This study sought to understand the experiences of family caregivers of institutionalized persons with dementia and how family centered care and psychoeducation contributes to their role as a caregiver. Participants were recruited from one Alzheimer’s Association chapter and various nursing facilities in the Midwest. Interviews were conducted with 13 family caregivers of institutionalized relatives with dementia. Employing thematic analysis, four central themes emerged from the participants’ stories: the role of the facility, role of education, caregiver’s role, and the role of meaning. The findings not only emphasize the importance of nursing staff recognizing family members as partners in care, but also they expose how the medicalization of care can impede a facility’s ability to meet the needs of the family and the individual with dementia. Further research should explore obstacles to family-centered care and implementation of psychoeducational interventions.
FAMILY CAREGIVING BEYOND INSTITUTION DOORS

Thesis

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Masters of Gerontological Studies

by

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This thesis titled

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Dedication

I dedicate my thesis to my beloved family, with special consideration to my mother and my dear husband. My mom has been the biggest source of encouragement for me to finish my graduate degree. From a young age, I was inspired by her example once I learned that she had completed her Master’s degree in Gerontology, at none other, than Miami University. Although it was not my original intent to follow in her steps so closely, I’m so thankful that I did, for she was the one who first introduced me to the idea to love and cherish people of all ages. And I know, without a shadow of a doubt, I would not have been able to finish my thesis without knowing that had my husband’s full support. His unwavering belief in me has seen me through many a low time during my journey to complete this program and I am forever grateful.
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Introduction

In 2014, 34.2 million Americans had active roles as unpaid family caregivers to an adult age 50 or older (“Caregiving in the US,” 2015). Although family caregivers are a diverse group in regards to gender, socioeconomic status, and race, the typical profile of a family caregiver is a white woman (60%) who works full-time (56%) and provides care for a parent or parent-in-law (49%) in a community setting (“Caregiving in the US,” 2015). With a reported 22% of care-recipients having a diagnosis of Alzheimer’s or dementia, family caregivers of individuals with dementia provided approximately 17.9 billion hours of unpaid care in 2014 alone - highlighting how informal caregiving is a “cornerstone of dementia care” in the United Sates (Afram et al., pg. 891, 2015). Undoubtedly, family caregiving can be a rewarding relationship for both the care recipient with dementia and the caregiver; however, it is not without cost. Not only is caregiving of people with dementia time consuming, putting in jeopardy work responsibilities and creating financial strain; but also, family caregivers experience an increased risk of burden, emotional stress, depression, social isolation (Brodaty & Donkin, 2009), neuroticism (Maseda et al., 2015), and anxiety symptoms (Cooper et al. 2007). While many of the negative effects of caregiving mentioned above could be applicable to family caregivers in general, several studies have shown that caring for a person with dementia is more demanding and stressful than providing care for a person with a physical disability, underling the importance of having an in-depth understanding of this particular demographic (Brodaty & Donkin, 2009; Ory et al., 1999).

Although only 8 percent of care recipients of family caregivers reside in institutional settings, such as nursing or assisted living facilities (“Caregiving in the US,” 2015), on average family caregivers “provide, arrange, or oversee care…between 4.0 and 9hr/week visiting and/or performing tasks” (Williams, Zimmerman, & Williams, 2012, p. 1). Furthermore, potentially due to the unique demands and stresses of caring for a person with dementia (e.g. “relative’s incapacity to recognize familiar people, lack of interest in things…agitation,” and incontinence), care recipients with dementia are the most likely to live in a nursing facility (“Caregiving in the US,” 2015; Levesque, Ducharme, & Lachance, 1999, p. 474). Indeed, more than 50 percent of nursing home residents have some form of dementia, and roughly 67 percent of individuals with dementia receive their end of life care and pass away in nursing facility setting (Givens et al., 2015). Common predictors of institutionalization involve both the person with dementia (e.g., deteriorating cognitive health, heightened prevalence of challenging behaviors like wandering, safety issues) and the family caregiver (e.g., accumulation of stress, decreased physical and psychological health; see Johansson et al. 2014). Challenging the long-held assumption that the relinquishment of care to a nursing facility significantly alleviates caregivers’ burden and improves
their well-being, studies have revealed that institutional placement is often a painfully difficult transition for the family caregiver because of stressors introduced by the institutionalization itself such as role disruption, guilt over placement, uncertainty about the future, and conflicts with nursing staff (Johansson et al., 2014). Moreover, while a growing body of literature affirms that continued family involvement can greatly preserve the quality of life and well-being of individuals with dementia, how family involvement affects the family caregiver as well as the barriers and facilitators to family members continuing their caregiver role in a facility setting has been understudied (Cohen et al., 2014).

Owing to the growing prevalence and awareness of both dementia and family caregiving, now more than ever we have a well-informed portrait of family caregivers to people with dementia in the context of home and community based settings (Dauenhauer, 2006; Givens et al., 2015). However, there is a dearth of information on the experiences of family caregivers who have a relative with dementia. The lack of recognition and research on this particular subset of family caregivers mirrors the scarcity of nursing facilities that have formalized their approach to integrating the family member in the care of their residents. Likewise, few educational resources target the specific challenges and needs that family caregivers’ face after the institutionalization of their relative with dementia. Given that family members continue to play a seminal role in the care of their institutionalized relative with dementia, an understanding of the family caregivers’ perspective on their role in a nursing facility setting is pivotal to optimizing institutionalized care for all stakeholders involved.

This study had four specific aims:

1) To better understand the unique challenges and benefits of being a family dementia caregiver in an institutional setting
2) To better understand family caregivers’ perceptions of the importance of education in their ability to care for their relative
3) To examine the family caregivers’ perceptions of how the nursing facility supports them in their caregiver role
4) To investigate how family caregivers derive meaning from their role in an institutionalized setting.

In order to achieve the above aims of this study, mixed method interviews were conducted with 13 family caregivers of institutionalized relatives with dementia. Participants were recruited through contacts made with a senior center, one chapter of an Alzheimer’s Association support group, and a nursing facility in the Midwest. Furthermore, this study utilized thematic analysis to present its findings.
Background

A Quick Word on Words

Espousing the belief that language matters, this paper declines utilizing the terms “formal” and “informal” caregiving due to such a dichotomy of expressions trivializes the work of “informal caregivers” (i.e. non-professional or family caregivers). There is nothing informal or casual about providing care for a relative, and denoting family caregiving as such devalues the relationship by suggesting that it is “unstructured [and] unofficial care” that is “pleasant but not essential” (Feinberg, 2014, para. 4). Furthermore, the term implies there is no cost physically, emotionally, and financially involved, which simply is not true. As Gleckman (2014) reports, “typical caregivers spend $5,500-a-year out of pocket to assist a family member” (para. 6). Banishing such words from the caregiving literature’s rhetoric can help assist in the process of recognizing family caregiving as “a public responsibility, not just an informal, family or private one” (Feinberg, 2014).

Continuity of Family Dementia Caregiver Involvement Post-Institutionalization

The majority of the existing literature that examines the continued involvement of family members whose relative lives in a long term care facility has conceptualized institutionalization as a “turning point” or a single watershed moment in the family member’s caregiving career (Gaugler, 2014, p. 520). Therefore, studies have been primarily interested in the predictors of institutionalization, the needs of the family caregiver before/during the care-transition, and the family caregiver’s experiences during the initial relinquishment of care to a nursing facility (Afram et al., 2015; Johansson et al., 2014). Researchers also have been interested in determining the frequency of family involvement. National Nursing Home Survey data from the 1970s indicated that 61% of residents received visitors once a week (Gaugler, Zarit, & Pearlin, 2003), while a 2014 study cites family visitation estimates that suggest between “23% and 76% of residents receive family visitors at least weekly” (Cohen et al., 2014, p. 523). From 1990 to 2000, studies began to examine the experiences and perspectives of family caregivers post-placement. This area of research has mostly emphasized determining the sources of stressors and strain for the family caregiver in an institutionalized setting. In fact, due to findings revealing that the facility setting introduces distinctive stressors for the family caregiver, such as negative interactions with the staff, Givens and colleagues (2015) developed a scale specifically designed to “capture the unique burdens of the nursing home environment” (p. 775). Conversely, other studies have found that even in facility settings, family caregivers are most troubled by the actual dementia symptoms of their relative (Lévesque, Ducharme, & Lachance, 2000; Stephens, Kinney & Ogrocki, 1991); a finding that led researchers to emphasize the importance of facilities recognizing family caregivers as “clients of the
institution who need support” (Lévesque, Ducharme, & Lachance, 2000, p. 235). As illustrated by a study found that family members particularly need support by means of guidance and education with surrogate decision-making (Givens et al., 2012).

Furthermore, recent caregiving literature has focused on determining factors that influence family caregivers’ perceptions of the quality of their visits in institutionalized settings. According to one qualitative study, establishing a connection with their relative, being able to take their relative outside, and staff being proactive in helping to distract an upset resident at the end of the visit were some of the characteristics that positively influenced family visits (Piechniczek-Buczek, Riordan, & Volicer, 2007). Joan Garity (2006), a researcher and nurse, advised that positive interactions between the individual with dementia and the primary family caregiver are the best deterrent of caregiver burden. Additionally, this study revealed that interacting with other residents provides family caregivers that human connection, helping them cope with their relative’s growing inability to communicate during a visit (Garity, 2006). Another aspect of family involvement literature looks at what family members do during visits with their relatives. One study discovered that, in comparison to family caregivers of cognitively intact residents, family members of individuals with dementia spent more time doing care-related activities such as discussing care with staff (Cohen et al., 2014).

Caregiver’s perception of their Role/Identity

A growing body of literature has gone beyond identifying the frequency and type of family involvement and instead has assessed the role of family caregivers after the institutionalization of their relative. Adjusting to their more detached role within a nursing home setting can be a difficult process. They often feel like outsiders in the caregiving process; once the primary caregiver of their relative, they are now seemingly rendered to the status of visitor (Dauenhauer, 2006; Garity, 2006; Davies & Nolan, 2006). Several researchers have termed the family caregiver’s transition from home to nursing home care as a “redefinition,” advising that this process is crucially important for the well-being of family members (Sandberg et al., 2001; Davies & Nolan, 2006). Based on a qualitative study conducted in the UK, Davies and Nolan (2006) operationalized the task of redefinition as “making it better,” which involved the family member finding purpose and adapting to his/her new caregiver role through maintaining continuity of the older person’s identity, keeping an eye on the quality of care provided by the facility, and finally, contributing to the community, which was achieved by the family member interacting with the staff and other residents. Similarly, a recent study produced findings that suggested that family involvement during mealtime helps ease family members’ difficulties with their distilled role
because it provides caregivers a tangible task, creating a sense of purpose and that they “made a
difference” (Durkin et al., 2014, p. 597).

Although few studies have exclusively focused on the distinctive role of family caregivers after
institutionalization, one relatively recent study examined caregiver identity through the lens of
caregiving styles (Corcoran, 2011). Working from the idea that attitudes and beliefs predict the intention
behind behaviors, this study utilized reasoned action theory to examine the nuances behind why and how
family caregivers of individuals with dementia do what they do (Corcorcan, 2011). Corcoran’s research
findings unearthed four caregiving styles – facilitating, balancing, advocating, and directing. Each
caregiving style or care strategy reveals how the family member derives purpose and meaning from their
caregiver role. For example, family caregivers with the advocating style find meaning through
protecting and ensuring their relative’s well-being and dignity. Knowing the meaning and purpose
family members derive from continuing their caregiving role post-admission provides critical insight to
facilities and researchers on how to best support and empower this demographic.

From Person-Centered to Family-Centered Care

Although the person-centered approach has become the standard for high quality care in nursing
homes across the United States, applying the concept of person-centeredness to the care of residents
with dementia remains problematically vague. According to Morhardt and Spira (2013), person-centered
care alone is asymmetric and limited due to its inability to “capture” the dynamics of relationships
inherent to the “social relational context” of caregiving (p. 37). Moreover, Kitwood challenged the idea
that individuals with dementia incrementally “lose themselves,” proposing instead that personhood be
viewed in “social rather than individual terms” (Kitwood & Bredin, 1997, p. 269) or more succinctly
put, family-centered care (Mohardt & Spira, 2013, p. 763). This model of care theoretically underlies the
importance of facilities actively incorporating family members in the care of their relatives with
dementia, recognizing that family members are best equipped to emphasize the person before the disease
(Vernooij-Dassen et al., 2010; Lopez et al., 2013; Warner & Stadnyk, 2014). Current person-centered
practices can place too much emphasis on the individual with dementia while ignoring or even
diminishing the role of the family caregiver, unintentionally creating negative emotional consequences
for both the caregiver and the individual with dementia. An example of this would be the “common
practice” of facilities advising family members to give the care recipient distance to facilitate adjustment
to the new facility setting (Mohardt & Spira, 2013, p. 41). In contrast, the family-centered approach
enhances person-centered care practices by recognizing all stakeholders involved in the caregiving
dynamic.
Moreover, this approach to caregiving can embolden the family member by mediating potential negative experiences such as role readjustment, guilt, and feelings of loss. Vernooij-Dassen and colleagues (2010) performed grounded theory research to investigate the success of family-centered counseling for family caregivers of individuals with dementia in a home-based setting. The findings suggested that obtaining the point of view of the care recipient and caregiver provides a more holistic understanding of the problems the dyad is facing, which improves the counselor’s ability to effectively advise solutions, resulting in a delay in institutionalization, a reduction of depressive symptoms for both members of the caregiving dyad, and an increased ability for caregivers to emotionally handle their relatives’ problematic behaviors (Vernooij-Dassen et al., 2010). Similarly, another study that examined the effect of a facility asserting the importance of relationships finds that the perspectives of family members can be essential tools in informing nursing staff of care practices that highlight or devalue the personhood of individuals with dementia (Palmer, 2013).

As previously discussed, role adjustment or redefinition undergone by the family caregiver post-institutionalization is typically a difficult and delicate process. Numerous studies have brought awareness to the commonly problematic interactions between staff and family members (Givens et al., 2012; Specht et al., 2005). Adapting to having lower control over the care of their relatives, family caregivers can often become frustrated with nursing staff who often don’t like having their care routines questioned and are limited by a resource and time restricted environment (Spetch et al., 2005). Relational or family-centered care can help to mitigate that conflict by supporting family through family-staff care partnerships, which are a negotiation of caring roles and responsibilities of family and staff according to the needs of the individual with dementia (Mass et al., 2004). The “carer as expert” model is emblematic of the family-staff partnership approach, giving the caregiver a role as an expert who has important knowledge to contribute to the care of their relative (Nolan, Bauer, & Nay 2009).

Acknowledging the many benefits of family-centered care, Lopez and colleagues (2013) sought to capture what qualities and strategies best facilitate family-centered care for individuals with advanced stage dementia by doing a one year follow up evaluation of the Care of Advanced Dementia at the End of Life (CASCADE), a program designed to encourage the collaboration between the facility and the family caregivers. The results revealed that one of the ways family-centered care can be most successfully implemented is by the facility creating an environment in which family members feel that they still have an important role in the care of their relative. Family members’ crave a “sense of belonging and attachment” in both their relationship with the resident with dementia and the nursing staff. In addition to wanting to belong, family members place great significance on achieving a “sense of
self-esteem and self-efficacy” in being able to fully exercise their role as an advocate for their relatives with dementia (Lopez et al., 2013). While the family-centered approach is a fairly novel concept, the limited research on this model of care produces compelling outcomes because it enables a facility environment that allows the caregiver to have a meaningful role, while also enhancing the personhood of the individual with dementia. Results that are so holistically beneficial merit further consideration and understanding.

The Role of Psychoeducation

Despite the well-documented benefits of dementia training/education for nursing staff (Beer et al., 2011) and family caregivers in community/home-based settings (Edwards, Voxx, & Lliffe, 2014; Lianque et al., 2015), research and educational resources geared towards the specific needs of family dementia caregivers in an institutional context are scarce. In a 2006 review of intervention strategies for home-based dementia care, Sörenson and colleagues (2006) identified “psychoeducational interventions as the most effective at improving [family] carer knowledge… reducing burden and depression symptoms, and increasing subjective wellbeing and satisfaction,” however, the role of dementia education for family caregivers of institutionalized relatives has been overlooked in both research and practice (p. 965).

To date, there seems to be only two psychoeducational programs that are intended for institutional application, the first being the Family Visit Education Program (FVEP), which was designed to help educate family members on how to optimize their visits with their relatives with dementia (McCallion, 1999). An evaluation of FVEP found that benefits of implementing this program were twofold: 1) it helps reduce the problematic behavioral symptoms of the resident and 2) it improves family members’ satisfaction with the visit in terms of communication/interaction with their relative (McCallion, 1999). Unfortunately, there is little to no recent information on FVEP, most likely because the program is complicated for facilities to employ due to it being time consuming and potentially impractical considering the staffing needs of the nursing home.

The Family Involvement in Care (FIC) intervention is a formalized psychoeducational program that links the family-centered care model with education, requiring a care partnership between the staff and family, while also providing dementia training for the staff and dementia education material for the family members (Bramble, Moyle, & Shum, 2011). A quasi-experimental study examining the outcomes of this intervention revealed major gains in the family caregiver’s knowledge of dementia, although the increased knowledge led to a decrease in satisfaction with the staff management (Bramble, Moyle, & Shum, 2011). It is unclear whether the deficiency of psychoeducational resources is the result of aging
professionals’ lack of awareness or due to a perceived lack of need; however, regardless of the respective limitations of the FVEP and the FIC, the measured benefits of such interventions underscore the importance of client-driven approaches such as family-staff partnerships and empowering caregivers through heightened knowledge. To cease continued development of psychoeducational programs would be a missed opportunity to achieve better standards of care.

**Purpose**

Clearly, admitting a relative with dementia into a facility does not equate to a family member ceasing their caregiving role. However, what is not so obvious are the experiences and challenges that face this particular demographic of caregivers. Within the predominantly patient-centered environment of an institution, the family caregiver can become the forgotten second client, and their stories are rarely told. Therefore, actual implementation of progressive models of care such as the family-centered approach has gained little traction in the healthcare world and family caregiving literature. The same lack of notoriety and prevalence holds true for the essentially absent educational programs designed for family dementia caregivers in institutional settings. In consideration of the scant amount of existing literature on family caregivers of institutionalized relatives with dementia, the research has primarily consisted of evaluations of the effects of family-centered care interventions or psychoeducational program implementation, producing helpful yet prescriptive findings. Alternatively, the current study seeks to examine the perceptions and needs of family caregivers in regards to both facility support and dementia education, by answering the following research questions: 1) What are the unique challenges and benefits of being a family dementia caregiver in an institutional setting? 2) How important do family members perceive the role of dementia education in influencing their ability to be a successful caregiver? 3) How important do family caregivers perceive facility support in influencing their ability to be a successful caregiver? 4) How do family caregivers derive meaning from their role in an institutionalized setting?

**Methods**

A thorough understanding of family caregiving in an institutionalized setting requires the insider perspective of the caregiver, and to obtain such privileged information, multiple studies have used the qualitative description because it provides an “in-depth description of the phenomenon in the words of those involved” (Lopez et al., 2013, p. 764). The descriptive approach is distinct from other qualitative methods because it identifies the varieties in which the phenomenon appears, while also determining the aspects within the phenomenon (Elliot & Timulak, 2005). In addition, such descriptive qualitative
studies are frequently supplemented with modest quantitative assessment, such as in Dauenhauer’s examination on mindfulness theory among family caregivers (Bergman, 2011; Dauenhauer, 2005). For this reason, the researcher also obtained data by having the participants complete and then mail in a survey, which consisted of the recently developed Family Distress in Advanced Dementia scale (FDADS) (see Appendix A). For those aforementioned reasons, a mixed methods approach was used to answer the research questions. Data collection involved semi-structured, open-ended interviews that were conducted in person with 13 participants (i.e., family dementia caregivers).

Recruitment

After Miami’s Institutional Review Board approved this study, recruitment began in the winter of 2015. The study used purposive and convenience sampling to recruit participants from contacts made with aging-related organizations in the Midwest region of the United States. Specifically, one participant was recruited from a senior center, 8 were recruited from a nursing facility, three came from an Alzheimer’s Association support group, and one was a friend of a colleague in the researcher’s office. The same recruitment materials (see Appendix B) were provided to each of these contacts, however, the process of recruitment varied. The director of the senior center passed along information about the research to potential participants, leaving it up to the individual to contact the researcher about participating in the study. Furthermore, prior to the researcher attending an Alzheimer’s Association affiliated support group, consent had to be granted by the support group’s facilitator; consequently, a support group was chosen based on their willingness to grant access to the researcher. At the support group, the researcher circulated a sign-up sheet that allowed interested individuals to provide contact information. The researcher followed up with the one individual who signed-up and gave more in-depth information about the study. That individual chose to participate in the study and also provided the contact information of two other potential participants who had been absent from the support group meeting the day the researcher had attended. The researcher contacted both of these individuals and recruited them into the study.

Recruitment through the nursing facility was the most extensive. First, the facility’s ethics committee had to grant approval, and then the researcher had a formal meeting with the facility’s nursing home administrator and social worker to explain the details of the study and establish how the researcher would get in touch with potential participants. The facility decided to create a contact information sheet, which consisted of the home addresses and phone numbers of 15 family caregivers who appeared to meet the study’s selection criteria. Excluding the individuals who lived outside the Midwest, the researcher called all the participants on the list. Of the 7 individuals who were not included
in this study, only one individual declined to be included in the study, three of the remaining contacts never responded to the voicemail messages the researcher left on their phones, one was deemed ineligible because they did not meet the selection criteria guidelines (i.e., their relative did not have a medical diagnosis of dementia), and two were not contacted because they lived outside the Midwest. Therefore, out of the 13 participants enrolled in this study, 8 were family caregivers of individuals with dementia that were institutionalized in the same nursing facility.

**Sampling**

To be eligible for inclusion in this study, potential participants were required to meet the following criteria: must be a spouse, blood relative, or in-law of only one older adult relative with a formal diagnosis of dementia; must be willing to claim primary caregiving duties of the institutionalized elder; must be 18 years or older; and must be able to speak English. Moreover, considering that this study’s methodology entails primary data collection through face-to-face interviews, travel limitations mandated that the participants be located in the Midwest.

This study had 13 participants, which was a fitting sample size in regards to both the scope and purpose of the research. With the goal of having an in-depth understanding of the lived experiences of this demographic of family dementia caregivers, generalizability to a large population would be both unnecessary and basically impossible to achieve given the research timeline and limited funding. Additionally, a sample size of 13 is comparable to other qualitative studies that examine family caregivers in institutionalized settings. For example, Bramble, Moyle, and McAllister (2009) conducted a compelling study utilizing data obtained from hour long, semi-structured interviews with 10 family dementia caregivers. Similarly, Swedish researchers determined some of the facilitators and inhibitors for family caregivers when relinquishing care to nursing facilities by conducting 10 interviews with family caregivers who had recently placed their relative with dementia in a facility (Johanssen et al., 2014). Additionally, Fusch and Ness (2015) advise that an indicator of reaching data saturation is no new data, and therefore, no new themes are being found in the interviews. In consideration of those aspects, halfway through the data collection process, the researcher had to add more participants from a the Alzheimer’s Association support group because the interview with one participant from that sample source had provided strikingly new data and new themes, compelling the researcher to enroll more participants so as to reach data saturation, which was eventually achieved with 13 interviews.

**Data Collection Procedures and Instruments**

The researcher chose the face-to-face interview because the method affords advantages such as visibility of social cues, synchronous communication, and the ability for the interviewer to establish
“good interview ambiance” (Opdenakker, 2006). Interviews were conducted by the researcher and were held separately at a location of the participant’s choice. Three interviews were held at the participants’ home, four were conducted in study rooms at the participants’ local library, two were completed in the participants’ local coffee shop, three were held where the participants’ relatives were institutionalized, and one was conducted at the participant’s work office. Having received verbal or written information about the study from the researcher when setting up a time for the interview, prior to beginning the interview session, the researcher sought informed consent by presenting the participant with an informed consent form (see Appendix C), which outlined the purposes of the research and what was expected of the participant. Although it was clearly stated in the informed consent form, the interviewer stressed that the information given by the participant would be kept confidential. Before the interview, the participants were also advised that they could stop the interview session and/or withdraw from the study at any time without risk of penalty or having to indicate any reason. Alongside those ethical considerations, the researcher also assumed that participation in the study could have some benefit to the family caregiver in that the interviews provided an opportunity for their voice and story to be heard. Other researchers have suggested that “narration itself” can be therapeutic and “provide a sense of relief” (Johansson et al., 2014, p. 3).

In addition to a copy of the informed consent form, the participants were also given a stamped addressed envelope containing the Family Distress in Advanced Dementia Scale (FDADS) (see Appendix D). After briefly explaining the scale, the researcher then asked the participant to fill out the paper survey and send it back to the researcher upon completion. Developed in 2015, the FDADS is new; yet, the researcher chose this scale over other caregiver distress measures due to its explicit focus on measuring the burden of family dementia caregivers in an institutional context. Additionally, this scale’s inclusion of dementia education elements is significant due to the fact that dementia education is an under-appreciated and vastly understudied area of distress for this particular subset of family caregivers (Givens et al., 2015). According to the results of a recent study (Givens et al., 2015), which had 130 participants, the researchers split up the scale into three domains, each having strong Cronbach’s alpha values, as follows: Emotional Distress (.82), Dementia Preparedness (.75) and Nursing Home Relations (.83). The scale items are designed to measure the frequency of events or symptoms in the past three months using the standard 5-point scale, as follows: 1 = never, 2 = rarely, 3 = sometimes, 4 = often, and 5 = always.

Furthermore, the first set of questions captured the demographic characteristics of the participants, including gender, date of birth, race, and highest completed level of education. Due to the
fact that these were in-person interviews, the participants were not directly asked a question about their gender, rather the interviewer independently recorded the gender category based on observation. In order to capture the family caregiver’s perspective on caregiving for a relative with dementia in an institutionalized setting, the interviewer asked the participants sixteen open-ended, semi-structured questions (see Appendix A). The questions were designed to elicit data that was applicable to this study’s research questions, however, the iterative and exploratory nature of qualitative interviews demands for flexibility – often a seemingly “off-track” side note yields fascinating data that enhances the profundity of the research findings. Participants were consistently asked to elaborate on their answers, and the interviews, which were audio recorded, ranged from 13 to 118 minutes (median = 44 minutes, mean = 49 minutes). Only three interviews were less than 35 minutes long.

Data Analytic Strategy

A professional transcriptionist and the researcher transcribed the 13 interviews. Ensuring rigor and trustworthiness, the researcher read over each transcript with its correlated audio file to verify transcription accuracy. Next, the researcher read over the transcripts multiples times to gain a sense of the participants’ stories and to become “immersed in the data” (Johansson et al., 2014, p. 2). According to Vaismoradi, Turunen, and Bondas’s definition (2013), the text was thematically analyzed, as opposed to content analysis, which categorizes data primarily based on frequency, thematic analysis places more emphasis on context while deriving emergent patterns and themes from the texts. The researcher followed the thematic analysis process outlined by Braun and Clark (2006) in their review of qualitative thematic method. After becoming familiarized with the data, the researcher began systematically coding interesting features of the texts into a spreadsheet. Then the researcher searched for themes within the coded texts. As themes began to emerge, the researcher continually went back to the original transcripts to gather all data relevant to each possible theme. From that point, themes were reviewed, evaluated, discarded, and collated based on their relation to both the coded extracts and the data set as a whole. Once themes were refined to a more concise thematic map that addressed the research aims, the researcher finalized the names of the thematic areas and themes. The text was eventually organized into four major thematic areas: role of facility, role of dementia education, caregiver role, and the role of meaning. Codes are abstracted and condensed into a total of 9 themes.

Besides its innovative design and growing popularity among researchers, the mixed methods approach utilized in this study affords the considerable advantage of cross-validating individual findings (Bergman, 2011). Nonetheless, one challenge to successfully conducting a mixed methods study is the small sample size restricting the quantitative analyses. In the case of this study, the FDADS originally
had 31 items, however, after Givens and colleagues (2015) tested the scale’s item coherence and reliability via Factor analysis and Cronbach’s alpha, they removed 10 items with factor loadings less than 0.4 (items 6, 8, 13, 15, 19, 20, 22, 25, 26, 31; see Appendix C). Considering that factor analysis typically must have a sample size of at least 100, it would have been futile to conduct an independent factor analysis with only 13 participants. Therefore, the researcher chose to adhere to the scale metrics found in the existing literature by only doing frequency distribution tests on the variables included in the 21-item FDADS (Givens et al., 2015). Despite this adaptation, with a survey response rate of 100 percent, the quantitative piece in this study provides a meaningful compliment to the research findings.

Results

Participants

The participants’ ages ranged from 50 to 73, with a mean of 58.54 years and a median of 58 years. The entire sample self-identified their race as white, and they were predominantly female (9 women and 4 men). Overall, the analytic sample was well educated; only one participant had no college experience. Of the participants, three had advanced degrees (one PhD, two masters), three obtained bachelor’s degrees, five had completed some college, and one had their high school degree. All participants were adult-child family caregivers of their institutionalized relative with dementia. In all, 6 different nursing facilities were represented. Of those interviewed, all but one had a parent with dementia who was alive at the time of interview, and all but two of the care-recipients were female. Each participant was given a pseudonym to protect his or her identity.

Table 1 below illustrates the visitation frequency of the sample. A little over half of the participants visited their relative with dementia at least two times a week, while 6 remaining family caregivers visited once a week or less.

Table 1. Family Caregiver Visitation Frequency

<table>
<thead>
<tr>
<th>Number of visits</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Every Day</td>
<td>4</td>
<td>31%</td>
</tr>
<tr>
<td>2-5 Days a week</td>
<td>3</td>
<td>23%</td>
</tr>
<tr>
<td>Once a week</td>
<td>5</td>
<td>38%</td>
</tr>
<tr>
<td>Once every two weeks</td>
<td>1</td>
<td>8%</td>
</tr>
</tbody>
</table>
Table 2. Final Items Grouped within Domains for the Family Distress in Advanced Dementia Scale

<table>
<thead>
<tr>
<th>Item</th>
<th>Frequency Percentages</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never</td>
</tr>
<tr>
<td>2. I have felt that I don’t know how to communicate with my loved one</td>
<td>8%</td>
</tr>
<tr>
<td>3. I have felt isolated from my loved one</td>
<td>46%</td>
</tr>
<tr>
<td>4. I have been concerned about what to expect when my loved one is close to death</td>
<td>39%</td>
</tr>
<tr>
<td>5. I have felt my loved one is less of the person he or she used to be</td>
<td>15%</td>
</tr>
<tr>
<td>7. I have felt scared or helpless because of my loved one’s illness</td>
<td>23%</td>
</tr>
<tr>
<td>9. I have felt anxious about my loved one’s illness</td>
<td>8%</td>
</tr>
<tr>
<td>10. I have felt a sense of longing for my loved one as they used to be</td>
<td>x</td>
</tr>
<tr>
<td>11. I have felt depressed or sad because of my loved one’s illness</td>
<td>8%</td>
</tr>
<tr>
<td>12. I have felt emotionally drained because of my loved one’s illness</td>
<td>15%</td>
</tr>
<tr>
<td><strong>Dementia Preparedness</strong></td>
<td></td>
</tr>
<tr>
<td>1. I have felt that I don’t know what to expect in my loved one’s illness</td>
<td>15%</td>
</tr>
<tr>
<td>14. I have wanted to have more information about the course of dementia</td>
<td>x</td>
</tr>
<tr>
<td>16. I have felt unsure about the course of my loved one’s illness</td>
<td>15%</td>
</tr>
<tr>
<td>17. I have not felt supported by nursing home staff in making medical decisions</td>
<td>69%</td>
</tr>
<tr>
<td><strong>Nursing Home Relations</strong></td>
<td></td>
</tr>
<tr>
<td>21. I have felt that the staff at the nursing home have not communicated with me about medical decisions for my loved one</td>
<td>54%</td>
</tr>
<tr>
<td>23. I have had difficulties communicating with staff at the nursing home</td>
<td>31%</td>
</tr>
<tr>
<td>24. I have had difficult relationships with staff at the nursing home</td>
<td>54%</td>
</tr>
<tr>
<td>27. I have felt that my loved one is not getting good medical care at the nursing home</td>
<td>61%</td>
</tr>
<tr>
<td>28. I have felt that my loved one is not treated with respect at the nursing home</td>
<td>46%</td>
</tr>
<tr>
<td>29. I have felt that my loved one has not been clean or well-groomed at the nursing home</td>
<td>23%</td>
</tr>
<tr>
<td>30. I have felt that I have not been made to feel welcome at the nursing home</td>
<td>85%</td>
</tr>
</tbody>
</table>

Table 2 above shows the data obtained via the participants’ responses to the FDADS. Although participants were given the full 31-item scale, the data presented here only contains 21 items. This item deletion is according to the guidelines set by the developers of the scale, who decided to omit ten items that had low factor loadings after the scale was tested on a significant sample of participants (Givens et al., 2015). The items are grouped under three domains that were designated by the developers of the scale, which are “Emotional Distress,” “Dementia Preparedness,” and “Nursing Home Relations.” Overall, the scale had a positive skew, meaning that participants had low distress values; as demonstrated by how “Never,” “Rarely,” and “Sometimes,” were the most frequently chosen response categories. Within the domain of “Nursing Home Relations,” participants indicated the least amount of
distress. For two of the items within that domain, participants exclusively chose “never” or “rarely” and for the remaining 5 items only 8-15% or 1-2 of the participants reported that they “sometimes” felt distressed.

The “Dementia Preparedness” domain was intended to capture stress associated with “lack of knowledge of the course of dementia” as well as “surrogate decision-making” (Givens et al., 2015, p. 779). Interestingly, two of the items that related directly to interactions with nursing home staff – items 17 and 18 – produced similar results as the items in the “Nursing Home Relations” subscale. That is, participants reported very low distress values, with both items having 69% of participants reporting “never” and the remaining 31% indicating “rarely.” In contrast, there is more variability and distress reported in the first three items of this domain, which are items 1, 14, and 16. These items more directly reflect the family members’ knowledge of dementia, and between 31-54% of participants chose the response category “sometimes,” and one participant (8%) felt that they “always” wanted to know more about the course of their relative’s dementia (Item 14).

In comparison to the other subscales, the “Emotional Distress” domain elicited the most frequent responses of distress from the participants. Out of the 9 items in this domain, 5 of the items consisted of at least one participant that “always” felt distressed. Moreover, 7 of the items within this subscale demonstrated that at least one participant “often” felt distressed. Item 11 represents the most clearly distressed responses, with 53% of the participants feeling either “often”/“always” depressed or sad by their parent’s illness. Likewise, item 10 drew predominantly distressed responses - 46% “often”/“always” and 38% “sometimes.”

As previously noted, four major thematic areas emerged from the data – role of facility, role of education, caregiver role, and role of meaning. Within these thematic areas are multiple themes that provide more descriptive insight. Exemplifying quotations and abstracts are included in the presentation of these themes. Additionally, specific items of the FDADS that relate directly to the themes are explored to compliment and provide further depth to the findings.

Role of Facility

The opening question of the semi-structured interview – “Tell me the story of how your loved one came to live at the nursing facility” – elicited some of the most rich and in-depth responses from the family caregivers. For all the participants, the nursing facility was an absolute necessity that had both a beneficial and negative impact on the lived experiences of the family caregivers. This facility-family caregiver dynamic is further explained in the themes below:
‘Peace of mind’

The twenty-four hour seven-day-a-week care provided by the nursing facilities was the most frequently named benefit of institutionalization. Family members consistently expressed relief about not having to worry because they were assured that their parent would be safe and secure in a nursing facility. The family caregivers viewed institutionalization as the best course of action to protect the well-being of their parent with dementia; all seemed to share in the mentality that “there’s too many risks, not to do what we did” (Frank). Even when the caregiver felt guilty about or reluctant to relinquish care of their parent to a nursing facility, they were unwaveringly certain that institutionalization was the best course of action for their parent. As one son stated:

Oh sure! It’s hard, I mean you... you think all your life – all of my life I’ve seen her at home. Now is the first time I’ve got to go someplace else to see her and I know that she’s going to lose her home, which is all she’s got left. So, you know, what do you do? You just got to think to yourself what’s the best thing for her – not what’s the best thing for me, because what I feel and what she needs to do is two different things. (Frank)

Impressed by institutionalized care, one participant said that many who keep their parents at home are doing it for selfish reasons:

These people, ‘Oh, I want to keep my mom!’ Well, you’re not helping her any – unless you are going to be there with her twenty-four seven, you know. And people say, ‘Oh well, you know, the money... ’ I’m like, ‘It’s their money. Spend it on taking care of them.’(Anne)

Another aspect of institutionalization that granted family caregivers peace of mind was the prevailing idea that medical experts know best and can do better. Numerous family members stated that their relative was “healthier”(Julie), in “better shape” (Frank), and “engaged in more activities.” These visible improvements in their parent’s health were often attributed to the medical expertise represented by a “team of caregivers” (Fitzgerald) who “know what to do” and have “got a process” (Julie). One participant gave an example of the benefits of medical expertise present in nursing facilities:

Knowing that there are people here that know she needed to start using a walker and you know, just all these different kind of things, you know, because had... had she stayed where she was, I mean, she was using a cane, well as it turns out, that’s like a worst thing you could do for somebody, is have them... I mean walkers are so much safer, you know, so I never realized that. (Collen)
But within the family caregiver’s respect for nursing facility staff, there is a subtle nuance, which can be best delineated as the consumer dynamic. That is, the majority of family members have an expectation that entrustment of their parent in the facility’s knowledgeable, but expensive care, warrants excellent service. Comments and expressions such as “when you spend that kind of money what we spend every month to live here….” (Colleen) were commonly made. And as one caregiver judicially explained:

Consumers like me and others – and my mom has enough means, just enough to be able to afford that – you sort of expect it to be good, and I think there’s probably this underlying current of, you know, I think the people that work there know that there’s an expectation that this is... you know, they have to really provide something special because of the capital part of it, right? (Fitzgerald)

‘They tell me everything’

When talking positively about the facility and the care they provide their parent with dementia, the family caregivers seemed most impressed by staff that was proactive in their communication and inclusion of the family member when making any medical decisions about their parent. Even if it meant being called daily by nursing staff for the smallest change in medication, the family members felt more connected and a part of the caregiving dynamic in the facility when the staff was “always keeping me informed of what’s happening” (Rosamund). When asked why she felt the staff supported her as a caregiver, Natalie earnestly replied, “They listen, uh, they’ll ask questions, they call, they’re very good.” Another participant, Donna, described a situation where she and the staff were confused as to why her mother was not sleeping at night. The staff eventually figured out that the nurse on duty at night was African-American and the woman’s mother had never closely interacted with black people. Consequently, her mother was too frightened to fall asleep at night. The staff eventually figured out that the nurse on duty at night was African-American and the woman’s mother had never closely interacted with black people. The whole event bonded the family caregiver to the caregiving staff; in her own words:

I felt very taken care of by them, that they pointed it out to me and how they handled it and they figured out why she wouldn’t sleep and yes, I feel like I work with them. (Donna)

Staff keeping the family caregiver updated about their relative’s well-being also contributed to the family member’s sense that the nursing staff “care[d] about your loved one” (Fitzgerald). Staff
taking time to “stop and talk” (Rosamund) to the caregiver about their parent, or informing the family
caregiver that their mom or dad is “having a bad day” (Donna), were key interactions that facilitated a
feeling of partnership that was so deep that some participants referred to the nursing staff as “friends”
(Alan) or even “part of the family” (Fitzgerald). Moreover, this transparent communication is not limited
to phone calls, but also, family caregivers highly valued transparency and responsiveness when they ask
the staff questions or expressed concerns. Being receptive to the participants’ needs and being willing to
listen to “the family’s concerns” (Donna) were acts of good will that were extremely meaningful to the
caregiver.

The participants’ overall positive assessments of the nursing facility in the interviews were
reflected in the quantitative results. Within the Nursing Home Relations subscale, 11 (85%) of the
family caregivers never felt that they had not been made to feel welcome at the nursing home (Item 30);
and each of the participants have never/rarely felt that the staff at the nursing home has not
communicated with them about medical decisions for their parent (Item 21).

‘It’s just a job’

Conversely, family members spoke the most disparagingly of the nursing facility when they felt
the staff was lacking in sensitivity and attentiveness in the care of their parent with dementia – “my
other issue is the dining… the dining staff. Um, they just here recently are not very friendly, and this is
where they [the residents] live” (Natalie). From relatively minor offenses such as not making their
parent’s bed in the morning, to strikingly disconcerting events like staff not feeding one of their parents
breakfast, family members were highly frustrated when they perceived that some of the “aides just don’t
care” (Anne). Absence of compassion among the nursing staff was a key source of disillusionment for
family members. In the words of one participant:

But, I did see a division, almost as plain as night and day when my dad got to a point, mentally
and physically, where he was being a real burden on some of them and the others, it was
unconditional love – it didn’t matter, but, the other ones were like…. and that bothered me,
because I’m like ‘Oh my Gosh, you were so nice to my dad until he got like this!’ You know, that
hurt. (Mike)

As illustrated in the above excerpt, just as strong connections are made on a shared understanding and
desire to care for the individual with dementia, so to are sharp divisions made in the family-staff
relationship when the staff mistreats the family member’s parent on the basis of physical decline.
Furthermore, family members found it problematic when the facility had “new staff” (Donna) because
they are oblivious of the specific preferences of their parent. For example, one participant said:
I would change the turnover. I mean, like, it would be nice to have consistent people in there... They just don’t get to know her. You know, like, she drinks hot tea, she doesn’t like coffee. New staff will give her coffee all the time and then she gets mad. (Michelle)

Interestingly, some of the family members would rationalize much of the uncaring or lazy behavior of some of the nursing staff by making comments such as, “I can’t imagine doing that kind of work day after day” (Mike) and “You have to protect your heart, I would imagine” (Alan). In contrast, other family members view the lack of caring and “observing” (Julie) from a consumer-driven perspective, stating simply, “you chose this job. If you don’t want to be in it, choose another one” (Anne).

Despite the complaints mentioned above, the participants’ frustrations did not translate quantitatively. Only 1 participant “sometimes” had difficult relationships with staff at the nursing home (Item 24). While 53% of family members indicated that they “rarely” had difficulties communicating with staff at the nursing home (Item 23). In contrast to the grievances mentioned about staff sometimes being apathetic and uncompassionate, almost 50 percent of the participants have “never” felt that their parent was not treated with respect at the nursing home (Item 28).

Role of Education

‘fait accompli’

Despite their caregiving role being quite transformative in the lives of the participants, the majority of family members in this sample took a very casual and learn-as-you-go approach to being a caregiver of an individual with dementia. These family caregivers often characterize their parents’ health state in fatalistic language, generally expressing that learning more about dementia is futile because “dementia is going to be dementia” (Anne), “it is what it is” (Colleen) and their parent getting their memory back is “never going to happen” (Frank). One family caregiver even described a situation in which his sister excitedly called about a potential new dementia-related drug, and the participant replied, “We’re past that…” (Alan).

Participants who viewed dementia education in this light often said they “learned a little bit by just watching,” (Mike), “learned from experience” (Fitzgerald) or they cited prior experience such as witnessing a “friend’s parents go through it” (Deborah). Formal dementia education tools such as books, seminars, and support groups hold little interest for the ‘fait accompli’ family caregivers. One participant, Julie, said, “I don’t really want to read a book about dementia, I’m living it!” These caregivers identified intuition as being the best teacher and “going with the flow” (Donna) as the
primary strategy for navigating the unexpected twists and turns that are inherent in a family dementia caregiver’s career. Underlying this sense of fatalism is an ignorance-is-bliss dynamic. Knowledge about dementia can be disheartening to the caregiver in regards to both their parent’s progress with the disease and also the caregiver’s own potential genetic propensity:

*The whole genetic thing kicks in, so you’re sitting there going, ‘cause you know. I was in the OMA training yesterday and she was like, ‘Okay, so Alzheimer’s,’ you know, she started giving the statistics about it and everything was 65 and older and I’m going okay, ‘58, 59, 60 I’ve got 7 years!’ So, there was a lot of stuff, personal stuff going on. (Julie)*

*It’s terrifying, and every time I forget something, you know, when you’re stressful, you don’t get enough sleep, you tend to forget and then I forget and then I’m like ‘Oh no... I’m not going there, am I?’ (Michelle).*

So, while some caregivers are most comfortable to “not cross that bridge until [they] have to” (Frank), for others, bringing up the topic of dementia education in the interview actually challenged their preconceived ideas on the topic:

*I’ve never thought about them going catatonic, and now it’s like now you got me going, maybe I should know a little bit more. Because I would not... when that happens, I would be like ‘You broke my mother! What happened?’ (Alan)*

The dementia preparedness subscale in the FDADS contains aspects related to dementia education. The quantitative results were rather inconclusive. Only 46% of participants “sometimes” felt that they don’t know what to expect in regards to their parent’s illness (Item 1), and 31% of family members “sometimes” wanted to have more information about the course of dementia. Interestingly, the remaining 9 consisted of 8 participants (61%) who “rarely” felt the need for more information and then 1 (8%) that “always” wanted to have more information about the course of dementia (Item 14). In addition, more than 50% of the participants have “sometimes” felt unsure about the course of their parent’s illness (Item 16).

*‘kinda like an art’*

In contrast to the theme above, these family caregivers regard dementia education as having an integral and defining influence on their capabilities as a caregiver. Only three participants could be placed in this theme and each of them were actively involved in an Alzheimer’s Association support group. Education is not only a valuable asset for these caregivers, but they actually name “education as
being the number one most important thing” (Rosamund). By immersing themselves in the dementia literature and being consistent participants in support groups, these caregivers felt empowered by their knowledge. As described by one participant, “I’ve become so educated that I think it kind of prepares me for each day” (Rosamund). Books were often mentioned as a treasured resource for strategies and for providing knowledge about the progression of their relative’s dementia:

...there’s a book called The 36-Hour Day... It is very overwhelming to read it from cover to cover, but it’s a great research, like, even now I’ll look at that and say “She’s doing thus...”, you know what I mean, and there’s like – it’s a great resource... but it has different stages, so I think she’s probably a solid stage five. I know that at some point she is not going to be able to walk, she is not going to be able to talk, she is not going to be able to have eye contact and those things... will be a lot harder to deal with... (Michelle)

Furthermore, according to these participants, the involvement in the support groups seems to remain therapeutic for the caregiver no matter where they are in the trajectory of their caregiving career, for they provide both an opportunity for sharing as well as the invaluable reminder that the caregiver, is indeed, not alone.

You can learn from others by talking and sharing and through that you learn that you’re not alone... sharing your story, because I’ve learned my advice by sharing, you know and opening up, and finding connections, and, you know, you’re not alone. (Natalie)

It’s amazing what you learn from people from the support groups. I mean, everybody learns from each other, and now you know, other people come in there in the same place I was and, you know, I can offer them advice now, too. (Rosamund)

Just hearing other people’s stories, you know, as soon as you think it’s horrible, then you hear something else and it’s like... you know, you feel better. (Michelle)

Besides support groups being a rich source of caregiving tips and emotional encouragement, the caregivers also learn jargon, such as being an “advocate” for the relative with dementia, and they can adopt strategies such as “therapeutic fibbing,” which altogether enables the caregiver to better conceptualize their role and experiences as a family caregiver. One caregiver that was involved in support groups explained:

So, when somebody new comes to our support group, that’s really kind of what we teach them about is “Therapeutic fibbing.” And we have a guy who has been coming for some time, he used to be a pastor administer or something, and it was really difficult for him to lie to his wife and
he’s actually gotten really good at it now. But yeah, he had a really tough time, but if you can do that, it’s super helpful. I mean… You cannot reason with them. (Rosamund)

‘Information on dementia?… Well, not really’

When asked if the facility has taught the family caregiver anything about their parent’s dementia, the participants typically answered by providing information about the clinical support the facility offers. The most cited example is the quarterly family-care conference meetings offered by each of the nursing facilities represented in this study. According to the participants, these meetings focus more on the medical conditions of the individuals with dementia such as high blood pressure, weight goals, and sodium intake, however, little is discussed in relation to the resident’s dementia. One caregiver states:

I can’t think of any way other than we have family care conference meetings that were every… I forgot when they were now... once every... quarterly, I believe, and... but there wasn’t much discussed about that [dementia]. (Mike)

Just kind of to see as what to expect next, that would be really helpful. Especially when we do the care meeting, because it’s mainly on ‘Now we need to put her on physical therapy to do this, or medications, or this and... we still got her on a low-salt diet, but not the one you want.’ But, you know, that’s what the care meetings are, but if you could go ‘Okay, nobody can tell me for sure, but just so that you know, here’s what could happen next.’ (Alan)

I would say the Alzheimer’s group has helped more than the staff. Sometimes, I’ve seen them and heard them redirect, you know what I mean, so I’ve kind of maybe learned a little bit of that from them, but I would say mostly it’s the group. (Michelle)

Nevertheless, numerous caregivers noted that the facility modeled for them how to effectively deceive their family member during challenging interactions, like saying “goodbye” at the end of a visit. Potentially due to dynamics imposed by an institutional authority, staff modeling behavior in the context of interacting with residents greatly shapes what the caregiver considers as appropriate and not. The tendency to hold in high esteem the opinions and behaviors of medical experts is clearly seen in this excerpt:

So, I mean, I have, you know, one time I was leaving and she was getting upset, “Well, who’s going to have dinner with me. I’ll be eating alone.” Well, the activities director came over and said, ‘You are gonna have dinner with me.’ Of course, she wasn’t, but you know, at that point, it wasn’t going to be an issue a half hour later who she was having dinner with because she wasn’t going to remember that Michelle had promised to have dinner… But, you know, there, they have no. There is no like hesitation on their part. They have no problem, just saying what needs to be said to make the situation go away. And it’s good to watch them do that because then you get clues. (Julie)
Yet another caregiver was encouraged to use deception to mitigate his mother’s challenging behavioral outbursts. Although the caregiver originally felt uncomfortable deceiving his parent, he justifies the behavior advising that, “once you pay attention to what professional people are telling you, it usually gets you through” (Frank).

**Caregiver Role**

‘It’s watching your mother become your child’

A predominant metaphor employed by the entire sample was the reversal of child-parent roles. For family caregivers, the image of the parent becoming the child and the child becoming the mommy/daddy is twofold in meaning. First, it denotes the difficulty and intensely painful transition of “losing” (Alan) the person that their parent used to be; one caregiver expressed, “it’s a sad way to see your parent, you know, especially somebody who you’ve looked up to all your life” (Colleen). Alan described his disbelief at the seemingly cruel cyclical journey of life:

*There’s no way, this is my mom! This is the mom who takes care of me, she can’t...you know, lost all of things, and I’ve watched it go from my mom driving and my kids not, into my kids driving and my mom not, and then, you know, my mom’s ninety-two, but she thinks she’s ten years old, you know...* (Alan)

Second, the “becoming the parent” metaphor is how these family caregivers have come to understand their role as a caregiver. Deborah, who cried the day she signed the papers to put her mother in the nursing facility, stated, “I just feel like a mother hen.” As their family member grows increasingly dependent, the caregiver takes the role of “making the decisions for the parent” (Deborah) and even on day to day interactions they “remind [their parent] like [they] were a child” (Mike). The participants’ persistent tendency to infantilize their parent with dementia was not meant to be disrespectful or demeaning, rather it seemed to be the best way for the family caregiver to explain their role. Comparing their parent to a baby underscored their loved one’s helplessness while simultaneously providing a reason for the participant to be so consistently involved in the care of their parent – “I feel like I have to be here to make sure she’s okay. Like a baby” (Deborah).

The responses to items within the Emotional Distress subscale dovetail with the qualitative results above, producing the highest distress scores. The participants’ sense of loss and longing was pervasive. 5 participants (38%) “often” felt a sense of longing for their parent as they used to be, while one family member (8%) indicated that they “always” felt that yearning (Item 10). Moreover, more than half of the participants indicated they “sometimes” felt emotionally drained because of their parent’s
illness (Item 12) and 46% have even “sometimes” or “often” felt scared or helpless because of their parent’s dementia (Item 7).

‘I feel like the staff needs to see me’

_It feel like the staff needs to see me, they need to know I’m involved. They call me regularly anyway to tell me things that are going on, which is really great, and I don’t know if that would be the case if I never came, so it’s a really good thing personally and I think it’s good for my mom and I think it helps with the staff to be engaged._ (Fitzgerald)

Participants consistently associated their active involvement and presence in an institutionalized setting with staff providing better and more attentive care for their parent with dementia. These family caregivers see their role as being an advocate for their parents, as one daughter expressed, “I do, because there’s so much that she won’t do for herself…I think I need to be her voice” (Anne). Visiting consistently is a priority, in fact, for some, it is nonnegotiable, as evidenced by one caregiver who advises:

_Somebody once said to me, ‘When you have a parent in a nursing home, you need to visit them every day’… You’ve got to keep an eye on what’s going on, you have to be their advocate, you know._ (Colleen)

Moreover, primarily participants were convinced that their involvement in care provided that extra set of eyes and layer of attentiveness that made institutionalized care more detailed and personal. Therefore, visits often primarily involve the family caregiver “mak[ing] sure everything looks okay” (Anne) and “see[ing] what needs done and just try to fix it” (Donna). They were concerned with maintaining their parents’ dignity. Stains on the shirt, a “shirt [being] inside out” (Alan), not letting “strangers do [their parent’s] laundry” (Colleen), and “making sure [the] TV works” (Anne) are just a few of the ways the participants are “watching out” (Colleen) for their parent and making them “feel cared for” (Fitzgerald). One participant (Alan) explained this aspect of his role was enforcing “those things that to me are… quality of life things,” such as ensuring that his mother’s hearing aids always have batteries. Another participant (Rosamund) went as far as to say that, “I don’t suggest that anybody have their loved ones in a facility without somebody close by… I mean, I’ll go in and I’ll find, you know, towels that don’t belong to my mother in her room.” Even in a situation where the individual with dementia seems to be exhibiting problematic behaviors such as being incorporative, the family caregivers were willing to delve deeper to distinguish the reason behind the “acting out.” This is clearly illustrated in a situation described by Natalie:
You have to be careful. Like, um, there was as situation, where they were saying, you know, “your father is starting to throw medication”... and everything. And at first you’re like, “Oh!” And that’s, um, not uncommon, and so, but, you know, my husband and I are always, you know, seek first to understand. And so, I went and you know, I wanted to hear my dad’s side of the story. Well, according to my dad’s side of the story, which sounded pretty legit... I don’t blame him! What they were trying to do is, um, another very common situation is their sleep schedule gets wacked out...they were wanting to give him his sleeping pills at 9 o’clock at night.... (long pause)... He’s not ready to go, I mean, even if he does go to bed, it’s 11 o’clock. I mean he is not an early – different story – he’s, he’s, if he’s going to bed it’ll be after 11. I mean, he’s been that way for years. So, he doesn’t want his sleeping pill at 9 o’clock at night. And that’s okay... And so, that was then addressed and now he gets it you know. So, we’ve agreed any time he wants it after 9 until whenever the, 1:30am-2:00am...(Natalie)

Despite the presence of a twenty-four seven care team, family members saw their parents needs as more than medical, as illuminated by the words of one caregiver who was often frustrated that the staff told her mother when to go to bed – “I just wonder as I’m in there, what do these people do that don’t have somebody help take care of them?” (Anne).

Role of meaning

‘I’m important’ vs. ‘she’s not going to remember’

One of the implied purposes or meanings imbued within the family caregiver advocator role is that the caregiver still feels as though they are important and necessary to their parent’s well-being. Indeed, one participant, Donna validated her identity as a caregiver saying, “I consider myself just... yeah, I’m still a caregiver because I’m important to her life” (Donna). Some participants believe that their involvement “contributes a lot to [their parent] not going downhill with [the] dementia” (Donna), saying that they could even “tell the decline” (Mike) if only a few days were missed. Participants derived a profound sense of meaning and purpose when they felt their visits “spur [them] on” (Fitzgerald) and made their parent “happy” (Rosamund) (Deborah). Regarding living in a nursing facility as “not the greatest life and most of them know that,” one participant said he felt his visits provided necessary “encouragement” (Mike). To sense that their parent was “getting a lot out of” (Fitzgerald) the visits, validated the caregiver’s continued involvement in care because they felt purposeful in their role and connected to their parent.

I feel good. I mean, I’m glad that I live close enough that I can go a lot because I know that her world is... confused, so she sees me, and I know she’s happy to see me. (Rosamund)
On the other hand, when their parents’ dementia is at a point in which the parent is becoming less verbal and does not remember visits, the participants struggled with feeling as though their contribution to their parents care does not matter. As one participant explained, “I can go in, I can walk out to the car, come back in and ‘Where have you been? I haven’t seen you for a week’” (Michelle). Another caregiver admitted the lack of remembering made it harder to go on visits, saying

*It’s harder to go now because she doesn’t remember as much as to whether when I’ve been there or haven’t been there – she still does really well, but it’s like, ‘Oh, I haven’t seen you in so long.’ I was like ‘What? I was just here the other day. (Anne)*

In a moment of true candor, Alan described the conflict within his heart about the necessity of his involvement:

*When I’m there, two minutes later she doesn’t remember, and so... I’ve got all the things going on with the kids and our family, and it’s like ‘They’re going to remember.... but if I’m over here?’ There’s a constant tug. And there’s that feeling that I should be there instead of here and you know, just kind of the way I prioritized and rationalized it... She’s not going to remember, and go and make her as happy as I can when I’m there... (Alan)*

When Alan was asked what he wishes he could change about his visits with his mother, he simply replied, “I wish it (his role as a caregiver) was more important.”

Numerous participants cited that their parent not being able to recognize them was one of their most pressing future concerns – “Is she going to know us? That’s a big deal… recognize us still…” (Deborah). The possibility of interacting with their parent who has no grasp of the historical past and is unable to recognize their child can seem an unbearable situation for some caregivers. In the words of one participant:

*I mean, none of it’s hard. Just trying to keep on top of everything, keep everything straight and... make sure they’re taking care of her. But it's not really hard. No, hard would be having to go see her when she doesn’t know me, and... having to go see her, you know, because she might know me one day and not the next day or something like that, and the thing that she wants the most is not to outlive her mind. (Anne)*

‘Love them through this’

Some participants had learned to evolve and develop the meaning that they derived from caregiving, enabling them to find purpose in not “giving up on” (Mike) their parent despite the progressing symptoms of the disease. One participant described the process of finding his caregiving
role meaningful despite his mother’s severe cognitive impairment by letting go of his expectations and personal needs. In his own words:

*Well, I’m not so concerned with myself anymore. Like I want to see my mom, I want to hug my mom, I want to tell her something... you know. I... that’s all gone now. I can tell her things but they won’t... it doesn’t register perhaps or... she won’t remember. So, you have to let that all go... Yeah, it has to be about other things. Can’t be about you anymore...it’s more about understanding that I’m bringing something to her. That’s been good, and then also sharing my life with the residents.* (Fitzgerald)

Another participant articulated the transcendent purpose of their caregiving role in a different manner, saying, “It is... it’s my job, you know, she’s my mom. I need to go see her” (Collen). Finding purpose by still honoring and loving ones’ parents was a powerful motivator for numerous family caregivers in this study. These family caregivers work to “go where it is” (Fitzgerald) and meet their parent where they are because their caregiving role was their primary expression of love and respect for their parent. As one caregiver explained, “to love her through this is my biggest goal, it’s to just love her through this” (Colleen). Describing a situation in which his father with dementia accused the participant of not loving him, one participant, Mike, replied, “I’m like “Dad! That insults me! I come here every day. I don’t get paid to do this, why do you think I’m doing it?” Participants arriving at this point of self-actualization are best able to derive true enjoyment from caregiving and thereby they become one of the key bastions of personhood for their parent:

*“Dad’s still there. The old dad that we loved is gone. But, this is the dad we have now, we need to love this dad. We have to make the most of it.”* (Natalie)

**Discussion**

Distinct from the majority of past research, which prescriptively evaluates the effects of family-centered care and psychoeducational interventions, this study sought to inductively assess the felt-need of such programs through a mixed method design. With a particular focus on how education and the concept of family-centered care factor into their caregiving role, the aim of this study was to understand the experiences of family caregivers of institutionalized persons with dementia. Four thematic areas (i.e., role of facility, role of education, caregiver role, role of meaning) emerged from the thirteen face-to-face, semi-structured interviews, producing the following findings as related to the four research questions:
1) *What are the unique challenges and benefits of being a family dementia caregiver in an institutional setting?* Family dementia caregivers had difficulty with staff that were lazy and/or uncompassionate, yet, they benefited greatly from the peace of mind afforded by their parent having twenty-four hour seven-day-a-week medical care.

2) *How important do family members perceive the role of dementia education in their ability to be a successful caregiver?* Family members either rendered dementia education as unhelpful or even bothersome in their caregiving role or they considered education the most important enabler to their success as a caregiver; however, many of the participants had questions and confusion in relation to their relative with dementia.

3) *How important do family caregivers perceive facility support in their ability to be a successful caregiver?* Family dementia caregivers highly valued facility support; specifically, they most prized the facility being proactive in informing them of what was happening with their relative in regards to their behavior and care decisions.

4) *How do family caregivers derive meaning for their role in an institutionalized setting?* The majority of family members felt they were important to their relative’s well-being by continuing their involvement in the facility setting; a few family members purely derived meaning by equating their care involvement with loving and honoring their parent.

Within each of the aforementioned thematic areas are various themes. The subsequent section will discuss the themes further, relating them to past research in order to establish whether the data supports the need for family-centered care and psychoeducational interventions.

*Family-Centered Care*

In this study, the family dementia caregivers most valued the “peace of mind” afforded by knowing their relative was safe and secure in an institutional setting. In addition, many of the family caregivers were encouraged by their parent’s improved health due to both the attention of 24/7 medical staff as well as an increased opportunity for engagement. Utilizing Maslow’s hierarchy of needs as framework, Lopez and colleagues (2012) produced similar findings, which suggested that the foundational attribute in the family-centered approach should be the provision of basic care and
assurance of safety for the person with dementia (Lopez et al., 2012). They found that to best reassure family caregivers that their parent was safe in the hands of the nursing facility, the researchers find that staff must be in frequent and timely communication with family caregivers about the care and happenings of the care recipient. The significance of communication between staff and family caregivers is also present in the current study, as evidenced by the second theme, ‘they tell me everything,’ which represented how participants most consistently praised the staff for keeping them informed about their parent’s well-being.

Related to the above finding, the existing literature has provided a rich theoretical foundation as well as practical outcomes in support of “enabling communications” (Morhardt & Spira, 2013, p. 40) by means of staff-family partnerships (Bauer, Tarzia, & Chenco, 2013; Garity, 2006; Nolan, Bauer, & Nay, 2009). For example, one advantage of involving family members in the caregiving process is “forging a sense of ‘togetherness’” (p. 40) between staff and family, which contributes to the family members’ sense of purpose within a facility setting (Davies & Nolan, 2006). Finding purpose or meaning in their continued care involvement enables family members to successfully redefine and adjust to their role in a facility setting, minimizing role loss and potentially family caregiver burden (Davies & Nolan, 2006). The fact that this current study correlates with past research in relation to the importance and advantages of communication between staff and family members suggests that facilities should maximize the potential of such a collaboration by more intentionally implementing the partnership aspect of family-centered care.

The need for family-centered care was also reinforced by the data reflecting the challenges faced by family caregivers in institutional settings. The sub-themes, ‘It’s just a job’ and ‘I feel like the staff needs to see me,’ cohesively illustrate the family member’s desire to protect and preserve the personhood of their relative with dementia. ‘It’s just a job’ captures how family member’s became hurt and frustrated over some of the staff’s apathetic and insensitive actions towards their parent, such as not making their mom’s bed in the morning or not knowing that their relative prefers tea over coffee. The participants’ preoccupation with assuring that their parent received personalized care resonates closely with the conclusions of Palmer (2013), who found that the family caregivers’ perspectives can best educate nursing staff of practices that respect and practices that devalue the personhood of individuals with dementia. Although it may seem counterintuitive, rather than abandoning the fundamental attributes of person-centered care, family-centered care enhances them by recognizing that the “relational context in which the person lives” most influences and “contributes to the individual’s quality of life” (Mohardt & Spira, 2013, p. 40).

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In addition, the ‘I feel like the staff needs to see me’ theme illuminates how family caregivers believe they must be advocates for the quality of their parent’s care; an idea that is well documented with the family-centered care literature (Bramble, Moyle, & McAllister, 2008; Palmer, 2013; Specht et al., 2000). Esteeming the family member’s concern for and specialized knowledge of their relative, Nolan’s “carer as expert” model entails a conglomerate of care involving the staff, care recipient, and family member. Members in this caregiving partnership have their own expertise to contribute. The staff often provides more objective medical knowledge, while the family caregivers typically have a better grasp of the “experiential world” of the person with dementia (Nolan, 2001, p. 94). This reoccurring emphasis on staff-family collaboration is not only a vital element of the family-centered approach, but also, the equal standing between staff and family challenges the traditional power-relations existing in the bureaucratic, medical models that predominate institutionalized care (Rockwell, 2012). In the present study, the family caregivers intuitively recognized the limitations of this medicalization of care, and many understood their role as providing that “special care” as a way to “make a difference in the life of their relative,” which, consequently, elevates the personhood of their parent, rather than reducing them to the prescriptive identity of a “patient” (Davies & Nolan, 2006, p. 289). Ultimately, facilities should formally appropriate this relational approach to care because it promotes the “quality of lives and the importance of reciprocity and caring in social relationships” (Mohardt & Spira, 2013, p. 40), while also fostering positive staff-family relationships that are “linked to unity, trust, respect, and the recognition that family and staff each [have] their loyalties” (Nolan, Bauer, & Nay, 2009, p. 145).

Although the interview findings are well-supported by past research, some of the quantitative data obtained through the FDADS seems to undermine ‘I feel like the staff needs to see me’ theme. Notwithstanding the participants primarily positive reviews of the facilities represented in this study, it still seems logical to assume that if family caregivers considered their presence so vital in ensuring that their parent receives quality care, then they may express more distress in regards to the FDADS items related to the nursing facility or interactions with the staff. However, this was not the case, rather the Nursing Home Relation domain produced the lowest distress scores. The apparent discrepancy in the findings may be attributable to various factors. First, as reported by Stephens and colleagues (1991), the primary stressors and hassles experienced by family caregiver in institutional settings “involved care recipients’ cognitive functioning” (p. 220), rather than any staff-family dynamics. Second, family caregivers may have been hesitant to strongly accuse staff of providing inadequate care because that could have been considered a poor reflection on the family member’s ability to choose a good facility for their parent. Nevertheless, it should be kept in mind, that the facilities in this sample may objectively
provide exceptional care. However, perhaps the most compelling reason behind family member’s positive assessment of the facilities in the quantitative data is partly due to the predominant lack of education among the sample. Bramble and colleague’s recent evaluation of the Family Involvement in Care (FIC) program found that the family caregiver’s increase in knowledge of dementia was correlated with a decrease in both their regard of “management effectiveness” and their satisfaction with the staff (Bramble, Moyle, & Shum, 201q, p. 1001). The study revealed that the dementia education heightened the family member’s awareness of best care practices, resulting in an expectation and demand that the facility complies accordingly (Bramble, Moyle, & Shum). Therefore, the participants’ predominant disinterest in dementia education may make them less critical consumers.

Psychoeducational Interventions
Perhaps most importantly, this research contributes an inductive investigation on the influence of dementia education of the family caregiver role. The sample was clearly divided in relation to their esteem of education – the three family caregivers who were involved in Alzheimer’s Association support groups saw dementia education as essential, whereas the remainder of the participants thought dementia education would be exasperating and preferred learning from experience. However, those dubbed ‘fait accompli’ caregivers tended to express the most anxiousness over the future progression of their parent’s dementia, which is captured in the theme ‘I’m important’ vs. ‘she’s not going to remember.’ This particular group of family caregivers had trouble believing that their involvement in care was meaningful if their parent with dementia was no longer able to recognize the caregiver. Mirroring this finding, a recently published study termed this idea as “provisional meaning,” which refers to caregivers who primarily find meaning when “they can see a positive response to their caregiving in the older adult, feeling confidence in their care providing, and having the subjective experience that they are changing and growing” (Sánchez-Izquierdo, Prieto-Ursúa, & Caperos, 2015, p. 746). In contrast, the authors of the study reported that family caregivers who find “ultimate meaning” (i.e., a deeper sense of life meaning, typically spiritual) in their caregiving role have a better caregiver-care recipient relationship and more life satisfaction than their “provisional meaning” counterparts (Sánchez-Izquierdo, Prieto-Ursúa, & Caperos, 2015, p. 746).

The concept of “ultimate meaning” is consistent with the ‘love them through this’ theme that emerged in this current study, which represents how family members articulated their intrinsic motivations for caregiving that allowed them to feel a sense of purpose that did not vacillate according to their parent’s increasing cognitive decline. Moreover, there seems to be a link between having dementia education and being able to derive “ultimate meaning” from caregiving. As illustrated by the
‘kinda like an art’ theme, the three caregivers who were actively involved in support groups felt that their education empowered them to more effectively face future challenges in relation to their parents’ dementia, in part due to having the terminology to better conceptualize and adjust to their role; a sense of normalization or “I’m not alone in this;” strategies for dealing with their relatives challenging behaviors, and the opportunity to give back by supporting others. The positive outcomes associated with psychoeducational programs, such as support groups, are consistent with the work of Hepburn and colleagues (2005) who affirmed “psychoeducation intervention’s ability to relieve or forestall dementia caregiver distress” (p. 53). Therefore, despite the fact that the majority of the participants in the current study had a negative estimation of dementia education, their prevalent concerns and tendency to rely upon “provisional meaning” indicates their need for psychoeducational services that can provide them the tools, information, and emotional support that could better enable them to cope with the challenges of dementia caregiving.

Furthermore, this study uncovered how the medicalization of care within nursing facilities can preclude an opportunity for offering psychoeducational support. As seen in the theme, ‘information on dementia... well, not really,’ family caregivers noted how the facility’s quarterly care meetings concentrated on updating the family members on the medical conditions of their parent, but never intentionally addressed any of the family’s potential concerns/confusion about their parent’s dementia, especially in terms of how to interact with or care for a relative who was exhibiting challenging dementia-related, behavioral symptoms. Related to this, Johanssen and colleagues (2014) reported that family caregivers who lacked in information on dementia and the progression of the disease found it more difficult to relinquish care to nursing facilities. These researchers suggest that facilities should offer “easy-available and person-centered information about dementia disease and its progression” to help family members “better anticipate the future and feel better prepared” (Johannesen et al., 2014, p. 6). Findings from this study suggest that facilities should integrate a relational element in their quarterly care meetings to more holistically address the needs of family caregivers and also to fill the gap in services for those family members who either do not have the time or are uncomfortable with more public psychoeducational services such as caregiver support groups.

**Limitations**

There are several limitations associated with this research. First, although generalizability is not a goal in qualitative research, the applicability of the findings was even more limited owing to the utilization of convenience sampling as well as the homogeneity of the sample. The white and predominately well-educated participants in this study were recruited from a single geographic area in
the Midwest. Further research should explore whether the findings are replicable among a more diverse population, especially in consideration of past research on family staff partnerships that revealed there was a significant difference “in the types of activities agreed upon by African American and Caucasian family members and staff” (Specht et al., 2000, p. 72). Additionally, besides there only being 6 nursing facilities represented in this study, all of them were on the higher end of institutionalized care in both quality of care and expense, which may have potentially skewed the participant’s perceptions of the facility. Another notable area of sample homogeneity was kinship; all of the participants were the adult children of the care recipient. Seeing that the child-parent relationship significantly influences the participants’ experiences and perceptions of their caregiving role, as explicitly demonstrated by the subtheme, ‘It’s watching your mother become your child,’ further research should explore how marital relationships and other kinship ties contribute to the family member’s perception of caregiving in an institutionalized setting.

Second, there are several limitations related to this study’s methodology that potentially resulted in a more superficial understanding of the multifaceted phenomenon of caregiving. The data collection process involved a single interview with each of the participants, which resulted in findings that fail to reflect changes in the participant’s perceptions over time. For example, a longitudinal study may better reveal if family members’ perceptions on caregiving are heavily influenced by the progression of their relative’s disease. In addition, not all the themes found in the interview data were expressed in this paper, however, those that were excluded were outside of the scope or aim of this study, but may be revisited for future research. As an illustration, the data included one interview that was distinct from the rest, and lasted only 13 minutes. The premature length of this interview seemed to be indicative of the participant’s estranged and contentious relationship with her mother, suggesting that the quality of the family caregiver and care recipient relationship significantly influences the family member’s caregiving experience within a nursing facility. Moreover, the researcher found that many of the mailed in survey responses had explanatory notes or questions written beside their answers, suggesting that more accurate answers may have been obtained if the participants completed the survey in the researcher’s presence.

**Considerations for Future Research**

Although the findings may not be widely generalizable, they do generate important hypotheses that merit further exploration in subsequent research. Owing to the fact that the conclusions drawn in this study propose significant changes in the provision of institutionalized dementia care, research examining staff’s perspectives on barriers and challenges to adopting the family-centered care approach could provide crucial insight for successful implementation and standardization of family-centered care.
In regards to the apparent need for psychoeducational services that specifically cater to family caregivers in nursing facilities, the best methods for implementation as well as the details of what information these educational programs should address could also be further determined in future studies. Additionally, further research should consider the possible complications and limitations engendered by the family-centered care approach. For example, the three participants that were actively involved in family caregiver support groups were all encouraged to adopt the “therapeutic fibbing,” which was a coping strategy that entailed the family member intentionally lying to their relative with dementia in order to mitigate instances when their parent was upset or exhibiting problematic behaviors. Although “therapeutic fibbing” may be a helpful tactic for both the family member and staff, it challenges and possibly undermines the idea of respecting the personhood of the individual with dementia. Therefore, those who implement and support family-centered practices and family-staff partnerships must give pause to reflect and consider whether the needs of the family member are usurping the wishes and desires of the person with dementia. Given that relational-centered care involves the input of more stakeholders in the dynamic of care, the process of effectively and successfully implementing such practices will be more delicate and complex, although ultimately resulting in a more holistically beneficial situation.

Building upon past research that provides evidence that facilities need to more formally and systematically recognize family members as partners in the provision of dementia care for their relative (Bramble, Moyle, & McAllister, 2008), this study brings awareness to how a relationally-centered approach to institutionalized care heightens the quality of living for both the care recipient and family member. Facilities need to look for ways to intentionally provide the family members opportunities to express their preferences, concerns, and anxieties in regards to the care of their relative. Moreover, adding a relational element to care meetings could be a both feasible and practical way for the nursing staff to educate and address any confusion a family caregiver has in regards to their relative’s dementia. Ultimately, the beauty of the family centered approach is both simple and profound, for it takes care beyond prescriptive medical treatments, recognizing that “humans are not free-floating individuals unconnected from the communities that surround them” but are “social beings who thrive most when we have thick ties to kindred spirits, when we are nurtured in institutions and relationships that connect us to something larger than our selves” (Jones, 2011, para. 8).
References


Johansson, A., Ruzin, H. O., Graneheim, U. H., & Lindgren, B. M. (2014). Remaining connected despite separation–former family caregivers’ experiences of aspects that facilitate and hinder the process of relinquishing the care of a person with dementia to a nursing home. *Aging & mental health, 18*(8), 1029-1036.


Appendix A.

Demographic Questions:
1. Gender: Male or Female (will be selected by the researcher conducting interview)
2. What is your date of birth?
3. Please specify your race: White, Black or African American, Hispanic or Latino, Asian, Native American or American Indian, or other?
4. What is the highest degree or level of school you have completed?

Interview Questions:
1. Tell me the story of how [your relative] came to live in ________________?
2. What was the process of admitting them like for you?
3. How often do you visit [your relative]?
4. What does a typical visit look like? What do you do with [your relative]?
5. How do you feel about those visits? What things do you wish you could change?
6. How would you describe your relationship with the staff at the nursing facility?
7. What would you change about the staff?
8. How has the staff helped you understand [your relative’s] dementia?
9. What kinds of things have you done to learn about [your relative’s] dementia?
10. Are there things about [your relative’s] dementia that you want to know more about?
11. What have been the benefits of having [your relative] live here?
12. What has been difficult about having your relative live here?
13. How has your role as a caregiver changed now that [your relative] is in a facility?
14. Do you feel this facility supports and encourages you as a caregiver? What makes you feel that way? What do you wish you could change?
15. Thinking about the future as [your relative’s] dementia progresses, what concerns do you have?
16. Is there anything else I should know about how you learn to be a caregiver for someone with dementia?
Hello, my name is Jennifer Reep. I am a second year graduate student in the Masters of Gerontological Studies program at Miami University. For my thesis, I am examining the potential challenges and barriers faced by family caregivers of institutionalized older adults with dementia. To complete this study, I will need to interview family caregivers who have relatives that are institutionalized and suffer from dementia. I was hoping that you would allow me to advertise my research opportunity to get eligible and willing recruits.

Thank you for your time and consideration,

Jenn Reep
Appendix C.
Family Caregiving Beyond Institution Doors Study Consent Form

You are being asked to take part in a research study exploring the challenges and difficulties faced by family caregivers of older adults that have dementia and are residents of a nursing facility. Please read this form carefully and ask any questions you may have before agreeing to take part in the study.

What the study is about:
The purpose of this study is to learn about the challenges experienced by family caregivers of older adults that suffer from dementia and live in a nursing facility. To take part in this study you must be the spouse, blood relative, or in-law of the resident with dementia. You must be 18 years or older and you must be the primary caregiver of the resident with dementia.

What we will ask you to do:
If you agree to be in this study, we will conduct an interview with you. The interview will include questions about how your experience putting your loved one in a nursing facility and challenges you face in interacting with your loved one in the nursing facility. The interview will take about one hour to an hour and 30 minutes to complete. With your permission, we would also like to tape-record the interview. Once the interview is complete, you will also be given a survey that looks at any problems family caregivers experience. This survey can be completed at your own time and it will come with a prepaid envelope for you to send back to the interviewer after it is completed.

Risks and benefits:
There is the risk that you may find some of the questions about your caregiving experience to be sensitive.
1. Your answers will be confidential. The records of this study will be kept private. In any sort of report we make public we will not include any information that will make it possible to identify you. Research records will be kept in a locked file; only the researchers will have access to the records. If we tape-record the interview, we will destroy the tape after it has been transcribed, which we anticipate will be within three months of its taping.
2. Taking part is voluntary: Taking part in this study is completely voluntary. You may skip any questions that you do not want to answer. If you decide not to take part or to skip some of the questions, it will not affect your current or future relationship with the interviewer or Miami University. If you decide to take part, you are free to withdraw at any time.
3. If you have questions: The primary investigator conducting this study is Jennifer Reep. Please ask any questions you have now. If you have questions later, you may contact Jennifer Reep at westjk@miamioh.edu or at (937) 543-9915. If you have any questions or concerns regarding your rights as a subject in this study, you may contact the Institutional Review Board (IRB) at 607-255-5138 or access their website at http://www.units.miamioh.edu/compliance/irb/. You will be given a copy of this form to keep for your records.

Statement of Consent: I have read the above information, and have received answers to any questions I asked.
I consent to take part in the study.
Your Signature ___________________________________ Date ________________________

Your Name (printed) ____________________________________________________________

In addition to agreeing to participate, I also consent to having the interview tape-recorded.
Your Signature ___________________________________ Date _________________________

Signature of person obtaining consent ___________________________________ Date __________

Printed name of person obtaining consent ______________________________ Date __________
Appendix D.

Participant Name: ________________________________________________

In order to answer the 31 items below, respondents rate the frequency of a particular symptom or event over the past 3 months according to the following 5-point scale: 1 = never, 2 = rarely, 3 = sometimes, 4 = often, and 5 = always.

**Family Distress in Advanced Dementia Scale**

1. I have felt that I don’t know what to expect in my loved one’s illness
2. I have felt that I don’t know how to communicate with my loved one
3. I have felt isolated from my loved one
4. I have been concerned about what to expect when my loved one is close to death
5. I have felt my loved one is less of the person he or she used to be
6. I have felt worried that my loved one will die alone*
7. I have felt scared or helpless because of my loved one’s illness
8. I have felt that my loved one has endured enough suffering*
9. I have felt anxious about my loved one’s illness
10. I have felt a sense of longing for my loved one as they used to be
11. I have felt depressed or sad because of my loved one’s illness
12. I have felt emotionally drained because of my loved one’s illness
13. I have felt a sense of disbelief over my loved one’s illness*
14. I have wanted to have more information about the course of dementia
15. I have wanted to be more involved in medical decisions for my loved one*
16. I have felt unsure about the course of my loved one’s illness
17. I have not felt supported by nursing home staff in making medical decisions
18. I have not understood the medical decisions regarding my loved one
19. I have felt unsure about what my loved one would want in terms of medical care*
20. I have felt conflict with other family members about medical decisions for my loved one*
21. I have felt that the staff at the nursing home have not communicated with me about medical decisions for my loved one
22. I have felt a sense of guilt over having my loved one in the nursing home*
23. I have had difficulties communicating with staff at the nursing home
24. I have had difficult relationships with staff at the nursing home
25. I have felt the need to watch over the care my loved one is getting at the nursing home*
26. I have not been able to visit the nursing home as much as I would like*
27. I have felt that my loved one is not getting good medical care at the nursing home
28. I have felt that my loved one is not treated with respect at the nursing home
29. I have felt that my loved one has not been clean or well-groomed at the nursing home
30. I have felt that I have not been made to feel welcome at the nursing home
31. I have had concerns about not being able to pay for nursing home care for my loved one*

*denotes scale items that were removed from analysis due to low factor loadings (Givens et al., 2015)