Alternative Therapies in Person-centered Care for Persons with Dementia in Nursing Homes

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ALTERNATIVE THERAPIES IN PERSON-CENTERED CARE FOR PERSONS WITH DEMENTIA IN NURSING HOMES

by

KALLOL KUMAR BHATTACHARYYA
Under the Direction of Jennifer Craft Morgan PhD

ABSTRACT

Increasing numbers of people are living with dementia in every part of the globe. Curative options are unavailable through traditional medical model; alternative therapeutic approaches are required urgently. Using a grounded theory methodology, this study seeks to build an understanding of the barriers and facilitators to person-centered care (PCC) approaches and the integration of complementary and alternative approaches for people living with dementia (PLWD) and residing in nursing homes throughout the state of Georgia. This study will generate implications for implementing PCC and culture change, its barriers, facilitators and how PCC can improve the daily lives of persons living with dementia in an institutional setting. This study will describe different engagement activities and alternative therapies which promote relaxation and improve quality of life of those individuals. This knowledge of the landscape of activities will help us identify and improve strategies for supporting PLWD at a deeper, more meaningful level.

INDEX WORDS: Dementia, Person-centered care, Barriers, Facilitators, Alternative therapies
ALTERNATIVE THERAPIES IN PERSON-CENTERED CARE FOR PERSONS WITH
DEMENTIA IN NURSING HOMES

by

KALLOL KUMAR BHATTACHARYYA

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of
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ALTERNATIVE THERAPIES IN PERSON-CENTERED CARE FOR PERSONS WITH
DEMENTIA IN NURSING HOMES

by

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Office of Graduate Studies
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May 2019
DEDICATION

This work and accomplishment is dedicated to my adorable God, late Sri Sri Manimohan Goswami.
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The current study uses data from the Federal Civil Monetary Penalty (CMP) grant funded study, “Building Resources for Delivering Person-Centered Care in Georgia Nursing Homes,” (Grant Number. CON 009319, received from the Centers for Medicare and Medicaid Services (CMS), in partnership with the Georgia State Survey Agency, Georgia Department of Community Health, Healthcare Facility Regulation Division) where Dr. Jennifer Craft Morgan and Dr. Elisabeth O. Burgess are the Co-Principal investigators.

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1 INTRODUCTION

The global population is aging rapidly. This demographic change has implications for the lives of older adults across the globe. Morbidity over the life course has a profound impact on the quality of life of older adults. Many countries were home to over a million of people with dementia in 2015; among those, the US (4.2 million) held the second and India (4.1 million) the third spot behind China (9.5 million) (Alzheimer’s Disease International, 2015). It is estimated that the number of dementia patients will almost double every 20 years, to grow from 46.8 million in 2015 to 131.5 million in 2050 (Alzheimer’s Disease International, 2015). As we proceed towards late adulthood our general cognitive abilities tend to decline (Lezak, Howieson, Bigler, & Tranel, 2012; Murman, 2015; Salthouse, 2010). As a consequence of increased longevity, there are different age-related conditions occurring which lead to increased neurodegeneration (Murman, 2015; Salthouse, 2010). The obvious consequence of this is the increasing number of people living with dementia in every part of the globe.

Dementia, which is defined as the progressive deterioration of cognitive function of an individual, is probably the most unrecognized and undertreated chronic condition in the world today (Maalouf, Ringman, & Shi, 2011). Dementia can be regarded as an umbrella term covering different cognitive impairment and neurodegenerations causing various functional and behavioral problems (Tampi, 2013). Dementia has no definite curative intervention available through modern medications; as such it is a major public health challenge (Fan & Chen, 2011; Mapelli, Di Rosa, Nocita, & Sava, 2013; Tarawneh & Holtzman, 2012). If we see this issue from the gerontological perspective, this is not only a concern of physicians; rather, it poses a challenge for all the people involved in care. Management of dementia is now more a social problem than clinical. This social problem requires socially meaningful solutions which include
a tailored, individualized approach to care (Kitwood & Benson, 1995). The people involved in care have to gather practical experiences and realize how the persons living with dementia lead their life, so that we can plan accordingly how to improve their quality of life. These education and eventual skills will allow us to contribute meaningfully to improving the care and quality of life of individuals living with dementia and their care partners.
2 LITERATURE REVIEW

2.1 Management of dementia: A new care approach

A person-centered approach shifts care from a traditional medical model to a social model in the management of dementia, where personal autonomy, choice, comfort and dignity, and purposeful living are foregrounded (Desai, Wharton, Struble, & Blazek, 2017; Fazio, Pace, Flinner, & Kallmyer, 2018; Power, 2010). The progression of disease process in dementia varies depending on the underlying disease; even this varies from person to person coping with different multiple comorbidities. In some, the onset of cognitive decline may be slow, while in others, this decline shows rapid progression. Likewise, the behavioral, psychological symptoms, and the family and social environments also differ from person to person (Molony, Kolanowski, Van Haitsma, & Rooney, 2018). Different discrete factors determine the actual mental state of a person with dementia (PWD) and those can be discerned only through detailed observation (Fazio, Pace, Flinner, & Kallmyer, 2018; Kitwood & Bredin, 1992). Therefore, the evaluation of every PWD is different and management should be individualized according to the person’s need and living environment to provide optimal care (Takeda, Tanaka, Okochi, & Kazui, 2012).

Direct care workers provide 80-90% of the care of older adults in formal services. As such, it is very important to learn about the experiences of the frontline staff and direct care workers regarding “Person Centered Care” and “Culture Change”. By definition, “Person centered care is an individualized goal-oriented care plan based on the person’s preferences, where care is supported by an inter-professional team in which the person is an integral team member” (CMS Ref: Definitions 483.5). “Culture change is the common term given for the transformation of older adult services, based on person centered values and practices where the choice, dignity, respect and quality of living of older adults and those working with them are
considered and respected” (CMS Ref: S&C: 11-42-NH). Culture change increases resident choice, empowers staff, and is associated with improved care and outcomes for nursing home residents (Miller, Lepore, Lima, Shield, & Tyler, 2014). Also, it is very important to learn about the barriers and facilitators in implementing person-centered care at different organizations from the different point of views of various caregivers. Currently, in managing dementia, the medical model focuses on deficits and loss, but the social model focuses on individual experience and remaining strengths and abilities (Power, 2010). Person-centered care has the potential to interrelate those two approaches. This positive energy of any member of the care-team impacts the activities of all other members of the team involved in person-centered care. Dementia not only causes personal (physical and mental) harm to the persons having it; sometimes residents have bad days (in terms of mood), and care workers need strategies to redirect anger, frustration and associated behaviors. The current study is focused on finding pragmatic ways to get the maximum benefit of person-centered care in order to improve the quality of life of the residents.

Loneliness, helplessness and boredom are three major factors responsible for most of the suffering of older adults (Desai & Grossberg, 2001; Thomas, 1996). Therefore, we also need to promote joyous feelings in these people (Fazio, Pace, Flinner, & Kallmyer, 2018). Respecting the wisdom and experiences of older adults, we have the opportunity to help them find ways to contribute based on strengths, past experiences and social engagement to their communities and social groups.

2.2 Management of dementia: Traditional medical model

Dementia is an outcome of different diseases (like Alzheimer’s disease, Parkinson’s disease, post cerebrovascular accident etc.), but most of these diseases causing dementia are progressive, which means that the persons with the disease will likely only get worse over time.
As there is no specific curative management available, drugs are used either for symptomatic relief or to slow the disease progression. Cholinesterase inhibitors such as donepezil and tacrine are the most notable examples showing a slowed rate of clinical decline (Casey, Antimisiaris, & O’Brien, 2010). But most of these costly drugs have limited effectiveness for most patients (Casey, Antimisiaris, & O’Brien, 2010). Often, they can cause undesirable side-effects such as liver toxicity (tacrine) and sleep disorder (donepezil) (Casey, Antimisiaris, & O’Brien, 2010). PWD are likely to be on numerous medications, due to multiple comorbid conditions. It is the responsibility of both informal caregiver and medical service provider to ensure that they are taking those medicines properly and in optimal dosage (Poland et al., 2014). But, practically maintaining all these responsibilities together is impossible in most of the cases, so only of limited value. Research on the medical model of therapy occupies a huge amount of funding, but constructive results have yet to come (Takeda, Tanaka, Okochi, & Kazui, 2012). Currently the aim of treatment is not restricted to the reversal of the cognitive damage associated to the disease process, but on the management of the associated symptoms and enhancing the quality of life of those persons having dementia (Kaldjian, Shinkunas, Bern-Klug, & Schultz, 2010).

2.3 Management of dementia: Promising alternative approach

The complementary and alternative medicine (CAM) has a potentially significant role in the management of dementia and the use of CAM in the USA is increasing rapidly (Lavretsky, 2009). According to the American Cancer Society, CAM is defined as “supportive methods used to complement evidence-based treatment. Complementary therapies do not replace mainstream treatment and are not promoted to cure disease. Rather, they control symptoms and improve well-being and quality of life” (Takeda, Tanaka, Okochi, & Kazui, 2012). A national US survey noted a 47% increase in total visits to CAM practitioners, from 427 million in 1990 to 629
million in 1997 (Lavretsky, 2009). According to a survey done in Boston, the United States in 2001 on 2055 persons aged 18 years and above, diagnosed with a mood disorder, 57% of persons with anxiety disorders and 54% of people with depression were using CAM treatment to get beneficial effects (Kessler et al., 2001). It can be assumed that the perceived helpfulness of CAM therapies is similar to that of conventional therapies (Kessler et al., 2001; Lavretsky, 2009). In another study, i.e. Health and Retirement Study (n=1099), approximately 88% of respondents over 65 years used CAM, which is much more than preceding years (Ness, Cirillo, Weir, Nisly, & Wallace, 2005). In some places, these so-called non-traditional approaches are used with existing conventional medical management (complementary) and in other places, they are used alone (alternative). The beneficial role of CAM health interventions and their effectiveness on the outcomes of health status and healthy aging is already established (National Center for Complementary and Integrative Health, 2016). Currently, different CAM practices are used, such as using natural products, Ayurveda (ancient Indian herbal medication), yoga and meditation (mindfulness practices), chiropractic manipulation, dietary modification with different food-items, laughter therapy, music therapy, etc. (Desai & Grossberg, 2001; National Center for Complementary and Integrative Health, 2016) (Figure 1). The popularity of mindful practices has increased dramatically in the last decade; the number of adult residents of the United States practicing this has doubled in this time (National Center for Complementary and Integrative Health, 2016).

Different psychosocial practices are showing encouraging results in terms of the reduction of behavioral and psychological symptoms of dementia (BPSD) and in improvement in quality of life for PWDs (Testad et al., 2014; Fazio, Pace, Flinner, & Kallmyer, 2018). Common behavioral and psychological strategies are engaging the PWDs with validation therapy,
reminiscence therapy, music therapy, pet therapy, and other meaningful activities (Scales, Zimmerman, & Miller, 2018). Current “alternative joy practice,” espoused by the Eden Alternative model tells us to engage older adults in meaningful and spontaneous activities. Cognitive rehabilitation therapy is a behavioral model of management for the persons having cognitive impairment to improve cognitive skills through continuous practice of compensatory activities (Choi & Twamley, 2013; Kurtz, 2003). Engagement as a part of cognitive rehabilitation therapy is also a tool used to mitigate worsening cognitive incapability (Choi & Twamley, 2013).

2.3.1 Dementia care: The present scenario

Many researchers have used different designs and methods to show the positive effects of CAM for persons having dementia. In my literature review, I seek to integrate ideas from the commonly implemented mindful practices used in the wellbeing of PWDs to understand the methods used in different studies and how they were evaluated.

Currently there are 374 nursing homes available for nearly 69% of the older adults (aged 65 years and older) who need long term care in the state of Georgia (GHCA, 2017). In the context of a continuous increase in the older adult population, the need for nursing home care will continue to grow. In most nursing homes, the residents’ management plan generally follows a fixed schedule designed for groups of residents to support staff to manage care activities; individual treatment plans have not traditionally been the primary focus (Bergman-Evans, 2004). The professionals engaged in resident management in the nursing home settings are challenged to implement new ideas in caregiving due to an increased workload within a limited time frame. But fresh concepts are required as an alternative management tool, which need awareness generation and ongoing education of the residents and employees (Bergman-Evans, 2004).
Another challenge faced by the direct care workers is that often the older adults show resistance to learning new skills, and can feel as if their current knowledge is being challenged. Often, attempts to change individual behaviors and organizational care practices become very difficult, and usually end in old and traditional practices (Maslow, 2013).

2.3.2 Dementia care: The common symptoms

As a consequence, the nursing home residents feel monotony in their lives and subsequently develop feelings of loneliness, boredom, and helplessness (Hinman & Heyl, 2002). These are the three most common causes responsible for most of the sufferings of the PWD. Bill Thomas (1996) first introduced the term “the three plagues” to denote loneliness, boredom and helplessness. Loneliness is the unpleasant sensation felt when an individual wants companionship, but can’t get it (Thomas, 1996). Loneliness generates from the dearth of social contact, and from the absence of persons available to share social and emotional experiences (Victor, Scambler, Bond, and Bowling, 2005). Loneliness is a common feeling of older adult residents in different long term care facilities and is a consequence of various losses experienced by them. The losses may be of the companionship of family and friends, or of autonomy and self-identity (Butler, 1995; Tijhuis, De Jong-Gierveld, Feskens, & Kromhout, 1999). Loneliness has a profound impact on both the physical and mental well-being of older adults, especially in long term care settings; it is associated with increased blood pressure, sleep disturbances, depression, and anxiety (Cacioppo & Hawkley, 2009). Nummela, Seppanen, and Uutela (2011) conducted a longitudinal study for 3 years on older adults, where they found loneliness was a significant contributor to poor self-rated health scores, both in outpatient and inpatient settings. They also emphasized that the reduction of loneliness led to an improvement in self-rated health.
According to Thomas, helplessness is the sensation of pain felt by an individual when he/she receives persistent care and support, but the individual has little to no opportunity to contribute to others, whereas boredom is the pain felt when an individual’s life becomes monotonous and lacks spontaneity (1996). If residents feel bored during any phase of management, the concerned caregivers experience burnout (Thomas, du Toit, & van Heerden, 2014). Vodanovich, Verner, and Gilbride (1991) conducted a study where they assessed the relationship between boredom and other unpleasant affective conditions and reported how boredom proneness scores significantly correlates with depression (r = .44), hopelessness (r = .41), and loneliness (r = .53).

2.3.3 Dementia care: Engagement through companionship

Loving companionship is one of the remedies for these factors (Thomas, 1996). This may come from the same age group (older adult community), paid care workers, or different age groups of informal caregivers (traditional multigenerational family with company of grandchildren). There are very few studies which have focused on how older adults respond to their interaction with children. In a study conducted by Ivey (2001), the author assessed the feelings and perceptions of older adults with the groups of children who participated in a routine visitation program to a nursing home over a period of three months and compared the result with same-age groups which did not participate in the program. After evaluating the results, she found the feelings and perceptions of older adults were more positive with the participants than nonparticipants, irrespective of age groups. The children participants generally expressed their views that the older adult residents have characteristics of their grandparents, are friendly and willing to spend time with them. In another study among nursing home residents, the nursing home staff reported that the residents who interacted with children in different situations
expressed increased participation in treatment plan and physical activities. They also showed reduced stress, and enhancement in emotional wellbeing (Banes, 1997).

2.3.4 Dementia care: Engagement through mindful practices

Mindfulness practices are gaining huge popularity nowadays in the management of many chronic diseases, especially dementia. Meaningful engagement in everyday life is required for individual wellbeing, and it enhances the quality of life for the persons having dementia (Cohen, 2006). On the other hand, meaningless activities, i.e. activities that don’t promote individual wellbeing, gradually destroys the human spirit (Thomas, 1996). Therefore, always we must try to engage ourselves in different meaningful activities in our life. This study will explore something which will be therapeutically beneficial for humankind, for numerous persons suffering from cognitive impairments and dementia.

2.3.4.1 Mindful practices with yoga and meditation

Yoga is an ancient Indian technique of mind-body interrelated practice, which consist of physical postures (asana), breathing exercises (pranayama) and meditation (dhyana), which is gradually popularizing in the Western world also (Gothe, Kramer and McAuley, 2014; Hariprasad, Koparde, Sivakumar, Varambally, & Thirthalli, et al., 2013). Yoga has the power to boost memory; thereby it could have a profound impact on dementia. In our body “down regulation” is the physiological process of reduction of cellular receptors to a particular substance, such as a hormone or neuro-transmitter. When the receptors are frequently exposed to an excessive amount of that particular substance, it reduces cellular sensitivity of that substance. Yoga has a down regulatory effect on sympathetic nervous system and hypothalamus-pituitary-adrenal organs in response to stress, and also has a profound influence on one of the major neuro-transmitters, dopamine. It can reduce neuro-inflammation and improves cognition. The
combined effect of loneliness, boredom and helplessness causes fear and anxiety. Also, in some individual this can cause depression, which is one of the risk factor for developing dementia (Kales et al., 1999). Yoga, through its down regulatory mechanism has a negative feedback effect to develop further loneliness, boredom and helplessness. There are about 86 billion neurons in the human brain (Eswar, 2017). Dopamine acts as a major neurotransmitter in our brain. It boosts our drive, focus and concentration. Researchers found that many of our positive aspects of behavioral and cognitive effects are associated with high dopamine levels in brain (Ashby, Turken, & Isen, 1999). Low dopamine levels can lead to stress, anxiety, lack of will power and memory loss (Eswar, 2017). But there are plenty of natural ways to increase dopamine in our brain, such as avoiding addictions (tobacco, alcohol etc.), eating tyrosine-rich food items (banana, almond, chocolate, egg etc.), regular physical and mental exercises, increasing and improving social relationships (Eswar, 2017). Hariprasad et al. (2013) showed that yoga-based intervention causes significant improvement in both immediate and delayed recall of verbal and visual memory, attention, and executive function. They conducted a study on 87 older adult residents in an elderly home for 6 months and concluded that yoga-based intervention proved to be beneficial in many aspects of cognitive function and memory among elderly individuals.

2.3.4.2 Mindful practices with music

Over the last few decades, music has been studied as an influential factor in the management of cognitive decline (Hegde, 2017). In this respect, classical music (both Western and Eastern) has a great importance. The impact of the Western classical music has been researched to a great extent. Vleuten, Visser and Meeuwesen (2012) carried out a study where, in an institutional setting, individuals with different levels of dementia were exposed to live music
for a span of 45 minutes (one time). The impact of live music on PWDs was evaluated for four criteria: involvement of participants, communication, physical wellbeing, and mental wellbeing. The assessment were done by the researchers based on a three-point Likert scale with 17 different items. The researchers found that communication, care relationships, and emotional behaviors of PWD were improved after the live music performance. In another study, Hays (2005) studied 54 older adult participants from the community to assess the effect of music on their emotional and social wellbeing. They found that music provides the participants an opportunity to develop their self-identity by introducing themselves and how they want to be recognized by others and to maintain emotional well-being. Music also helps them to achieve healthy aging by maintaining a positive self-esteem, feel confident, independent, and avoid feeling of loneliness. In another study, the researchers found that music therapy has a positive impact on older adults with dementia by reducing agitation. The researchers also found a positive correlation of music with improved mood and socializing skills (Wall & Duffy, 2010). Among the Eastern part, *Ragas* (Sanskrit word, meaning “one which induces emotion in the mind”) are the core material of Indian classical music. There are certain Ragas, for example “Desi-todi”, which, if listened to “for 30 minutes every day for 20 days, has been shown to produce a significant decrease in systolic and diastolic blood pressure, to reduce stress, anxiety and depression, and to enhance feelings of life satisfaction, experience of hope and optimism” (Hegde, 2017, p. 31).

2.3.4.3 Pet therapy

Pet therapy or animal-assisted therapy (AAT) has also been shown to have a positive influence on PWD. AAT includes the interactions of the PWD with an animal (Bernabei et al., 2013). Neuropsychiatric symptoms like agitation is very common in PWD. Agitation not only
causes harm to the PWD, but also creates confusion and complexity for the caregivers, both formal and informal. It is evident that AAT, involving either live or robotic pets may cause reduction of symptoms like agitation in PWD (Desai, Wharton, Struble, & Blazek, 2017).

Animal assistant intervention has a positive effect on cognitive impairments of PWD, by increasing social interaction and lowering agitation (Bernabei et al., 2013). Based on the Mini Mental State Exam score, Kanamori et al. (2001) conducted a cross-sectional study of AAT for three months on 27 individuals, and found that AAT improved the cognitive status of PWD. They compared the Mini-Mental State Exam (MMSE) scores at baseline to that measured after three months. The researchers found significant improvement in the average baseline MMSE scores in the AAT subjects (n=7) compared to the control (n=20) group (Kanamori et al., 2001). They also evaluated the salivary chromogranin A (CgA), as a mental stress index, and found a decreasing tendency of CgA in the AAT group.

### 2.3.5 Dementia care: Limitations

Globally, gerontology is relatively a new field in the domain of care and management. Currently, in the United States there is a shortage of caregivers; fewer than one percent of registered nurses, physician assistants and pharmacists identify themselves as specializing in geriatrics (Institute of Medicine, 2015). Similarly, only four percent of social workers have formal certification in geriatric social work (Institute of Medicine, 2015). The awareness of general people regarding management of dementia is very limited. Healthcare professionals also do not encounter many cases in their practice, because there is rarely a special emphasis on dementia diagnosis and management in the training of healthcare professionals. On the other hand, people who are not aware of dementia assume it to be the same as normal aging. This affects the way they support and treat persons with dementia. As person-centered care is a
relatively new approach, implementation and assessment of effectiveness is a work in progress. Recruitment, retention and education of those individuals in leadership roles is key to implementing person-centered care and leading organizations on the culture change journey. Identifying and providing high-quality training to nursing home staff is also a persistent challenge as nursing home staff have very little time to devote to such activities given acuity and workload. Therefore proper utilization of caregivers in the management of PWD is also necessary and for this they need to be trained properly.

Elder abuse is another challenge in providing optimal level of care for older adults. Person-centered care requires active involvement of the PWD themselves. When the capacity of an individual to direct their own daily routine changes due to dementia or other chronic conditions, they become victimized more easily. These can further increase the already existing loneliness, helplessness and boredom. The caregivers should realize the feelings of those persons and should be concerned about their attitude towards those persons. Abuse appears to occur most often in domestic home situations, and may be perpetrated by adult caregivers, family caregivers, or other persons (Bond & Butler, 2013). It may also occur in institutional settings such as long-term care facilities, nursing homes, or hospices (Jayawardena & Liao, 2006). Recent studies, however, have established rather clearly the troubling fact that most cases of the abuse of Alzheimer’s and other dementia victims actually take place in the family home setting, by their own family members or paid caregivers. The main types of elder abuse are physical abuse, sexual abuse, emotional and psychological abuse, neglect and self-neglect, abandonment, and financial exploitation (National Center on Elder Abuse, 2010). Elder abuse now is a silent epidemic; one in every nine American over 60 has experienced abuse. Only 1 in 23 cases are
reported. Experience of elder abuse is showing an increasing trend among persons with dementia (Dong, Chen, & Simon, 2014).

2.4 Literature review: Limitations and gaps in the literature

Despite the various solutions this review has suggested, there are only some initial indications of positive results in the management of dementia. I found only limited information available in the literature about the capacity on the part of residents having dementia to direct their own care. Further, the existing literature does not fully address how person-centered care in the management of dementia relates to resident quality of life in nursing home settings. I couldn’t found significant longitudinal studies to show how different engagement activities promote relaxation and help PWD have control over their daily lives in an institutionalized environment. Also there is a dearth of comparative studies on the perspectives of caregivers of different levels regarding the engagement activities in dementia care.

2.5 Purpose of the study

In this study, I seek to fill the gaps in the current literature and is in search for a positive and pragmatic role of CAM for PWD in the nursing home setting. But what are the resources available in the context of nursing home care? How well are the caregivers trained to provide mindful support to the care recipients? Given this backdrop, this study seeks to understand the social problem of dementia and the opportunities available for CAM to provide complementary and alternative supports for PWD toward improved quality of life.

2.6 Research objectives

In this study, I address the following questions:

1. Person-centered care requires capacity on the part of the individual to direct their own care. When this capacity changes due to dementia or other chronic conditions, how does
a caregiver continue to support the resident in person-centered care, to help them exercise control over their daily lives?

2. What, if any, is the role of alternative therapies such as yoga, meditation and deep breathing, animal assisted therapy or music therapy in improving resident’s quality of life?

3. What types of engagement activities do staff believe promote relaxation, increase concentration and calmness in the residents?

4. What are the differences (if any) in views of caregivers at different levels of professional hierarchies, i.e. direct care workers and administrators, regarding both PCC and the role of CAM in PCC?
3 METHODS

3.1 Method rationale and research strategy

The main purpose of this study is to understand how different engagement activities promote relaxation, reduces agitation, and improve quality of life of the residents having dementia of Georgia nursing homes based on staff perceptions. I have chosen a qualitative approach to developing this understanding. The outcome of a qualitative, exploratory approach using in-depth, semi-structured focus groups results in thick description and an understanding of the process of care and its perceived impact on outcomes.

This project uses data from the grant-funded study, “Building Resources for Delivering Person-Centered Care in Georgia Nursing Homes” (Morgan & Burgess). The study was reviewed and approved by the Georgia State University (GSU) Institutional Review Board (IRB). This larger project will include a three-staged needs assessment using in-depth qualitative research to inform and supplement a representative survey of Georgia nursing homes. My embedded project examines data from focus groups collected from managers and direct care workers in a range of nursing home settings.

3.2 Participants and recruitment

This study has employed a purposive sampling approach in the recruitment of research participants. Firstly, the BRPCC team used a purposive sampling method to recruit study participants from a diverse group of nursing homes across the state of Georgia (e.g., geographic variation, urban, rural, hospital-based, large nursing homes with more than 200 beds, and state-based quality ratings).
Table 1. Characteristics of Nursing Homes in the Sample

<table>
<thead>
<tr>
<th>Sl. No.</th>
<th>Name and Location of Nursing Home</th>
<th>Pattern (rural/urban) of Nursing Home</th>
<th>Type (size) of Nursing Home</th>
<th>Type of Focus Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>NH 1, Atlanta Metro Area, GA</td>
<td>Urban</td>
<td>Medium size, Non-profit</td>
<td>1 - Mgrs &amp; 1 - DCWs/CNAs</td>
</tr>
<tr>
<td>2</td>
<td>NH 2, South-Central GA</td>
<td>Urban</td>
<td>Large, corporate</td>
<td>1 - Mgrs &amp; 1 - DCWs/CNAs</td>
</tr>
<tr>
<td>3</td>
<td>NH 3, South GA</td>
<td>Rural</td>
<td>Hospital-based</td>
<td>1 - Mgrs &amp; 1 - DCWs/CNAs</td>
</tr>
<tr>
<td>4</td>
<td>NH 4, Atlanta Metro Area, GA</td>
<td>Urban</td>
<td>Large, corporate</td>
<td>1 - Mgrs &amp; 1 - DCWs/CNAs</td>
</tr>
<tr>
<td>5</td>
<td>NH 5, North GA</td>
<td>Rural</td>
<td>One-star rating, special focus</td>
<td>1 - Mgrs &amp; 1 - DCWs/CNAs</td>
</tr>
</tbody>
</table>

3.3 Data Collection: Demographic survey and focus groups

The focus group guides consisted of two parts. After obtaining formal written consent, participants were given a short demographic survey and then participated in a focus group. Ten focus groups were completed, including five manager focus groups (36 managers) and five direct care worker focus groups (44 DCWs) in five Georgia nursing homes. These nursing homes are characterized as large, corporate, urban (2); medium-sized, nonprofit, urban (1); rural, hospital-based (1); and rural, one-star, special focus (1). The focus groups were made up of individuals in similar positions, and each of them included 6-10 participants. In each nursing home, the research team conducted two focus groups divided into 1) direct care worker (DCW) and
auxiliary workers (e.g. dietary, housekeeping, maintenance) and 2) administrators, nursing, and other department leads. A complete recruitment chart is included in Table 1 and complete interview guides are included in Appendices 2-5.

Focus groups generally covered four topic areas. First, each participant was asked about their thoughts on PCC, and how activities of an individual staff member influence the collaborative approach of PCC. Second, they were asked about their views on the role of organization on PCC, and how it was maintained in their own organization. Third, they were questioned about their views on the types of engagement activities which they believe promote relaxation, focus, and calm in residents – and that thus, improve their quality of life. Finally, the participants were asked if they think any training program regarding the current issue might be beneficial for them and also if anything remained beyond these questionnaire that they think might be helpful to implement PCC in nursing home settings. The interview guide was developed to generate thoughtful answers on the PCC, its barriers, facilitators and how PCC exercise control over the daily lives of residents. This guide also incorporated questions about different engagement activities and alternative therapies (if any) which promote relaxation and improve quality of life of those individuals. Interviewees expressed their professional and personal views about PCC.

All the interviews were done in person, in the nursing homes. The focus groups were held at times most convenient to the participants. All focus groups were digitally recorded and transcribed verbatim. All interviews took about three-quarters of an hour. The average focus group lasted about 47 minutes in the case of DCWs and 50 minutes for the managers. After each audio-file was transcribed, the study team went through the transcripts while listening to the audio-file, to correct any errors in the transcription.
3.4 Data analysis

My analysis of focus group transcripts was guided by the Grounded Theory Method (GTM) of Strauss and Corbin (1990). Using the interview guide, I created an initial list of codes for the “open coding” phase of this study. The initial list was approved by the study team (see Appendix 7 for the final code list). Using N-Vivo 10 software, the study team completed initial coding of each interview, as they became available. The study team also made some revisions to the code book after initial coding to make sure application of the codes maximized relevant data coverage.

After completing the initial coding phase, I proceeded with “axial coding.” Strauss and Corbin (1990) described “axial coding” as “process of rearranging data” based on the similarities and differences of views the interviewees express. I created a chart that listed the nursing home staff either as direct care workers or supervisors and listed their views and thoughts on person centered care, its barriers and facilitators and how different engagement activities helps improving quality of life of nursing home residents having dementia. Utilizing the chart, the coded data and the interview transcripts, I created a summary of the perspectives of each group of participants regarding their person-centered care.

Once the axial coding was completed, I started performing “selective coding.” Strauss and Corbin (1990) described “selective coding” as the “descriptive narrative of the central phenomenon of the study” in which the researcher writes “the story.” Through the process of coding, categorizing and summarization, a story line began to form, which is different for the two different groups of participants.
4 RESULTS

While the research team asked liaisons at each nursing home to recruit staff into direct care worker (DCW) and manager groups respectively, there was some variation in how they were sorted by site. For the most part, Certified Nursing Assistants (CNAs), along with housekeeping and dietary aides were sorted into the DCW group and nurses and department heads were sorted into the manager group. Licensed Practical Nurses (LPNs) were sometimes sorted into the DCW group and sometimes in the manager group. This could be because they are used differently in different homes (e.g. as floor managers). Educators and social workers tended to sort themselves into the manager group and ward clerks (administrative personnel) put themselves in the DCW group. Tables 2 and 3 show the detailed job titles for both types of focus groups. Many of the titles given by individuals in the manager focus group are required to be held by registered nurses (RNs) (MDS coordinator, unit managers, etc).

Table 2. Job Titles for Focus Group Participants by Nursing Homes (DCWs)

<table>
<thead>
<tr>
<th>Type</th>
<th>Site 1</th>
<th>Site 2</th>
<th>Site 3</th>
<th>Site 4</th>
<th>Site 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housekeeping assistant</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>CNA/ Staffing coordinator</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CNA/ activity coordinator</td>
<td>1</td>
<td></td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CNA</td>
<td>6</td>
<td>5</td>
<td>5</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>CNA/ Phlebotomist</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CNA/ Restorative aide</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Food service aide/dietary</td>
<td>2</td>
<td></td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Laundry aide</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Ward clerk</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type</td>
<td>Site 1</td>
<td>Site 2</td>
<td>Site 3</td>
<td>Site 4</td>
<td>Site 5</td>
</tr>
<tr>
<td>----------------------------------</td>
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<td>--------</td>
<td>--------</td>
<td>--------</td>
</tr>
<tr>
<td>Activity director/ Eden educator</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HR director/ Eden educator</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Social services directors</td>
<td>2</td>
<td></td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dietary director</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Director of admissions</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LPN</td>
<td></td>
<td></td>
<td></td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Nursing home administration</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RN</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Infection control coordinator</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Director of nursing</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial consultant</td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>REI director</td>
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<td></td>
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<td>1</td>
<td></td>
</tr>
<tr>
<td>Respiratory director</td>
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<td></td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Unit manager</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 3. Job Titles of Focus Group Participants by Nursing Homes (Supervisors)
<table>
<thead>
<tr>
<th>Position</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rehab director</td>
<td>1</td>
</tr>
<tr>
<td>MDS coordinator</td>
<td>1</td>
</tr>
<tr>
<td>Staff development manager</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total (n=36)</strong></td>
<td>7 6 9 6 8</td>
</tr>
</tbody>
</table>

### 4.1 Person-centered Care

Analyzing focus group discussion I found that among 44 DCWs 16 participants told that they are well aware about PCC, 3 of them informed that they have no idea about PCC and remaining 25 did not expressed their views. On the other hand, among 36 managerial level staffs, 22 participants told that they are aware about PCC, while the rest did not expressed their opinion. Though most of the employees (both DCWs and Supervisors) are aware of the concept of PCC, but they are less clear on how to apply this knowledge in practical situations. This is clearly delineated when a DCW (Interviewee 2/ Site 1) defined PCC as:

> The elder’s the most important – the most important person in the factor. When you- I think person-centered care to me is when I’m going to do a service for an elder, it’s none of me and all of them. And I have to treat people as you want to be treated.

According to another DCW (Interviewee 4/ Site 2), “What feels good about it is that the patient is being treated equally and is concerned of what they like and want to do.”

Whereas according to one supervisor (Interviewee 3/ Site 2) PCC is a, “Holistic care. Just what it says. The care centered on each person, their needs, their wants, their situation.”

Another managerial staff (Interviewee 10/ Site 3) holds the opinion that PCC is, “Individualized care, whatever you need to do to take care of the patient that fits their needs, fits their wellbeing, fits their overall health—mental, spiritual, physical.”
Still there are few staff members who do not have basic ideas on PCC. When they were asked about PCC, these DCWs clearly (Interviewee 1 and 8/ Site 3) said, “I’m not familiar with it.” But there is one positive finding emerged in this study. The majority of staff members, at least 52 among 80 focus group staff members, think that PCC is a team-effort and they are willing to get further training related to their jobs. One DCW (Interviewee 3/ Site 1) said, “Yes. Because I feel like they need to keep reiterating customer service. Keep training. Keep training.” According to another staff member (Interviewee 8/ Supervisor/ Site 4), “Training and education is all the time. Something we’re learning all the time.” Regarding usefulness of training on PCC, one participant (Interviewee 6/ DCW/ Site 5) said,

I think that, no matter what your title is, that you shouldn’t be working on the floor by yourself until you are fully comfortable doing what you’re doing. Because if you’re not and you get out and you mess up or do something the wrong way, it could be something important that needed to be done in the right way, you know, and could affect everybody’s jobs. I think you should be comfortable.

How PCC is understood among nursing home staff of different levels is more or less the same. Generally, however, they believe PCC is difficult to implement in nursing home settings, because of non-acceptance from the residents. According to one DCW (Interviewee 3/ Site 1),

Like, the elders have to basically do what you tell them—let them do. Personal-centered care, and that’s kinda like the elders telling you what they want, you doing what they want, when they want it, how they want it, long as they want it. I feel like that’s what person-centered care—still making that person feel like they are home and that they’re in control of their life, which now I think in nursing home they feel like they’re not in
control, that everything has been taken away, and they no longer have control of their life. With personal-centered care, they’ll be able to tell you what to do.

I also found an indirect but beneficial effect of PCC on residents. One staff of managerial level (Interviewee2/ Site1) said, “We've really tried to make it where every decision we're making even as an organization or just as a management team, that we are involving the elders and really trying to let them make those decisions as much as possible.” “To provide a more homelike environment as possible as well too” (Interviewee 5/ Supervisor/ Site1), with a “try to give them some of that control back about decisions (Interviewee 5/Supervisor/ Site1).” One supervisor (Interviewee 3/ Site 2) told, “I think we have a big family atmosphere, and that makes a different. That makes a difference.” Through this process they become more involved in their new living environment with residents in a similar life situations. This involvement becomes so deep that according to one supervisor (Interviewee 8/ Site1), even “With the death and dying process, I definitely think they wanted to be an honorable mention.” Another supervisor (Interviewee 3/ Site1) added, “They wanted to know. They wanted to be a part of it. They didn't want to just suddenly find out their friend that they’ve been living with, basically, sharing a home with, for five or six years is no longer here.” According to one participant (Interviewee 1/ Site1), "Share old stories. Really, we call it a celebration of life. We don't call it a memorial because we really gather and talk about that person and fun things.”

4.2 Direct Care Workers

PCC also creates confusion for the DCWs. They think that doing something based on the choice of the concerned resident may not always be beneficial for the health of the resident. Therefore, should he/she respect the choice of the resident or as a health care provider he/she will perform that activity which best suits the patient? One participant (Interviewee 3/ DCW/ Site 2)
expressed her confusion,

Yeah, it’s like, am I killing this person?... It’s their rights. They sign the waiver. I’m responsible for going to the store a lot for them, and I get a list from a diabetic woman—two-liter Cokes, a package of Hershey’s kisses, extra sharp cheese, and all this long list of stuff, and you’re diabetic. I have to go get this stuff because you have signed the waiver to have these things. That’s the hard part for me.

Absence of any clear cut care plan in the practice goals and strategic priorities, as articulated by the management, makes it more difficult for the DCWs to implement person-centered care. DCWs seem often confused about to whom to obey, the resident, family members or their immediate supervisors in the nursing homes. They are always being pressured by these people and often in competing ways. One DCW (Interviewee 10/ Site 3) said, “Mostly what the family say.”

In this issue another DCW (Interviewee 5/ Site 3) expressed her opinion,

Respect for their opinions. Kind of keeping a cool, calm tone. You get upset sometimes. You kind of take it out on other people. Got to keep it calm and collected, make sure that they get what they need too.

Again, DCW (Interviewee 9/ Site 3) has to keep in mind, “Is that against the law in a facility?”

One major complaint related to implementing person-centered care, was about staffing stability. If a DCW has to do added on works regularly in understaffed condition (referred to by workers as “working short”) the idea of focusing on the person-centered care and achieving mental satisfaction becomes a luxury. Their care for the residents becomes synonymous with only delivering help in the basic daily necessities of the residents within working hours and holistic care
becomes secondary and neglected. In this situation, a lack of meaningful personal engagement from both caregivers and residents always persists; also, no new ideas or strategies related to reducing loneliness, boredom or helplessness, for example, come to the caregivers’ mind. The majority of the DCWs feel that, in practice, PCC is “impossible” to execute in nursing home settings. One of the DCW in focus group 1 (Interviewee 9/ Site 1) repeatedly said, “It’s impossible…. It is impossible.” According to her, staffing and rising resident care needs make PCC hard to execute in nursing home settings. “We don’t have the staffing for it. It’s a lot of staffing that you need. A lot of people have a lot of needs. Each one can’t be met in less than 20 minutes.” One DCW (Interviewee 5/ Site 2) said, “They [nursing home administration] see you’re short, but they still add in more residents.”

Regarding rising resident care needs, another DCW (Interviewee 1/ Site 3) in different setting found, “You get so many demands up there.” One DCW (Interviewee 6/ Site 5) finds PCC as, “I think it would be chaotic that way, honestly….. Because there would be no structure, and everybody’s doing what they want, so there’s no certain way of doing things…. It would be harder to manage them.”

Further, we found that many DCWs felt that the majority of supervisors did not understand and respect their jobs and the stress related to their jobs. This condition exacerbates the barriers to PCC by inhibiting team work and performance. One DCW (Interviewee 3/ DCW/ Site 1) expressed her frustration during group discussion:

[T]he supervisors needs to walk in our shoes, the shoes of the caregivers, care partners. You need to know that I can’t do 15 things at 1 time, that maybe if you see me doing this, and you need me to do that, then you can go do that while I’m doing this, and I’ll come finish that while you’re doing that. But they need to know that because sometimes I don’t
think they understand that. They just think, “You need to do this. You need to do that. You need to do this. You need to do that.” I can’t do all that at once—not efficiently. You know what I mean? So, sometimes I may need your help. There’s nothing wrong with a supervisor getting their hands dirty, too. That’s just how I feel about it.

These frustrations are very common for the majority of DCWs. 29 DCWs among 44 expressed their frustrations for their supervisors. When someone (Interviewee 2/ Site 1) says, “If the CNAs are so busy and somebody needs to be toileted, “I’m certified. I just don’t do it.” I could put somebody on the toilet.” According to another DCW (interviewee 1/ Site 3), “That they feel like their position is higher, more important.”

We also found that, from the DCWs perspective, some supervisors are exceptionally kind-hearted, but overall they do not want to respect and appreciate the works done by the DCWs.

Training programs were seen by DCWs as generally productive ways to improve their skills. One participant (Interviewee 3/ DCW/ Site 1) expressed her gratitude to the Virtual Dementia Tour as a must-include part in training programs for the caregivers engaged in the management of the PWDs.

Virtual Dementia Tour, where um, you put on these glasses. You have all this noise in your ear and things like that. It’s kinda like letting you be that person that has dementia that has no control over anything that they’re doing. It’s kinda to get the staff to imagine how our elders feel when they’re taking care of them.

According to another participant, also about the VDT (Interviewee 7/ DCW/ Site 3), Before, I did that to where I didn’t really know how to be with them, but now I understand it a lot more. I would honestly be uncomfortable before I took the tour, and
now I’m a whole lot more comfortable when I talk to them and how I can react to what they’re saying. I know something’s wrong, but it’s not really something is wrong like I have to go get immediate attention for them. Because I used to freak out, honestly. I’d be like, “Oh, my God. Something’s wrong.” But I know they’re just disoriented and I just try to make them comfortable.

We found that some CAM exists as recreational activities in many nursing homes in the form of pet therapy, music programs, yoga and mindfulness. Other activities such as horticulture, aromatherapy and cooking classes are also available for residents in some nursing homes. DCWs show a lot of enthusiasm regarding these activities. They even feel happy to arrange birthday parties, beauty queen parties and fun games, such as bingo and technology-enabled games/engagement for the residents. Use of these activities appears to be a joyful experience for both staff and care-recipients. They show spontaneous involvement in these planned activities. On one hand, these help residents by promoting relaxation, reducing agitation and increasing quality of life, and on the other hand, these help minimize loneliness, boredom and helplessness among the residents.

One DCW (Interviewee 3/ Site 4) holds the opinion, “It breaks the monotony of just staying in their room and then all wheelchairs just watching TV and waiting for family members to come and visit you.”

While according to her colleague (Interviewee 4/ Site 4), “Anything that keeps them active and sharp and alert is meaningful and will extend their lives.”

According to one managerial staff (Interviewee 9/ Site 3), “The socialization was a big issue…… as well.”
4.3 Supervisors

From the focus group it seems that supervisors also have some ambivalence about implementing person-centered care even though they demonstrate better understanding of PCC. They become sandwiched between the competing needs and priorities of nursing home authorities, direct care workers and care-recipients. They often get confused while choosing an option between ‘task-oriented’ and ‘person-inclusive’ issues. According to one supervisor (Interviewee 3/ Supervisor/ Site 1),

Sometimes, we get so caught up in institutional thinking that we don't even know that that's what we're doing. I have a person here that—he's, of course, older. He doesn't eat breakfast. You have to eat breakfast because we serve breakfast. That's how we're thinking. We have breakfast, lunch, and dinner. You have to eat it. All his life, probably 50, 60, 70 years, he doesn't eat breakfast, so we need to honor that kind of stuff and make sure everyone's aware of stuff like that. It's not a risk to him because he's been doing it all his life, but we get so caught up in wanting to help and making sure you're doing it the right way.

On the team-work issue, some of the supervisors are aware about their own limitations regarding companionship and some of them (such as, Interviewee 2/ Supervisor/ Site 1) point out the understaffing issue as the biggest challenge.

I would say one of the biggest challenges or barriers is staffing and just having the time. More and more, the recruiting aspect of it is challenging. Just being able to spend more—I think ideally, if we could spend more time with our new hires in that onboarding process to try to really prepare them which, of course, is money. It's time delaying them getting them on the floor. I really think it's going to help with our CNA team leaders to
have that peer there to really help coach them and just investing the time in educating them. I think that will help. I would say that's probably one of our biggest obstacles is just that time and cost because I feel like a lot—we want to do it. We want to get them there.

Supervisors also believe that communication, cooperation and teamwork are the key to executing PCC. One Manager (Interviewee 6/ Site 2) said, “It makes it really hard, because a good CNA can only be a great CNA if they’re part of a team.”

This is not only applicable for CNAs, but for every team member. Also this communication and cooperation helps maintaining continuity of care, i.e. the relationship between care team and patient that extends beyond specific episodes of illness or disease.

The managers also point out that the pay structure, especially for DCWs, is an important barrier to PCC. The pay structure came up in all 5 manager focus groups as a barrier to implement PCC. One participant (Interviewee 6/ Supervisor/ Site 3) told that DCWs are usually paid much less than even the workers of grocery stores. “There’s a lot of competition with—you’re seeing they might be making $8.00 an hour. They’re paying 9 or 10 or might pay you 10……..Walmart’s 13……..Much easier job, too.”

Regarding CAM activities, managerial level staffs also showed their enthusiasm to discuss those in detail. One participant (Interviewee 1/ Supervisor/ Site 1) told that,

We have aromatherapy on the floor, and we also do yoga as well. We have a live stream of yoga, pretty much videos that are catered to elders or people sitting in chairs and things. There’s Conductor-cise. It's upper movements, and they play music. We do all that. Yeah. We do have lots of exercise videos and streams to pick from that are geared to them. It's on a machine. It's never too late machine. We go from there.
According to one Manager (Interviewee 3/ Site 2), “I think they really enjoyed these.” Many staff members are aware that the activities should be individualized. According to one supervisor (Interviewee 4/ Site 5), “They interview the residents prior, or when they first arrive, to see what activities are best geared towards them.” Regarding involvement of residents in meaningful activities, such as music, one supervisor described, “They did a beautiful choir for us. They all got together and learned Christmas songs and caroled throughout the facility.” But still it seems like the activities are not enough organized. Though a participant (Interviewee 2/ Site 1) told, “As far as the quality of life, we have the music therapy, the horticulture therapy, things like that where maybe they're trying something new or learning something new.” This is clear when, regarding exercise program, another supervisor (Interviewee 8/ Site 3) said, “range of motion, kind of— restorative.” The study team found the existence of different kinds of recreational activities in every institutions. At some places there is Pet therapy (the interactions of the PWD with an animal), somewhere Music therapy, somewhere this exists as Yoga and mindfulness, even cooking class, Bible study, Birthday parties are also available. In every nursing home there is Bingo used as fun game for the residents. Table 4 shows the list of different recreational activities available in participating nursing homes for the residents.

Table 4. Recreational Activities Available (for Residents) in Participant Nursing Homes

<table>
<thead>
<tr>
<th>Activities available</th>
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<th>Site 2</th>
<th>Site 3</th>
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<td>Common CAM practices</td>
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<td>Aromatherapy</td>
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4.4 Difference between DCWs and Supervisors

One significant finding coming out from this study is regarding the power dynamics; there is a remarkable difference in the attitudes of DCWs and supervisors. DCWs think that their immediate boss, i.e. the supervisors are very powerful but they are reluctant do anything beneficial for them. In all focus groups, supervisors are criticized by DCWs usually for lack of respect for the job or realities of direct care work or an unwillingness to “get their hands dirty” and “pitch in.” According to one DCW (Interviewee 1/ Site 3), “That they feel like their position is higher, more important.” A suggestion of one DCW (Interviewee 5/ Site 4) is probably the best way to execute PCC, “Teamwork makes the dream work.”

The DCWs also expressed unhappiness on their authorities, too. According to one DCW (Interviewee 1/ Site 2), they need to come for their regular duties, even in natural disaster, without any special benefits. “I got to leave my kids at home just to come stay here so I can…You don’t know if your kids are safe out there.” “I mean it’s going to happen, it’s going to happen, but it’s not fair.”
From the supervisor perspective, the frontline managers feel their hands are tied to make big changes for the DCWs. They do not have the power to do anything related to pay structure or staffing issues, they just follow the policies structured by the nursing home authorities. Most supervisors express sympathy for the DCWs based on the difficulty of the job. Managers also seemed much more reluctant to criticize the nursing home policies or practices during their focus groups. When a manager (Interviewee 3/ Site 2) was asked to tell some changes that can be made to support direct care workers to do—to participate and do person-centered care, she said, “Recruitment, recruitment, recruitment.” Another manager (Interviewee 4/ Site 4) said, “More money. Higher salary. More staff.” One manager (Interviewee 6/ Site 2) honestly expressed her views about management role, “My main thing is communication. I think if you communicate with your staff and let them know this is what’s going on, this is this, you going to get more.” But everyone expressed their opinion within a restricted language. When asked about what they follow to maintain work environment in her institution one supervisor (Interviewee 5/ Site 3) said, “The core values…the ethical teamwork and helpful and innovative and compassionate and attitude.”
5 DISCUSSION AND IMPLICATIONS

A person-centered approach to care shifts the mindset of care partners from a traditional medical model to a social model in the management of dementia, where personal autonomy, choice, comfort and dignity, and purposeful living are maintained (Desai, Wharton, Struble, & Blazek, 2017). This study examined the potency of PCC to interrelate the traditional medical model with the promising social model in the management of persons with dementia in nursing home settings. The main purpose of this study is to find out how does a caregiver continue to support the resident in person-centered care, when the capacity on the part of the individual to direct their own care changes due to dementia. I have also tried to find out from the focus groups conducted, what are the different barriers to implementing the PCC for the residents.

This study reveals that there is long way to go to achieve job satisfaction for the DCWs, regarding standardization of training, compensation and benefits they receive, and recognition and respect from managers and owners. Patient care is a complex job that requires teamwork, which includes empowering the direct care worker as a full member of the team, otherwise the outcome will be a burnout for the ones who have no control on the situation. Preliminary analyses show that factors such as turnover, “working short,” supervisor support and rising resident care needs make it difficult to implement person-centered care in nursing homes.

The DCWs are the group of workers that struggles most. They have to take a variety of responsibilities which increase their workload and as a consequence leads to burnout. In reality, DCWs have to assist residents in all activities of daily living and are often asked to do it for an unrealistic number of residents throughout their shift. When asked about the person-centered approach, the DCWs struggle with the issue of understaffing at their workplace, which is neither created by them, nor do they have any control to solve the problem. The most challenging part in
their job is self-motivation. Most of the supervisors do not recognize and respect their jobs, their posts, as if they are only filling the gaps, without only what others see as the most basic competencies. The frustration created on the DCW seems to be the greatest obstacle for successful implementation of PCC. This should be the ultimate responsibility of the institutional authorities. A little respect and appreciation from the supervisors for the works done by the DCWs can make the team-work much better. DCWs also have some confusion regarding the extent to which they should allow the residents to satisfy their own choices. This lack of understanding is a big barrier in implementing PCC in nursing home settings and requires education and clear person-centered conversations related to quality of life, risk, and safety priorities with residents, family and staff. Limited time and institutional restrictions are also barriers in this issue.

A caregiver should understand and recognize that it is important for the individual to do things that give meaning and purpose in the resident’s life. For this they have to understand knowing the person and their life-story to provide appropriate environment to make the nursing home a ‘home away from home’ for the residents. For this, one needs time. Unless a caregiver creates time from the core of his/her heart, caregiving will remain as mere “nursing home job”, and the goal of PCC will not be satisfied for anyone. In most of the institutions there are some kind of CAM practices that essentially exist as recreational activities. But these are just present as “activities” and are not given prime importance anywhere as alternative therapeutic regimens. These “activities” exist as “extra” and “nice” but not as integral to the main goal – high resident quality of life. Some DCWs are aware that these kind of activities can be beneficial for the residents as part of a therapeutic regimen but the coordination of and integration of these “activities” falls short. The DCWs know that they must support and encourage the individuals to engage in meaningful activities, which can help residents in maintaining functional abilities and
promoting the quality of life. But they are constrained by the obstacles of “working short” and the complexity of regular maintenance or ADL care. In my opinion, new universal policies are urgently needed in this issue from the government level so that the care workers are empowered to not only provide basic ADL care but also have time to engage residents in pursuits or vocations that support the highest quality of life possible.

The interviewed supervisors are mostly administrative personnel (such as activities directors, social service directors, admission directors, dietary manager, financial consultant etc.), LPN, and RN and some of them are certified Eden educators. They are sandwiched. On one hand they are concerned deeply about the care of the residents they are responsible for and on the other hand they are tasked with the priorities of the nursing home administration which include constraints on staff allowance, personnel costs and regulatory requirements. Regarding implementation of PCC, they also face the understaffing issue. Compared to the DCWs, definitely they are more knowledgeable about the resident’s care, but somehow their expressions on the values of person-centered care seem similar to the DCWs. In order for PCC to be implemented in more nursing homes, more dedication to the implementation of PCC is required from staff at all levels. The supervisors are also aware about the beneficial role of different CAM practices, but in their institution these are generally present as recreational activities unless integrated by physical therapy. All staff think that PCC is a team-effort and they are willing to get further training related to their jobs better.

Though the awareness of person-centered care approach in nursing home setting is increasing, its fullest implementation and application remains elusive. Thus the findings of this study confirms previous work in this issue done by Koren (2010). To ensure satisfactory care for all nursing home residents, the Omnibus Budget Reconciliation Act (OBRA) of 1987 has a great
importance. This act was introduced to improve the quality of life for nursing home residents to “be provided with services sufficient to attain and maintain his or her highest practicable physical, mental, and psychosocial well-being” (Koren, 2010, p. 312). But practically there is long way to go. PCC should always be directed towards residents; the nursing home staff are also the integral part of this two-way intervention process. In my opinion, the concept of PCC is a triangular model (Figure 6), where one point is care-receiver, one point is caregiver and the other point is the availability of resources. Therefore unless we concentrate equally on the caregiving-staff, their satisfaction and dissatisfaction factors, and the resources available, PCC approach will remain fictitious. This finding confirms previous work in this regard done by Brownie and Nancarrow (2013). According to Brownie and Nancarrow (2013). The success of PCC is very much linked with pleasure and ability of the concerned staff to provide personalized care. The domain of healthcare is now regarded as one of the business sectors. Now, almost every nursing home is a business center; therefore government policies are very much required in every steps for successful implementation of promising PCC.

The findings indicate that a wide range of engagement activities are offered in nursing homes including some alternative therapeutic activities (e.g. music therapy, pet therapy, aromatherapy, massage, meditation). The staff mentioned the activities as therapy, but practically these are offered to the residents as recreational activities only, not as therapeutic regimen. Though these restorative practices are the result of evidence-based programs, more awareness is required to implement these activities as therapies as part of the tailored care plan. The effectiveness of different CAM practices are not the same for every resident. Since different social factors are associated with different residents having dementia, one resident may show responsiveness to a CAM practice, while another resident may response to another (Takeda et
A PCC team has to choose one from the available resources that will be the best fit for the resident as well as the caregivers, as alternative therapeutic management. PCC is a team approach, therefore every decision related to the management requires approval from every staff members, residents, as well as representative of family members. Different engagement activities are present in different nursing homes, but it is unclear from the focus group whether those activities were thought through by the full team member in relation to particular residents. Is there enough participation of DCWs, who are likely to know the most about resident preferences, in selecting those activities for the person? Also from the study it is not clear if there is any recorded data available on any individualized activity. Almost everywhere these activities are offered on weekly schedules. Any modification in those weekly schedule may provide more positive results. Therefore, finding an optimum dosage for each activity should also be a concern for the care planning teams. Nursing homes tend to hire professional for CAM practices. But if the nursing home staff get proper training, those activities can be performed on a regular basis even in absence of the particular professional so that the therapy can be uninterrupted. Therefore nursing home regulation is a barrier in implementation of PCC in this issue.

Chronic stress, sleep impairment, mood disturbances along with cognitive decline forms a vicious cycle which progressively decline the condition of the person having such cognitive impairment. Meditation has a huge importance in this aspect, by declining inflammation, blood pressure, heart rate; it is also associated with increasing cortical thickness and increasing gray matter volume, thereby improve health outcomes in adults with memory disorders (Innes & Selfe, 2014). In a similar study with 81 individuals with mild cognitive impairment, Eyre et al. (2017) found that Kundalini Yoga also has both short- and long-term effects on prevention of cognitive decline. In another study on the beneficial effects of Hatha Yoga (HY), it was found
that physical performance of the individuals with dementia is related to increased brain blood circulation, which can decrease risk of further cognitive damage (Gallego, Alexey, MaClara, Lina, & Reyes, 2011). This is an example of remarkable success of Yoga in the future therapy of dementia. It has been suggested that if older people become engaged in these restorative activities regularly, old age problems can be prevented by way of good balance, blood stream and tissue liveliness, and at the same time reload most essential brain functions with the relaxing characteristics of mindfulness practices, and ultimately, the memory becomes retentive making later life less vulnerable to develop dementia (Shukla, 2015). Also, daily meditation practices can lead to increased mental and cognitive functions for the family dementia caregivers, who at the same time can be benefited by improvement in stress induced cellular aging (Lavretsky et al., 2013).

5.1 Conclusion

Therefore, from the above discussion it is clear that my first question regarding implementation of PCC when the resident’s capacity to direct their own care changes due to dementia or other chronic conditions, the current system has to go a long way. The caregiving staff of all levels need further training to support residents’ ability to exercise control over their daily lives. Many studies focuses on the basic content of staff training, but identifying the interactive methods of training, like demonstration, role play, intervention delivery in the DCWs workplace, hands-on activities are still not clearly suggested (Kemeny & Mabry, 2015). My study findings also corroborate with the existing literature. Active learning among either DCWs or managerial level staff members can be enhanced by ongoing supervision, evaluation, and motivation (Kemeny & Mabry, 2015; Morgan, Haviland, Woodside, & Konrad, 2007).

The current study clarifies the answer of my second question regarding the role of
alternative therapies such as yoga, meditation and deep breathing in improving resident’s quality of life. There is strong and promising role of those alternative therapies. But this needs active participation and support from other interdisciplinary team members, such as physicians, nurse practitioners, policymakers etc. Further these should be individualized, according to residents need. The contribution of DCWs through their dedication will enhance chance of execution of those alternative therapies in practice by making it more relevant to PCC.

The current study also helps to find out the answer of my third question regarding the types of engagement activities do staff believe promote relaxation, increase concentration and calmness in the residents. Every activities are not commonly used as CAM. But each activity has the potency to be used as a therapeutic regimen in the management of dementia, in the future. Because it is evident from the findings that residents are actively involved in those activities, in every nursing homes. The restorative activities are already present in different nursing homes, still further implementation of those programs can be challenging because of current socioeconomic conditions, low job quality, lack of motivational resources for the caregiving staffs and organizational policies.

Finally, the current study points out some significant differences in views of caregivers of different levels, i.e. direct care workers and administrators, regarding the PCC and execution of alternative therapies for the residents. Almost every caregivers feels the recreational activities are valuable and promote better quality of living among residents. Therefore, there is not much differences in views regarding the role of CAM in PCC, but regarding PCC itself, DCWs are more unfiltered in raising their voices and waiting for a critical demand of resources to their proper execution, whereas supervisors are more focused on maintaining their job dignity. As caregivers’ active participation is very much required in execution of restorative activities,
therefore, indirectly their views on PCC effect on successful implementation of CAM in PCC.

The supervisors need to identify pathways for optimum execution of PCC in nursing homes, as they are the ultimate links between the residents and the DCWs on the one hand and the nursing home authorities on the other. They need to understand their role are most valuable in this regard and need to raise their voice to meet the demands of their subordinate staff and thereby PCC as a whole. In this issue, program adaptations are very much needed in the form of changes to facilitate uptake by the health care team. Because ultimately this is the job of the staff and without monetary or other rewards for performance for DCWs and other care team members, both team productivity and job quality would be hampered. Figure 6 delineates the factors needed for successful implementation of PCC.

5.2 Limitations

There are few limitations of the present study. First, the sample population is small. Given that it is a qualitative exploratory study, a total of 80 respondents should be enough to achieve content saturation. While sample size and lack of probability sampling limits my external validity, the purposive sampling and the content saturation suggest the transferability of my findings particularly with regard to processes and understanding. Second, group-interview in this study may reflect a positive bias among the participants. Third, the focus groups carried out here are only one side of the story. Though my study is focused on person-centered care, but in practical, this study contains no comments or thoughts from the residents or their family members. If it would have been done, my study findings might show more in-depth implications. As already mentioned, this study is only a part of a larger study, I hope this larger study may bring more in-depth findings regarding the current issues. Also more research is very much
needed in this promising area of research for improving the quality of life for nursing home residents living with dementia.

The qualitative nature of this study is one of its strengths. The semi-structured focus group interviews helped the participants to express their views in unhesitating and fearless attitude. My intention was not only to find out the positive sides of the person-centered care, but also the negative aspects, so that we can identify and improve future strategies. In this regard the spontaneous and unfiltered expressions of the participants were very much helpful toward the study findings. Additionally, the results of this study further support the previous works done in this topic.

5.3 Implications

From practical standpoint, the findings of this study have many implications. The study points toward the barriers and facilitators of person-centered care. These will help us identify, improve strategies and create a sustainable model for improving the quality of life for nursing home residents living with dementia. Person-centered care always focuses on the resident concerned, but this study showed another side of the story also; without reducing caregiver burden, person-centered care model cannot truly exist. The findings indicate that a wide range of engagement activities are offered in nursing homes, including some alternative therapeutic activities (e.g. music therapy, pet therapy, aromatherapy, massage, meditation); but practically, those are not prioritized as therapeutic regimens. We need to implement policies that will recognize these alternative therapeutic approaches parallel to the medical management.

PCC has the potential to transform management of persons with dementia in institutional settings. However, for the successful implementation of PCC, collaborative approach from every caregiver is needed. This is only possible with a mindset change to full dedication to engaging
residents with basic care insured. The findings of the current study provide useful guidance for
developing PCC through different CAM interventions across different nursing home settings in
the State of Georgia. These interventions need to be adjusted to fit the needs of both residents
and caregivers. PCC leadership and training can help address different barriers and facilitate
changes to traditional management of dementia. Professionals, who are trained and dedicated can
also motivate other co-workers to implement PCC in nursing home settings, to maintain the
quality of life of residents. Finally, new policies and practices from every level to support
PCC/Culture Change is very much needed for its fullest execution.
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https://doi.org/10.1093/geront/gnx173


Appendix A: Interview Guide

Interview Guide

Written Consent: Before starting any interview, written informed consent was obtained from each participants. As this study is a part of a larger project, *Building resources for delivering person-centered care in Georgia nursing homes*, therefore the consent form used in this study is a form as approved by the Georgia State University Institutional Review Board for the larger project. Before the interview, the interviewer will explain the main points of the consent form including, i) the interviewee’s right to refuse to answer any question without explanation for refusing to answer the question, ii) the interviewee’s right to request without explanation that any part of the interview not to be recorded, iii) the interviewee’s right to end his/her part of the interview at any time without explanation, and iv) how the privacy and of the interviewee and the confidentiality of the interview will be protected and to whom knowledge of the interviewee and the interview will be available.

Preliminaries: After obtaining the written consent, the interviewer will go through the steps of the interview with the interviewee including, i) the recording of an opening statement that will be comprising of interviewee’s verbal consent to the interview and confirmation of interviewee’s name and age, ii) the demographic survey, iii) the semi-structured interview, and iv) the chance for the interviewee, at the end of the interviewee, to add any other thoughts or information they might have.

Recording Opening Script: (Start recorder after informing the interviewee that you are doing so) This is (researcher’s full name) from the Gerontology Institute, Georgia State
University. It is (date). With me today is (interviewee’s full name). We are at (place). We are here today to talk about different personal comments and thoughts on person-centered care.

(Researcher addressing interviewee) Before we begin do I have your permission to record the interview? (If Yes, proceed for the interview. If No, stop the recording and thank the interviewee for their time).

(Researcher addressing interviewee) Would you please state your name and your age?
Appendix B: Staff Demographic Profile (DCWs)

Date: ____/____/____

1. What is your position title at this organization? ________________________  

2. How long have you been employed with this organization?  
   _______ yrs. _________ mos.  

3. What shift do you currently work? (Circle all that apply)  
   a. First  
   b. Second  
   c. Third  
   d. Other: ________________________________

4. How long have you been employed in any health care organization?  
   _______ yrs. _________ mos.  

5. Age: _______ yrs.  

6. Sex: (Circle One)  1. Male  2. Female  

7. How many years of school did you complete?: ________________ (Years)  
   (Examples: 10th Grade = 10 years, High School Graduate = 12 years, Associate Degree = 14 years, etc.)

8. Are you Spanish/Hispanic/Latino?  
   1 No, Not Spanish/Hispanic/Latino  
   2 Yes, Mexican, Mexican American, Chicano  
   3 Yes, Puerto Rican  
   4 Yes, Cuban
5. Yes, Other Spanish/Hispanic/Latino

Mark one or more races to indicate what you consider yourself to be: (Select all that apply)

a. White
b. Black, African American
c. American Indian or Alaska Native
d. Asian Indian
e. Japanese
f. Native Hawaiian
g. Chinese
h. Korean
i. Guamanian or Chamorro
j. Filipino
k. Vietnamese
l. Samoan
m. Other Pacific Islander
n. Other race: please specify___________________________

9. What is your marital status?

10. Were you born in the U.S. or were you a U.S. citizen at birth?
   1. Yes
   0. No
   IF NO, in what country were you born? ______________

11. What is your first language? (English/ Spanish/ Others) _____________

12. How many hours do you work each week in this position? _____________ hrs/week

13. Do you have a second paid job?
   0. No   1. Yes

14. Do you have health insurance from any source?
   0. No   1. Yes
15. Do you care for an elderly or disabled person outside of paid employment?

1. Yes  IF YES, how many hours per week ______
2. No
   
   Who is that person you care for: parent/spouse/children under 18 years?

16. Which of the following best describes your financial situation? (Circle One)

1. I and/or my family depend on my paycheck.
2. I and/or my family can live better because of my paycheck.
3. I and/or my family do not depend on my paycheck to maintain our lifestyle.

17. Average Household income (per year/ month).

18. Is there anything in your workplace that you are not satisfied with/ thinking changing your job, i.e. low salary, increase workload etc.
Appendix C: Focus Group Questionnaire (DCWs)

Focus Group: Direct Care Workers (Phase I)  Estimated Length – 45 minutes

The purpose of this interview is to talk about your opinion regarding ‘Person Centered Care’ and ‘Culture Change’, while caring older adults. By definition, ‘Person-centered care’ is an individualized goal-oriented care plan based on the person’s preferences, where care is supported by an inter-professional team in which the person is an integral team member. Whereas, ‘Culture change’ is the common term given for the transformation of older adult services, based on person-centered values and practices where the choice, dignity, respect and quality of living of older adults and those working with them are considered and respected.

We believe you are the experts when it comes to taking care of older adults with disabilities. We are interested in your overall thoughts about the model, you opinion about improving quality of care, and the supports that workers need to be successful in these types of programs. Please feel free to talk at length and in detail about your thoughts, and to add things you think are important that I may not have asked you about.

1. In your opinion, what are the qualities and characteristics that a good direct care worker should have?

2. Now picture someone who gives poor care or doesn’t do their job well. What is it that makes her or him not so good?

3. Let’s switch gears a bit, what do you think about “Person-centered care” and “culture change”?
   - Do you like about it?
   - What did you dislike about it?
   - Do you think direct care workers are well aware about the concept of Person-centered care?
   - What responses do you expect from residents and their informal caregivers regarding this issue?
4. What resources and support do you think that workers need to successfully involve in a person-centered care?
   - Do you think you have the necessary resources and supports to provide person-centered care at your best? Why or why not?
   - Do your co-workers work well together with you/ others?
   - Do your immediate supervisor guides you in your work?

5. Do you think your organization has the ability to deliver the Person-centered care program at its best?
   - If Yes, why? If No, why?
   - How do you apply ‘culture change’ concept to deliver Person-centered care in your organization? Do you expect full support from other workers also?

6. If an interactive online training is offered for nursing home workers, what content would you like to see in that training material?

7. How do you think interactive competency-based online continuing education training for direct care workers (like you) in nursing homes, together with nursing home residents and their informal care partners could enhance your ability to care better to the older adults?

8. What are the barriers, do you think to successfully implementing person-centered care model within your organization?
   - What are facilitators, if any?

9. Sometimes residents may have bad days and care workers need strategies to redirect anger, frustration and associated behaviors.
   - What types of engagement activities, do you think promote relaxation, focus and calm in residents?
   - How do you motivate yourself, if the resident has Dementia as a special case?
   - What is the role of alternative therapies such as yoga, meditation and deep breathing in improving resident quality of life?
   - Do you think you need some special training regarding this issues?

10. Do you think this care-model is going to be helpful for better management for the persons with dementia?
    - Do you think this model will help you to reduce stress as a caregiver (as responsibility will be divided)?
    - Why or why not?

11. Is there anything else you want to tell me about your experience in the training program?
Appendix D: Staff Demographic Profile (Supervisors)

Date: ___/___/____

1. What is your position title at this organization?
   a. Physician
   b. Administrator
   c. Development Coordinator
   d. Nursing Supervisor
   e. House Supervisor
   f. Other (please specify)________________

2. How long have you been employed at this facility/agency?
   __________ yrs. __________ mos.

3. What shift do you currently work? (Circle all that apply)
   e. First
   f. Second
   g. Third
   h. Other:____________________________

4. Do you directly supervise frontline health workers?
   0. No   1. Yes

5. Do you directly train frontline health workers?
   0. No   1. Yes

6. Age: ______ yrs.

7. Sex: (Circle One)  1. Male    2. Female
8. Are you Spanish/Hispanic/Latino?

1. No, Not Spanish/Hispanic/Latino

2. Yes, Mexican, Mexican American, Chicano

3. Yes, Puerto Rican

4. Yes, Cuban

5. Yes, Other Spanish/Hispanic/Latino

Mark one or more races to indicate what you consider yourself to be: (Select all that apply)

- A. White
- P. Black, African American
- Q. American Indian or Alaska Native
- R. Asian Indian
- S. Japanese
- T. Native Hawaiian
- U. Chinese
- V. Korean
- W. Guamanian or Chamorro
- X. Filipino
- Y. Vietnamese
- Z. Samoan
- Aa. Other Pacific Islander
- Bb. Other race: please specify ____________________________

9. What is your highest nursing/ non-nursing degree that you’ve earned?

________________________

(like CAN/ Bachelor/Masters etc.)

10. Were you born in the U.S. or were you a U.S. citizen at birth?

1. Yes

0. No

If No, in what country were you born? ____________
11. Do you care for an elderly or disabled person outside of paid employment?
   1. Yes   IF YES, how many hours per week ______
   0. No

   Who is that person you care for: parent/spouse/children under 18 years?

12. How many hours do you work each week in this position? ____________ hrs/week

13. Do you have a second paid job?
   0. No 1. Yes

14. Do you have health insurance from any source?
   0. No 1. Yes

15. Roughly, what is the total yearly income before taxes of your immediate family? This includes: your income, the wages of everyone else in the family who works, and income from any other sources.

   Please circle the letter beside the range that best describes your yearly family income.

   a. $0 - $9,999   b. $10,000 - $19,999   c. $20,000 - $29,999   d. $30,000 - $39,999
   e. $40,000 - $49,999   f. $50,000 - $59,999   g. $60,000 - $69,999   h. $70,000 or more

16. Is there anything in your workplace that you are not satisfied with/ thinking changing your job, i.e. low salary, increase workload etc.
Appendix E: Focus Group Questionnaire (Supervisors)

Focus Group: Supervisors (Phase I)               Estimated Length: 1 hour

We would like to learn more about your experiences on the job, with frontline staff, and your opinion regarding ‘Person-Centered care’ and ‘Culture Change’, while caring older adults. By definition, ‘Person-centered care’ is an individualized goal-oriented care plan based on the person’s preferences, where care is supported by an inter-professional team in which the person is an integral team member. Whereas, ‘Culture change’ is the common term given for the transformation of older adult services, based on person-centered values and practices where the choice, dignity, respect and quality of living of older adults and those working with them are considered and respected.

We’re particularly interested in learning about how the program will influence your organization, including its barriers and facilitators. I will use questions to guide our conversation, but other questions may come up. Please feel free to talk at length and in detail about your experiences, and to add things you think are important that I may not have asked you about.

This focus group is confidential [refer to consent form].

1. Briefly describe your role in the organization.
   - How closely do you work with frontline workers?
   - How would you describe your management style or approach?

2. We are interested in your perceptions of the relationships between frontline workers.
   - Do the frontline workers you supervise work well together?
   - Do your frontline workers participate in any formal orientation or training process?
   - What is your perception of the biggest issues your frontline workers face?
   - What is the single most important thing your employer could do to improve the job of frontline workers?

3. Do you think your frontline workers are well aware with the term “Culture change” while caring older adults with disabilities?
4. We are interested in your overall perceptions of the “Person-centered care” model.
   • How aware, do you think your employees in this domain?
   • Why do think that they are/ are not aware enough about person centered care model? Can you give me some examples, based on which you are giving your assumption?
   • Why do you think your organization chose to participate in the Person-centered care (culture change) program? Do you think it has satisfied expectation/ been worth this investment?

5. Do you think work-based learning has any impact on frontline workers as a successful teaching tool in the Jobs regarding person-centered care?
   • How would you define work-based learning?
   • If an interactive online training is offered for nursing home staffs (all level), what would you like to see focused in that module?

6. Do you think interactive competency-based online continuing education training for nursing home staff (all levels), together with nursing home residents and their informal care partners will enhance practicability of this program?

7. What are the main barriers to successfully implementing person-centered care model within your organization (HR policies, organizational culture, management practices, work processes, poor relations with unions or educational partners, etc.)
   • Is there any facilitators regarding this issue, in respect to your organization?

8. Do you think the person-centered care model has been widely supported within your organization?
   • Would you support the continued implementation of the program within your organization?
   • What are the main reasons you support the program? What are your main reservations about the program?
   • Are there any changes you think should be made to better support frontline workers participating in the program?

9. Sometimes residents may have bad days and care workers need strategies to redirect anger, frustration and associated behaviors.
   • What types of engagement activities, do you think promote relaxation, focus and calm in residents?
   • How do you motivate your employees, if the resident has Dementia as a special case?
   • What is the role of alternative therapies such as yoga, meditation and deep breathing in improving resident quality of life?
10. Finally, we are interested in learning what management can do to better support for supervisors like you.
   - Do you feel supported by your work environment?
   - What could be done to better help supervisors perform their jobs?

11. Do you think this care-model is going to be helpful for better management for the persons with dementia?

12. Is there anything I haven’t asked that you think is important for me to know?
Appendix F: Participants Recruitment Information Sheet

Alternative Therapies in Person-Centered Care for Persons with Dementia in Nursing Homes

A research project by

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ABSTRACT

Increasing numbers of people are living with dementia in every part of the globe. Curative options are unavailable; alternative therapeutic approaches are required urgently. A person-centered approach to care shifts the mindset of care partners from a traditional medical model to a social model in the management of dementia, where personal autonomy, choice, comfort and dignity, and purposeful living are maintained. This paper is part of a larger project, *Building resources for delivering person-centered care in Georgia nursing home*. Using semi-structured interviews, this study seeks to build an understanding of both the barriers and facilitators of person-centered care approaches for people living with dementia and the level of integration of complementary and alternative approaches in nursing homes throughout the state.
of Georgia. It is hoped that the proposed study will generate thoughtful comments regarding the implementation of person-centered care, the barriers and facilitators and how person-centered therapeutic approaches including different engagement activities can improve the daily lives of persons living with dementia. Implications to policy and practice will be discussed.
Appendix G: Coding List

CMP Codes: Building Resources for Delivering Person-Centered Care in Georgia Nursing Homes

A Person-Centered Care Strategies

A1 Compatibility
   Extent to which program activities are consistent with organizational and/or professional mission and values; Acceptance from residents/families
A2 Risk
   Perceived risks of implementing the program (e.g., strength of evidence base, how difficult to implement, etc.)
A3 Nature of knowledge on PCC and Culture Change
   How aware, the employees (both DCWs and Supervisors) are in this domain; Program, education and care plan

B Health System Characteristics

B1 Structure and Payer-mix
   Distribution of payer sources (e.g., Medicare, Medicaid, self-pay)
B2 Strategic priorities
   Practice goals and priorities as articulated by management
B3 Leadership support and reporting structure
   Program and organizational leaders’ ability to communicate a rationale for innovation and make resources available
B4 Workforce policies and practices
   Existing workforce practices, policies, and strategies

C Implementation Policies and Practices

   Formal actions taken by management to promote implementation, e.g., changes to organizational policies and practices

C1 Provider and staff training
   Interactive competency-based online continuing education training, work-based learning regarding person-centered care, Skill and/or team-based training for DCWs and other care team members
C2 Job quality context
   Monetary or other rewards for performance for DCWs and other care team members
C3 Program adaptations
   Changes made to the program to facilitate uptake by health care team
D Implementation Context/ Barriers and Facilitators

Extent to which individuals feel that program activities are expected and supported

D1 Organizational context
HR policies, organizational culture, management practices, work processes, poor relations with unions or educational partners, etc.

D2 Resident’s context (Acceptance from residents/families)

D3 Worker’s context

D4 Other Barriers

D5 Other Facilitators

E Other Practice Context

E1 Presence of a culture change champion
Individual(s) that promote the program with leadership and/or targeted care teams

E2 Care team functioning
Team size, composition, member roles and responsibilities, communication and other interaction patterns, etc.

E3 Workplace climate
Perceived organizational support to reduce worker burnout

F Outcome: Care at Resident/ Family Level

F1 Complementary and alternative medicinal (CAM) practices, e.g. Yoga, Music therapy, etc.
How these help residents by promoting relaxation, reducing agitation and increasing quality of life
How these help minimize Loneliness, Boredom and Helplessness

F2 Resident satisfaction
Resident evaluation of the care experience, e.g., interaction with care team, physical environment of care, etc.

F3 Continuity of care
Relationship between care team and patient that extends beyond specific episodes of illness or disease

G Outcome: Organizational

G1 Workforce stability
Tenure and turnover among staff; absenteeism/call out
G2 Team productivity
  \textit{How these increase creativity among workers and reduces burnout}

**H Outcome: Worker Level (Positive & Negative)**

H1 Job satisfaction and job quality
  \textit{Overall job satisfaction and other measures of job quality, including workload and relationships with co-workers}

H2 Organizational commitment
  \textit{Worker identification with and involvement in the organization; Promotion and other opportunities with employer}

H3 Compensation and benefits
  \textit{Actual compensation and benefits received, as well as satisfaction with compensation and benefits}

H4 Opportunities for advancement
  \textit{Professional training opportunities}

**I Outcome: Movement toward Culture Change/PCC**

I1 Resident/Family level
  \textit{Acceptance of PCC and various CAM practices; Culture Change}

I2 New policies and practices to support PCC/Culture Change
Figure 1. Different CAM Practices Recently Used in USA

Figure 2. Types of Recruited Nursing Homes

Figure 3. Job Titles of Complete Focus Group Samples (DCWs)
Figure 4. Job Titles of Complete Focus Group Samples (Supervisors)

Figure 5. Activities Available for the Residents in Participant Nursing Homes
Figure 6. Schematic Representation of Factors for Successful Implementation of PCC