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Responding To Behavioral Expressions Of Residents Living With Dementia In Assisted Living

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RESPONDING TO BEHAVIORAL EXPRESSIONS OF RESIDENTS LIVING WITH

DEMENTIA IN ASSISTED LIVING

by

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Under the Direction of Candace L. Kemp, PhD

ABSTRACT

This thesis focuses on direct care workers' (DCW) interpretations of and responses to the behaviors and expressions of assisted living (AL) residents with dementia. Data are drawn from a five-year grounded theory study of AL residents' care arrangements that involved interviewing, participant observation, and resident record review. This study analyzes data from a sub-sample of 29 residents living with dementia and their care network members from 7 diverse AL settings studied over 2 years. The aims are to: examine DCWs' reactions to resident behaviors; and understand how and under what circumstances DCWs seek assistance from external network members. DCWs responses included being patient and working directly with residents to reaching out to others, especially in instances of perceived aggressive. Resident- and DCW-factors influenced staff perceptions and responses and were highly variable. Findings underscore the importance of enhanced dementia care training for DCWs and the value of family participation in care.

INDEX WORDS: Behavioral and Psychological Symptoms of Dementia, BPSD, Assisted Living, AL, dementia, BioPsychoSocial Distress, Behavioral Expressions

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DEDICATION

I would like to dedicate my thesis to my parents who have, despite not wanting me to move to Atlanta, supported me unconditionally and without question on my journey here. They are the greatest role models I could have ever asked for and who I strive to be like every day. I thank you both for the hundreds of opportunities you have given me in life and for having the courage to leave Puerto Rico not to find a better life for yourselves, but to find a better life for Yomayra, Miguel, and me. I love you.

I would also like to dedicate my thesis to Stephanie. When I told you that I wanted to move to Atlanta, Georgia to complete my Master's degree you never questioned our relationship or asked for anything. You willingly moved away from your family in Orlando, not because you wanted to, but so that I could do my thesis and that we could continue to be together through this crazy journey. You relocated your life, your job, and everything else just so that we could be together. Then on top of that you have stuck by me and supported me despite our ups and downs, even believing in me when I didn't. I never would have imagined that the loud, boisterous, know-it-all Latina that I thought you were when we first met in Tampa would become the fun, caring, loving, still know-it-all woman that I am completely in love with. Thank you for always supporting, believing, and loving me these 5 (almost 6!) amazing years. You are my wind.

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LIST OF ABBREVIATIONS

- BPSD – Behavioral and Psychological Symptoms of Dementia

- AL – Assisted Living

- DCW – Direct Care Worker

- PCH- Personal Care Home

1   INTRODUCTION

It is estimated that by 2020, 42.3 million people will be living with dementia worldwide (Rizzi, Rosset, & Roriz-Cruz, 2014). In the United States (US) current estimates suggest that 5.7 million people are living with Alzheimer's disease (Herbert, Weuve, Scherr, & Evans, 2013). Yet, this estimate does not include those living with other forms of dementia or the estimated 100,000 additional people in the US who have undiagnosed dementia (Koller & Bynum, 2014). Given that the likelihood of dementia increases with age, as the US experiences population aging, the number of individuals living with dementia will grow (Herbert et al., 2013).

Dementia is a complex disease that has various different forms with numerous symptoms, most of which inhibit an individual from performing daily tasks (Fazio, Pace, Maslow, Zimmerman, & Kallmyer, 2018b). The most frequently experienced symptoms of dementia, shared by most, but not all of its types, include: memory, language, and problem-solving difficulties (Alzheimer's Association, 2018).

The most common form of dementia is Alzheimer's disease, which accounts for 60 to 80 percent of all dementia cases (Alzheimer's Association, 2018). In the US, Alzheimer's disease is the 6th leading cause of death (National Center for Health Statistics, 2017). The degenerative disease ultimately results in the individual having difficulty speaking, swallowing, and walking (Alzheimer's Association, 2018).

Due to the eventual need for supportive care, people living with dementia have a significant need for long-term care services and supports. Typically, family and friends of the individual living with dementia are the ones who take responsibility for providing any supportive care (Whitlatch & Orsulic-Jeras, 2018). At present, over 16 million people in the US are providing this unpaid care (Alzheimer's Association, 2018). As dementia progresses an

individual's care needs may become too great for family or friends to provide, causing them to consider alternative care options (Whitlatch & Orsulic-Jeras, 2018). With the increasing prevalence of dementia, there is an increased demand for long-term care communities to support the needs of this population (Zimmerman, Sloane, & Reed, 2014). For older adults living with dementia, assisted living (AL) has become a major provider of residential care (Zimmerman et al., 2014). Residential care is any place, such as AL or personal care homes (PCH), which provide assistance and care to individuals living in the community. While it is important to note that estimates of prevalence of dementia in AL vary, a national study examining residents in residential care communities found that approximately 42% of residents living in a residential care community have some form of dementia (Khatutsky et al., 2016).

Individuals living with dementia may experience distress exhibiting what clinicians and others in the medical field frequently label behavioral and psychological symptoms of dementia (BPSD) (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012). Behavioral symptoms include, for example, aggression or pacing; examples of psychological symptoms include anxiety, delusions, or hallucinations (De Souto Barreto, Lapeyre-Mestre, Vellas, & Rolland, 2014; McKenzie, Teri, Pike, LaFazia, & Leynseele, 2012). Medical clinicians examine BPSD as byproducts of dementia and something that is part of the normal progression of dementia. There is an alternative interpretation of BPSD among certain advocates, practitioners, researchers, and those living with dementia, that BPSD should stand for "*Bio-psycho-social distress*" (Dementia Action Alliance., 2016). The reason underlying this alternative interpretation is the belief that aggression, pacing, anxiety, and other behaviors/psychological states result from environmental/social factors which could cause biological, psychological, or social distress for the individual living with dementia (Scales, Zimmerman, & Miller, 2018). Supporters of this social model of BPSD believe that

determining what triggers individuals to experience bio-psycho-social distress should be the goal of care partners rather than assuming the responses are simply due to the individual's dementia (Dementia Action Alliance., 2016).

Despite these competing views of BPSD, research shows that its symptoms/expressions can increase the stress of those caring for individuals living with dementia (Schmidt, Dichter, Palm, & Hasselhorn, 2012). This stress may cause direct care workers (DCWs) to seek assistance from family, friends, physicians, and other external care partners of the person living with dementia for assistance on how to address the BPSD of the individual. Even with assistance, care partners or providers may resort or be encouraged to use medications in order to control behavior (Berry & Apesoa-Varano, 2017). Such an approach is potentially problematic as many medications used to control behavior are being used off label (i.e. not for their intended or approved purpose) with deleterious outcomes (Austrom, Boustani, & LaMantia, 2018). A medication-first approach to behavioral management could lead to medical complications for persons with dementia (Cerejeira et al., 2012). The issues with medication use has led some to champion the use of techniques that do not require the use of pharmacological intervention to calm individuals experiencing BPSD. These evidence based non-pharmacological therapeutic approaches include aromatherapy, music therapy, and massage (Scales et al., 2018). The problems with these approaches is that they require considerable time, personalization, and training to implement effectively (Fazio et al., 2018b). When used appropriately, both medications and evidence based non-pharmacological therapeutic approaches can have a positive effect on the quality of life of the individual living with dementia, therefore it is important to understand the impact collaborations with external care partners, as well as the preferred method of addressing BPSD, can have on the person living with dementia.

With the older adult population and the numbers of people living with dementia increasing, it is important to understand how DCWs respond to the BPSD, or behavioral expressions, of people living with dementia. Given the increasing role that AL communities play in caring for those with dementia, it is imperative to understand DCWs' perceptions and responses to behaviors as they provide the bulk of care and are on the "frontline" (Lepore, Ball, Perkins, & Kemp, 2010). Also, understanding how and when DCWs collaborate with family, friends, and external care partners to address these behavioral expressions helps to reveal how the dynamics influence the care the person living with dementia receives. The goal of this proposed research is to learn how in AL DCWs understand and respond to behaviors of residents living with dementia. This research has two aims:

1. Examine DCWs' responses to BPSD among AL residents living with dementia;

2. To understand how and under what circumstances AL staff seek outside assistance from family and external care workers when addressing BPSD.

Secondary data analysis using data from the "Convoys of Care: Developing Collaborative Care Partnerships in Assisted Living" study will be completed to address these aims. Grounded Theory Methods (Corbin & Strauss, 2015) will be used to perform open, axial, and selective coding on the data collected from the study, focusing only on resident participants who have a confirmed diagnosis of dementia. This project will seek to increase the understanding of how approach to BPSD in AL can impact the overall quality of care and quality of life of individuals living with dementia. The information gathered in the study will have important practice implications for the senior living industry to improve the quality of care and quality of life of persons living with dementia and those who care for them.

2   LITERATURE REVIEW

There are four areas of literature most relevant to the aims of this project: dementia, dementia care practices, perspectives of BPSDs, and BPSD in residential care settings. Dementia delves into the facts about the various forms of dementia as well as their prevalence. Dementia care practices reviews information about the impact family members play as well as the differences between nursing homes and AL. Perspectives of BPSDs serves to elaborate on the two distinct views about BPSDs, especially how the two perspectives define BPSDs and drive different approaches and techniques to care for those living with dementia. BPSD in residential care settings presents literature that examines how BPSDs are perceived and handled in formal care settings.

2.1   Dementia

Dementia has become a popular topic of research due to the growing public health concern of these conditions (Herbert et al., 2013). Dementia is characterized as a complex neurological disease, having numerous cognitive, behavioral, and physical symptoms– for example dementia often causes problems that affect the ability of an individual to perform daily tasks (Fazio et al., 2018b). Common symptoms of dementia include having issues with memory, language, and problem solving skills (National Institute of Health, n.d.). There are many types of dementia that have distinct pathology and clinical presentation but all share similar cognitive/behavioral symptoms. There are variations such as: Vascular dementia, Dementia with Lewy Bodies, Fronto-temporal lobar degeneration, Parkinson's disease, Creutzfeldt-Jakob disease, Normal pressure hydrocephalus, and mixed dementia (Alzheimer's Association, 2018). Each disease has a unique clinical presentation associated with the distinct pathology of each condition. For example, vascular dementia, which occurs most commonly due to blockage of or

damage to blood vessels, often results in primary impairment in judgement and orientation (Rizzi et al., 2014). In contrast, fronto-temporal lobar degeneration is most often defined by difficulty understanding language and changes in personality (Alzheimer's Association, 2018). Meanwhile, mixed dementia occurs when a person has multiple types of dementia; the symptoms depend on the combination of underlying pathologies associated with the dementias (Alzheimer's Association, 2018).

Although there are various types of dementia and various symptoms for each, Alzheimer's disease is the most common form (Rizzi et al., 2014). Symptoms can include trouble remembering events or names, difficulty with verbal and/or written communication, confusion, and even behavioral changes (Alzheimer's Association, 2018). Alzheimer's disease is caused by a buildup of proteins called beta amyloid and tau (National Institute of Health, n.d.). These proteins accumulate both inside and outside neurons ultimately leading to the damage and death of the neurons (Rizzi et al., 2014). Due to the death of the neurons in the brain, individuals living with Alzheimer's disease eventually will have difficulty speaking, swallowing, and walking (Alzheimer's Association, 2018). The degeneration of the brain begins years before a person exhibits noticeable clinical symptoms of Alzheimer's disease (Wilson et al., 2012). Currently, Alzheimer's disease is the 6th leading cause of death in the US (National Center for Health Statistics, 2017).

A reason why dementia is so complex can be attributed to its numerous forms and the fact that individuals can display cognitive impairment without having dementia, contributing to the complexity of diagnosis. Conditions like depression, delirium, thyroid problems, alcohol abuse, vitamin deficiencies, and side effects from medications can cause cognitive impairment. Unlike irreversible dementias, those with these conditions can often have their symptoms be

reversed with treatment. Identifying who has reversible dementia and who has irreversible dementia is important so that unnecessary treatments and medications are not used which could potentially harm the individual more (Chari, Ali, & Gupta, 2015).

As for risk factors, women have a higher risk of developing dementia than men, while Black people and Latinos have increased risks compared to White people and other ethnicities (Koller & Bynum, 2014). One proposed reason as to why women develop dementia more than men is due to the fact that women typically live longer than their male counterparts (Rizzi et al., 2014). Family history also plays a role in the risk of developing dementia. Those who have an immediate family member or multiple family members living with dementia are at an increased risk for developing dementia (Loy, Schofield, Turner, & Kwok, 2018). Although there is considerable research on the prevalence of dementia and its risk factors there is no cure for any form of dementia.

2.2   Perspectives of BPSDs

People living with dementia commonly experience BPSD over the course of their condition (Cerejeira et al., 2012). Currently there are two competing perspectives of BPSD and what it should stand for. In its original articulation, BPSD stands for "behavioral and psychological symptoms of dementia" and was used to describe the common symptoms that individuals living with dementia can experience on a daily basis (Cerejeira et al., 2012). This definition of BPSD is considered to be a medicalized framework that does not get to the root cause of BPSD (Dementia Action Alliance., 2016). Recently an alternative perspective of BPSD has emerged, with researchers trying to apply a more sociological perspective. This competing perspective defines BPSD as *Bio-psycho-social distress* (Dementia Action Alliance., 2016). The purpose of this definition is to show that BPSD is much more than just symptoms a person

emotes (Dementia Action Alliance., 2016). The social model of BPSD frames behavioral

expressions as reactions of the person living with dementia to stimuli and not just a byproduct of

a neurocognitive disorder (Dementia Action Alliance., 2016). In the following sections, each

model will be presented with a focus on understanding both perspectives of BPSD and the

implications of each model in care.

2.2.1   *Medical model.*

Behavioral and psychological symptoms of dementia are seen as a very common result of

dementia pathology that can cause a great deal of distress for those living with dementia and

their care partners (Cerejeira et al., 2012). Behavioral symptoms of dementia include

aggressiveness, wandering, and psychosis (De Souto Barreto et al., 2014). Meanwhile

psychological expressions or co-morbidities of dementia include depression, anxiety, delusions,

or hallucinations (McKenzie et al., 2012). These symptoms can cause disturbed emotions,

perceptions, motor activity, as well as altered personality traits; all of which are associated with

greater use of health care services (and hence greater cost) (Cerejeira et al., 2012). This

definition frames BPSD as a collection of symptoms that can affect the individual living with

dementia.

The medical framework manages BPSD by seeing it as a collection of symptoms that

need to be treated medically. From this perspective, BPSDs are treated using clinical

interventions such as medications. This approach has been challenged because it remains

difficult to pinpoint the etiology of BPSD due to the wide range of symptoms that can occur

(Cerejeira et al., 2012). Cerejeira, Lagarto, and Mukaetova-Ladinska (2012) suggest that taking a

syndrome approach to studying BPSD could be helpful due to the similarities it shares with

primary psychiatric disorders. Despite the various symptoms and how some symptoms differ

based on the specific dementia diagnosis, the overall medical consensus is that BPSD is the result of pathophysiological brain changes caused by dementia (Cerejeira et al., 2012).

When caring for an individual who is exhibiting BPSD maintaining order in the household is an important objective for the care partner (Berry & Apesoa-Varano, 2017). In a national study conducted for the CDC, Khatutsky et al. (2016) found that in the 30 days leading up to the survey, 52 percent of the residents in the homes surveyed expressed BPSD. Of the 52 percent that expressed BPSD, 61 percent were given medication to control behavior or reduce agitation (Khatutsky et al., 2016). By medicating a person with dementia to control for behavioral expressions, care partners explain that they are able to provide proper care and cause minimal disruptions to the household (Berry & Apesoa-Varano, 2017). When an older adult is not properly medicated they perceived as a health risk to themselves and others, causing disturbances in daily routine and sleeping schedules (Berry & Apesoa-Varano, 2017). Drugs are often percieved by the lay person as being helpful and for the most part harmless, which gives care partners the perception that medications are a safe and effective tool (Kerns, Winter, Winter, Kerns, & Etz, 2017).

Kerns et al. (2017) conducted a study aimed at determining what factors contribute to formal and informal care partners utilizing medications for BPSD. They found that care partners, including nurses who had years of dementia care experience, reported observing no severe side effects to the medications used to control BPSD. Care partners in the study believed that medication use was appropriate and warranted when non-pharmacological approaches failed to work. Care partners also shared that physicians typically were unhelpful in providing resources other than medication when trying to deal with BPSD, and described community resources, such as adult daycare, as being expensive or inadequate. As a result, of these experiences, care

partners viewed the use of medications to address the BPSD as being cost effective and beneficial. Care partners also viewed the use of medications as relieving suffering and delaying institutionalization. Such views perpetuated the use of medication for the treatment and management of BPSD.

Various medications are used to treat BPSD, including "antipsychotics, antidepressants, anticonvulsant mood stabilizers, ChEI, benzodiazepines, and others such as memantine" (Cerejeira et al., 2012, pp. 14). A major problem with using these medications is that older adults with dementia typically have co-morbidities and combining these medications with others already present in their system can lead to increased risk of medical complications and drug interactions (Cerejeira et al., 2012). Older adults do process medication differently than younger adults, which means that as people get older there may be certain medications that their body can no longer tolerate (Austrom et al., 2018). Due to changes in the body, some medications can be the cause of BPSD among those living with dementia (Austrom et al., 2018). Research shows that another concern about using medication to control BPSD is that their use can lead to increased falls (Wei, Simoni-Wastila, Lucas, & Brandt, 2017). Wei et al. (2017) examined antidepressants and antipsychotics to see which carried a higher fall and fracture risk. The researchers concluded that antidepressants were associated with a higher risk of fractures due to falls; but compared to those who did not have medication both antidepressants and antipsychotics increased the chances of falls and fractures. The other problem researchers identified was the absence of guidelines regarding when to use antidepressants versus antipsychotics, use was determined by the pros and cons seen in the specific resident. The lack of guidelines, regulations, and risk involved in the use of medications for residents living with dementia raises significant concern about their use (Wei et al., 2017).

2.2.2   Social model.

In a recent article, Macaulay (2018) expressed that BPSD or behavioral and psychological symptoms of dementia is an inappropriate label to describe the individual expressions of people living with dementia. From this perspective referring to individual expressions of people living with dementia as BPSD feeds into the stigma of dementia, does not identify the root cause of the expression, can cause unnecessary distress, and can result in sedation through the use of medications. Medicalization and use of the label "behavioral and psychological symptoms of dementia" are perceived as perpetuating the stigma of dementia and the idea that people with dementia are diminished (Dementia Action Alliance, 2016). Research supports this viewpoint by showing that when staff view behaviors as being caused by dementia it makes them more likely to unconsciously treat residents as subordinates (Doyle & Rubinstein, 2013). This scenario can then create an environment where residents living with dementia are seen and treated as being different and as an "empty shell of a body" (Doyle & Rubinstein, 2013, p. 958). The phrase, behavioral and psychological symptoms of dementia, does not take into account that an individual's reaction or behavior may be due to the external factors (e.g. environment, approach) causing distress to the individual (Dementia Action Alliance, 2016). In order to better treat individuals living with dementia, the Dementia Action Alliance (2016) suggest retaining the acronym BPSD but changing the meaning to *bio-psycho-social distress*. The reasoning for this change is that bio-psycho-social distress reminds care partners to determine the cause of the distress being displayed instead of assuming it is a result of the dementia (Dementia Action Alliance, 2016).

The change from treating symptoms of dementia to trying to understand why someone is behaving a certain way and determining the underlying cause is strongly influenced by the idea

of person-centered care. Originally utilized by Thomas Kitwood as a type of care that was different from the medical approach, the concept of person-centered care centers on the belief that care should revolve around the needs of the care recipient (Kitwood, 1997). Person-centered care challenges the medical model of care which often prioritizes process, schedule, staff needs, and organization needs (Fazio, Pace, Flinner, & Kallmyer, 2018a). Instead person-centered care asks care partners to focus on the needs of the individual and is based on having an interpersonal relationship with the care recipient (Kitwood, 1997). A person-centered approach tries to promote well-being by considering the care recipient's goals and preferences (Dementia Action Alliance, 2016). In order to make individuals living with dementia feel like they are involved in their care, people have begun to apply person-centered care to dementia care (Fazio et al., 2018a). The Dementia Action Alliance (2016) defines person-centered dementia care as:

> Person-centered dementia care and support is based on the fundamental belief that every person has a unique background, skills, interests and the right to determine how to live his or her own life. Person-centered dementia support is focused on nurturing the person's emotional, social, physical, and spiritual well-being. This is achieved through reciprocal, respectful relationship by:
>
> - Valuing personal autonomy, choice, comfort, and dignity;
> - Focusing on the individual's strengths and abilities;
> - Enabling opportunities for continuation of normalcy and growth of self; &
> - Enhancing individual purpose, meaning, enjoyment and belonging. (p.15)

The definition demonstrates how traditional medical approaches to care are often too narrow and do not incorporate all elements of person-centered care (Dementia Action Alliance., 2016). Person-centeredness encompasses a more holistic approach and does not center only on physical

health (Dementia Action Alliance., 2016). Allowing care recipients to maintain their selfhood is the main goal of person-centered care (Kitwood, 1997).

Person-centered dementia care addresses the bio-psycho-social distress individuals living with dementia exhibit by examining how intrinsic and extrinsic factors impact the person and cause distress. The BPSD individuals exhibit often is a reaction to a stimuli of the surrounding social or physical environment (Scales et al., 2018). Simply put, BPSD is often a way of the person with dementia conveying any stress they may feel or unmet needs, it is often a reaction to something in their environment whether it be physical or social (Scales et al., 2018). Triggers of BPSDs are unique to each person as he or she reacts to their environment and circumstances individually, as such, having a person-centered approach to care is often recommended (Scales et al., 2018). BPSDs and their triggers may change over time; this variability means that the interventions and approaches that may have worked to address symptoms before may no longer be as effective and new practices or techniques may be needed, stressing the importance of person-centered care which relies on relationships with care partners (Scales et al., 2018).

Proponents of person-centered dementia care champion the use of evidence based non-pharmacological strategies to address BPSD. As stated above, BPSD is often a reaction or response to stimuli meaning that it is a type of meaningful expression that if understood can allow for the care partners to reduce or remove the stimuli causing the BPSD (Scales et al., 2018). Evidence based non-pharmacological strategies are often recommended by researchers to be the first line of defense when treating BPSD and should always be considered prior to using medication (Austrom et al., 2018). Encouraging people living with dementia to help with daily chores and maintain past hobbies has been shown to not only improve mood and quality of life but reduce agitation as well (Austrom et al., 2018). Other evidence based non-pharmacological

techniques such as aromatherapy, massage, bright light therapy, music therapy, and pet therapy have also been shown to help individuals suffering from distress (Scales et al., 2018). Evidence based non-pharmacological techniques are suggested as the first step to addressing BPSD because they are safer than medications, while their downside is that they can be very time consuming and require training (Cerejeira et al., 2012; Fazio et al., 2018b). Finding techniques or practices that help address BPSD while also being feasible for the DCWs to learn or execute is important because it reduces the burden for DCWs, but more importantly improves the quality of life of residents living with dementia. (Scales et al., 2018).

2.3   Dementia Care Practices

The diagnosis of dementia not only impacts the person but also their social network including family, friends, coworkers, and other acquaintances (Whitlatch & Orsuli-Jeras, 2018). The progressive nature of dementia means that persons living with dementia will require increasing and different levels of support and care over time. Initially, the person living with dementia may only need help with cooking and cleaning but later need help with eating and going to the bathroom (Whitlatch & Orsuli-Jeras, 2018). The care network of the person living with dementia can play an important role in the care they receive. Understanding how an individual's network or community affects how they age and the care they receive is important because it can highlight the differences people experience during the disease process.

Dementia care typically takes a team or network of people to ensure that the needs and desires of the person are met. These teams often evolve depending, in part, on the changing needs of the care recipient. For older adults in need of care, factors such as society, community, and facility can play a role in determining the make-up of the team. The team can be composed of informal care partners, such as family and friends, or formal care providers, such as doctors

and nurses. In 2013, Kemp, Ball, & Perkins created a conceptual model, "the Convoys of Care model" to explain the changing dynamics that occur in the interactions between informal care partners, formal care partners, and the care recipient. The Convoy of Care model utilizes the metaphor of a convoy to illustrate how the network of a care recipient can communicate, change, and influence care. The Convoy of Care model defines convoys as:

> The evolving community or collection of individuals who may or may not have close personal connections to the recipient or to one another, but who provide care, including help with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), socio-emotional care, skilled health care, monitoring, and advocacy. (Kemp et al., 2013, p.18)

Each person's convoy is unique and as needs change so too can the roles people fulfill in the convoy; convoys evolve as members adapt to dynamic care needs and negotiate care (Kemp et al., 2013).

When individuals move into a residential care community their convoy of care immediately expands. These convoys can include DCW, volunteers, and possibly other residents. However, upon moving to AL a convoy can also lose members such as neighbors. In AL, residents can create close, even family like, relationships with other residents and DCWs, blurring the lines of formal and informal care (Kemp et al., 2013).

Understanding how formal and informal care partners navigate these ever changing roles is important to understanding the care an individual living with dementia receives. AL DCWs typically see their roles as helping with ADL care and medications, while family are expected to provide socioemotional support and perhaps other support such as transportation or buying care items (Kemp et al., 2013). Depending on the level of involvement of family and friends this can

place more or less responsibility on the DCWs causing a renegotiation of care and roles (Kemp et al., 2013). For stakeholders, (i.e., residents living with dementia, families, and care organizers/providers) understanding how formal and informal care partners navigate care and collaborate with one another is imperative to understanding the quality of life and care an individual receives.

The care network/team an individual has is important to establishing good care, but the quality of care is also influenced by the type and severity of dementia, symptoms, co-morbid conditions, and functional limitations of the individual. Understanding the difference between the various types and severity of dementia is important to providing the appropriate care (Whitlatch & Orsulic-Jeras, 2018). The progression of dementia is also something that is very unique and affects everyone in different ways. Evaluating the unique needs of each person living with dementia is imperative to providing the appropriate level of care needed (Prizer & Zimmerman, 2018). For example, with the "early-stage" of Alzheimer's disease the individual diagnosed is fairly independent and does not require much assistance ("Stages of Alzheimer's," n.d.). In the "middle-stage" of the disease the individual may begin to require help with IADLs such as housekeeping, taking medication, and using the telephone ("Stages of Alzheimer's," n.d.; Whitlatch & Orsulic-Jeras, 2018). It is in the "middle-stage" where care partners often feel higher levels of stress and burden from the diagnosed individual (Whitlatch & Orsulic-Jeras, 2018). Finally, in the "late-stage" the stress of the disease is high for both the individual living with dementia and their care partner ("Stages of Alzheimer's," n.d.; Whitlatch & Orsulic-Jeras, 2018). It is at this point where care needs can become too great for care partners and alternative care settings may be considered (Whitlatch & Orsulic-Jeras, 2018). While this may be a typical case of Alzheimer's disease the speed at which the disease progress is unique to each individual

and can vary based on type of dementia. Understanding the type of dementia and how it is progressing in the individual is important in order to provide the appropriate level of care and support so as to maintain their quality of life.

Dementia Care is most often provided by family or friends of the individual living with dementia (Whitlatch & Orsulic-Jeras, 2018). Nationwide, over 16 million people currently provide unpaid care for someone living with dementia; at a total cost of 18.4 billion hours of care in 2017 (Alzheimer's Association, 2018). Unpaid care partners often experience stress and burden associated with caring for someone living with dementia (Whitlatch & Orsulic-Jeras, 2018). In a recent survey of unpaid care partners of individuals living with dementia, when asked if their health had gotten worse due to the responsibilities of caring for someone living with dementia 35% claim that their health had indeed gotten worse (National Alliance for Caregiving, 2017). Also, unpaid care partners often give up their jobs or advancing in their career to care for a loved one living with dementia (Callahan, 2017). By 2037 it is estimated that there will be 10 million individuals living with dementia in the US and that they will spend at least 5 years receiving care from a family member before moving to long term care housing (Callahan, 2017). Unpaid family care partners are important in caring for individuals living with dementia. Ensuring that care partners are aware of support services such as support groups, counseling, and respite care is important to ensure that they can maintain their health and the health of the care recipient (Whitlatch & Orsulic-Jeras, 2018).

For older adults living with dementia, AL has become a major provider of residential care (Zimmerman et al., 2014). One reason AL residences have become popular is due to the fact that they provide more care than an independent living community but less care than a nursing home (Sengupta et al., 2015). Another benefit of AL communities is that, while also providing 24-hour

care, they are not associated with the same stigmatizations as nursing homes (Bowblis, 2012).

An important difference between the AL and nursing home industries is how they are regulated; the former is regulated at the state level while the latter is federal creating greater homogeneity in the care and services among nursing homes (Bowblis, 2012). AL communities also differ from nursing homes in that they attempt to be less medical and institutional (Roth & Eckert, 2011).

They strive to be more home-like where they can receive the care they need in a more social model of care approach instead of a medicalized model of care (Bowblis, 2012; Roth & Eckert, 2011). For those with the financial means and the appropriate care needs, AL communities are seen as an alternative to nursing homes (Simmons et al., 2017).

In 2016, 42 percent of residents living in residential care communities in the United States had been diagnosed by a physician or other health care provider as having dementia (Khatutsky et al., 2016). Of the homes in the US, Harris-Kojetin et al. (2016) reported that 10.1 percent of residential care homes served only residents living with dementia. As for the residential care homes that were not dementia only, Harris-Kojetin et al. (2016) found 12.1 percent offered a dementia care unit somewhere in the community. Nearly 80 percent of residential care communities in the United States do not have specialized dementia care units (Harris-Kojetin et al., 2016). A reason for the lack of uniform services in residential care communities is due to the lack of federal regulation; the licensing and regulation of residential care communities is done by the state which is a reason for the differences in services and standards (Carder, O'Keeffe, & O'Keeffe, 2015).

2.3.1 Georgia state regulations.

In this section information presented about AL communities and PCHs in Georgia, and their requirements derives from the "Compendium of Residential Care and Assisted Living

Regulation and Policy: 2015 edition" by Carder et al. (2015). This thesis will be utilizing data from AL communities and PCHs that are based in the state of Georgia. For this reason, understanding the relevant state regulations, including what differentiates AL communities and PCHs regulated in the state of Georgia is important.

In Georgia, the state differentiates between AL community and PCHs. An AL community is defined as:

> A personal care home that serves 25 or more persons and is licensed to provide "assisted living care," defined as the provision of personal services, the administration of medications by a certified medication aide, and the provision of assisted self-preservation. Assisted self-preservation defines the capacity of a resident to be evacuated to a designated point of safety within an established period of time, as determined by the office of the Fires Safety Commissioner. (Carder et al., 2015, p. 144)

The definition of a PCH is as follows:

> A setting that provides or arranges for the provision of housing, food service, and one or more personal services for two or more adults who are not related to the owner or administrator. Personal services include individual assistance with or supervision of self-administered medication, and assistance with essential activities of daily living (ADLs), such as eating, bathing, grooming, dressing, toileting, ambulation, and transfer. (Carder et al., 2015, p. 144)

By definition AL communities have more services for residents than PCHs. AL communities are allowed to administer medication with a certified medication aide but PCHs are only allowed to assist or supervise with self-administered medications. PCHs are also not allowed to use the term "assisted living" in marketing themselves as that is reserved for licensed AL communities. Prior

to admitting residents in both settings an assessment must be done to determine the residents'

functional capacity and care needs, this is to ensure that the homes do not admit residents who

require more care than the homes can provide.

Every AL community must have a full-time administrator, DCWs who provide assistance

with personal care, a house manager who is responsible for the community when the

administrator is not available, and have a certified medication aide who can administer

medication. The staff to resident ratio is a minimum of 1:15 during the day and 1:25 during the

night. All staff must be trained in residents' rights, identification of abuse or neglect, general

infection control principles, reporting requirements, and emergency preparedness; all of which

must be taught within the first 60 days of employment; those who are DCWs must also be

trained in characteristics of the resident population, special needs of resident with dementia, job

specific duties, proper food preparation, emergency first-aid, and cardiopulmonary resuscitation.

Finally, all staff must complete 24 hours of continuing education in their first year of

employment and then 16 hours each following year.

In Georgia there are also specific provisions for facilities that serve people living with

dementia. For communities that have memory care units the state of Georgia defines them as:

> The specialized unit of an assisted living community or personal care home that either
>
> presents itself as providing memory care services or provides personal services in secured
>
> surroundings to persons with diagnoses of probable Alzheimer's disease and other
>
> dementia. Memory care services means the additional watchful oversight systems,
>
> program, activities and devices that are required for residents who have cognitive deficits
>
> that may impact memory, language, thinking, reasoning, or impulse control, and which

place the residents at risk of eloping (i.e., engaging in unsafe wandering activities outside

the home). (Carder et al., p. 144-145)

Communities with memory care units must include a multipurpose room, secured outdoor spaces

that allow residents to move safely, appropriate flooring, appropriate lighting, free movement

between the resident's room and the common space, and much more. For care staff in these

memory care units there must be at least one person who is awake at all times supervising the

unit; the staff in the memory care units also are required more training such as learning about

dementia including Alzheimer's disease, common behavior problems, communication skills,

positive therapeutic interventions, and much more.

2.4 BPSD in Residential Care Settings

As stated earlier, when caring for an individual living with dementia becomes too much

for the care partner alternative options may be considered, options such as AL (Whitlatch &

Orsulic-Jeras, 2018). In AL, individuals can get help with their ADLs while being in a home like

environment with 24-hour care (Bowblis, 2012). When individuals living with dementia

transition to AL DCWs become their main provider of help with ADLs and IADLs. DCWs are

very important to resident care as they help with physical care, engage residents in meaningful

activities, and are really the ones in charge of maintaining residents' quality of care and life

(Gilster, Boltz, & Dalessandro, 2018). These individuals can influence the quality of life and

overall experience that residents receive in AL (Gilster et al., 2018).

Despite the impact DCWs have on the quality of life of residents in long term care

communities keeping up with the demand for these individuals as well as retaining these care

providers continues to be a challenge (Gilster et al., 2018). Reasons for difficulty in retaining

DCWs has been attributed to low wages, lack of benefits, and few opportunities for career

mobility; the median income for DCWs in AL is approximately $18,152 US (Kelly, Morgan, Kemp, & Diechert, 2018). Jobs in AL are considered accessible to those looking for entry level jobs as less formal training is required, when compared to nursing homes, but the lack of career opportunities makes workers view AL as a temporary job until they can reach their true professional aspirations (Lepore et al., 2010). Researchers also point to lack of job satisfaction as another reason for the lack of job retention (Vernooij-Dasssen et al., 2009). Providing workers with opportunities of education, training, mentoring, and keeping them appropriately compensated were seen as being facilitators of job satisfaction (Vernooij-Dasssen et al., 2009). As the older population grows and demand for long term care communities increases, AL communities will need to find solutions to the problem of worker retention so that proper care can be provided to residents and to prevent a shortage in the AL workforce (Vernooij-Dasssen et al., 2009).

Scant research attention has been paid to AL staff perceptions of and reactions to "BPSD" or the behavioral expressions of those with dementia. McKenzie and colleagues (2012) address this knowledge gap by studying the effects of BPSD on direct care staff in AL, who typically cared for residents on a daily basis, but had limited training in caring for individuals living with dementia. Researchers found that the majority of direct care staff identified BPSD as upsetting and bothersome; depression-related behaviors affected the staff the most and were linked with increased staff reaction. McKenzie et al. (2012) concluded managing symptoms of depression among those living with dementia was seen as a concern and emphasized the need to train staff on how to address BPSD in ways that reduced staff stress. McKenzie et al. (2012) concluded that by training the staff not only will the emotional well-being of the staff improve but so too can the quality of life for residents.

Additional research on the effects of BPSD on staff focused on staff in nursing homes. A study conducted in Germany looked at the stress nurses faced when caring for individuals with "challenging behavior" (Schmidt et al., 2012). Schmidt et al. (2012) explained that BPSD often fell under this challenging behavior category and learned that residents with challenging behavior would increase the stress of the nurses who help the individuals exhibiting the behaviors. The stress related to BPSD could increase the risk of nurses feeling burned out which in turn would lead to the nurses quitting and creating a staff shortage at the nursing home (Schmidt et al., 2012). While not directly translatable to AL communities, it is still relevant. If nurses who are taught and trained on how to care for residents living with dementia are experiencing increased stress and burnout due to the expressive behaviors that can arise from those living with dementia, then the impact it can have on the DCWs and care partners who do not have as extensive training, could theoretically be even more severe.

In order to provide residents living with dementia high quality of care and prevent the over use or abuse of medication, researchers also recommend providing staff with more training on how to address the behavioral expressions of those living with dementia (McKenzie et al., 2012). Training staff has been shown to reduce BPSD in residents living with dementia (Spector, Orrell, & Goyder, 2013). The positive effects obtained after staff training has also been shown to be maintained over time (Spector et al., 2013). While the efficacy of various training programs may still require further research, the literature does show that providing staff and DCWs theoretical and practical techniques on how to address distress improved quality of life for residents (Serelli et al., 2017). DCWs also stated that after training in programs such as the STAR training program they began to believe they were more competent in providing the appropriate care (Serelli et al., 2017). DCWs reported having fewer negative reactions to

problems and felt greater job satisfaction (Serelli et al., 2017). Training programs that employ a strong theoretical base with good management and supervision may be the most beneficial to DCWs and residents living with dementia (Spector et al., 2013).

2.5   Research Question/Purpose

Although AL is becoming popular among persons living with dementia there is not much literature evaluating dementia care and approach to BPSD in an AL setting. The majority of research focuses on the effects of dementia and BPSD on nursing home residents and staff. While understanding the effects of dementia in nursing homes is important, AL is a unique health care context with different environments, care philosophies, training, regulations, and resident characteristics as compared to nursing homes. Understanding how BPSD not only affects residents in an AL setting but also the care staff is imperative to finding solutions that will provide both DCWs and residents greater quality of life. What is also lacking is research examining the use of medication and evidence based non-pharmacological techniques for addressing BPSD among residents living with dementia and which is preferred among staff in AL. Determining how care staff understand and interpret behaviors among residents with dementia and identifying the preferred strategies for responding to instances they find challenging can be useful in understanding their perspectives. The influence of their strategies on resident care outcomes including quality of life can provide insight into potential areas for intervention, education, and training.

The purpose of this thesis is to:

1. Examine DCWs' responses to "BPSD" among AL residents living with dementia.

2. To understand how and under what circumstances AL staff seek outside assistance from family and external care workers when addressing "BPSD".

   The thesis attempts to address the gaps in the literature concerning BPSD in AL. The thesis will not only look at the reactions that DCWs have to BPSD but also consider how these reactions influence the care of the individuals living with dementia. It will provide insight into how DCWs negotiate providing care with residents' external care partners and the impact different convoy members can have on an individual's quality of life. Convoys are unique and understanding how different convoy members handle similar situations can provide insight into the different levels of care individuals living with dementia receive. By understanding how care is negotiated with the convoys of residents living with dementia, DCWs and external care partners may be able to provide better support and increase the overall quality of life not just for the residents but for all convoy members involved.

3   METHODS

Secondary data analysis was done using data from the five-year qualitative study, "Convoys of Care: Developing Collaborative Care Partnerships in Assisted Living." The study was conducted at Georgia State University with approval and oversight from the university's Institutional Review Board and funding from the National Institute on Aging within the National Institutes of Health. This chapter begins with an outline of the primary study's methods and provides an overview of the methods used in the secondary study.

3.1   The Primary Study

The overall goal of the primary study "Convoys of Care: Developing Collaborative Care Partnerships in Assisted Living" was: "To learn how to support informal care and care convoys in assisted living in ways that promote residents' ability to age in place with optimal resident and caregiver quality of life" (Kemp et al., 2017a, p.1191). The study was guided by the "Convoy of Care" model with its emphasis on understanding care networks and relationships holistically and overtime, and utilized Grounded Theory Method (Kemp et al., 2013; Kemp, Ball, & Perkins, 2017b). Grounded Theory Method is an approach to qualitative research that emphasizes theory development from the data collected, rather than utilizing an existing theory to drive data collection (Corbin & Strauss, 2015). This approach allows data collection and analysis to occur hand-in-hand with the researcher allowing the analysis of the initial data collected to influence the collection of subsequent data (Corbin & Strauss, 2015).

The longitudinal study was set in eight diverse AL communities, purposely selected to ensure variations in size, location, and resident characteristics (Kemp et al., 2017a). The study was organized in two waves of four sites each: wave one took place from 2013 to 2015 and wave two took place from 2016 to 2018 (Kemp et al., 2017a). Wave one AL communities included:

Feld House, Hillside, Garden House, and Oakridge Manor. Feld House is a not for profit, corporately-owned community, that is licensed for 47 residents and caters mostly to the Jewish community. Hillside is a privately-owned community that is licensed for 11 residents, whom are all White. Garden House is privately owned, features a dementia care unit, and is licensed for 34 residents. The residents are predominately White. Oakridge Manor is corporately owned with a capacity for 74 residents and features a dementia care unit. This community is the only one in the sample with the "assisted living community" licensing category (i.e., as opposed to PCHs, see chapter two). The residents of Oakridge Manor are predominately Black. Meanwhile, wave two homes included: Riverview Estates, Magnolia Gardens, Thames Place, and Camellia's Cottage. Riverview Estates is a corporately-owned community that caters mostly to White residents, features a dementia care unit, and is licensed for 48 residents. Magnolia Gardens is smaller home that is also corporately owned, features a dementia care unit, and is licensed for 19 residents. Thames Place is a privately-owned PCH licensed for 12 residents that caters mostly, but not exclusively, to Black residents and those with limited resources. Camellia's Cottage, the smallest site, is licensed for three residents, privately owned and caters to the Black population.

Each study home has an assigned team of researchers; members coordinated to make visits at least once per week. The purpose of these visits was to learn about care in the home and to collect relevant data. Researchers maintained regular contact with residents and staff members in the study communities over a two-year period. Fifty residents were recruited and provided informed consent (either directly or through their legally authorized representative) that allowed researchers to speak with them, contact their convoy members to speak about their health and care at the homes, and gave permission to access to their resident facility record (Kemp et al., 2017a). Residents who provided consent and agreed to be a part of the study became "focal"

residents. These residents were purposively chosen by the investigators based on variability in factors thought to influence care experiences and arrangements such as personal characteristics, health status, and functional status.

To determine if a resident could provide informed consent the researchers used the National Institutes of Health's guidelines (Kemp et al., 2017a). For those who were determined to be unable to provide consent, then proxy consent was obtained from a legally authorized representative (Kemp et al., 2017a). Throughout the study continuous assent and consent were sought out before each interaction with focal residents (Kemp et al., 2017a). The same process was used for internal and external DCWs from the homes (i.e. AL staff and for instance, hospice, and home health) as well as focal residents' informal convoy members, such as family, friends, or doctors. Everyone who provided consent was interviewed and followed by researchers in order to learn about continuity and change within their convoy. Researchers attempted weekly check-ins with focal residents and AL staff weekly and twice-monthly contact with one of their informal convoy members, over a two-year period or until the focal resident died or no longer lived at the home (Kemp et al., 2017a).

Data collection centered around four specific methods. Researchers performed formal, semi-structured interviews with focal residents and convoy members who were able to do so, as well as informal interviews during in home observations or through electronic contact (Kemp et al., 2017a). Researchers also collected data by visiting the homes and observing participants in their home setting, as well as reviewing resident facility records (Kemp et al., 2017a). For focal residents, key information collected from the four methods were put into profiles, called "resident profiles," that summarized the care convoys, health status, medical needs, family history, and perspectives of the focal residents living in the care homes.

Researchers used NVivo 10, later NVivo 11, to store and manage the collected data (Kemp & Perkins, 2018b; Kemp, Ball, & Perkins, 2018a). Researchers used NVivo to apply codes to field notes and interview data, which allowed for easy retrieval and searching of coded data (Kemp & Perkins, 2018b). Researchers used a codebook based on the research aims and the data itself developed (Kemp & Perkins, 2018b). Researchers were given NVivo training and coding tasks, that was later compared to others, so as to achieve high inter-rater reliability (Kemp et al., 2017b).

The team also used Statistical Package for the Social Sciences (SPSS), another computer software program to organize quantitative data and run statistical analysis. Data stored in SPSS included, demographic information associated with focal residents, DCWs, and informal convoy members. Researchers also employed twice-monthly meetings with the entire team to discuss data, coding, and analysis (Kemp et al., 2017b). These meetings allowed for open team discussion and helped researchers make adjustments to their data collections and analysis (Kemp et al., 2017b).

3.2   The Secondary Study

3.2.1   *Participants and settings.*

Data for the secondary analysis derived from seven of the eight study sites used in the primary study. The home Camellia's Cottage was excluded from the secondary analysis because it did not have a focal resident diagnosed with dementia living in the home during the two-year observation of the primary study. Of the seven homes, three had a capacity of less than 20 residents while the other four homes all had a capacity greater than 30 residents. The majority of the homes were PCHs with only one home being classified as an AL community. Only one home was foundation owned and not for profit, the rest were either privately, corporately, or family

owned and all for profit. Table one displays specific characteristics of each of the residential communities used for the secondary analysis.

Table 1 Study Home Characteristics

Characteristics	Feld House	Hillside	Garden House	Oakridge Manor	Riverview Estates	Magnolia Gardens	Thames Place
Capacity	47	11	34	74	48	19	12
For Profit	No	Yes	Yes	Yes	Yes	Yes	Yes
Ownership	Foundation	Private	Family	Corporate	Corporate	Corporate	Private
Residents (Majority)	White/ Jewish	White	White	Black	White	Black/White	Black
Dementia Care Unit	No	No	Yes	Yes	Yes	Yes	No
% of residents with Dementia	54%	50%	60%	78%	75%	69%	83%
Monthly Rates	$3145-$5505	$2500-$4000	$2950-$3350	$2700-$5295	$2750-$4750	$1995-$3049	$1750-$2250
Licensing Category	Personal Care Home	Personal Care Home	Personal Care Home	Assisted Living Community	Personal Care Home	Personal Care Home	Personal Care Home

Oakridge Manor is the largest home in the sample having about 68 apartments and employing 35 staff members. It caters mostly to Black residents many of whom are heavily involved with the local church and had strong family ties. In contrast Hillside, was the smallest home with a capacity of 11 residents and is located in a rather large house that was not built originally as an AL but was modified to accommodate resident needs. They employ ten staff members and espouse a Christian mission philosophy of care. The majority of the residents are White.

Table 2 Focal Residents Living with Dementia by Home

Homes	Number of Focal Residents Living with Dementia
Feld House	3
Hillside	2
Garden House	2
Oakridge Manor	4
Riverview estate	11
Magnolia Gardens	3
Thames Place	4
Total	29

There were at least two focal residents in each of the seven homes who had a diagnosis of dementia. For this secondary study only focal residents with a diagnosis of dementia in their AL records are included in the sample. Having been labeled as someone living with dementia allows for the researcher to examine the extent to which their behavior is attributed to the condition by staff or other members of their convoy. This also creates a standard and does not let those who may have some mild cognitive impairment affect the results. Based on this sampling criteria, a total of 29 focal residents in seven of the "Convoys of Care: Developing Collaborative Care Partnerships in Assisted Living" homes met the criteria. Table 2 shows the distribution across homes.

Table 3 Resident Demographic Information

Characteristic	Mean	Min-Max
Age (Years)	81.5	57-96
	Frequency	**Percentage(%)**
Gender	N=29	
Male	11	37.9
Female	18	62.1
Race		
Black	7	24.1
White	21	72.4
Asian	1	3.5
Education		
Less than High School	1	3.5
High School	13	44.8
Some College	4	13.8
College Graduate	6	20.7
Post Graduate	5	17.2
Martial Status		
Married	5	17.2
Cohabitating	1	3.5
Divorced	7	24.1
Widowed	15	51.7
Never Married	1	3.5

Table 3 provides demographic characteristics of the 29 focal residents included in this study. As shown the majority were female, White, widowed, and had a high school education or greater. Twenty-one of the residents were White, seven were Black and one resident was Asian. The youngest of these focal residents was 57 years; the oldest was 96. The average age of the sample was 81.5 years.

Table 4 Residents' Diagnosis of Dementia by Type

Dementia Diagnosis	Frequency	Percentage (%)
Alzheimer's Disease	2	6.9
Lewy Body Dementia	3	10.3
Parkinson's Disease	1	3.5
Vascular Dementia	2	6.9
Behavioral Variant Fronto Temporal Dementia	1	3.5
Unspecified Dementia	20	68.9

Table four shows the range and frequency of dementia diagnosis by type. As shown, the vast majority (n=20) had an unspecified type of dementia. Two residents had a diagnosis of Alzheimer's dementia and two residents had vascular dementia; the two most common dementia types. The highest frequency of a confirmed diagnosis was for Lewy Body Dementia (n=3). It is likely that 20 residents had an unspecified form of dementia due to 1) the diagnostic challenge of determining the type of dementia; and 2) care providers often place individuals under the umbrella term "dementia" without determining which specific dementia type the individual has. Each dementia type is unique, determining the exact form of dementia a resident has could play an important role in determining what kind of care is necessary for the individual moving forward.

3.2.2 *Secondary analysis.*

The goal of this analysis was to understand how staff perceive BPSD, as well as to determine how DCWs reacted to said BPSD, how and under what circumstances they communicate with external convoy members when their assistance was required, and determined the implications of those communications in terms of the resident's care. The aim was to

determine if, and how, reactions by staff towards behavioral expression influenced the overall outcome of care an individual living with dementia received.

Following the primary study, I utilized Grounded Theory Method (Corbin & Strauss, 2015). Due to the large amount of data collected through the primary study, Grounded Theory Method was used to develop theories based on the themes and concepts that emerged from the large qualitative data. For the analysis I analyzed resident profiles, field notes, interviews, and memos that were related to the 29 focal residents and their convoy members.

I started my analysis by examining the resident profiles of the 29 residents in my sample. Resident profiles provide a summary of the individuals' experience in the care communities and also any key moments (such as health declines or behavioral problems) in their lives at the homes. Starting with these key moments, I determined what were common behaviors or actions that seem to be considered problematic by staff. This initial or open coding was done with the field notes, interviews, and memos as well. Relevant data was found by performing "queries" (i.e. searches) using NVivo 11 on the available data. Queries were run using codes from the "Convoys of Care: Developing Collaborative Care Partnerships in Assisted Living" housekeeping code book; selecting only the codes which were pertinent. I utilized the study's aims to determine which codes were relevant to the study and then used those aims to guide the analysis of data. All relevant codes (i.e., those pertaining to dementia and cognitive decline) in the code book were used to determine areas of interest in the data, for example: "Socio-emotional care," "Medical Care," and "Resident Cognitive Status." From the search results of the queries I went through, line by line, and determine the key concepts and categories that emerge from the data, comparing for similarities and differences. Once the results of those queries were analyzed, further queries were done using key words that were found in the initial queries. Some

examples of potential keywords were: "aggression," "anxiety," "wandering," and "hallucinations." These keywords were then used to run a text search in NVivo on the available data pertaining to the selected 29 residents. By performing these text searches using the keywords, the goal was to identify additional instances where residents displayed behavior that staff consider troublesome or problematic. These instances were then used to determine how staff responded to the behavior, how (if at all) they include external convoy members in addressing the behavior, and what was the outcome of care for the resident living with dementia. The goal of the text searches was to find other concepts or themes that could have been missed from just running queries based on the parent study codebook on Nvivo. While analyzing the data any relevant quotes or passages were collected to be used as primary examples of the data and to increase validity of the findings.

The concepts, themes, and categories extracted from the existing data were placed in a chart that organized the data for analysis. The table aided axial coding by identifying similar key behaviors that were deemed problematic by staff, as well as DCWs reactions and communications with external convoy members. The table also included the overall outcome of care that resulted for residents living with dementia and the key factors that played a role in developing perceptions, responses, and outcomes. Table 5 shows an example of how this analysis chart was structured. The purpose of this chart was to determine the similarities and differences among subcategories and determine which should become focal categories. The data analysis table also helped to show any major similarities and differences between focal residents and the communities. This comparative approach allowed for the identification of behavioral expressions, DCW responses to these expressions, and the outcomes for residents. Ultimately,

the analysis generated a typology of responses and led to the identification of key influential

factors.

Table 5 Sample Data Collection Chart

Focal Resident	Key Behaviors that Cause Issues with DCWs	Response of DCWs	Communication with Informal Convoy members	Outcome of Care	Key Factors that Influenced Care for Resident
1					
2					
3					
4					
5					
6					
7					

4   RESULTS

In this chapter, I address my research aims by presenting the collected data and analysis. To gain a better understanding of the behavioral expressions DCWs encounter, I begin by identifying and examining the most common behavioral expressions documented among the 29 residents in my sample. Next, I consider the variety of ways DCWs perceive and react to the behavioral expression of residents living with dementia, including how perceptions and reactions impact care in different ways. I examine circumstances DCWs typically reach out to external convoy members for help with the behavioral expressions of a resident. Finally, I will list the key factors that play a role in the outcome of care residents experience from the home and its DCWs.

4.1   Behavioral Expressions

I began by examining the entire sample to understand what, if any, patterns might be observed regarding perceived behavioral expressions. Based on the longitudinal data and information on behaviors for each resident over time, I identified a total of 11 different behavioral expressions that were perceived by researchers and staff at the various homes. The 11 behaviors included: confusion, aggression, agitation, refusal of/resisting of care, anxiety, depression, elopement, hallucinations, pacing, self-neglect, and sun downing. As shown in Table 6, certain expressions were more common than others.

Table 6 Prevalence of Behavioral Expressions Perceived/Described by AL Staff and Researchers (n=29)

Behavioral Expressions	Number of Residents Exhibiting Behaviors	Percentage (%)
Aggression	8	27.6
Agitation	7	24.1
Anxiety	5	17.2
Confusion	12	41.4
Depression	5	17.2
Elopement	3	10.3
Hallucinations	3	10.3
Pacing	3	10.3
Refusal of/resist care	6	20.7
Self neglect	2	6.9
Sundowning	2	6.9

4.1.1 Confusion

As shown in Table 6, the most common behavioral expression perceived by AL staff and researchers was confusion. Confusion included inaccurate perceptions or being mixed up about: place, time period, identification of family and friends, and their role in the care community. Instances of confusion sometimes meant residents living with dementia believed that the care home was not their home or they believed that they were back in the 1980s rather than the present, such confusion frequently led to feeling lost in place and time. Individuals living with dementia sometimes confused children for a significant other or staff as childhood friends. There also were instances of residents believing that they were employed at the care community and needed to get back to work. All of these instances were included under confusion.

An example of a resident experiencing confusion in time and place was Ashley, a 94-year-old White Garden House resident. She often experienced confusion at the home, especially

close to the end of her life, thinking that she was someplace else or consistently losing her

personal belongings such as her dentures or hearing aid. An excerpt from a researcher's field

note describes an example:

> Ashely then asked me again about the funeral home. She then asked me if I knew Sue or
>
> Carol. I said that I did not, but reminded her that I know Pam and Carmen, her daughters.
>
> She nodded and again asked me if I was there to "view the body." I told her that I'd just
>
> come by for a visit and to say happy Thanksgiving. Rachel [DCW] mouthed to me "For
>
> some reason, she thinks she's in a funeral home."

In the field note, Ashley believes someone has died and that people are at the home to view the

body. Her confusion continues even after people tell her that they are not there for that reason.

Rachel, the DCW mentioned in the quote, later described how unusual it was that she believed

she was in a funeral home and suggested that a recent change in home décor could be the reason

for Ashely's confusion.

4.1.2   Aggression

The second most common behavioral expression perceived by AL staff and researchers

was aggression, which was recorded among 8 of the 29 participants. The eight ranged in age

from 57 to 94 years, suggesting that aggression was not limited to younger and potentially less

frail residents. Aggression occurred when residents became violent or confrontational with

others, including their fellow residents, family, staff, or even the surrounding environment.

Instances of aggression typically involved residents becoming annoyed with a fellow resident or

a staff member, or escalating due to their confusion in time and place. There were instances of

residents becoming violent with staff and other residents and destroying property.

At Hillside there lived a 94-year-old White woman named Shelly whom the DCWs would often infantilize, describing her as being gentle. She rarely showed any type of agitation, let alone aggression, but in a telephone conversation with Shelly's daughter in-law a researcher learns of an act of aggression that occurred between Shelly and a DCW. The researcher recalls what the daughter in-law told her in a field note:

Shelly hasn't had any falls or illnesses, but last week, she attacked a DCW, pulling her hair. The worker was leaning over Shelly's chair, one hand on each armrest, so she could speak loudly enough for Shelly to hear her and lean close enough for Shelly to see her. It seemed in a moment of fearful confusion, Shelly reached up and grabbed the woman's hair on either side of her head above her ears, and began pulling down as if she was trying to wrestle her. It passed after a moment and Shelly became non-violent. Otherwise, the week has been non-eventful.

Shelly was known as not being aggressive at all, so this behavior was surprising. This example shows that these events can escalate quickly and deescalate just as quickly. Aggression does not necessarily mean physical violence every time. It also includes verbal confrontations where residents may use threatening language or expletives towards DCWs, other residents, or external convoy members. Aggression also could result in an escalation of agitation, the third most commonly expressed behavior.

4.1.3   Agitation

Agitation typically involved a participant becoming annoyed or bothered, sometimes as a result of a participant's confusion or anxiety. An interaction between Sadie, a Thames Place resident, and a DCW, Catherine, captured in field notes, provides an example of agitation. Sadie a 70-year-old White woman with vascular dementia, had a reputation among staff as being rude,

loud, and at times, demanding. The following documents an exchange with Catherine trying to tell Sadie that at night if she needs to urinate she can do so in her underwear because it is designed to soak it up and not to take them off and go on the bed:

> Catherine began to talk with Sadie about staying in bed at night and not trying to get up when she needed to use the bathroom. Catherine reminded her that she had pull-ups and that it was okay to pee in the pull-ups. [This is the language Catherine used when talking to Sadie.] Catherine instructed her that it was wrong for her to take off the pull-up and pee in the bed. Sadie was clearly agitated from this conversation and argued with Catherine about getting out of bed. Sadie got very frustrated and began to yell at Catherine, "I don't need nobody telling me what to do!" Catherine let the conversation drop.

In this example, Sadie becomes agitated when Catherine tells her how to relieve herself at night. Sadie has difficulty walking which is why she is unable to go to the bathroom by herself at night and why she wets the bed. Despite this Sadie believes that she does not need instructions on how to relieve herself at night and that she is fully capable of handling it herself. This interaction is not considered aggression because Sadie does not use threatening language or expletives, she is merely annoyed with Catherine for discussing such a sensitive subject and telling her what to do. Other examples of residents displaying agitation include a resident living with dementia becoming annoyed with the noise another resident is making or a resident becoming agitated when confused or anxious about location in time and place or when they are unhappy about care routines.

4.1.4   Refusal of care/resisting care

Similar to the aforementioned expressions, refusal of care or resistance to care is not unique to people living with dementia. Often residents refuse care in a manner that suggests they still wish to be independent. Rather, they perceive that they do not need assistance with daily life routines and care activities. Understandably, some residents wished to continue picking out their clothing while others wished to do laundry on their own- for the most part, DCWs were able to accommodate these preferences. However, in other cases, residents refused to believe they needed help in other areas. One example of a resident refusing care involves Thames Place resident, Warren. Warren, a 72-year-old Black man with vascular dementia, typically, was very easy going but did not like people helping him with things or limiting his independence in any way. Warren had diabetes and DCWs fear that he was not taking proper care of his feet, which affected his gait, and hence well-being and safety. A researcher recalls Warren refusing care for his feet, observing in a field note:

> I seemed to miss every joke, but noticed how much Catherine and Warren joked with each other. I got the idea that his jokes were a little racy sometimes. They seemed to have a good rapport. At one point he said he wanted something sweet. Doris said he could have a diet coke and a sugar free cookie. He said he wanted a real coke. Catherine told him that she would give him a real coke if he let her wash his feet. He said no way. He was also not interested in the new podiatrist. He said he could do it himself. Doris and Catherine were clearly concerned that he was diabetic and should not be cutting his own nails. But after trying for a bit, Doris told Catherine to let it go. It was clearly a contentious issue that they argued about a lot.

Warren had a history of refusing care and not letting people help him with daily hygiene. Warren truly believed that his feet were fine and that whatever needed to be done to maintain them he could do himself. If DCWs did not push to provide Warren with the appropriate care it may have led to a decline in health and potential hospitalization. Warren was hospitalized multiple times during his stay at Thames Place due to various reasons including his diabetes and refusal of care but ultimately Warren was discharged from Thames Place and transferred to a nursing home due to his increased care needs.

4.1.5   *Depression*

Symptoms of depression and anxiety affected five residents each out of the 29 residents in the sample. Depression and anxiety are not necessarily symptoms of dementia but can be experienced by those living with dementia, and DCWs must learn how to address these states of being in order to provide quality care to residents. Oakridge Manor resident, Irene, an 84-year-old Black woman, frequently experienced depression. She had chronic pain in her body that made it difficult for her to walk or be independent in any way. Due to the pain, her limited independence, and anxiety about getting older, Irene was depressed. She would also become sad when she did not have her convoy come visit her weekly. During an interview with a DCW, the researcher asked if any residents experience boredom, which led the DCW to reference Irene, a resident living with dementia, and explain that the residents do not have boredom but do experience depression, specifically addressing Irene's depression:

> Boredom? Irene isn't at a point now where she's bored, but she's more so depressed due to her physical condition, and she loves to bring up how when she first came, she was walking every day. She's thinking about where she used to be and what point she used to be at to where she is now, and that makes her depressed.

Irene thinks about the past when she was able to walk and be independent but due to her physical and mental conditions, she is no longer able to be as independent as she was. This comparison to her past self and her feelings about her current condition, as well as the chronic pain, bring about her depression. Then because of her depression and pain, Irene refuses to leave her room and socialize with other residents or staff at the home. The lack of engagement or socialization can lead to declines in self-care as well as exacerbate the progression of dementia in the individual.

4.1.6   Anxiety

Anxiety is a sense of worry or nervousness about something that is happening or going to happen. If left unchecked, anxiety can hinder an individual's lifestyle by leading to depression, agitation, or even panic attacks. Feld House resident, Sloan, was known for having high anxiety and it affecting her daily life. Sloan, a 92-year-old White female, was diagnosed with Alzheimer's disease. Her anxiety often led her to opt out of activities with the other residents at Feld House and to also decline spending time with her family outside of the community. While speaking to a researcher, Sloan explained the anxiety she was having over her out-of-town son leaving from his visit with her and how it affects her:

> Sloan was in the extra care TV room. We visited a while. Her son is leaving today or tomorrow. She told me she was shaking a lot due to the anxiety she is feeling not knowing exactly when he is leaving. She said that always makes her feel worse- she calls it "inside anxiety." At some point she was ready to go back to her room for a while. I told her I would be glad to take her up. She said one of the caregivers would do it.

In the passage above, Sloan admits her anxiety is associated with not knowing when her son was leaving. The anxiety gets in the way of Sloan enjoying the daily things in her life, and makes her shake which could increase the chances of her falling. Understanding appropriate techniques to

manage anxiety is important to providing quality care to all residents and for people with very

bad anxiety medication may be necessary.

4.1.7   *Pacing or walking around*

Pacing/walking around was a behavior observed in 3 of the 29 residents included in the

sample. Pacing/walking around was defined as any time a resident living with dementia was

seen as walking around the community without, what DCWs perceived, a defined purpose or

motive, or walking into areas that they were not, for all intents and purposes, supposed to be,

such as staff areas or other residents' rooms. Pacing or walking around without observing social

or physical boundaries, was seen as a behavior that DCWs encountered. Kari, an 85-year-old

White female resident of Magnolia Gardens had a diagnosis of dementia- type unspecified. She

frequently paced and would repeatedly go into other residents' rooms, especially late at night. A

fellow resident at Magnolia Gardens shared her perceptions about Kari's increased pacing with a

researcher. A field note captures this exchange:

> Joann told me that Kari seems to be declining significantly. She said she has been
>
> wandering the halls at night and becoming agitated frequently, particularly in the
>
> evenings. Joann has tried to soothe her with lavender oil, but Kari is not always interested
>
> in letting her rub it on her wrists. According to Joann, a new resident has moved into the
>
> community. He is African American man from Chicago who uses a walker. Joann
>
> indicated he is particularly bothered by Kari's wandering, and she has frightened him by
>
> standing at his bedside while he sleeps.

Kari's pacing was affecting other residents especially while they sleep. While typically not too

problematic, when residents begin walking into other residents' rooms, especially while they are

sleeping, such behavior can trigger or escalate into agitation and aggression from either or both

residents. Addressing and observing residents pacing/walking around when it affects other residents and their safety, is important to preventing any problematic confrontations or scenarios that put residents in harms' way.

4.1.8   Elopement

Elopement was a behavior associated with a small number, 3 of the 29 residents, in the sample. Elopement includes any time a resident actively tried to leave the community without supervision or permission of the DCWs in charge. Joe, a 74-year-old White resident from Magnolia Gardens had an ongoing reputation for leaving the home without permission. Captured in field notes, Joe recounted to a researcher a time he left Magnolia Gardens right through the front door:

> Joe told me that he had been leaving using the front door lately. [I am not sure how true this is] Joe continued on and said that he had never lived in a home where he was unable to leave and come at his leisure. He shared a story about how he had left the home and went for a walk by himself. He said that the home had called the police on him and he saw them down the road. There was a woman and a man police officer. The officers stopped Joe and asked him why he left the home. Joe told them that he was being locked in at the home and apparently the officers told Joe he could press charges.

Elopement is an example of how behavioral expressions can lead to emergency resources being used to help DCWs find a missing individual. In another instance, DCWs found Joe trying to climb a fence and had to increase surveillance of Joe whenever he was outside. Due to individuals living with dementia having an increased chance of becoming confused as to where they are, ensuring that residents do not run away from the community is important so that they do not get lost or harmed. At another home, Riverview Estates, Sarah (89-year-old Asian

resident) once convinced a Fed-Ex delivery person that she was being held against her will at the home; the Fed-Ex delivery person called police. Once the home resolved the situation Sarah's daughter then had to put a sign in her room saying that Riverview Estates was her home so that she would not try to leave again. Both examples show how quickly local authorities can become involved and potentially strain the relationship between DCWs and residents.

4.1.9   Hallucinations

Another behavioral expression experienced by 3 individuals out of the 29 residents was hallucinations. Hallucinations involve an individual perceiving something as being present when it is, in fact, not present. Hallucinations did not occur frequently among the three residents who were observed to have them. However, when experienced, hallucination could be quite frightening. For instance, Bethany, a 92-year-old White woman from Riverview Estates, believed that someone was in her room while she slept. During a visit to Riverview Estates she discussed the experience with a researcher; field notes captured the following:

> Bethany looked quite different than usual. Her hair was completely straight and slicked back almost looked like it was wet. I could tell she was upset about something and finally was able to go over and talk to her. She told me she could not stay in her room another night. She said someone had come into her room and held a gun to her head, taken her phone. She was almost in tears and very agitated. She kept saying she had lived by herself after her husband died and nothing like this had ever happened. I sat with her and held her hand and she finally calmed down. She thanked me and at one point said it helped to have a "friend…"

Bethany's hallucination caused her to become agitated, lose sleep, and she was frightened. Believing that a man went into her room to rob her at gunpoint. While it was true that her cellular

phone was missing, in reality her son took her cellular phone away because she was calling him multiple times daily, disrupting his work and daily life. It seems that she was not coping well without the phone and staff theorized that she perhaps had the hallucination as a result.

4.1.10 Self-neglect

Self-neglect was experienced by a small number of residents in the sample: 2 of the 29. These residents often refused to bath or perform other basic and necessary self-care hygiene routines. Both were diabetic and lack of self-care eventually lead to other physical and care difficulties. For instance, Leeroy, an 84-year-old Black resident from Magnolia Gardens, was known to ignore important self-care routines. He had issues regulating his diabetes that in turn would lead him to have increased bladder incontinence. Leeroy believed he did not need assistance and thought he could take care of all of his needs alone. In a discussion with a DCW, Jen from Magnolia Gardens, one of the researchers discovered that Leeroy had been moved to a nursing home:

> Jen said that Leeroy is very difficult to care for, and things have been quieter and easier since he has left, because he will not look after himself. [I think she was implying that he would have incontinence episodes because of not controlling his diabetes.] Leeroy's girlfriend told Jen that he has always been that way. Apparently, he went to the hospital with heart problems, but also has dementia, which I don't think we realized. He was discharged from the hospital last week and released to a skilled nursing facility, but Jen was not sure if he was there for rehab or for permanent placement. All of his things are still at Magnolia Gardens, but she does not think he will be back because of his care needs.

Due to Leeroy's self-neglect DCWs had difficulties providing the appropriate level of care that he needed. In the end he ended up staying at the nursing home because Magnolia Gardens said they were unable to meet his care needs.

4.1.11 Sun-downing

There is very little information about residents who experienced sun-downing from the sample of 29 residents but one of the residents was Sarah from RE. Sun-downing occurs during the time that the sun is setting and presents when individuals living with dementia appear to have increased confusion which can in turn lead to aggression. Sun-downing is a collection of behaviors that can occur during a specific time of day causing increased stress to the resident living with dementia and the DCWs at the home. While not necessarily an individual behavior, but a collection of them, sun-downing is still important to discuss as DCWs and care partners view it as being distinct from other behaviors displayed by residents. It was reported that Sarah, an 89-year-old Asian woman, would become aggressive and one time tried to break a window in order to escape from the home:

> Sarah's daughter is concerned about Sarah's physical decline; she said she was walking when she came to RE. When she visits, she does exercises with her and makes her walk behind her wheel chair. She also has gotten increasingly forgetful and experiences sun downing in the evening and has been aggressive. One time she tried to break a window to get out.

Sarah's increasing aggression is being blamed on the sun-downing she is experiencing and causing her family to be noticeably worried. This decline in her caused Sarah's daughter to question the home's ability to care for her mother.

4.2   DCWs' Reactions

How DCWs responded to the behaviors of residents living with dementia depended on various factors. For example, how a given DCW perceived residents when they were experiencing confusion, aggression, or hallucinations played a big part in whether DCWs were kind and helpful to the resident or were impatient and brusque. Consequently, there was considerable variation in how the DCWs in the study communities responded to the 29 residents in the sample living with dementia. There were examples of staff being patient and providing emotional support, such as telling residents that they love them, and there were examples of DCWs being tired of dealing with the same issue multiple times and being rather short and rough with residents. In general, the majority of behavioral expressions were addressed by DCWs with minimal friction between them and the resident. Most DCWs handled such expressions in a manner that did not exacerbate negative aspects of the expressions. The times when DCWs were not professional or patient with resident were usually when they were tired with dealing with the same resident over and over or the same situation over and over. If DCWs were also overwhelmed with other residents, they were more likely to be impatient and curt with residents displaying behavioral expressions.

Overall, I identified common trends in terms of how DCWs responded to a resident's behavioral expressions. In general, DCW responses fell into one of seven categories: 1) assisting/being patient, 2) redirecting/being deceitful, 3) isolating, 4) ignoring/avoiding, 5) reaching out to coworkers, 6) reaching out to family and friends, and 7) reaching out to external care partners.

4.2.1   *Assisting/being patient*

The assisting/being patient response included when a DCW was helpful and/or patient with a resident living with dementia displaying behavioral expressions. This response could involve immediately solving a problem such as finding a lost object that is giving the resident anxiety because they cannot remember where they put it. It could also be when a DCW is willing to sit down with a resident and listen to their frustrations. When a DCW's reaction is put in this category they are typically being empathetic and understanding with the resident and do not add to the resident's stress. An example of a DCW assisting/being patient included the instance of Megan, an 84-year-old Black resident from Oakridge Manor, who was living with dementia and routinely believed that the DCWs had not given her prescribed daily medication. Megan was constantly losing personal belongings and arguing with staff about whether or not she got her medications. In order to address her concerns and confrontations about the medications the DCWs came up with the idea to log in a pocketbook when they gave her the medications each day. Both a DCW and Megan had to sign it. In an interview with a DCW the DCW recalls how the new "receipt book" had been helpful in managing her medications:

> Now we get a receipt book when they give her her meds, they sign, she signs, and she's fine, as long as she has her receipt. She comes in. She says, "They didn't give it to me." The first thing the ladies will say, "look in your pocketbook. Maybe I didn't. Look and see if you have your receipt." When she looks, she says, "You know what? You did give it to me."

In this example the DCWs are aware that Megan had difficulties remembering whether or not she received her medications. DCWs found a practical solution to her confusion and subsequent frustration and agitation. By logging when she receives her medications every day they are able

to have physical proof of her taking her medications and by having her sign it, Megan cannot argue that it did not happen. This is a practical solution that not only solves the problem but also helps Megan have some independence, control, and involvement in her care by being involved in tracking her daily medication intake. It is a helpful solution to a common problem that promotes the resident's independence and well-being.

4.2.2   Redirecting/being deceitful

The next category is redirecting/being deceitful, which refers to DCWs redirecting a resident or even deceiving them when they are lost or confused so as to bring them back to center without causing more distress. DCWs did not engage in this strategy in order to take advantage of residents or in an intentionally malicious way. Rather the strategy was used by staff in an attempt to distract or calm residents down without escalating any potential distress. An example of this by a DCW occurred with Samantha, an 80-year-old Black resident of Thames Place living with Lewy Body dementia. She often complained about wanting to leave the home and having severe back pain. In the example Samantha was complaining of back pain and wanted Tylenol to relieve it:

> Samantha entered the dining room complaining of back pain and asking for medication. Catherine told her she could have another dose of Tylenol in 30 minutes. Samantha went back to her room and returned about five minutes later asking for medication. Catherine again told her she could have another dose in 30 minutes. The same exchange happened five minutes later, Catherine explained the cycle had been going on for some time. Catherine thinks Samantha is imagining her back pain and that it is somehow connected with her dementia diagnosis. Catherine explained that too much medication will cause problems with Samantha's stomach, so she is trying to avoid giving her anything. Her

plan was to ask her to wait 30 minutes every time she asked for medication and that

somewhere around dinnertime Samantha would stop asking and forget about it for the

evening.

In the above example the DCW, Catherine, decides to deceive Samantha by telling her she had

just given her Tylenol every time she asks for it when in reality she never did. This response,

from Catherine's perspective, was protecting Samantha from overmedicating. She did not raise

her voice or become frustrated when Samantha repeatedly asked about medication. Rather,

Catherine understands that Samantha has dementia and is patient when speaking with her.

However, with this response, it is possible that Samantha's pain remained unaddressed.

4.2.3   Isolating

Whenever residents were perceived as behaving in an aggressive or unruly way, certain

DCWs responded using the strategy of isolation, which involved moving the resident from their

current location and placing them in a room or area where they were separated from the other

residents and staff. The goal of such isolation is for the resident to calm down as well as

protecting everyone involved by preventing any physical confrontation. This strategy also

allowed the resident to leave where they were and escape whatever stimuli was perhaps causing

them distress. Agnes, a 63-year-old White women with Alzheimer's disease, at Feld House had a

history of aggression and physical outbursts. In one incident where Agnes became physically

violent the DCWs placed her in her room to isolate her from the rest of the residents at the home

and so she could calm down. A DCW recounts what she heard of the situation:

So, I wasn't here, but from what I understand she physically attacked a 3rd resident so she

just went up and, I don't know if she swatted, I don't know exactly how but she

physically touched in an aggressive way a 3rd resident. Um, and they tried to calm her

down, they tried to isolate her, they put her, they walked her to her apartment and tried to

get her back there kind of in a quieter environment and I guess they left her back there for

a little bit and she just demolished her room.

Agnes physically assaults three residents and DCWs respond by isolating her. By doing this they

remove her from the common area and keep the other residents from receiving further harm. It

also allows Agnes the opportunity to calm down in her own space. Obviously, this strategy does

not go well because it leads to Agnes damaging her room.

4.2.4 Ignoring/avoiding

Although most DCWs were well intentioned, worked very hard, and were supportive of

residents, some simply ignored or avoided a resident living with dementia when they were

unable or unwilling to cope with certain behaviors. Individuals living with dementia may be

forgetful and may do the same thing repeatedly, when DCWs were tired of dealing with the same

issue over and over again they may have ignored the resident's pleas for help. Sometimes if a

DCW did not like a resident, whatever the reason, they may even go so far as to avoid them as

best they can. Ignoring or avoiding a resident can lead to gaps in care or actual harm to the

resident if there is a legitimate need for help. One example of DCWs avoiding a resident

involved Ryan, a 57-year-old White resident of Riverview Estates who was a tall man and

diagnosed with fronto-temporal dementia. Due to his age, size, and dementia diagnosis some

DCWs were afraid to care for him out of fear of him lashing out. In an interview, a DCW shares

her opinion about Ryan and her strategies to a researcher:

She confirmed that she is the only staff person who does help him. She thinks he can

sense when someone is afraid of him and this makes him tell them to "get out." She says

that she tries to just go in and ask if he wants a shower for example. If he says no, she

tries again later. Usually he will let her do what she wants but sometimes she knows that he will not agree and does not push him.

Ryan had a history of aggression, which was a reason why previous care homes discharged him. Due to his history of aggression, dementia diagnosis, size, and age DCWs were afraid to be alone with him. Ryan's mother, his primary external convoy member, found him improperly clean numerous times because they would avoid him and would not check to see if he or his room was clean. This lack of care could lead to a decline in physical health and cause unnecessary medical complications to residents who are already vulnerable.

4.2.5 Reaching out to coworker

When a resident living with dementia displays a behavioral expression, it can be overwhelming for some DCWs, as they might not know or be able to handle it without assistance. A DCW reaching out to another DCW or any staff member at the home can be helpful in addressing a resident who is being aggressive or someone who is inconsolable. Such was the case with Bailey, an 83-year-old White resident at Garden House living with Lewy Body Dementia, when a DCW was attempting to give her a bath. Bailey became very aggressive when the DCW attempted to get her undressed for her bath, the DCW recalls what happened in an interview:

> I was getting her prepared to take a shower. She didn't wanna take a shower. She was just saying all kind of racial remarks. Plus, that she didn't wanna get in the shower. She raised up my shirt and stuck her fingernails into my stomach, and grinded them into my stomach and just repeatedly said, "How would you feel if someone was trying to put you in a shower?" Then I got her to calm down with the assistance of another person. She did it a few times after that, not the fingernail situation, but just fighting.

The DCW uses the help of another staff member to help her calm Bailey down and get her to take a shower. This strategy is often used when a resident is aggressive or violent. Ensuring the safety of both the residents and staff at the homes is very important, and ensuring that help is close by for both the residents and fellow staff members is imperative to that safety.

4.2.6 Reaching out to family and friends

When DCWs perceived or interpreted residents' behavioral expressions as problematic or a danger to themselves or others, and they do not know how to address these behaviors, AL staff sometimes reached out to the resident's informal convoy members such as family or friends. Contacting the family or friends of an individual can be helpful in calming them down, as hearing the voice of loved ones may be beneficial or if the family lives close by they may be able to stop by and assist the DCWs with the resident. It also creates a dialogue between staff members of the home and family/friends of the resident, ensuring that multiple perspectives are being consulted. At Magnolia Gardens, Joe had a job where he would get the mail and deliver it to whomever the letters were addressed to. During a researcher's visit to the home the DCWs on duty did not let Joe pass out the mail to the other residents in the home for some undetermined reason. Instead they took the mail from him as he returned from getting the mail from outside. Since it was one of his chores around the home that kept him busy it made Joe very angry to the point that he threatened physical violence to the two DCWs who did not let him pass out the mail and use expletives to describe them. In a field note, the researcher who was present reflected on what had happened:

> Getting the mail has become such an important task for Joe that if anyone takes it away
> from him, he reverts to threats of physical violence and curse words. This was also the

first time that I had a DCW tell me that they felt threatened by a resident and scared. I

believe this is why DCW Penelope was waiting to speak to Joe's son on the phone.

Joe's son is very involved in his father's care and is helpful to the DCWs. They know that Joe's

son is one of the few people that Joe really trusts so by getting him involved they hope to calm

Joe down before he lashes out physically to any of the residents or staff members. Whenever the

staff have a serious issue with Joe they do reach out to his son as he is the only family member

who is involved in his father's care. In other care convoys staff may contact family or friends to

help reprimand a resident, especially if that resident's main person of contact outside of the home

is a parent, older relative, or adult child.

4.2.7   *Reach out to external care providers*

Another reaction staff members have to a resident's behavioral expressions is

communicating with external care providers such as doctors, nurses, or therapists. Sometimes

reaching out to family or friends of a resident is not perceived as the best course of action

because staff believe that certain family members can actually make the situation worse. Some

family members may be perceived by staff as being overbearing or adding to the stress of a

situation. For reasons such as these AL staff may bypass the family or friends of the resident

displaying the expression and actually directly contact the resident's doctor or nurse practitioner.

This strategy was frequently used in cases where AL staff suspected that a resident was

experiencing a urinary tract infection or having an adverse reaction to a certain medication. By

contacting the doctor or nurse practitioner they may solve the situation prior to communicating

with the family. The AL staff can then report the incident to the family members as well as how

they took care of the situation. This was the case for Bailey at Garden House. Her family

members who were involved in her care were very protective of her. If staff reached out to them

for an emergency they would try to be at the home as fast as they could. Out of fear that the family would increase stress to Bailey the staff at the home decided not to contact the family first when they suspected she had a urinary tract infection. Instead they contacted her doctor who ordered her some antibiotics:

> She had also been wandering a good bit over the last few days, especially in the evenings. One evening, she attempted to water the flowers painted in the mural in the dining hall in GH. The staff at GH had called the doctor in to see her, and it turned out she had a UTI. She seemed to be doing a little bit better now that she was on antibiotics, but the week without rest seemed to have taken a toll.

After Bailey's doctor determined she was experiencing a UTI and put her on antibiotics then the AL staff reached out to the family to share what had happened. This made it easier for the staff to determine what was wrong and find a solution without the stress of family or friends asking more questions and adding to the stress of not only Bailey but also the DCWs trying to help her.

4.3 Understanding DCWs' Communication with External Convoy Members

When residents have an issue or need help with something DCWs typically are able to assist the residents with whatever it may be, but even DCWs need assistance. Part of this study was to determine under what situations do DCWs and other AL staff reach out to family and other external convoy members of a resident living with dementia for help with behavioral expressions. I identified four main circumstances under which DCWs and AL staff reached out to a resident's external convoy members for assistance, when residents: 1) engaged in repetitive behaviors; 2) were perceived as being aggressive; 3) resisted care or self-care was lapsing; and 4) were thought to have a medical problem or medication issue.

4.3.1 *Repetitive behavioral expressions*

Repetitive behavior is whenever a DCW believes that a resident is repeating the same behavior consistently and over time. This behavior may not be problematic to the DCW or the other residents. Often times DCWs will address the behavior the first few times it happens. It typically is deemed meaningful or important to address when the DCW observes this behavior as being consistent over a period of time such as a week or month. The behaviors range from pacing around or confusion to elopement or aggression. The reason that AL staff call external convoy members is because repetitive behavior can often be a sign of something more serious. When staff notice the repetitive nature of an action they may communicate with external convoy members to let them know their observation and to see if perhaps a new care plan needs to be formulated for the resident exhibiting the repetitive behaviors. Some reasons why a resident might exhibit repetitive behaviors include for example, the progression of dementia or perhaps, they have a urinary tract infection (UTI). By reaching out to external convoy members AL staff can determine if the behavior is part of the natural progression of dementia or if it can be addressed with treatment. UTIs are common among older adults and have been known to increase behavioral expressions among older adults, by determining if an individual is living with a UTI and treating it, there is a possibility that the increased behavioral expressions or repetitive behaviors may cease with it. In order to test for a UTI or create a new care plan the input of the resident's external convoy members are necessary.

At Riverview Estates Sarah, an 89-year-old Asian woman, would often pack her bags and try to leave the facility. In a field note a researcher recalls what Sarah's daughter told them about her mother's repeated attempts to leave the home:

Sarah has consistently wanted to leave Riverview Estates and regularly packs her clothes.

Sarah's daughter has put a sign in her room which tells her Riverview Estates is her home

and not to pack. Once Sarah convinced a Fed-ex delivery person that she was being held

against her will and he called the police. Sarah's daughter has not taken her home for fear

she will not be able to get her to leave.

Sarah has tried so many times to leave Riverview Estates that even her daughter is heavily

involved in trying to keep her there. Her use of a sign explaining that her home is RE shows that

Sarah needs constant reassurance that she is exactly where she is supposed to be. Repetitive

behavior can be tiring to deal with for both DCW and external convoy members but dealing with

these behaviors with patience and empathy is important for the wellbeing of the residents.

4.3.2   *Perception of aggression*

The second reason AL staff reached out and communicated with a resident's external

convoy members was due to aggression. As stated earlier, aggression was when a resident is

violent or confrontational. When these behaviors become repetitive or physical, staff at a home

may reach out to external convoy members in order to find a solution to whatever is bothering

the resident. When a resident becomes agitated to the point that DCWs believe that the resident

may become physically aggressive AL staff will reach out to family if they believe they can help.

Some family members were helpful in calming down a resident by soothing the aggressive

resident or by helping discipline residents who are not obeying DCWs.

At Thames Place, Sadie was known to be rather loud and aggressive. She would get

agitated very easily and did not like it when people told her what to do. After lunch when a DCW

was giving medications to the residents Sadie got very upset that she had to take her medication.

The DCW and Sadie then began to have a shouting match as they both wanted things to go their way. A researcher describes the encounter in a field note:

> Towards the end of the meal, Doris retrieved the trays of medications and began to hand them out to residents. Most accepted without incident but Sadie became upset about it. She did not want Doris telling her to take her medication and began to yell at her about not telling her what to do. Sadie always speaks loudly and can seem angry when I don't think she intends to but this time was different. Her tone was confrontational and direct. Doris reacted to her and yelled back at her. The exchange went back and forth several times at a volume that made everyone uncomfortable. Doris went to Sadie's room and asked Sadie's boyfriend for help. He approached the table and asked Sadie to take her pills. She yelled at him several times before they went to her room where the loud conversation continued for several minutes.

The agitation and aggression Sadie expressed from having to take her medications show how quickly a situation can escalate to the point that people are yelling at each other. Sadie's aggressive behavior as well as her history of being easily agitated make it important to handle the exchange carefully so as not let it get out of hand. Doris gets Sadie's boyfriend in hopes that he will be able to get her to take the medication and avoid further confrontation, but this strategy back fires as Sadie begins to yell at her boyfriend as well. Sadie may have felt betrayed that her boyfriend was trying to help the DCW rather than take her side of the argument, showing how reaching out to family or friends can also make a situation worse.

4.3.3   *Resisting care and lacking self-care*

When residents resist care from DCWs or neglect self-care it can be challenging to respect a resident's autonomy while trying to make sure they are as healthy as possible. It is for

this reason that resisting care or neglecting self-care is another reason why staff at a care home communicate with external convoy members. All residents, including residents living with dementia, have the right to refuse care or refuse participating in something they do not wish to participate in. The problem arises when resisting care/neglecting self-care leads to a decline in their personal health and wellbeing. DCWs are there to respectfully help residents with their daily care needs, but if a resident resists care or is neglecting self-care then this could lead to a decline in their health and possibly hospitalization. When issues like these arise the staff at a home will call on external convoy members, typically close family or friends, to help ensure the resident's wellbeing. This communication allows the staf to share with external convoy members that the resident is resisting care/neglecting self-care and hopefully gets the convoy involved in their care. Family may come to speak with the resident in order to explain to them the importance of self-care or persuade them to have a DCW provide the necessary care they may need.

An example of DCWs reaching out to family due to a resident refusing care was when Kari at Magnolia Gardens refused taking her medication. Kari takes medications at night before going to bed but on this day did not want to take any of her medications. DCWs reached out to Kari's daughter to help her mother take her medications:

> Kari's daughter said she is reading a book called "Oh My God We're Parenting Our Parents," and that it suggests that when an older adult is being uncooperative the adult child tries to guess what age the parent is acting, and treat them this way. Kari's daughter said DCW Pamela recently called her and said Kari wouldn't take her night-time medication, so Kari's daughter ended up going to MG a 9:00pm. Kari was refusing her medication, but kept talking about how beautiful the comforter in her room was. Kari's

daughter said her mother was acting about six years old. So she told her if she didn't take

her medicine, she would take the comforter away. Kari took the medicine and her

daughter headed home.

In the example the DCW trying to get Kari to take her medications decided to reach out to Kari's

daughter to help her. Magnolia Gardens had a strong relationship with Kari's family especially

her daughter who would visit often. The DCWs also felt comfortable reaching out to Kari's

daughter over the phone due to her high level of involvement in her mother's care. Kari's

daughter was able to speak with her mother and develop a strategy to get her to take her

medications which were important to her long term wellbeing.

4.3.4   *Medical problems or medication issues*

The last reason why AL staff reached out to external convoy members was due to

medical problems or issues with medication. Medical issues included residents falling or getting

hurt to having a urinary tract infection or behavior change. If a resident has a fall or seems to be

displaying symptoms of a UTI then the staff will often contact external convoy members in order

to get that resident to a doctor or other medical professional. There were even some cases where

AL staff contacted medical professionals directly if they believed that it was in the best interest

of the resident. In regards to medication sometimes residents would get new medications or need

to be taken off of old medications, something DCWs need to keep track of, making sure not to

give residents the wrong medications. Due to this there may be some confusion among the

various DCWs causing a resident to miss a medication that they need or even take medications

they no longer should be taking. If this happens or if a DCW needs clarification as to why

medications are necessary, then the AL staff may contact external convoy members in order to

clarify which medications are needed.

At Garden House, Bailey was having issues with pacing, insomnia, and showing signs of aggression towards the DCWs. Bailey's family recently had her switched to a new physician, Dr. M, who makes house calls. Dr. M had prescribed Bailey Seroquel and had ordered it in a bottle rather than in the blister packs that the home is typically accustomed to dealing with. The medication being in a bottle separate from the blister packs and the homes lack of communication with each other about Bailey's new medication caused Bailey to miss almost a week's worth of Seroquel which lead to her having insomnia, being aggressive, and walking around the house. The staff at the home contacted the family who helped determine that she was missing her medication, Bailey's daughter recalls the incident:

> We ran into Mabel on Saturday and she didn't know anything about it. She dug around the med cart and found the bottle, but there was no note. No communication. It really explains why mom had gone off the deep end. She was not herself. She was foul-mouthed referring to the staff at GH saying "You leave me alone, you big fat f-ing n-word." That's not my mom.

Due to the lack of communication between Dr. M and the DCWs at Garden House, Bailey missed doses of Seroquel which was believed to be the cause of her insomnia, pacing, and verbal aggression. The incident demonstrates the importance of communication between all parties and how communication between DCWs is fundamental to providing the necessary care required. Since no one put a note explaining that Bailey had medication in a bottle, separate from the blister packs, DCWs were unaware that they were not giving her all of her medications. After the incident Bailey's husband was angry at the lack of communication and made sure to speak with both parties to ensure that it did not happen again.

4.4 Case Studies

In order to better explain how DCWs perceive behavioral expressions and address them, 4 cases studies are included. Each case study is meant to showcase how DCW perception and reaction affects the outcome of care for the resident as well as reveal how individual factors play a role in determining that outcome of care. Each case study is of a resident from a different home and meant to show the various convoy types that exist for individuals living with dementia.

4.4.1 Ryan

Ryan is a 57-year-old White man who lived in Riverview Estates and was diagnosed with behavioral variant fronto temporal dementia. Ryan spent his life working as a concrete dispatcher and has a high school education. Ryan lost his job due to the development of his dementia and his wife cared for him until she was unable to meet his care needs. He then lived with his mother, Lauren, for a period until she was unable to care for him and moved into a care home. He stayed there until he was discharged due to aggressive behavior and then moved to Riverview Estates. Lauren recalls the previous home in an interview:

> It was a real nice place and I thought that would be good for him. We all did but the staff was afraid there because he would come out of his room and he would say, "I want to go home, I want to go home" and he would slam the doors and he would kick the door.

Ryan has a wife who lives outside of the city as well as two kids who also live outside the city. Due to his wife and children living out of town Lauren is the primary external care partner that the DCWs communicate with and who Ryan sees most often. She tried to visit twice a week to check on Ryan and provide any care that he may be lacking. Ryan's wife and kids would visit every other week and would only help when there were major problems at the home. Lauren discuses Ryan's wife's lack of involvement in a field note:

His wife lives about an hour and a half from here. He also has siblings. Lauren said his

wife had "given up on him" and I don't think they visit often. She implied they were

afraid to come, at least uncomfortable.

Overall Lauren was the only one who provided support to Ryan outside of the home. Lauren

makes it seem that Ryan's wife and kids, referred to as "they" in the field note, were afraid or

uncomfortable with Ryan's dementia.

At Riverview Estates the DCWs do not provide Ryan with the appropriate level of care

because they are afraid of him. Ryan, compared to other residents, is quite young and is a

relatively tall man. Those qualities combined with his known history of aggressive behavior

made DCWs afraid to be alone with him especially in his room. In an interview with Lauren, she

tells the researcher that the DCWs are afraid of him:

He was very aggressive when he first came here. Now he basically stays in bed all the

time. Jacob [DCW] feels like they can't take care of him because everybody is afraid of

him.

The DCWs at the home perceive Ryan as being aggressive and easily agitated. Lauren was then

forced to help clean his room, clean his clothes, toilet him, and even help him bathe. This lack of

care frustrated Lauren because when she was not there the care that the staff provided to Ryan

was lacking and negligent. In a field note a researcher documents Lauren's frustration at the

condition of Ryan's room:

Lauren asked me to look in the bathroom. The toilet was a mess, nothing had been

cleaned. She was working on the shower. She was furious. She took a few pictures and

said she might just send them to the state board. She asked, "what were Jamie and Emily

doing in here so long? They did not mop, there is trash on the other side of Ryan's bed

and the bathroom is filthy." She said she was going to find them and ask.

Eventually Lauren had Ryan moved to a different home where the staff at that home provided the

necessary care he needed. Initially Lauren did not want to move Ryan out of fear that moving

him would cause him distress but the lack of care he received from staff at Riverview Estates

was worse than any distress she believed he would experience from moving.

4.4.2   Samantha

Samantha, an 80-year-old Black woman diagnosed with Lewy body dementia, lived in

Thames Place. Samantha, originally from the Caribbean, had three children, one daughter lived

outside the country, and the other daughter and son lived in other states. Prior to living at

Thames Place Samantha lived in a house with her niece. Samantha's children decided to put her

in a personal care home due to her increased forgetfulness and increased aggression, Samantha's

daughter discusses this in an interview:

> …They say you will know it when Alzheimer's does set in, but I'm still not clear, but we
>
> realized that she was forgetting a lot of things. She just couldn't focus and was having a
>
> really hard time. At that time, she was living with one of my cousins. Actually, my cousin
>
> was living with my mom. She had started to become violent with my cousin…

They decided to leave her in Georgia close to her niece, rather than moving her closer to one of

her children, because that was where Samantha's friends were and where she was familiar with

the surroundings. Samantha's niece, whom she previously lived with, was the external convoy

member who visited the most and helped take her to doctor visits. Even so, the niece only got

involved when necessary, leaving the DCWs to typically deal with any issues regarding

Samantha among themselves. The family was more involved through the telephone rather than in

person. Due to her family living so far away Samantha acknowledges, in an interview, that she feels lonely but does not want to be a burden to her children:

> Well, I have to understand. My family, they have children. They work. I don't put stress on them. I don't stress them out that, "you aren't coming to see me." I don't have a phone for them to call me. I understand. I feel sad sometimes you know? I try to make it through. I understand they have families, too. When I had a family, I couldn't leave my family to come see them. You can't be selfish. You have to understand. Sometime I feel lonely. I make myself comfortable. I don't cry. I cry now, because we talk about it. I don't talk about it, because I have nobody to talk to about it.

At Thames Place Samantha had a history of elopement, confusion, and refusal of care. Samantha would pack her bags at the end of the day saying she wanted to go home. She did this so many times that Doris, the main DCW at the home, would often tell her to put back her bags in a rather impatient manner. She had little patience for Samantha's confusion even making jokes when Samantha claimed to be a DCW at the home. A researcher recorded an instance of Doris making a joke about Samantha being a worker at the home in a field note:

> I asked Samantha if she had been busy and she said that she was not, that she would just have a couple of baskets of laundry to fold after lunch. Doris heard us and called over that she had her paycheck for her, a banana. Samantha said she better not mess with her like that.

If Samantha refused care or continued trying to leave the home the DCWs would call her daughters or niece in hopes of one of them calming her down over the phone. In an interview with Doris she explains how she tries to use the family to get Samantha to shower:

Yeah, she [Samantha's niece] was here yesterday. She called me in the morning and told

me she was going to get her to take her out. Samantha said, "okay." When Samantha's

niece come, I said, "You have to come and bathe her, 'cause she don't want to bathe." I

went back to Samantha, and I said, "Your niece is coming to get you. You have to go

take a shower." Samantha said, "I bathed already. I bathed when I was coming in here

this morning." I said, "Samantha, you are here from when?" "I bathed already; I bathed

already." When the niece come now, I don't know if Samantha bathed for her and I leave

them. After a while, they went out.

Doris's frustration with Samantha could be due to her exhaustion of having to manage a home

with 12 residents often times by herself or with limited help from other staff members at the

home. Eventually Samantha stopped trying to leave the home but still had issues of confusion as

to where she was, whether she lived there or not, and refusing care.

4.4.3   Agnes

Agnes, a 63-year-old White resident of Feld House diagnosed with Alzheimer's disease,

had issues with walking around and aggression. First diagnosed in 2006, Agnes lived

independently for two more years. When her family found that she was hoarding and spending

too much money they decided to move her to a community for assisted living prior to Feld

House. In the assisted living community, the family found that the care was lacking and were not

meeting Agnes' care needs. Agnes' sister Denise shared her disappointment in the home in an

interview:

I would get there and she wouldn't have toilet paper. I would go in there and the toilet

paper roll would be empty or it would be, or the holder wouldn't be in the holder. Which

tells me that my sister didn't even have the use of toilet paper to wipe herself and they

weren't ensuring that she had toilet paper to do something as basic as wipe herself. When

you see that lack of care, and they are supposed to be assisting them, right?

Being dissatisfied with the care the family decided to move her to Feld House because of its

connections with a Jewish home that they planned on moving her too when they no longer could

afford Feld House. Agnes' sisters would help with the financial and legal issues but her children

were the ones that helped with health issues or doctor appointments. Her sisters were the ones

who were the most supportive and involved with Feld house while Agnes' three children were

less involved. Agnes' sisters wanted Anges' children to stay on top of their mother's care but due

to her sisters' heavy involvement this responsibility often fell on them. Whenever the staff

needed to communicate with an external convoy member in Agnes' convoy the staff at Feld

house felt more comfortable contacting Agnes' sisters. A staff member of the home explains, in

an interview, how she determines who to call in Agnes' convoy based on the situation as well as

the issues with communication Agnes' children have:

> Well there's different, so if I need something financially, it's Donna [sister], like rent
>
> invoices always go to Donna. Um, if we need something medically, it's the kids. So like
>
> she just had a couple issues recently and you leave messages and they call back but not
>
> necessarily as quickly as we might need. I think the kids are ranked as, it's Jessica, Jamie,
>
> and then Jeff, or Jamie then Jessica. I think it's the girls in one way or the other and then
>
> Jeff. Um, I could be wrong. They just don't always get back as quickly as we need and
>
> they don't communicate on their end so like Jeff could show up at 2:00 today to take
>
> mom to a doctor's appointment that I don't know about, that mom's not ready for, that
>
> we haven't copied the med list for. So they don't communicate to us what we can do to
>
> make that easier. If you show up at 2:00, I don't know where she is, I don't know if she's

gone to the bathroom, I don't know if her med list is ready so it makes it more difficult

for them ultimately.

At the home Agnes was very easily agitated which often led to her being aggressive.

Agnes had multiple issues with aggression where she hit a fellow resident or a staff member.

This behavior led her to being sent away for a psychiatric evaluation multiple times as well as

having changes in medications meant to keep her calm. During an incident where Agnes was

being aggressive, she hit a fellow resident, the staff put her in her room in hopes that she would

calm down by being by herself. Instead Agnes began throwing her belongings around and

damaging the stuff in the room. A researcher who visited the home the next day saw Agnes'

room and recorded her findings in a field note:

> Agnes's room was indeed a mess. Chairs were tipped over, the small desk that had been
>
> against the wall next to the bathroom door had been pulled out and pushed halfway in
>
> front of the bathroom door. There were clothes and various items strewn across the floor.
>
> The TV was turned to a station that was playing 60s music. I think it was the Mamas and
>
> the Papas or something. The whole scene was very surreal.

This behavior caused the staff to contact her children. The only one who answered was Jeff who

did not respond till 2 am and who did not believe that his mother could trash her room. A DCW

recalls the communication and incident in an interview:

> I think they called Tina [staff], they called Tina once before they, before the room stuff
>
> and she said just see if she'll calm down and this happened and they called back and she
>
> said well let me try to call the family, nobody answered except for Jeff [son], he
>
> answered, it was like 2 in the morning and he was like "what do you want me to do?"
>
> They are just very uncooperative, very unhelpful and very like "why would you leave her

in her room, she doesn't have the capability to mess up her room." Like he doesn't

understand what she can physically do. He kept saying she can't even walk. Of course

she can walk, so I think they sent her, I think they sent her to the hospital. (Kemp et

al.,2018b, p. e20)

Due to Agnes' family being unwilling to help the DCWs had to send Agnes to the hospital where

she had another psychiatric evaluation, medication change, and was then sent to another facility

for monitoring. After the incident occurred the management at Feld House told the family that

Agnes was no longer welcome at the home and that she was being discharged due to her consist

aggressive behavior.

4.4.4   Bailey

Bailey, an 83-year-old White resident of Garden house, lived with Lewy body dementia.

Her family, consisting of her husband and four children, were very involved in her care at the

home. They would call the home once a day to check on her if they did not visit daily. Bailey's

daughter, Sarah, who lives nearby explains the support the family gives each other in an

interview:

Brittney tries to come in. Dustin calls daddy on the phone just about every day, coming

home from work. Troy pops in and out. He calls on the phone, talks to me on the phone.

We have lot of communication. I'm sure that there have been times that people don't

necessarily like what somebody else has done, but, for the most part, we enjoy a good

relationship. Daddy and I are pretty much- we have our finger on the pulse. We tell them

what's going on. I think that gives them a sense of ownership, and a sense of being a part

of the decision-making.

The convoy that Bailey had, between the staff at Garden House and her family, was strong and supportive. Despite having a good relationship with the family staff noted that the family's involvement could be overbearing at times and too much for Bailey, causing the staff at Garden house to be cautious when contacting her family for help. In an interview with a DCW at Garden house the DCW recalls how overbearing Bailey's family can be when there is an emergency:

> I don't with them until it's over. Bailey's husband's first thing is to wanna jump in the car and come up here if he's not already up here or on his way. They eat here almost every day. I usually don't. We used to call them all the time because we would assume she had a UTI. We stopped doing that because we felt like we were causing more stress on Bailey because they would come up, crowd here, she would become more agitated. You give a lot of these people medication for agitation and it makes them fall asleep. You just don't wanna do that. We can deal with the agitation. That's what we're trained in. The family's not usually trained in that.

Based on collected field notes, Bailey was known to resist care, be aggressive, experience confusion, and pace around the home. She often paced around the home at night and would sleep in the next morning. Staff would try to get her up for breakfast but Bailey would be confused and become agitated, at times becoming aggressive with the staff. The family explained that Bailey was never a morning person and to just let her sleep in. Bailey's daughter who lives nearby recalls the incidents in an interview with a researcher:

> The only thing I do know is that they were trying to get her up in the morning, and I guess maybe she was having a great deal of difficulty dealing with that. Maybe fighting with the staff, or whatever. I guess Dillion told the staff that if she wanted to sleep in to

let her sleep in. I think they do get her up in time for lunch, but she's never been a

morning person.

With the support and open communication that the staff and Bailey's family have, they were able

to find a solution that worked for all parties. Bailey was able to sleep in which helped with her

mood and aggressive behavior, the staff were able to work with her without threat of harm, and

the family would visit around lunch time so that Bailey had time to rest. Due to the

communication and support that the family and staff provided to Bailey and to each other, Bailey

was able to age in place at the home.

4.5   Factors

To understand when and why DCWs and other AL staff reach out to external convoy

members for help with the behavioral expressions of residents living with dementia, I identified

four types of factors that played a role in whether or not a DCW or other staff member reaches

out to a resident's convoy. The four factors were: 1) Family involvement, 2) Relationships

between staff and external convoy members, 3) Resident's personal characteristics, and 4) Staff

characteristics. Each of these factors plays a role in influencing the DCWs' perceptions of

residents and whether or not the home would contact external convoy members for assistance.

4.5.1   *Family involvement*

Family involvement signifies the involvement of family members such as siblings,

children, spouses, or parents in the care of the family member living in the care home or the

complete lack of involvement from those individuals. All families are different and each

relationship between family and resident was unique. When a loved one is in a care home some

families come together to help the staff and resident with any issues as much as they can, while

other families believe that once their loved one is in the care home any issues are the responsibility of the staff.

For families that are involved with the care of their family member there are some common traits. Family members who live close to the home seem more likely to visit and be involved in the day to day care of their family member. Those who live far away can also be involved through the phone, calling often, or may depend on a relative who lives closer to receive updates on care. Another trait that was related to family involvement was the age of the external family members. Individuals who were of the same age or older than the resident in the care home were more involved with the care of the resident. The individuals in this group typically were parents, spouses, and siblings. Those who are younger than the resident living in the care home were often less involved. For example, children, nieces, nephews, and grandchildren were less involved in the care of their loved one. While not the case in every family this reflects the families of the residents included in the study sample.

In the paper "Maneuvering Together, Apart, and at Odds: Residents' Care Convoys in Assisted Living," Kemp et al. (2018b) discussed how there are three types of convoys that explain how care roles and structures influence care. The three convoy types are: 1) cohesive, 2) fragmented, and 3) discordant. Cohesive convoys were convoys where family and other external care partners were heavily involved in the resident's care; where each "care partner had clearly defined care goals, unified efforts, and maneuvered the care process together" (Kemp et al., 2018b, p. e17). Fragmented convoys were convoys that "had some consensus about care goals but minimal communication, collaboration, or cooperation among care partners" (Kemp et al., 2018b, p. e18). Finally, discordant convoys were convoys where "convoy leadership, particularly among informal caregivers, was either absent, unclear or contested" and where convoy members

"lacked agreement about care goals, including appropriate roles and behaviors" (Kemp et al., 2018b, p. e18).

The case studies contained examples of these traits and convoy types. In Ryan's case study, his mother was the only one who was consistently involved in his daily care. She lived close by and would visit him at least twice a week. Meanwhile his wife and children who lived farther away only visited about once every two weeks. Ryan's convoy type was classified as fragmented because even though his mother is heavily involved in his care Ryan's other convoy members, the DCWs and his wife and kids, were not on the same page with Ryan's mother. Ryan's mother, Lauren, is unable to get the DCWs and Ryan's wife to collaborate or cooperate. The DCWs were hesitant to provide care for Ryan and were not good at communicating with Lauren about how they could improve the care they provide. Meanwhile Ryan's wife and children were not involved.

In Samantha's case, all of her children lived either in another state or another country. The only relative she had nearby was a niece who only got involved if it was necessary; this gave Samantha less familial support. Due to the family's physical distance and the cousin's minimal involvement Samantha's convoy was classified as fragmented. Collaboration between staff and family was limited since the family was minimally involved. At times the family would be absent in Samantha's care requiring the DCWs at Thames Place to coordinate her care. Even so, at times of need the family would come together to provide support for Samantha, ensuring that she had the care she needed to continue living at the home.

In Agnes' convoy her sisters were the ones who were involved in her day to day care while her children were difficult to contact. This lead to strain within the family and between the family and the staff at the home. The lack of involvement from Agnes' children was partially

why Agnes was ultimately discharged from the home. Agnes' convoy was classified as discordant because Agnes' sisters and children did not understand each other's roles and would disagree as to who was the person in charge when an emergency occurred. Agnes' sisters wanted the children to be more involved but the children expected the DCWs at the home to resolve any issues Agnes had. That misunderstanding as well as a lack of communication from the children made the convoy discordant.

In Bailey's convoy her husband and daughter lived very close by and were very involved in her care. So much so that they were able to work with the staff at the home to help figure out solutions to problems they were having in providing care to Bailey. Due to the involvement from Bailey's husband and daughter, as well as open communication between DCWs and the family, Bailey's convoy was classified as cohesive. Bailey's convoy was able to effectively work together, had strong communication, and understood each convoy member's role. The cohesive nature of Bailey's convoy led to her ability to age in place.

4.5.2   Relationships between staff and external convoy members

When looking at resident care of people living with dementia, the relationship between staff at the care home and the external convoy members seemed to play an important role. An external convoy member who is involved with the residents' care typically had a positive relationship with the staff, by communicating daily with DCWs and helping the staff with providing care to the resident. The problem was that this was not always the case and sometimes external convoy members who were very involved were overbearing and push their own care agenda rather than follow the DCWs care plans, creating tension and conflict.

When external convoy members have a positive relationship with the staff and DCWs of a home it is usually due to a level of mutual respect. DCWs and external convoy members

understand that working together is important for quality care and that respecting each other as well as good communication is imperative to those goals. The reality is that sometimes people do not get along. Whether it is the fault of the DCWs or the family does not matter, because in the end it is the resident living with dementia who loses. An example of how a bad relationship can impact the care of a resident can be seen in Ryan's fragmented convoy. Due to Lauren's frustration with Ryan's unmet care needs when she is not present she had to move him to a new care home. During the transition she sent an email explaining that Ryan was moving and asking the DCWs at the home to please help provide a smooth transition. In the email she addresses the fact that she has provided a lot of the care for Ryan and how the staff at Riverview Estates have been uncooperative with her:

> I understand that you have told me that there is a 30-day notice which I was very sad to hear. I was hoping you could help relieve some of the cost since I've done the cleaning, showering, washing, activities, etc. for my son at least every 3 days. You did tell me that the caretakers were afraid of him at a previous meeting, I asked several and they said they weren't. I also talked to several and expressed that I would be glad to show them how I was able to get Ryan to take showers, etc. I was disappointed that this suggestion was not taken. I understood that this is a family-oriented facility and we could work as a team. I'm also very stressed that several of your past residents have left and then died because they couldn't get used to the new facility. I hope that you will consider hiring more caretakers and especially more experienced caretakers in the areas of memory care so you can take some of the burden off the families.

In the email Lauren expresses disappointment with Riverview Estates in multiple aspects. Due to her not providing 30-day notice of Ryan's departure from the home she was forced to pay a fine

which she is upset about since she, as she says, had "done the cleaning showering, washing, activities…" for Ryan. She also showed the issues with communication she had at the home because some DCWs told her that they did not work with Ryan due to fear while other said they were not afraid at all. This conflicting information left her confused and wondering why the staff was not more cooperative in providing care to Ryan. Finally, she expresses disappointment at the staff's unwillingness to work with her to learn how to provide care to Ryan where he would not be aggressive to them. The lack of cooperation from the staff, as well as the issues with communication, created a bad relationship between the staff at Riverview Estates and Ryan's mother Lauren. Due to this strained relationship Lauren decided to move Ryan to a care home closer to her house as well as Ryan's wife's house so that they could all visit more. In a follow up with Lauren after Ryan's move she stated that Ryan was doing much better at the new home and was receiving the level of care he needed.

4.5.3 Resident personal characteristics

Everyone who lives with dementia is different and has their own set of unique characteristics. It is these unique characteristics that also play a role in the outcome of care for residents living with dementia. The personality of a resident is an example of a personal characteristic that may influence care. At care homes some residents may be easy going and very cooperative with DCWs. Typically, these residents are favored for their willingness to comply with DCWs, they would receive better care than other residents who are not so compliant. On the other end of the spectrum there are residents who do not like being told what to do or receiving help. They may refuse care and may become easily agitated by DCWs. These residents were more likely to be ignored by DCWs because they can be difficult to work with and care for. An example would be Sadie from Thames Place. In section 4.1.3 (Agitation) Catherine tried to

instruct Sadie to urinate in her underwear that is designed to soak up urine, rather than on the bed. This agitated Sadie who told Catherine, "I don't need nobody telling me what to do!" Due to Sadie's short temper and unwillingness to listen to staff Catherine let the conversation end. Sadie is very quick to anger and does not like being told what to do, which makes the staff such as Catharine and Doris reluctant to confront her when they need to address an issue. Residents who do not like help from DCWs or residents who ask for more help than they actually need are seen in a negative light by DCWs. Residents with these personalities were ignored or avoided because DCWs do not want to work with them.

Other personal characteristics that can influence care from DCWs are resident gender, age, and physical size. At care homes small, older, women are typically seen as sweet and kind, therefore generally easier to provide care for. At Garden House staff often viewed 94-year-old Ashley as sweet, a DCW commented in an interview about Ashley, "Miss Ashley, she's a sweetheart." On the other hand, the younger and bigger a man is, at least among residents living with dementia, can lead to DCWs being intimidated or even frightened to provide care. Ryan was only 57 years old and was a rather tall man. That along with his specific type of dementia and his history of aggression made DCWs scared to be alone with him in his room. While he stayed at Riverview Estates, he did not have many instances of aggression but because of his size and history, DCWs would avoid providing him care and even ignore him. Ultimately this lead to Ryan's mother taking him out of Riverview Estates and putting him in another care home. Prior to his move a researcher spoke with Lauren, his mother, and noted how his age and history play a role in his acceptance into homes:

> I think she will look into various options for him but she is not very savvy about speaking
> to administrators about Ryan. His age is a factor for admittance to many places and his

outburst of anger is another. She needs help placing him somewhere else that can meet his needs.

4.5.4 *Staff characteristics*

Staff characteristics are one of the factors that plays a role in the way DCWs perceive behavioral expressions and ultimately the outcome of care for the resident. Staff characteristics are everything from their level of training regarding dementia to the personality of the staff member. Training is of the utmost importance when working with residents living with dementia on a day to day basis. Homes that have dementia care units or areas of the home specifically for individuals living with dementia typically have DCWs and other staff members who are trained specifically in how to interact with residents living with dementia. By Georgia law the individuals that work in these dementia care units are required to have had training in dementia such as learning about common behavioral expressions, communication skills, and positive therapeutic interventions. Understanding how dementia affects individuals and not believing misconceptions of dementia is important to provide quality care. In the sample 4 of the 7 homes had dementia care units: Garden House, Oakridge Manor, Riverview Estates, and Magnolia Gardens. According to Georgia law dementia care units or memory care units are required to have "additional watchful oversight systems, program, activities and devices that are required for residents who have cognitive deficits that may impact memory, language, thinking, reasoning, or impulse control, which place the residents at risk of eloping" (Carder et al., p.144-145). In the case studies, this means that Ryan and Bailey lived in homes with dementia care units and Agnes and Samantha did not.

While training is important it does not guarantee quality care. Bailey lived in Garden House and was well taken care of. At Garden House 9 staff members were interviewed for the

Convoys of Care study. Of the 9 staff members 6 were registered Certified Nursing Assistants (CNA), and of the 6 CNAs 2 had medication certificates and another 2 had additional nurse training but no degree. The other 3 staff members had no specialized health care training or credentials. Of those interviewed, the majority had training on how to deal with Bailey's agitation and aggression, as well as being patient and understanding with Bailey and her family. Due to these factors and numerous other factors as discussed earlier, Bailey was able to age in place at the home. This story is very different from that of Ryan who lived in Riverview Estates.

Riverview Estates also has a dementia care unit and DCWs with training on how to interact with residents living with dementia. At Riverview Estates 4 staff members were interviewed for the Convoys of Care study. Of the 4 staff members 3 of the individuals interviewed were registered CNAs while 1 was a registered Licensed Practical Nurse (LPN). Out of the 3 CNAs all had medication certificates as well as being certified medical assistants. Only 1 registered CNA also had training as an AL administrator, nursing home administrator, and had activities assistant certification. Despite all this training from the 4 interviewed staff members DCWs did not feel comfortable in interacting with Ryan. The DCWs were so fearful of Ryan that only his mother was willing to be alone with him. Despite the training that the DCWs at Riverview Estates were required to have by Georgia law they still did not provide the care that Ryan required on a daily basis. It was because of this lack of care and numerous other factors that Ryan was ultimately removed from that home by his family and placed in another care home.

As for Samantha and Agnes, both of the homes they lived in did not have dementia care units, despite this Samantha was able to age in place at the home. At Thames Place, 7 staff members were interviewed. Of the 7 staff members interviewed 5 were CNAs, 1 was a certified

medical assistant, and 1 was a registered nurse (RN). Additionally, of the 7 interviewed, 1 had a medication certificate and was trained as a nursing home administrator. Despite not having a dementia care unit many of the staff at Thames Place had specialized health care training. The staff was at times impatient with Samantha, especially since there was a lack of involvement from her family, but they were always able to get her the care she needed so that she could remain at the home. Samantha was for the most part very easy going as well so the DCWs were willing to work with her whenever there were any issues that needed to be addressed.

On the other hand, the home Agnes lived in, Feld House, was very patient with Agnes and her family but did not have the ability to care for Agnes to the level that she required. For the Convoys of Care study 6 staff members were interviewed, 2 were CNAs, 2 had no specialized health care training, 1 was a LPN, and 1 had a Master's degree in family therapy. Agnes had multiple instances of physical aggression at the home and the staff tried multiple times to accommodate Agnes. The problem was her repeated aggression and fragmented familial support that frustrated DCWs at the home and caused them to discharge her.

The homes that Samantha and Agnes lived in did not require the same level of specified training as the ones Ryan and Bailey lived in but the outcomes of care share some similarities. Overall, family involvement, the relationship between staff and external convoy members, resident characteristics, and staff characteristics all played large roles in how DCWs perceived the behavioral expressions of those living with dementia, communicated with external convoy members, and ultimately the outcome of care for the residents living with dementia. The 4 case studies show how each individual factor affects care but most importantly how they all interact with one another to influence the residents' overall outcomes of care. The examples also show how behavioral expressions affect the resident, the staff, and the external convoy of that resident.

While there is not a clear connection between resident behavior and DCW response, there is a connection between the factors and the overall outcome of care for each resident.

5   DISCUSSION

The goal of this qualitative study was to determine how DCWs at seven diverse AL settings responded to the behavioral expressions of residents living with dementia and to understand under what circumstances DCWs reach out to external convoy members for assistance with those behaviors. The results section lists out all of the behavioral expressions that were found to be exhibited among the 29 residents included in the study and provided real life examples of what DCWs had to manage on a daily basis. The data collected in the study revealed that the perceptions and responses of the DCWs, to the behavioral expressions listed, to be diverse and varying. While the reactions of DCWs were various, the reasons staff would get in contact with external convoy members were specific among the collected sample. The circumstances in which DCWs and other staff members would reach out to external convoy members was when behaviors were repetitive, aggression was perceived, a resident's self-care was lapsing or resisting care, or if the resident had a medical/medication issue. What was the most revealing in the data were the factors that were found to not only influence the perception DCWs had of residents and their behavioral expressions, but also influenced whether or not the staff at a home actually reached out to residents' external convoy members. These factors were further highlighted by the four case studies that were presented, demonstrating how the various factors and behavioral expressions impacted the perceptions and responses of the DCWs. All of which ultimately impacted the outcome of care for the residents living with dementia.

While all of the behavioral expressions are important to understand in order to provide quality care to a resident living with dementia, the behavioral expression that had the most impact on the residents, DCWs, and external convoy members in this study was aggression. In a study conducted by McKenzie et al. (2012) the researchers state that depression related behaviors

were what affected and upset staff the most, but based on the data analyzed in this study aggression came up time and time again. Aggression was the second most common behavioral expression after confusion, was a behavior that influenced DCW perception and response, was one of the reasons why AL staff reached out to external convoys, and if it was considered a resident characteristic it heavily influenced how DCWs interacted with that individual. Aggression being the most impactful behavior in this study is understandable given that the idea of someone lashing out violently can cause anyone concern. Therefore, making sure DCWs and residents are safe is always a top priority, but so is making sure that residents receive the level of care they need regardless of perceived behaviors. Research shows that training staff on how to address behavioral expressions not only reduces the expressions among those living with dementia but also improves the job quality of the staff, stating that they feel more competent and confident (Serelli et al., 2017; Spector et al., 2013). The training of DCWs and staff on how to manage residents displaying aggression is important because despite the perceived aggression a resident may be displaying it is the responsibility of DCWs to make sure that the resident is cared for at the level that they need to ensure a good quality of life. Training and understanding is the first step to maintaining that goal.

While it is important to understand how to address someone who is exhibiting aggression it is more important to understand why the individual living with dementia is exhibiting aggression in the first place. Upon analyzing the data, in situations where residents living with dementia are exhibiting aggression or being perceived as aggressive, the aggressive behavior was typically due to a stressor in the environment whether that be the DCWs, other residents, or the environment. Scales et al. (2018) explains that behavioral expressions are a reaction to a stimuli and that it is often just an individual's way of conveying stress or an unmet need. Understanding

what causes a person living with dementia stress and anxiety is important because it then allows DCWs the opportunity to identify why the individual is stressed and remove the stimuli that is causing the distress (Scales et al., 2018). DCWs and other care partners need to understand that people living with dementia may have issues expressing themselves, therefore understanding what agitates them or causes unnecessary confusion is important to prevent the chance of physical or verbal aggression. By understanding what is causing an individual to be aggressive and applying preventative measures DCWs and other care partners can be proactive rather than reactive.

After analyzing and understanding the data, it is apparent that there is not a strong connection between the behavioral expressions and responses of DCWs to those behaviors, instead the factors played a larger role in influencing not only perceptions DCWs have of residents and their behavioral expressions but also their responses. An obvious exception to this is aggression which was discussed above. Family involvement and relationship between staff and family of a resident show how impactful the family can be in terms of the care a resident receives. These findings support Kemp's and colleagues' (2018b) work on care convoys and how they maneuver "together, apart, and at odds" (p. e15). A resident's internal (DCWs, staff, residents) and external (family, friends, medical professionals) convoy play important roles in the residents' care outcomes. Residents with families that had consistent involvement and developed positive relationships (cohesive) with the DCWs at a home seemed have the best overall care and positive outcomes of care (Kemp et al., 2018b). While those with little or sporadic family involvement (fragmented), as well as negative relationships with DCWs (discordant) had gaps in their care arrangements leading to negative care outcomes (Kemp et al., 2018b). If AL staff perceive the family of a resident as being overbearing or, the opposite,

nonexistent, then the staff were reluctant to communicate with the resident's external convoy when they needed help leading to breakdowns in communication and potentially care.

Looking at the four case studies presented in the findings, there was an example of each type of convoy (cohesive, fragmented, and discordant) and how each type produced different challenges and outcomes for the residents living in the homes. What was also supported is the idea of how these convoys can change over time, allowing them to come together or pull apart (Kemp et al., 2018b). Of the case studies presented in this thesis, Bailey had a cohesive convoy that was supportive and communicative, but when the family decided to switch physicians and bring in a new doctor, the switch brought along some conflict and fragmented the convoy as the family's goals did not match that of the new physician. Samantha's convoy was fragmented but in times of need the family would come together to provide the care that Samantha required. Care convoys are fluid and are constantly needing small readjustments or fine tuning (Kemp et al., 2018b). As the level of care required for a resident living with dementia changes so too can the care convoy. This change may entail bringing in new convoy members, such as hospice or palliative care, or may require that current convoy members reevaluate their roles.

Resident and staff characteristics also played an important role as well. DCWs and other staff are more willing to help residents living with dementia if they are easy going, compliant, and patient. The problem is that when a resident is experiencing distress they are not going to be easy going, compliant, or patient. Characteristics does not limit itself to personality, as physical appearance also plays a role. Residents who were younger and larger had negative experiences in care because DCWs were afraid that these residents are going to lash out, even though the resident did not show any signs of aggression. DCWs may bring in this bias and be less willing to work with the resident as was the case with Ryan. This is where the staff characteristics is so

important. Having staff that are trained in how to manage residents living with dementia, especially when they have behavioral expressions, is important for the residents well-being (McKenzie et al., 2012). Proper training and knowledge can help DCWs keep themselves safe when they do feel threatened but also help eradicate any myths or biases that they may have about dementia, allowing for better care and better outcomes for both DCW and resident (Serelli et al., 2017; Spector et al., 2013).

One aspect of training for DCWs that has received attention from the research community is the use of medications to control residents' behaviors. In a study conducted for the CDC, Khatutsky et al. (2016) found that out of the residents in care homes who exhibited behavioral expressions, over half of them received some type of medication to control their behavior. The literature reports that DCWs are willing to use medication because they see no side effects from the medications and think it is an appropriate solution to when other approaches fail (Kerns et al., 2017). Meanwhile other literature states that polypharmacy is a problem among older adults and can lead to increased confusion and potentially increased falls (Cerejeira et al., 2012; Wei et al., 2017). The data collected in this study does not show DCWs using medication as a response to behavioral expressions or using medications on an as needed basis. In all of the homes most DCWs gave residents their medications at their scheduled times as recommended by the residents' physicians. Some of these medications were for controlling behaviors and moods among residents living with dementia, showing that medications were used to control behavior but as a preventative measure rather than as a reactionary one. When a resident was expressing a behavior DCWs typically evaluated the situation and addressed the behavior as best as they could without having to give residents additional medications. When behaviors were repetitive, residents were aggressive, or behaving strangely then AL staff might communicate with the

residents' external convoy (family, friends, physicians) to see if perhaps a medication change was necessary. Despite the lack of data showing DCWs using medications on an as needed basis, the data did show that medications were being utilized to control the behaviors and moods of residents living with dementia in a preventative manner. Demonstrating the willingness of AL staff to utilize medications in a preventative manner despite the consequences that could occur from their use.

Another tool that the literature states is important for DCWs to learn and understand are evidence based non-pharmacological techniques. Research states that evidence based non-pharmacological techniques should be the first line of action among DCWs addressing behavioral expressions and that by utilizing evidence based non-pharmacological techniques one can improve an individual's mood and quality of life (Austrom et al., 2018). In regards to evidence based non-pharmacological techniques and relating it to the data found in this study it is a bit difficult to connect. The reason being that from the data collected, and examples presented, DCWs did not use aromatherapy, pet therapy, or any other type of evidence based therapy to calm residents down when they were experiencing distress (Scales et al., 2018). What occurred was that a DCW would evaluate the situation trying to understand why a resident was distressed, confused, agitated, etc. and attempt to address that immediate issue by utilizing one of the seven reactions described in the results section. The DCWs in the sample did not utilize evidence based therapies to help with distress but there was evidence of DCWs trying to help residents by utilizing non-evidence based practices such as getting them to help with every day chores. An example of this can be found with Samantha, one of the four case studies, where the DCWs would sometimes have Samantha help with folding laundry. Another example was Joe from MG whose daily task was to go get the mail from the mailbox and hand it out to the other

residents at the home, a task that was so important to him that when a DCW prevented him from

handing out the mail to his fellow residents Joe became aggressive and agitated. These tasks,

while not evidence based therapies, allowed residents to feel like they had a purpose in the home,

a level of personal autonomy, and a sense of contribution to the daily life at the home. They

were, to the DCWs, simple chores, but to the residents they made them feel important and

needed. While not evidence based techniques used to calm down the residents living with

dementia, it shows the importance of respecting a resident's independence and recognizing their

ability to be productive members of their community. While these activities were not done when

a resident was experiencing distress they did help with resident mood and behavior.

Non-pharmacological practices go along with the person centered care approach where

care partners are expected to respect a resident's personal autonomy, enable opportunities for

growth, and understanding that their situation and life is unique to others around them (Dementia

Action Alliance, 2016). The DCWs in this study practiced person centered care to an extent.

Whenever there was a situation where residents were experiencing distress they did take the time

to determine what was wrong or what was causing them distress, but they did not utilize

evidence based non-pharmacological techniques to relax the individual, they often did whatever

was most convenient to them at the time. This could be isolating, ignoring, redirecting, or any of

the other four reactions stated. The lack of using evidence based non-pharmacological techniques

could be due to a lack of training as to what are useful evidence based non-pharmacological

techniques or not wanting to engage in those techniques due to how potentially time consuming

they could be.

The literature also states that staff that must address behavioral expression among

residents living with dementia find the behaviors upsetting, face higher levels of stress, and lead

to higher rates of burnout and turnover (McKenzie et al., 2012; Schmidt et al., 2012). The data

collected for this study did not focus on the turnover and burnout of DCWs at the various care

homes, and therefore cannot comment or contribute to the validity of these claims. As for the

increased levels of stress the data did not have specific moments where DCWs expressed feeling

more stressed than usual when having to address behavioral expressions, but there were

examples in the data of researchers who witnessed events in person describing DCWs as

appearing frustrated and tired at times when having to confront residents experiencing distress.

This does not necessarily mean that they were frustrated and tired due to the behavioral

expressions or distress, as there could be numerous other factors that could have contributed to

that reaction.

5.1   Implications and Recommendations

With the prevalence of dementia increasing, the demand for long term care communities

catering to this vulnerable population is also increasing (Zimmerman et al., 2014). It is currently

estimated that 42% of residents living in a residential care community have some form of

dementia, and with the prevalence rising that number is most likely going to increase (Khatutsky

et al., 2016). To put it into perspective, Alzheimer's disease is the 6th leading cause of death in

the United States of America, that means that this disease is not only going to affect the people

who must live with it, but also their family, their friends, and the care partners that are there to

provide support (National Center for Health Statistics, 2017). In order to provide quality,

comprehensive care to these individuals living with dementia we must understand the

implications the disease can have not only on them but on their convoy which helps them

navigate the many stages of care.

What the data analyzed for this study has shown is the impact both DCWs and families (and other external convoy members) can have on the care a resident living with dementia receives in an AL setting. Looking firstly at DCWs at these various care homes, these individuals see the residents on a daily basis and are the first line of defense in the case of an emergency. Many of the staff who were interviewed in the primary study were CNAs showing that they have had training on how to bathe and dress residents, dress wounds, document health issues, provide hands on health care to residents, etc. Many of these individuals are trained on how to provide care to individuals who need assistance with ADLs and IADLs. Residents who live with dementia require so much more. While they require ADL and IADL assistance like other residents, they also need assistance with confusion, anxiety, and any other type of distress that may occur when living with a disease such as dementia. While general geriatric training is important there needs to be more specialized training for DCWs and staff who work in AL communities caring for residents living with dementia. Understanding dementia, its many forms, how it affects people as it progresses, the impact it can have on care partners, and how to manage behavioral expressions are all important topics that DCWs working in AL communities should learn. Learning how to effectively communicate with people living with dementia, how to provided proper person-centered care, and learning which evidence based non-pharmacological practices are effective for managing behaviors are just some of the concepts that can help establish a stronger understanding of dementia specific care among care providers. Research has shown that training staff on how to address behavioral expressions reduces staff stress, improve the emotional well-being of the staff, improve the quality of life for the residents, and even reduces the prevalence of behavioral expressions among residents living with dementia (McKenzie et al., 2012; Spector et al., 2013). Staff training has also been shown to provide staff

with greater job satisfaction, fewer reported negative reactions to problems, a feeling of greater competency in providing care, and that the information learned lasts and is maintained over time (Serelli et al., 2017; Spector et al., 2013). For these reasons, training staff on dementia care needs to be a focus for care communities moving forward, especially if they are catering to this population.

Although DCWs and staff are important, study data also show that family and external convoy members play an important role in the quality of care that a resident living with dementia receives. While further research needs to be done as to the extent of the impact family and other external convoy members have on residents living with dementia, the results from this study shows that they are a major factor in outcomes of care. DCWs are meant to provide ADL and IADL assistance as well as any other assistance that a resident may need, but it is the responsibility of the family to provide socio emotional support, transportation, and to assist in ways that DCWs cannot (Kemp et al., 2013). A resident's external convoy needs to understand that DCWs are not meant to provide everything, and that while DCWs are helping residents on a daily basis there still needs to be cooperation between staff and external convoy members. When families do not get involved and share the responsibility of care with the DCWs it places more pressure on the DCWs who have to balance providing care for multiple residents. Families and other external convoy members need to understand the importance their involvement plays in the resident's care and in the stress of DCWs.

Along with more training for DCWs and more involvement from a resident's external convoy, there needs to be a greater support of non-pharmacological techniques when providing care. The data of the study did not show a strong support or integration of evidence based non-pharmacological techniques. Many of the evidence based techniques, such as aromatherapy,

massage, or pet therapy, are time consuming and can also be costly to implement (Fazio et al., 2018b; Scales et al., 2018). Rather than trying to implement a time consuming or costly therapy, AL communities should implement simple activities for resident's to part take in that make them feel like they are being active, engaged, and part of the community. Some activities that can be done are tossing a ball, singing songs, helping with folding laundry, cleaning tables, walking, listening to music, or decorating a common space (Gitlin & Piersol, 2014). By creating activities residents are able to have a sense of purpose at the home and feel like a contributing member of their community (Gitlin & Piersol, 2014). Making sure residents are engaged in meaningful activities is important to maintaining their self-identity especially as they progress through the course of dementia. The implementation of simple activities for resident's living with dementia can potentially provide residents with a sense of self-worth, improve mood, and prevent behaviors (Gitlin & Piersol, 2014).

5.2   Limitations and Future Research

There were a few limitations to this study. The data used for this study came from a primary study and was not collected specifically to address the aims of this thesis. Therefore, in order to answer my research questions, I had to utilize the available data that was collected in the primary study. Also, with Grounded Theory Method, researchers who are collecting data can analyze the data side by side with data collection so as to ensure saturation of the data. If data is not saturated Grounded Theory allows for researchers to modify their data collection so as to ensure data saturation, such as revising interview questions or changing observational perspectives at a home. Due to this being a secondary study, I was not able to influence data collection so as to have a focus on dementia care. While the primary study does include residents living with dementia in their sample a future study looking specifically at the experiences of

residents living with dementia in AL would be ideal. Also since the data is qualitative in nature and collected first hand by researchers in the field, events or reactions that were recorded may have been misinterpreted, misunderstood, or not fully contextualized by the researchers in the field. While they may have taken precautions to be as objective as possible in their data collection our backgrounds and education play a role in the interpretation of our surroundings and in the biases we subconsciously hold. Another limitation to the study was what occurred to researchers over time, a form of data acclimation. As researchers spent more time among the residents, DCWs, and families at the various homes and learned their personal habits and traits, the reporting of behaviors that were considered characteristic of the subjects would lessen over time. For example, if the same resident frequently resisted care and it was something that they did on a regular basis, the more a researcher observed this behavior the less likely they were, over time, to share details or even report about why the resident was resisting care, how they resisted, and the reactions of DCWs at the homes. The researchers would become so accustomed to this behavior that the details of these repetitive interactions might not be shared due to observation fatigue or belief of data saturation. By not reporting in detail how DCWs handle the same situation over time I cannot compare new interactions to previous ones, limiting my perspective to how DCWs react to the behavioral expressions of residents and how those reactions may change over time. Another limitation was the diversity of the sample, the lack of Asian, Latino, and other minorities is apparent. As these minority populations increase in size, researchers will need to evaluate the effects of dementia and dementia care on these populations as they face their own unique challenges in giving and receiving care. It will also be interesting to see the impact culture plays on the level of care Asians, Latinos, and other minorities receive from their families and from DCWs.

Future research should look at dementia care in both PCH and AL and the effects they can have on residents living with dementia. As these care communities increase in popularity for persons living with dementia, their influence of care on this vulnerable population is important to understand and support. A follow up longitudinal study should be conducted looking specifically at residents living with dementia and how their care convoys navigate providing care and assigning care roles. There is enough variation within the dementia community to warrant further in depth study, and would be interesting to see if the Convoys of Care model is transferable to this population. Furthermore, looking at the impact behavioral expressions have on staff and DCWs at these care communities should be an area of interest for researchers. As the number of individuals diagnosed with dementia increases every year, more DCWs will have to learn how to manage and address residents experiencing distress. Understanding the stress and pressure this places on DCWs and other care partners, formal and informal, is important in ensuring that those serving in a care partner role are also taken into account and provided assistance on how to ensuring their wellbeing as well as that of their loved one living with dementia.

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