care for pain (Zulman et al., 2014). With respect to comorbidity and complexity of care, family caregivers may be required to have adequate skills in pain management. However, the findings suggested that FCGs lack skills in pain assessment and lack formal resources. When performing pain assessment, FCGs mainly relied on their own judgement. They did not use valid pain assessment tools because the tools were not available; or they had never been trained to use tools that were available in clinical settings. Family caregivers in the current study also reported that they did not receive adequate support from doctors. These findings were similar to those of other researchers, who noted that FCGs lacked training on use of observational tools (Eritz & Hadjistavropoulos, 2009); modified pain scales were rarely used by FCGs (Li et al., 2015); family caregivers felt lack of support from healthcare professionals when anticipating the end of life care (Tarter et al., 2016).

One of the most significant finding is that FCGs developed strategies in assisting with a better outcome for pain management. The strategies include self-efficacy and adaptation. Self-efficacy is a factor that reflects how people feel, think, and behave in response to situational demands. It represents a FCG's knowledge and preparedness in managing the challenges of care (Bandura, 1997; Merrilees et al., 2020). An early study has attested that FCGs' self-efficacy showed benefits of improved quality of care for dementia patients (Merrilees et al., 2020). In this study, FCGs were actively engaging in learning, utilizing resources, and seeking training opportunities. Education, training, learning, and interventions that target on FCGs' negative emotions have been associated with improvement in self-efficacy (Samia et al., 2018; Tang & Chan, 2016).

Adaptation is the other strategy utilized by FCGs in helping with pain management. Family caregivers often provide long-hours of cares (as many as 40 hours per week) (FCA, 2015). During the long-hours of care, FCGs received tremendous information from the patients, including the changes in pain condition. In order to "*takes the burden off of having to memorize it*" (from one participant's quote), this participant made a note to record the information. Taking note is the mechanism that the FCG used to adapt to the situation. This family caregiver also took this note to the doctor to help with answering all types of questions regarding the patient's health history. This note helped healthcare providers to develop a pain management plan that fits patient's needs. Adaptation is a useful strategy in decreasing caregiving burden (Perren, Schmid, & Wettstein, 2007).

Existing research has shown that non-pharmacological interventions and alternative methods were underused in the clinical setting for pain treatment among dementia patients (Li et al., 2015). The current study findings confirmed this report in that family caregivers do not know much about alternative methods for pain treatment. Some of them think alternative methods are not useful, especially for patients who are at the end of the life. Some FCGs were concerned that their loved ones with dementia are unable to follow the instruction of the meditation exercise. In addition, healthcare providers often do not mention alternative methods for their patients with dementia.

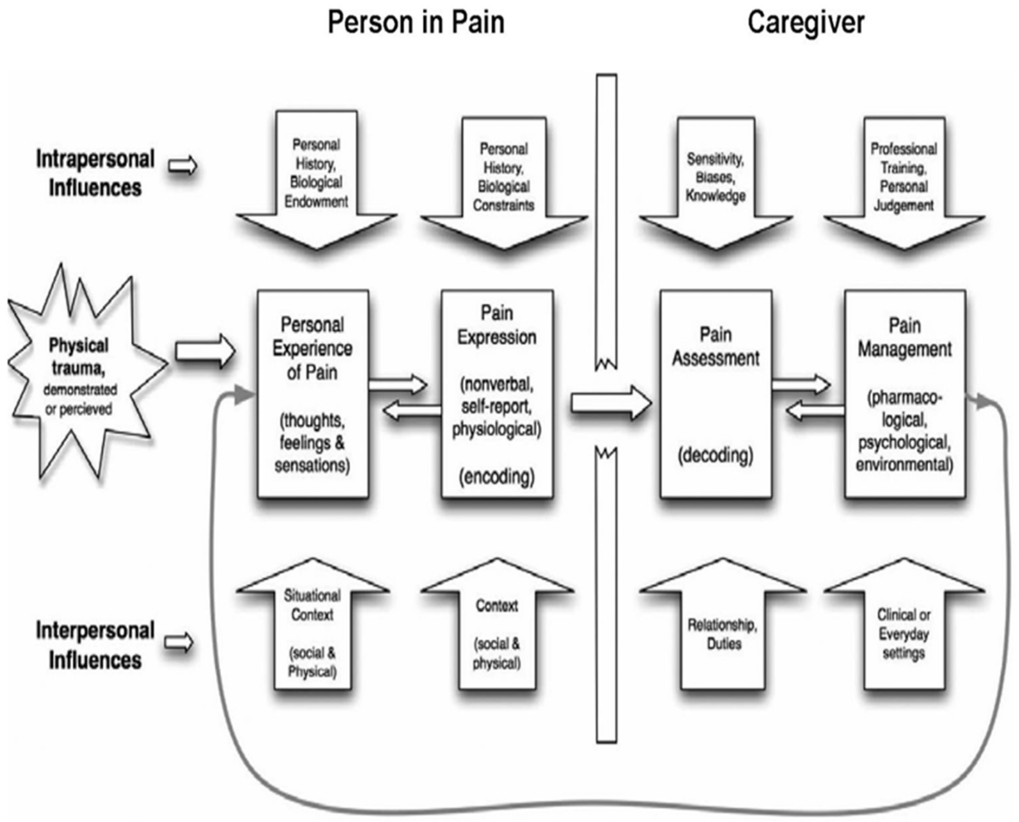
Alongside this study, implications were established. First, the finding of barriers highlights the importance of implementing educational and training programs for family caregivers. It further indicates the necessity in policy-making to support FCGs by providing guidance and protocols in pain management and opioid use in the community setting. Second, innovation methods for pain assessment should be considered due to the challenges in pain assessment. Portable devices for monitoring pain will be beneficial for FCGs who have difficulties in assessing pain. Third, literature recommended that an effective pain treatment plan should include both pharmacological and non-pharmacological method (Hunt et al., 2015; Martin et al., 2005). Therefore, the future research and interventions for pain management should include the two components of pain medicine. Fourth, researchers should develop a module to guide the research of pain management for people with dementia. Finally, my study employed the Social Communication Model of Pain (Craig, 2009) as the theoretic underpinning to provide guidance for the study. This framework was originally designed for assessing pain in infants and children. However, it is also useful in understanding pain assessment and pain management in adults with dementia. A major novel feature of this model is the inclusion of persons other than the suffering person in the model. The model integrates biological, psychological, and social perspectives at the level of interaction between the person in pain and the observers (Craig, 2009). A chronological process for pain management, from pain encoding → pain decoding → pain treatment was provided. These elements in this model ensured the needs of FCGs in pain management for people with dementia. Though the fit was testified, a specific theoretical framework of pain management for people with dementia should be developed to address all the unique aspects in dementia population.

Although this study was the first one to explore pain with this population, there are some limitations that should be considered. First, dementia is a progressive disease involving changes in patients' behavior, cognition, and function. The ability to express pain changes as the person's dementia progresses. Pain management along with dementia care should be continuously monitored to assess changes (Perren et al., 2007). However, questions in terms of how things change overtime were not asked. Little is known about how family caregivers handle this change in dementia progression when managing pain. Future longitudinal research addressing the change and progress should be conducted. Second, since family caregivers experienced high level of challenges in pain management, their level of depression and stress need to be assessed because mental health status affects the ability to provide care. Third, despite recruitment efforts, the study sample was homogeneous in gender, dominantly by female. Whether gender differences in pain management experiences exist is not clear. According to a study by Sharma, Chakrabart and Grover (2016), the majority of caregivers, 81%, are women. Finally, the study sample had variability in living arrangements, hours of care, and the types of family caregivers in relationship with care recipients. However, questions reflecting on the specific features were not asked. Therefore, how these variables influence pain management were not revealed.

Conclusion

This study is the first qualitative descriptive approach to explore how family caregivers manage pain for their loved ones living in the community settings. The findings provided a deep understanding of pain management experience among family caregivers, offered some explanation why FCGs experience persistent problems in pain management, and revealed ways to support family caregivers. The knowledge and understanding gained from this study will contribute to the future research and practice to improve outcome of pain management and ultimately advance the quality of life for both family caregivers and their loved ones with dementia.

Appendix A: The Social Communication Model of Pain (Craig, 2009)



Appendix B

Table 1. Characteristics of Participants

Characteristics	Participants N=25	Percentage
Age (Years)		
Range	29-95	
Median	63	
Gender		
Male	1	4
Female	24	96
Education		
Not complete High School	1	4
High School	8	32
Vocational School after High School	1	4
Some college/Associate Degree	5	20
Bachelor Degree	3	12
Graduate School	7	28
Relationship to Recipients		
Children	13	52
Spouse	7	28
Friends	3	12
Parent	1	4
Other (Sister-in-Law)	1	4
Race		
White	15	60
African American	9	36
Other Pacific Island	1	4
Marital Status		
Not currently Married	8	32
Married	17	68
Annual Income		
$10,000-$19,000	6	24
$20,000-$29,000	5	20
>$30,000	10	40
Declined	4	16
Employment		
Not Employee/Self-employee	3	12
Part-time	4	16
Full-time	7	28
Retired	11	44
Care of Hours		
24/7	18	72

>14 hrs	7	28
Not in Caregiving Role at Time of Interview	4	16

Table 2: Characteristic of Care Recipients

Characteristics	Care Recipients	Percentage
Living arrangement		
Living with caregivers	18	72
Living alone at home	5	20
Living in independent/retirement housing	2	8
Transferred to Assistant Living at the end of life	4	16
Deceased at the Time of Interviews	4	16

References

Achterberg, W. P., Pieper, M. P., Dalen-Kok, A. H., Waal, M. W. M., Husebo, B. S., Lauenbacher, S….Corbett, A. (2013). Pain management in patients with dementia. *Clinical Interview of Aging, 8*, 1471-1482.

Alzheimer's Association, (2017). Alzheimer's disease facts and figures. Retrieved from http://www.alz.org/facts/

Ando, H., Cousins, R., & Young, C. (2014). Achieving saturation in thematic analysis: Development and refinement of a codebook. *Comprehensive Psychology, 3*(4).

Andrew, J. S., Cenzer, I. S., Yelin, E., Covinsky, K. E. (2013). Pain as a risk factor for disability or death. *J Am Geriatric Soc, 61*, 583-589.

Ballard, C., Smith, J., Husebo, B., Aarsland, D., Corbett, A. (2011). The role of pain treatment in managing the behavioural and psychological symptoms of dementia (BPSD). *Int J Palliat Nurs.,17*(9), 420–422.

Bandura, A. (1997). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review, 84*(2), 191.

Barry, H. E., Parsons, C., Passmore, A. P., & Hughes, C. M. (2012). An exploration of nursing home managers' knowledge of and attitudes towards the management of pain in residents with dementia. *International Journal of Geriatric Psychiatry, 27*(12), 1258-1266.

Barry, H. E., Parsons, C., Passmore, A. P., & Hughes, C. M. (2015). Pain in care home residents with dementia: an exploration of frequency, prescribing and relatives' perspectives. *International Journal of Geriatric Psychiatry, 30*(1), 55-63.

Benedetti, F., Arduino, C., Vighetti, S., Asteggiano, G., Tarenzi, L., Rainero, I. (2004). Pain reactivity in Alzheimer patients with different degrees of cognitive impairment and brain electrical activity deterioration. *Pain, 111*,22-29.

Bernabei, R., Gambassi, G., Lapane, K., Landi, F., Gatsonis, C., Dunlop, R., … Mor, V. (1998). Management of pain in elderly patients with cancer: SAGE Study Group: Systematic Assessment of Geriatric Drug Use via Epidemiology. *JAMA, 279*, 1877-1882.

Bosley, B. N., Weiner, D. K., Rudy, T. E., Granieri, E. (2004). Is chronic nonmalignant pain associated with decreased appetite in older adults? Preliminary evidence. *J Am Geriatr Soc 52*, 247-251.

Briesacher, B. A., Limcangco, L. S-W, Doshi, J. A., Levens, S. R., Shea, D. G., & Stuart, B. (2005). The quality of antipsychotic drug prescribing in nursing homes. *Arch Intern Med., 165*(11), 1280-1285.

Brodaty, H. & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues of Clinical Neuroscience, 11*(2), 217-228.

Buffum, M. D. & Haberfelde, M. (2007). Moving to new settings: Pilot study of families' perceptions of professional caregivers' pain management in persons with dementia. *Journal of Rehabilitation Research and Development, 44*(2), 295-303.

Burge, E., Kuhne, N., Berchtold, A., Maupetit, C., & Gunten, A. (2012). Impact of physical activities on activity of daily living in moderate to severe dementia: A critical review. *European Rev Aging Act, 9*(1), 27-39.

Burns,M. & McIlfatrick, S. (2015). Nurses' knowledge and attitudes towards pain assessment for people with dementia in a nursing home setting. *International Journal of Palliative Nurses, 21*(10), 479-487.

Caughey, G. E., Vitry, A., Gilbert, A. G., & Roughead, E. E. (2008). Prevalence of comorbidity of chronic diseases in Australia. *BMC Public Health*, *8*, 221–234.

Cipher, D. J., Clifford, P. A., Roper, K. D. (2006). Behavioral manifestations of pain in the demented elderly. *J Am Med Dir Assoc*, *7*, 355-365.

Chow, S., Chow, R., Lam, M., Rowbottom, L., Hollenberg, D., Friesen, E….Herrmann, N. (2016). Pain assessment tools for older adults with dementia in long-term care facilities: A systematic review. *Neurodegenerative Disease Management, 6*(6). doi:10.2217/nmt-2016-0033

Corbett, A., Husebo, B., Malcangio, M., Staniland, A., Cohen-Mansfield, J., Aarsland, D., & Ballard, C. (2013). Assessment and treatment of pain in people with dementia. *Nat Rev Neurol. 8*(5), 264–274.

Corbett, A., Achterberg, B. H., Husebo, B., Lobbezoo, F., DeVet, H., Kunz, M........ Lautenbacher, S. (2014). A international road map to improve pain assessment in people with impaired coggition: the development of the Pain Assessement in Impaired Cognition (PAIC) meta-tool. *BMC Neurology, 14*, 229.

Corbin, J, Strauss, A. L.(2008). *Basics of qualitative research: techniques and procedures for developing grounded theory.* 3rd ed. Thousand Oaks, CA: Sage.

Covinsky, K. E., Lindquist, K., Dunlop, D. D., Yelin, E. (2009). Pain, functional limitations, and aging. *J Am Geriatric Soc 57*, 1556-1561.

Craig, K. D. (2009). The social communication model of pain. *Canadian Psychology, 50*(1), 22-32. doi:10.1037/a0014772

Craig, K. D. (2015). Social communication model of pain. *Pain, 156*(7), 1198-1199. doi: 10.1097/j.pain.0000000000000185

Emerson, R., Fretz, R., Shaw, L. (1995). Writing ethnographic fieldnotes. Chicago: The University of Chicago Press.

Eritz, H. & Hadjistavropoulos, T. (2011). Do informal caregivers consider nonverbal behavior when they assess pain in people with severe dementia? *Journal of Pain, 12*(3), 331-339.

Family Caregiver Alliance, (2015). Caregiver Statistics: Demographics. Retrieved from https://www.caregiver.org/caregiver-statistics-demographics

Foley, D., Ancoli-Israel, S., Britz, P., & Walsh, J. (2004). Sleep disturbances and chronic disease in older adults: results of the 2003 National Sleep Foundation Sleep in America Survey. *J Psychosom Res 56*, 497-502.

Fry, M., Chenoweth, L., & Arendts, G. (2016). Assessment and management of acute pain in the older person with cognitive impairment: A qualitative study. *Int Emerg Nurs., 24* (54-60). doi: 10.1016/j.ienj.2015.06.003.

Fuchs-Lacelle, S., Hadjistavropoulos, T., & Lix, L. (2008). Pain assessment as intervention - A study of older adults with severe dementia. *Clinical Journal of Pain, 24*(8), 697-707.

Guest, G., Bunce, A., Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods,18*, 59–82.

Hebert, L. E., Scherr, P. A., Bienias, J. L., Bennett, D. A., & Evans, D. A. (2003). Alzheimer disease in the US population: Prevalence estimates using the 2000 census. *Archives of Neurology, 60*(8), 1119–1122. doi:10.1001/archneur.60.8.1119

Hunt, L., Covinsky, K., Yaffe, K., Stephens, C., Miao, Y., Boscardin, W. J., & Smith, A. K. (2017). Pain in community-dwelling older adults with dementia: Results from the National Health and Aging Trends Study. *J Am Geriatr Soc. 63*(8), 1503-1511.

Jansen, B. D. W. K., Brazil, P., Passmore, H., Buchanan, D., Maxwell, SJ., McIlfactrick, SM., ……, Parsons, C. (2017a). Nurses' experiences of pain management for people with advanced dementia approaching the end of life: a qualitative study. J *Clin Nurs.26* (9-10),1234-1244. doi: 10.1111/jocn.13442.

Jansen, B. D. W. K., Brazil, P., Passmore, H., Buchanan, D., Maxwell, SJ., McIlfactrick, SM., ……, Parsons, C. (2017b). 'There's a Catch-22' - The complexities of pain management for people with advanced dementia nearing the end of life: A qualitative exploration of physicians' perspectives. *Palliat Med., 31*(8),734-742. doi: 10.1177/0269216316673549.

Jones, S. L., Hadjistavropoulos, H. D., Janzen, J. A., & Hadjistavropoulos, T., (2011). The relation of pain and caregiver burden in informal older adult caregivers. *Pain Medicine, 12*(1), 51-58.

Kools, S., Tong, E., Hughes, R., Jayne, R., Scheibly, K., Laughlin, J., & Gilliss, C. L. (2002). Hospital experiences of young adults with congenital heart disease:

divergence in expectations and dissonance in care. *American Journal of Critical Care, 11*(2), 115-127.

Krulewitch, H., London, M., Skakel, V., Lundstedt, G., Thomason, H., & Brummel-Smith, K. (2000). Assessment of pain in cognitively impaired older adults: a comparison of pain assessment tools and their use by nonprofessional caregivers. *Journal of the American Geriatrics Society, 48*(12), 1607 –1611.

Lethin, C., Hallberg, I. R., Karlsson, S. K., & Janlov, A. C. (2015). Family caregivers experiences of formal care when caring for persons with dementia through the process of the disease. *Scandinavian Journal of Caring Sciences*, *30*(3), 526-534. doi:10.1111/scs.12275.

Li, J., Snow, A. L., Wilson, N., Stanley, M. A., Morgan, R. O., Sanbhada, S., & Kunik, M. E., (2015). The Quality of Pain Treatment in Community-Dwelling Persons with Dementia. *Dementia and Geriatric Cognitive Disorders Extra, 5*(3), 470-481.

Lichtner, V., Dowding, D., Allcock, N., Keady, J., Sampson, E. L., Briggs, M…..Closs, S. J. (2016). The assessment and management of pain in patients with dementia in hospital settings: A multi-case exploratory study from a decision making perspective. *BMC Health Services Research, 16*(427), 1-15.

Martin, R., Williams, J., Hadjistavropoulos, T., Hadjistavropoulos, H. D., & MacLean, M. (2005).A qualitative investigation of seniors' and caregivers' views on pain assessment and management. *Can J Nurs Res., 37*(2),142-64.

McCarberg, B. H., Nicholson, B. D., Todd, K. H., Palmer, T., Penles, L.(2008), The impact of pain on quality of life and the unmet needs of pain management: Results from pain suffers and physicians participating in an internet survey.

Merrilees, J. J., Bernstein, A., Dulaney, S., Heunis, J., Walker, R., Rah, E……Possin, K. L. (2020). The care ecosystem: Promoting self-efficacy among dementia family caregivers. *Dementia (London), 19*(6), 1955-1973.

Morrison, R. S. & Siu, A. L. (2000). A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture. *Journal of Pain Symptom Management, 19*, 240-248.

Murray, T., Sachs, G., Stocking, C., & Shega, J. (2012). The symptoms experience of community-dwelling persons with dementia: Self and caregiver report and comparison with standardized symptoms assessment measures. *American Journal of Geriatric Psychiatry, 20*(4), 298-305.

Nahin, R. L., (2015). Estimates of Pain Prevalence and Severity in Adults: United States, 2012. *Journal of Pain, 16*(8), 769-780.

National Pharmaceutical Council & Joint Commission on Accreditation of Healthcare Organizations (JCAHO) (2001). *Pain: Current understanding of assessment, management, and treatment.* Retrieved from http://www.npcnow.org/system/files/research/download/Pain-Current-Understanding-of-Assessment-Management-and-Treatments.pdf

NVivo (Version 12) [QSR International]. Boston, United States.

Nygaard, H. A. & Jarland, M. (2005). Are nursing home patients with dementia diagnosis at increased risk for inadequate pain treatment? *International Journal of Geriatric Psychiatry, 20* (8), 730-737.

Perren, S., Schmid, R., & Wettstein, A. (2007). Caregivers' adaptation to change: The impact of increasing impairment of persons suffering from dementia on their caregivers' subjective well-being. *Aging & Mental Health, 10*(5), 539-548.

Pinzon, D. F., Claus, M., Perrar, K. M., Zepf, K. I., Letzel, S., & Weber, M. (2013). Dying with dementia: Symptom burden, quality of care, and place of death. *Dtsch Arztebl Int. 110*(2), 195-202.

Samia, L. W., O'Sullivan, A., Fallon, K. C., Aboueissa, A., & Hepburn, K. W. (2018). Building on self-efficacy for experienced family caregivers: The Savvy Advanced Program. *The Gerontologist, 00*(00), 1–11

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health, 23*, 334-340.

Sharma, N., Chakrabarti, S., & Grover, S. (2016). Gender differences in caregiving among family- caregivers of people with mental illness. *World J Psychiatry, 6*(1), 7-17.

Shega, J. W., Hougham, G. W., Stocking, C. B., Cox-Hayley, D., & Sachs, G. A. (2004). Pain in community-dwelling persons with dementia: Frequency, intensity, and congruence between patient and caregiver report. *Journal of Pain Symptom Management, 28*(6), 585-592.

Sudore, R., Landefeld, C. S., Williams, B. A., Barnes, D. E., Lindquist, K., & Schillinger, D. (2006). Use of a modified informed consent process among vulnerable patients. *Journal of General Internal Medicine, 21*, 867-873.

Tang, W. K. & Chan, C. Y. (2016). Effects of psychosocial interventions on self-efficacy of dementia caregivers: A literature review. *International Journal of Geriatric Psychiatry, 31*(5), 475–493.

Tarter, R., Demiris, G., Pike, K., Washington, K., & Oliver, D. P. (2016). Pain in hospice patients with dementia: The informal caregiver experience. *American Journal of Alzheimer 's disease and Other Dementia, 31*(6), 524-529. doi: 10.1177/1533317516653825

Tennstedt, S. L., Crawford, S., McKinlay, J. B. (1993). Determining the pattern of community care: Is coresidence more important than caregiver relationship? *Journal of Gerontology, 48*, S74–S83.

Teno, J. M., Weitzen, S, Wetle, T., & Mor, V. (2001). Persistent pain in nursing home residents. *JAMA, 285*, 2081.

U.S. Department of Health and Human Services. (2016). National plan to address Alzheimer's disease: 2016 updated. Retrieved from https://aspe.hhs.gov/system/files/pdf/205581/NatlPlan2016.pdf

Whitelock, E. L., Diaz-Ramirez, L. G., Glymour, M. M., Boscardin, W. J., Covinsky, K. E., Smith, A. K. (2017). Association between persistent pain and memory decline and dementia in a longitudinal cohort of elders. *JAMA Intern Med. 177*(8), 1146-1153.

Zulman, D. M., Asch, S. M., Martins, S. B., Kerr, E. A., Hoffman, B.B., & Godstein, M. K. (2014). Quality of care for patients with multiple chronic conditions: The role of comorbidity interrelatedness. J Gen Intern Med., 29(3), 529-537.

Zwakhalen, S. M. G., Hamers, J. P. H., & Berger, M. R.F. (2007). Nursing staff knowledge and beliefs about pain in elderly nursing home residents with dementia. *Pain Research & Management, 12*(3), 177-184.

Chapter 6. Conclusion

The study presented in this dissertation focused on FCGs who play an important role in pain management for their care recipients with dementia living in the community. The goals of the study were to increase the understanding of pain management experiences among FCGs of older adults with dementia and to enhance existing knowledge using qualitative description methods.

My literature review (manuscript 1) shed lights on the fact that pain is a major issue for older adults with dementia. Pain assessment and management in older adults with dementia are particularly challenging for FCGs due to the difficulty that patients have reporting their pain. Though the impact of factors on decision making in pain management and recommendations regarding pain management were revealed from the reviewed literature, existing research has only focused on formal caregivers' experiences in pain management (Eritz & Hadjistavropoulos, 2011; Fall et al., 2004; Krulewitch et al., 2000; Murray et al., 2012; Shega et al., 2004). Very limited studies have revealed how FCGs manage pain for their care recipients (Hunt et al., 2017). In addition, only a few studies involved patients with dementia living at community-based settings. (Buffum & Haberfelde, 2007; Fall et al., 2004; Peisah, Weaver, Wong, & Strukovski, 2014; Shega et al., 2004; Soscia, 2003; Hunt et al., 2017). Moreover, my review identified knowledge deficits among individual healthcare workers in pain assessment and management. It is unknown if the knowledge deficits also exist among family caregivers. Thus, it is clear that future research designed to advance the knowledge of pain management among family caregivers is necessary.

The concept analysis (manuscript 2) examined the unique characteristics of pain management in people with dementia. Attributes and consequences of pain management were synthesized. Form this analysis, attributes, antecedents, consequences, and empirical referents for the concept of pain were identified. This analysis provides a better understanding of the concept of pain management in people with dementia. The results offer direction for future studies to improve the quality of care in pain management for people with dementia.

The manuscript three is a report of a qualitative study that explored how family caregivers manage pain for their care recipients with dementia living at the community settings. Three themes were identified: 1) Values, 2) Barriers, and 3) Support. Each of the themes included several subthemes.

One notable finding was that while managing pain, FCGs' personal beliefs heavily affect their decision-making. This finding suggests that educational programs or interventions may be designed and tested to alter personal beliefs and to improve FCGs' skills in pain management.

My study also revealed the barriers for effective pain management. These factors could be intra- or inter- personal factors from patients or FCGs' perspectives. Regardless the resources of these factors, this finding provides direction for future research to overcome these barriers and ultimately assist with the quality of care in pain management.

Finally, potential solutions supporting FCGs' in pain management were also identified. This finding highlighted the needs of support from healthcare professionals and organizations. In this study, FCGs mentioned that they often had limited resources compared to professional healthcare providers. Therefore, support from individual, organizational, and systematic levels should be considered in the future research.

Overall, this dissertation adds to the body of knowledge and our understanding of how family caregivers manage pain for their care recipients with dementia in the community settings. This knowledge can influence the quality of care for patients with dementia, as well as decision-making by family caregivers, in making appropriate choice about pain management. Researchers and healthcare professionals should also understand this knowledge in order to help with the patients and their family caregivers in need. In sum, this study has a sustained scientific impact. The knowledge obtained from this study is crucial for intervention and policy development in order to promoting quality of life for both community-dwelling older adults with dementia and their family caregivers.

References

Buffum, M. D. & Haberfelde, M. (2007). Moving to new settings: Pilot study of families' perceptions of professional caregivers' pain management in persons with dementia. *Journal of Rehabilitation Research and Development, 44*(2), 295-303.

Eritz, H. & Hadjistavropoulos, T. (2011). Do informal caregivers consider nonverbal behavior when they assess pain in people with severe dementia? *Journal of Pain, 12*(3), 331-339.

Falls, D., Stevens, J., Andersen, M., Collin, S., Dodd, N., Fitzgerald, E…Wilson, V. (2004). Carers' perceptions of pain in people with dementia: a grounded theory approach. *Aust J Holist Nurs.11*(2),4–11.

Hunt, L., Covinsky, K., Yaffe, K., Stephens, C., Miao, Y., Boscardin, W. J., & Smith, A. K. (2017). Pain in community-dwelling older adults with dementia: Results from the National Health and Aging Trends Study. *J Am Geriatr Soc. 63*(8), 1503-1511.

Krulewitch, H., London, M., Skakel, V., Lundstedt, G., Thomason, H., & Brummel-Smith, K. (2000). Assessment of pain in cognitively impaired older adults: a comparison of pain assessment tools and their use by nonprofessional caregivers. *Journal of the American Geriatrics Society, 48*(12), 1607 –1611.

Murray, T., Sachs, G., Stocking, C., & Shega, J. (2012). The symptoms experience of community-dwelling persons with dementia: Self and caregiver report and comparison with standardized symptoms assessment measures. *American Journal of Geriatric Psychiatry, 20*(4), 298-305.

Peisah, C., Weaver, J., Wong, L., & Strukovski, J.-A. (2014). Silent and suffering: a pilot study exploring gaps between theory and practice in pain management for people with severe dementia in residential aged care facilities. *Clinical Interventions in Aging, 9*, 1767-1774.

Shege, J. W., Hougham, G. W.; Stocking, C. B., Cox-Hayley, D.; & Sachs, G. A. (2004). Pain in community-dwelling persons with dementia: Frequency, intensity, and congruence between patient and caregiver report. *Journal of Pain Symptom Management, 28*(6), 585-592.

Soscia, J. (2003). Assessing pain in cognitively impaired older adults with cancer. *Clinical Journal of Oncology Nursing, 7*, 174-177.