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UNDERSTANDING THE UNMET NEEDS AND NEED-DRIVEN BEHAVIORS OF INDIVIDUALS WITH MILD TO MODERATE DEMENTIA

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UNDERSTANDING THE UNMET NEEDS AND NEED-DRIVEN BEHAVIORS OF INDIVIDUALS WITH MILD TO MODERATE DEMENTIA

MORGAN J. MINYO

ABSTRACT

Research on individuals with dementia (IWDs) has received increased attention in order to gain knowledge of the illness experience. Previous studies suggest many IWDs experience unmet needs as well as need-driven behaviors (NDBs) influencing IWDs outcomes of well-being. One possible interpretation of these constructs includes the potential connection between unmet needs and NDBs. In this way, NDBs are a response to some form of unmet need. The aim of this research is to assess three main objectives: (1) to increase the understanding of the illness experience by having individuals with mild to moderate dementia self-report unmet needs and NDBs, (2) to understand the possible connection between unmet needs and NDBs, and (3) to understand how unmet needs and NDBs are related to outcomes of well-being. IWDs with mild to moderate cognitive impairment residing in an assisted living memory care facility were able to self-report their own unmet needs, NDBs, and outcomes of well-being; this provides increased rationale for the inclusion of self-report data collection methods within the research process. Additionally, though the current study did not find any relationships between self-reported unmet needs and NDBs, both unmet needs and NDBs were related to outcomes of well-being. Specifically, more unmet needs were related to greater depressive symptoms and lower quality of life; NDBs were related to depressive symptoms but not quality of life.

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CHAPTER I

INTRODUCTION

The term “dementia” refers to a group of progressive brain disorders that result in disturbances in multiple cognitive and behavioral impairments such as memory, thinking, comprehension, learning capacity, language, and judgment (Ballard et al., 2011; Husband & Worsley, 2006). Though some forms of dementia including those caused by drugs, alcohol, or non-organic disorders are reversible, most forms of dementia are incurable, and medications can only alleviate symptoms to a certain extent (Husband & Worsley, 2006). There are a variety of forms of dementia, including Alzheimer’s disease (AD), vascular dementia, dementia with Lewy bodies, and frontotemporal dementia (Ballard et al., 2011). These different types of dementia account for different prevalence rates. AD is the most prevalent form of dementia, accounting for 60 percent of dementia cases and is characterized by memory loss and progressive cognitive decline (Husband & Worsley, 2006). Additionally, vascular dementia accounts for 20% of dementia cases; dementia with Lewy bodies accounts for 15 to 20%; and frontotemporal dementia accounts for 5 to 20% of dementia cases (Husband & Worsley, 2006).

The Alzheimer's Association states that 5.7 million Americans are living with AD, and this number is projected to increase to nearly 14 million by the year 2050 (Stites, Karlawish, Harkins, Rubright, & Wolk, 2017; Alzheimer's Association, 2018). Furthermore, 47 million people worldwide are estimated to be living with some form of dementia, with this number also expected to increase to 135 million by 2050. With the immense number of individuals living with some form of dementia, as well as the personal, societal, and economical effects of dealing with dementia healthcare, the World Health Organization has declared dementia prevention and treatment a public health priority (Wortmann, 2012; Rekesh, Szabo, Alexopoulos, & Zannas, 2017). Although these differing forms of dementia have varying etiologies, the underlying constellation of issues are similar. Because of these similarities in strains and stressors that accompany the dementia illness and disease process as well as knowing that there is not yet a cure for any form of dementia, it is important to understand and research the psychosocial well-being that accompanies all individuals with dementia (IWDs) as opposed to looking at just one form of dementia (Stites, Karlawish, Harkins, Rubright, & Wolk, 2017).

Recently, increased attention has been devoted to providing IWDs the ability to 'live well' (Martyr et al., 2018). In order to do so, this includes "the best achievable state of health that encompasses all dimensions of physical, mental, and social well-being, such that to live well takes on a unique and equally important personal meaning, which is defined as self-perceived level of comfort, function, and contentment with life" (Martyr et al., 2018; Institute of Medicine, 2012). This concept of 'living well' is an approach that strives to understand the illness experience from IWDs perspective in order to potentially improve quality of life, as well as a number of other well-being outcomes.

As researchers have begun to understand the illness experience, new constructs have emerged that warrant further explanation. One of these constructs is unmet needs (Orrell, Hancock, Hoe, Woods, Livingston, & Challis, 2007). Unmet needs are a variety of possible needs that are of importance to the IWD and are not currently being met, such as socialization and activity levels, personal care, or pain management (Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015). It is possible that many IWDs experience unmet needs considering that research suggests the process of dementia includes a decrease in the ability to meet one's own needs due to increased difficulty with communication, physical abilities, and cognitive functioning (Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015). Similarly, another facet of dementia that has been shown to cause distress and affect IWDs' quality of life is need-driven behaviors (NDBs) (Norton, Allen, Snow, Hardin, & Burgio, 2009). NDBs are described as dementia-related behaviors that occur due to a caregiver's inability to comprehend needs, as well as IWD's inability to make his or her needs known (Kovach, Noonan, Schlidt, & Wells, 2005). Up to 90% of IWDs are negatively affected by NDBs during the disease process (Feast, Orrell, Charlesworth, Melunsky, Poland, & Moniz-Cook, 2016; Hongisto et al., 2017) and NDBs are associated with accelerated functional decline and depression. NDBs are most commonly expressed through apathy, depression, agitation, and irritability (Hongisto et al., 2017).

Instead of examining these two constructs separately, as has been done in previous research, one possible interpretation to consider is the idea that these NDBs are a response to some form of unmet need. In order to understand this possible connection, the literature on unmet needs and NDBs needs to be assessed. Alongside these constructs, other possible related constructs, including care values and preferences, which are aspects of everyday life that an individual considers important (Whitlatch, Feinberg, & Tucke, 2005), also need to be taken into consideration. Additionally, in order to understand these constructs while also increasing our understanding of the illness experience, IWDs need to self-report their own unmet needs and NDBs. However, several previous studies utilize proxy-reports of unmet needs assessment rather than self-reported unmet needs, or self-reported unmet needs are only considered a proxy-report from a formal or informal caregiver (Banerjee, Samsi, Petrie, Alvir, Treglia, Schwam, & Del Valle, 2009; Norton, Allen, Snow, Hardin, & Burgio, 2009; Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015; Clifford, & Doody, 2017; Hancock, Woods, Challis, & Orrell, 2006). Furthermore, there are no published studies to date that employs self-reported behavioral symptoms or NDBs within the research context.

Multiple studies have examined the differences between proxy-reports and IWDs' self-reports on a variety of topics and have suggested that proxy-reports do not fully or accurately describe the illness experience from IWDs' perspective, leading to biased results (Breland et al., 2014; Martyr et al., 2018; Hongisto et al., 2017). The misalignment between a proxy-report and self-report is critical to study in order to understand how IWDs' quality of life can be improved. Furthermore, most previous research on IWDs' unmet needs has been limited by assessing unmet need and NDBs at specific stages of the illness process without attempting to understand how these constructs may fluctuate across different stages of disease severity (Park, Choi, Lee, Kim, Kim, Go, & Lee, 2018; Moon, Townsend, Dilworth-Anderson, & Whitlatch, 2016; Hughes, Black, Albert, Gitlin, Johnson, Lyketsos, & Samus, 2014). This is an area of research that needs to be expanded upon due to the changing physical symptoms and needs of IWDs across the disease process (Kovach, 2012). Potentially, there are different behaviors and unmet needs for IWDs depending on their level of cognitive impairment and stage within the illness.

As previously mentioned, it is important to provide the potential for good life quality and an opportunity for IWDs to ‘live well’ during the progression of dementia. One possible way to improve or provide a good quality of life is through understanding NDBs, which might be an expression of an unmet need. Assessing the self-reported areas of IWDs’ lives that are not being attended to has the potential to increase researchers’ knowledge on the illness experience from IWDs’ perspectives. The following sections will discuss the illness experience, unmet needs, NDBs, and care values and preferences in more detail, along with the connect between these constructs and outcomes of well-being.

Illness Experience

Traditionally, dementia has been understood from a medical model perspective as a progressive disease associated with neurodegenerative changes and declines in all capacities (O’Conner et al., 2007). However, this view is limited in its ability to capture the illness experience from IWDs’ perspectives and provides only a narrow view of a multidimensional disease (Woods, 2001). The illness experience is a subjective component of the cognitive, functional, emotional, and psychological aspects of the dementia illness (Kitwood, 1997). In this way, the illness experience is not simply irrevocable decline, but personal histories and perceptions of physical, psychological, and social contexts that play a role in the performance, behavior, and quality of life of IWDs

(O'Conner et al., 2007). Acknowledging the perspective of IWDs can validate feelings, recognize differing forms of communication, and provide an important connection to each individual's reality (Fazio, Pace, Maslow, Zimmerman, & Kallmyer, 2018). Furthermore, IWDs respond to the changes they experience in different ways (Clare, Quinn, Jones, & Woods, 2016), which illustrates that IWDs are more than their diagnosis (Fazio, Pace, Maslow, Zimmerman, & Kallmyer, 2018). A better understanding of these differences within the illness experience could make it possible to provide information and support to these individuals in order to maximize their benefits for adjusting and coping with their illness (Clare, Quinn, Jones, & Woods, 2016).

A critical piece of the illness experience is its ability to build upon the traditional model by adding content and context to the areas that are missing within the medical model perspective. Specifically, this subjectivity provides information about the struggles with adapting to change, leading a fulfilling life, and understanding the condition and the impact on the individual (Harman & Clare, 2006). The traditional medical model does not take this into consideration. Applying the illness experience to dementia research has allowed for increased awareness into the needs and desires of IWDs. Specifically, previous studies have found that IWDs want to maintain their personal identity, functional independence, and current level of quality of life (Dawson, Powers, Krestar, Yarry, & Judge, 2012), as well as having an understanding of the dementia diagnosis, an understanding of successful coping mechanisms, and an understanding of the inevitable prognosis (Harman & Clare, 2006). These findings hint to a growing awareness of the subjective experiences whereby IWDs are providing information and insight into their own needs and preferences (O'Conner et al., 2007).

However, there are limitations to research in this area such as a focus on proxy-reports as opposed to self-reports from IWDs. The distinction between proxy-reports and self-reports has been a controversial topic within dementia research when discussing whether IWDs can accurately provide their own insights. Broadly speaking, studies recognize that IWDs are still able to express their views, needs, and concerns, and these reports are reliable (Trindade, Santos, Lacerda, Johannessen, & Dourado, 2018; Martyr, et al., 2018; Woods, et al., 2014; Hoe, Katona, Roch, & Livingston, 2005). Furthermore, gerontological research has stated that older adults with memory impairments can participate in research and provide consistent and accurate responses (Krestar, Looman, Powers, Dawson, & Judge, 2012). Showing support for this claim, many researchers and organizations state that in order to help IWDs live full lives, assessments should include a subjective report of cognitive, behavioral, and functional abilities, combining norm-based and individualized assessment approaches (Molony, Kolanowski, Haitsma, & Rooney, 2018). Having IWDs self-report perceptions, subjective feelings, and experiences allows more insight into the illness experience on outcomes of well-being such as depression, anxiety, and quality of life (Dawson, Powers, Krestar, Yarry, & Judge, 2012).

To highlight some of the discrepancies between self-reports and proxy-reports, Martyr, Nelis, and Clare (2014) found that caregivers' perceived stress was the most common predictor of proxy-reported functional abilities, suggesting that proxy-reported scores may be strongly influenced by the respondent's level of stress (Martyr, Nelis, & Clare, 2014). Additionally, Dewitte, Vandenbulcke, and Dezutter (2018) found that IWDs were able to provide reliable reports of their own quality of life, and proxy-reports of quality of life have (again) been linked to the proxy respondents' characteristics, such as burden, stress, and/or depression. Additionally, Hongisto and colleagues (2017) investigated neuropsychiatric symptoms among IWDs and self-reported quality of life, as well as caregiver proxy-reported quality of life across a five-year span. Here, IWD's self-reported quality of life did not change significantly, even while neuropsychiatric symptoms increased over time. In contrast, caregivers' proxy-reported of quality of life declined significantly as the neuropsychiatric symptoms increased; discrepancies between IWDs and caregivers also increased over the course of the five-year follow up.

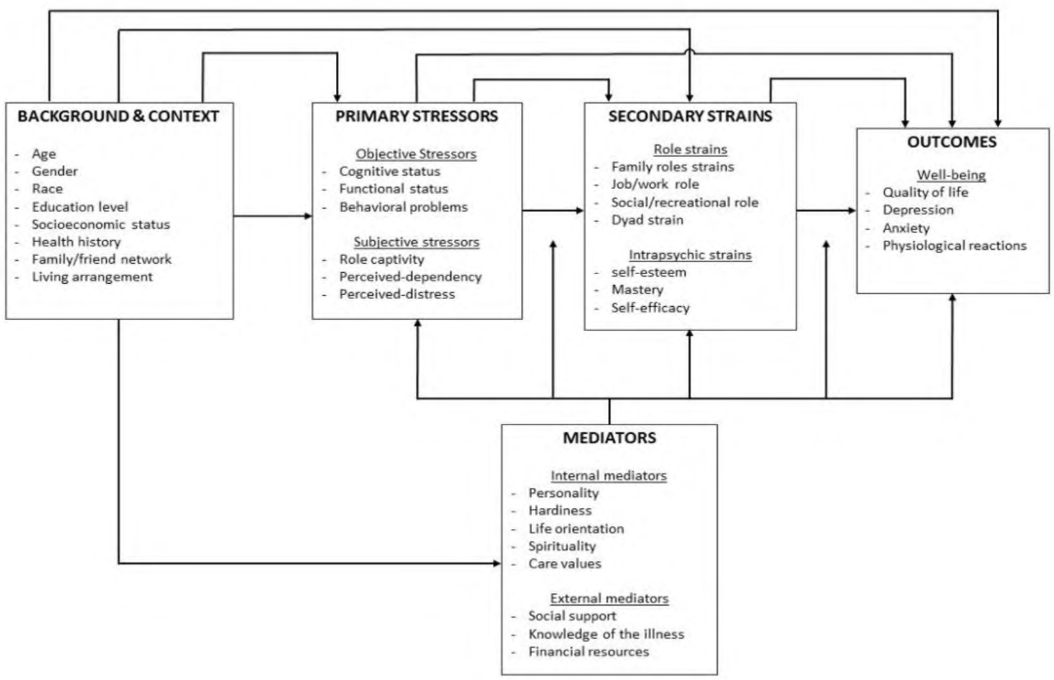
These results suggest that while IWDs' self-reported reliability has been questioned in the past, there are potential biases from proxy-reports that question the reliability of these reports in certain circumstances, which is further exemplified by proxy-reports not always providing an accurate illness experience for IWDs. Thus, there is a growing body of research utilizing and valuing self-report measures from IWDs due to the importance and impact of having a knowledgeable understanding of the illness experience. This is a critical research goal related to helping improve quality of life and facilitating lower depressive symptoms for IWDs. One theoretical model that has been specifically designed to understand the illness experience is the Stress Process Model for Individuals with Dementia and will be discussed in more detail in the proceeding section.

The Stress Process Model for Individuals with Dementia

The Stress Process Model (SPM) is a theoretical foundation and one of the primary paradigms for understanding the relationship between stress and health (Pioli, 2010). The advantage of this model is the focus on both micro and macro level relationships between stressors, resources, and outcomes of well-being (Judge, Menne, Whitlatch, 2010). This model has been adjusted in order to assess the stress and health relationship in a variety of domains. Some of these domains include sociological research (for understanding how societal stressors can influence health outcomes; Aneshensel & Mitchell, 2014), psychological research (for caregivers of IWDs in order to understand the objective and subjective stressors of being a caregiver, as well as the effects on outcomes of well-being and health; Son, Erno, Shea, Zarit, & Stephens, 2007), and environmental transitioning research (to understand how the experience of moving from the general community to living at a facility can impact older adults' stress and health; Gaugler, Anderson, Zarit, & Pearlin, 2003).

Judge, Menne, and Whitlatch (2010) also adapted the SPM based on work by Pearlin and colleagues (1990). The Stress Process Model for Individuals with Dementia (SPM for IWDs; see *Figure 1*) is a conceptual framework adapted in order to understand the illness experience of living with dementia. This includes understanding the stress process and well-being specifically for IWDs. The SPM for IWDs includes the following domains: (a) background and care context, (b) objective and subjective primary stressors, (c) role and intrapsychic secondary strains, (d) internal and external mediators, and (e) outcomes of well-being (Judge, Menne, Whitlatch, 2010). It is postulated that objective and subjective primary stressors, referring to the negative symptoms of a dementing illness, have an impact on secondary strains and psychosocial effects, and, in turn, directly or indirectly affects outcomes of well-being through potential internal and external mediators (Judge, Menne, Whitlatch, 2010). The SPM for IWDs domains will be discussed in further detail in the section below, as this serves as the theoretical framework for the assessment of unmet needs and NDBs in the present study.

Figure 1. Stress Process Model for Individuals with Dementia (SPM for IWDs; Judge, Menne, & Whitlatch, 2010).



Background and Care Context: In this domain, characteristics of lifelong attributes of IWDs are assessed in order to understand how these characteristics may impact the illness experience (Judge, Menne, & Whitlatch, 2010). These characteristics could include age, gender, race, education level, and/or socioeconomic status. Other background and care characteristics that need to be taken into consideration are health history, family and friend network, and/or living arrangements. These characteristics provide information on the IWDs current environment and circumstances, which may also impact the illness experience (Judge, Menne, & Whitlatch, 2010).

Objective and Subjective Primary Stressors: This domain focuses solely on stressors that arise from the experience of living with dementia. Objective primary stressors are the starting point of the SPM for IWDs when assessing the type and amount of primary dementia symptoms, which include etiology, cognitive impairment, functional abilities, and behavioral issues (Judge, Menne, & Whitlatch, 2010). On the other hand, subjective primary stressors are the psychological and emotional consequences that IWDs may experience due to cognitive, functional, and behavioral symptoms of dementia such as self-efficacy or distress from behaviors (i.e. NDBs). It is important to distinguish between the objective stressors and the subjective stressors because IWDs' perceptions regarding their situation may change over time, and such perceptions vary from person to person, possibly changing other domains in later parts of the model (Judge, Menne, & Whitlatch, 2010).

Role and Intrapsychic Secondary Strains: As previously mentioned, the SPM for IWDs is driven by primary stressors related to the disease process, which lead to additional stressors and are referred to as secondary strains. Secondary strains include life roles that are affected by living with dementia such as family, professional, work, social, and recreational roles (Judge, Menne, & Whitlatch, 2010). In this way, secondary strains are the stressors that occur as a direct result of living with dementia. The experience of living with dementia may cause strain to some of these roles while changing due to the disease progression (Judge, Menne, & Whitlatch, 2010). These strains may also be demonstrated through internal self-perceptions or could be intrapsychic, which would be exhibited through self-esteem, mastery and gain, loss of self, and self-efficacy (Judge, Menne, & Whitlatch, 2010).

Internal and External Mediators: This domain specifically speaks to the mediators or the mechanisms that govern the effect of stressors on stress outcomes, making them coping mechanisms that allow IWDs to cope and manage their disease process (Judge, Menne, & Whitlatch, 2010). Internal mediators come from within IWDs and are characteristics of lifelong persistent patterns of adaptation and coping (Judge, Menne, & Whitlatch, 2010). Internal mediators supply insight into how IWDs have approached challenges in the past and provide information as to how IWDs may approach new challenges during the dementia process. Examples of these internal mediators could include personality, resilience, and care values and preferences (Judge, Menne, & Whitlatch, 2010). Secondly, external mediators are adaptation and coping mechanisms that emerge from IWDs' environments. For example, informal and formal support, knowledge about the illness, and unmet needs are all external mediators. Both external and internal mediators have the ability to affect stress-related well-being outcomes for IWDs.

Outcomes of Well-Being: This final domain speaks to the dynamic interplay between all previous domains of the SPM for IWDs and general well-being outcomes. Specifically, this dynamic interplay includes the accumulation and influence of both positive and negative outcomes from prior domains (i.e., background and context, primary stressors, secondary strains, and mediators) and the general well-being outcomes that result. In this way, the SPM for IWDs uses the outcomes of well-being to illustrate how the combination of illness specific symptoms, such as cognitive impairment (i.e., objective primary stressor), perceived distress (i.e., subjective primary stressor), and relationship strain (i.e., secondary strain) can influence broad well-being outcomes. These general emotional, psychological, and physical well-being outcomes could include depression, anxiety, and/or quality of life (Judge, Menne, & Whitlatch, 2010).

The following sections will review multiple constructs including unmet needs, need-driven behaviors, values and preferences, and two specific outcomes of well-being, depressive symptoms and quality of life. The examination of previous research on these constructs will help provide evidence highlighting the importance of these concepts for IWDs given relational importance to well-being outcomes.

Unmet Needs

Conceptually, the term unmet needs constitutes a variety of possible needs that are considered important to an individual but are not currently being met (Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015). Throughout the literature, the construct of unmet needs has multiple definitions and measurement techniques depending on the research question. For instance, Hancock and colleagues (2006) defined unmet needs as “a situation in which an individual has significant problems for which there is an appropriate intervention that could potentially meet the need”. Unmet needs can also be assessed through a simple list of possible needs that one could find important and are not currently being met, including pain and/or physical discomfort, mental discomfort, the need for social contact, uncomfortable environmental conditions, and/or inadequate levels of stimulation (Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015). Furthermore, some studies have defined unmet needs as “the adequacy of care received and need for specific services” (Gaugler, Kane, Kane, & Newcomer, 2005). Despite an unagreed upon definition or method of measurement, the conceptualization of unmet needs remains consistent across the literature along with the role of unmet needs as a critical indicator of quality of life and distress for IWDs (Gaugler, Kane, Kane, &

Newcomer, 2005; Hancock, Woods, Challis, & Orrell, 2006; Orrell, Hancock, Liyanage, Woods, Challis, & Hoe, 2008; Martyr et al., 2018).

The dementia process includes a decrease in the ability to meet one's needs and the ability to provide for oneself becoming increasingly difficulty due to deficits in communication, physical functioning, and cognitive impairment (Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015). Most unmet needs derive from dementia-related impairment in functioning and environment, and/or caregivers not accommodating the preferences of IWDs. Thus, challenging behaviors may arise to alleviate or communicate the individual's unmet needs (Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015). These needs may include physical comfort, mental comfort, the need for social contact, and the discomfort of an undesirable environment or inadequate levels of stimulation (Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015). Cohen-Mansfield and colleagues (2015) described a necessity for understanding unmet needs at a deeper level by assessing the types of unmet needs, the associated behaviors, and possible interventions.

Previous research conducted on unmet needs has determined that IWDs have a variety of possible unmet needs, including inadequate daytime activities, lack of company, failing memory, lack of information, and psychological distress (Park et al., 2018). However, most research conducted on unmet needs among IWDs is examined from a caregiver's perspective, which is an issue when researchers are attempting to understand an IWD's illness experience (Walter, Iliffe, & Orrell, 2001; Mansfield, Boyes, Bryant, & Sanson- Fisher, 2016; Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015; Hughes et al., 2014;). This also creates another potential problem, as previous research with other aspects of proxy-reports (such as quality of life and depression) has found that caregivers' proxy-reports create significant discrepancies (Moon, Townsend, Dilworth-Anderson, & Whitlatch, 2016). Indeed, some literature suggests that these same incongruencies are observed for unmet needs between IWD self-reports and caregiver proxy-reports (Schölzel-Dorenbos, Meeuwsen, & Rikkert, 2010).

Specifically, two research studies have been conducted on self-reported unmet needs of IWDs. In the first study conducted by Orrell et al. (2008), IWDs were interviewed along with a formal caregiver to compare ratings of unmet needs. Results showed that of the IWDs who were able to complete the assessment items, IWDs identified more unmet needs as compared to formal caregivers. In particular, caregivers reported more unmet needs in daytime activities and physical health compared to IWDs. These results illustrate a misalignment in unmet needs identification between IWD self-reports and caregiver proxy-reports. Additionally, this study found only 67% agreement between IWD and caregiver reports, with four out of 24 needs having poor agreement, including IWDs identifying eyesight/hearing, physical health, psychological distress, and loneliness as the needs most unmet. In contrast, caregivers identified more unmet needs in the area of mobility and incontinence (Orrell et al., 2008). This suggests that not only are IWDs identifying more unmet needs than their caregivers, there is also inconsistency in the types of unmet needs identified.

Similarly, Schölzel-Dorenbos, Meeuwsen, & Rikkert (2010) conducted a literature review on possible measures of self-reported unmet needs for IWDs, as well as those needs differently identified by IWDs and caregivers. This literature review revealed similar results to those from Orrell et al. (2008), stating that IWDs' unmet needs were associated with psychological problems, including anxiety, depression, and distress. Furthermore, these unmet needs were rated as significantly higher than caregiver proxy-reports (Schölzel-Dorenbos, Meeuwsen, & Rikkert, 2010). Results from both Orrell et al. (2008) and Schölzel-Dorenbos et al. (2010) highlight the current literature on both macro and micro level conceptualizations of unmet needs. More specifically, it is apparent that there is increased attention being paid to unmet needs of IWDs at a macro level, as measured through clinical assessments and caregiver proxy-reports. It can be seen that there are various possible unmet needs that caregivers are attuned to, including functional needs, personal care needs, and adequacy of support (Gaugler, Kane, Kane, & Newcomer, 2005; Orrell, Hancock, Liyanage, Woods, Challis, & Hoe, 2008). However, less is understood regarding micro level of unmet needs, including IWDs' psychological distress, environmental discomfort, and care preferences (Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015; Schölzel-Dorenbos, Meeuwsen, & Rikkert, 2010). Thus, there is a need and demand for a better understanding and conceptualizations of the self-reported unmet needs from IWDs' perspectives. As suggested by the aforementioned literature, IWDs typically highlight subjective psychological and social needs, while caregivers are generally more attuned to objective functional and basic care needs of the individual (Schölzel-Dorenbos, Meeuwsen, & Rikkert, 2010; Orrell et al., 2008). Though functional and basic care needs are important for adequate care and quality of life, more insight is needed into the psychological, environmental, and social needs reported as important by IWDs in order to expand the illness experience literature.

Understanding these findings from the SPM for IWDs theoretical framework, it is likely that most caregivers report unmet needs that deal with objective stressors such as cognition, functional abilities, and behavior, as opposed to IWDs who are reporting more unmet needs in relation to role and intrapsychic secondary strains. Hancock, Woods, Challis, and Orrell (2006) assessed the unmet needs of IWDs in relation to clinical and demographic factors. These findings indicate that IWDs with more unmet needs, as determined by both self- and proxy-reports, had more challenging behaviors identified by formal or informal caregivers. Additionally, greater unmet needs were related to an increased incidence, frequency, and difficulty in challenging behaviors for formal and informal caregivers. From these results it could be postulated that an increase in unmet needs is being illustrated through an increase in the amount of challenging behaviors, creating a possible connection between unmet needs and NDBs. This connection between unmet need and NDBs will be discussed further in the proceeding section.

Need-Driven Behaviors

Traditionally, there have been multiple terms used to describe the specific set of behaviors exhibited by IWDs. Some of these terms include inappropriate behaviors, agitated behaviors, or challenging behaviors (Cohen-Mansfield, Marx, and Rosenthal, 1990; Feast, Orrell, Charlesworth, Melunsky, Poland, & Moniz-Cook, 2016). However, these terms express or reflect a view from formal and informal caregivers as behaviors exhibited by IWDs due to pathological injury or deficit (Algase et al., 1996). Rather, these behaviors could be seen as a response to an unmet need. In this way, exhibited behaviors are being attributed to the illness experience of a possible need not being met rather than due to illness symptoms. Consistent with this idea, the literature has explored the concept of need-driven behaviors, which conceptualizes these behaviors as an attempt to express a goal or need (Clifford & Doody, 2017; Norton, Allen, Snow, Hardin, &

Burgio, 2009). Need-driven behaviors (NDBs) are defined as those dementia-related behaviors that occur due to the inability of the caregiver to comprehend needs and the inability of an IWD to make his or her needs known (Kovach, Noonan, Schlidt, & Wells, 2005). Looking at behaviors previously termed “challenging” or “inappropriate” with a “need” framework, researchers and care providers are beginning to re-attribute these behaviors as need-driven, allowing such behaviors to be seen as more meaningful and in turn, potentially useful for caregivers when providing care to IWDs (Algase, Beck, Kolanowski, Whall, Berent, Richards, & Beattie, 1996). Additionally, research has shown that these behaviors make it more difficult for caregivers to provide care by interfering with effective communication, which can decrease quality of life for IWDs (Allen-Burge, Stevens, & Burgio, 1999). Thus, there is a sense of urgency to understand the underlying purpose behind these behaviors exhibited by IWDs in order to improve quality of life.

Understanding behaviors within the framework of “need-driven” began when a new lens was applied to research; a person-centered care (PCC) approach (Clifford & Doody, 2017). A PCC approach emphasizes the person who has dementia, as opposed to the medical model approach that emphasizes that IWDs are displaying random behaviors caused by disease (Camp, Bourgeois, & Erkes, 2018). A PCC approach incorporates a variety of principles; all persons are unique, deserve to be treated with respect and dignity, and IWDs should be an active participant in treating their own dementia by emphasizing abilities rather than deficits (Camp, Bourgeois, & Erkes, 2018). With this approach, dementia research has increased the use of the idea ‘living well’ (Martyr et al., 2018) with a PCC approach. When specifically looking at the behaviors exhibited by

IWDs using a PCC approach, one assesses meaning behind the behaviors and understanding that these behaviors are possibly an attempt to express an unmet need or are a result of having an unmet need (Clifford & Doody, 2017). Research has found that when nursing staff gain education concerning a PCC approach, nurses begin taking more time to interpret and understand what IWDs were trying to communicate and whether or not IWDs have a need that the staff were not meeting (Clifford & Doody, 2017).

There are a various behaviors that fall within the scope of NDBs such as agitation, aggression, repeating questions, depression, wandering, and apathy (Feast, Orrell, Charlesworth, Melunsky, Poland, &Moniz-Cook, 2016). These behaviors are typically separated into two categories: behavioral excesses, which describes the addition of a behavior as the problem (i.e. repeated questions) or behavioral deficits, which describe the non-occurrence of a behaviors as a problem (i.e. the inability to self-dress) (Allen-Burge, Stevens, & Burgio, 1999). Previous research has shown that behavioral excesses are more distressing to formal and informal caregivers however, as research has yet to study self-reported behaviors it is unclear as to whether IWDs would self-report this same pattern (Banerjee, Samsi, Petrie, Alvir, Treglia, Schwam, & Del Valle, 2009). It can be considered that IWDs do not understand the impact of their behaviors on caregivers because IWDs may be appraising the situation differently and possibly have a purpose in mind behind their behavior. In order to confirm this possibility, research needs to be conducted wherein IWDs self-report their own behaviors.

Empirical research on NDBs is mixed. Cross-sectional studies have found that as cognitive impairment worsens, NDBs increase (Norton, Allen, Snow, Hardin, & Burgio, 2009). Longitudinal studies, however, indicate that NDBs stabilize or even sometimes improve as cognitive impairments worsen (Norton, Allen, Snow, Hardin, & Burgio, 2009). Mixed results have also been found between NDBs and activities of daily living (ADLs) functioning, such that Vance et al. (2003) found no relationship between ADLs functioning related to NDBs. Conversely, Beck et al. (1998), found that ADL functioning was related to verbal disruption. These misalignments in findings could be expressing the natural progression of dementia. A key issue for IWDs in the later stages is getting their needs met, which primarily begins as a communication and awareness problem (Kovach, Noonan, Schlidt, & Wells, 2005).

NDBs can be a challenge to interpret, and they might be dismissed as problems by caregivers rather than an unmet need (Kovach, Noonan, Schlidt, & Wells, 2005). Kovach (2012) describes situations in case studies where behavioral symptoms of IWDs have been misinterpreted as anxiety and paranoia rather than symptoms of pain. Research has also shown that IWDs who exhibit verbally and physically aggressive behaviors receive more assessment and treatment than those who exhibit more passive behaviors (Kovach, 2012). This emphasizes a potential issue for many IWDs who may be expressing their unmet needs through NDBs such as apathy or depression, leaving these individuals with potentially inadequate care. As such, it becomes apparent that there are consequences for IWDs if their NDBs are not deciphered and appropriately handled (Kovach, Noonan, Schlidt, & Wells, 2005). These consequences include decreased physical, functional, and affective status. In addition, if important needs remain unmet, NDBs are predicted to worsen or change into new NDBs, which in turn can decrease quality of life for IWDs (Kovach, Noonan, Schlidt, & Wells, 2005).

In order to illustrate the possible connection between unmet needs and NDBs, picture an older adult man with dementia. Prior to the disease, he was a very social and active individual. Suddenly, he begins to stay at home more, not interacting with family and friends, and begins displaying the behaviors of apathy and a depressed mood. This individual may be experiencing the unmet need of socialization and inadequate levels of daytime activities, and this unmet need is potentially being expressed through the NDBs of apathy and depressed mood. For this individual, he might not be aware he has this unmet need; however, when using a PCC approach, it could be interpreted that this individual has an unmet need, and a caregiver could attempt to understand the behavior as related to an unmet need. Having a clear and deeper understanding of unmet needs among IWDs is vital. Furthermore, the current literature needs to be extended in order to understand the possible connection between unmet needs and NDBs.

Values and Preferences

One first step in examining the possible connection between unmet needs and NDBs is through understanding IWDs' care values and preferences. Values and preferences refer to those aspects of everyday life that an individual considers important (Whitlatch, Feinberg, & Tucke, 2005). The research on values and preferences first began when researchers were examining the decision-making process of older adults regarding their own health, as well as the level of involvement they have in decision-making about end-of-life care. This research presented the value and belief that older adults need to maintain autonomy and self-identity (Whitlatch, Feinberg, & Tucke, 2005). This area of research has since expanded to consider the values and preferences of older adults with chronic illness or degenerative diseases when making decisions about care. In addition, this research uses a PCC approach by attempting to understand how these older adults' choices and preferences can include not only everyday life aspects but family ties and show these care preferences may change over time (Whitlatch, Piiparinen, & Feinberg, 2009). Discussions about daily preferences have been shown to contribute to increased quality of life for IWDs by providing the opportunity for autonomy and decision-making preferences (Menne & Whitlatch, 2007). Values and preferences such as feeling safe in the environment, being with family and friends, and having reliable help have been shown to be everyday care items that IWDs deem most important within the decision-making process (Whitlatch, Piiparinen, & Feinberg, 2009).

For the present study, understanding IWDs' values and preferences could help identify areas of unmet needs that IWDs are experiencing as well as provide an additional context for the possible relationship between unmet needs and NDBs. For instance, if early on in the disease process, an IWD is able to express to a caregiver hose aspects of everyday life and care that he/she holds in high regard, then he/she may experience more autonomy and a higher quality of life. As the illness progresses and communication, physical, and cognitive impairment worsens, he/she may begin to experience unmet needs due to an inability to meet the need for himself/herself or by not being aware of the need. NDBs may then become apparent to the caregiver, and the caregiver can respond by taking a PCC approach. In this way, the caregiver may be able to look at aspects of everyday life and the care provided to the IWD, understand the IWD's care values and preferences, and determine if one or more of these preferences are not being met leading to the development of an unmet need and the expression of NDBs. Therefore, the construct of care values and preferences will be explored within this study as a possible internal mediator on the relationship between NDBs and outcomes of well-being. Previous research on care values and preferences has established this construct as an internal mediator within the SPM for IWDs (Menne & Whitlatch, 2007), and exploring this construct could shed light on the role of care values and preferences on the relationships between NDBs, unmet needs, and outcomes of well-being.

Little research has examined the possible connection between IWDs' self-reported NDBs to unmet needs or IWDs' values and preferences regarding unmet needs. However, these constructs, and the possible interrelationships, may help explain an intricate process that unfolds during the disease process for IWDs. This study will be a first step in attempting to understand self-reported unmet needs, NDBs, and values and preferences among IWDs in order to expand the literature on IWDs' illness experiences, as well as possible connections between these important constructs. Not only are the possible connections between these constructs vitally important for theoretical understanding, but the possible influence on outcomes of well-being need to be taken into consideration for potential intervention development. Unmet needs, NDBs, and values and preferences are all been found to be related to outcomes of well-being, including symptoms of depression and quality of life (Hancock, Woods, Challis, and Orrell, 2006; Martyr et al., 2018; Allen-Burge, Stevens, & Burgio, 1999; Menne & Whitlatch, 2007).

Outcomes of Well-Being

Guided by the SPM for IWDs, one of the major outcomes of this conceptual framework is psychosocial well-being. As discussed throughout the document, depressive symptoms and quality of life are two major psychosocial well-being outcomes, which have ties to the constructs of unmet needs, NDBs, and values and preferences. These psychosocial well-being outcomes will be discussed in the following sections along with their connections to unmet needs, NDBs, and values and preferences.

Depression: Among the population of IWDs, depression occurs in up to 50% of patients (Zahodne, Devanand, & Stern, 2013). Additionally, prevalence rates for depressive symptoms are three to four times more common in IWDs than in individuals without dementia (Yang, Yu, Xing, He, Liang, & Zhou, 2017). Cross-sectional research studies have found associations between depressive symptoms and worsened functional abilities among IWDs, independent of the individual's cognitive status (Zahodne, Devanand, & Stern, 2013). Pearson and colleagues (1989) made note that depressed dementia patients tended to lose their ability to perform specific instrumental ADLs despite having higher cognitive functioning compared to other patients who have lower cognitive functioning. Similarly, Zahodne, Devanand, and Stern (2013) using unconditional univariate models found that, over the course of 5.5 years, functional problems and cognitive symptoms worsened while depressive symptoms improved.

Findings such as these suggest that depression may be related to initial exaggerated functional and cognitive decline over the dementia disease course; however, depressive symptoms do not worsen (Agbayewa, Weir, Tuokko, & Beattie, 1991; Zahodne, Devanand, &Stern, 2013). Though depressive symptoms may not worsen over time, the initial acceleration of decline in functional and cognitive abilities for IWDs could have extreme negative implications. Thus, the importance of depressive symptoms as an outcome of well-being is apparent when attempting to understand possible ways to prevent and mitigate such symptoms.

When looking at depressive symptoms within the SPM for IWDs, if an individual has increased depressive symptoms causing an acceleration in cognitive decline, this could also cause an increased risk for subjective stressors such as distress and secondary strains, which could possibly lead to an increase in unmet needs. This connection to psychosocial well-being, demonstrated by Hancock, Woods, Challis, and Orrell (2006), found that individuals with clinical depression had significantly more unmet needs than individuals without depression. Additionally, the most common unmet needs related to depression included daytime activities, psychological distress, company, memory, and communication problems.

Quality of Life: Quality of life is a multidimensional, subjective construct and is a useful indicator of well-being. Quality of life is described as an individuals' perception of his/her position in life in the context of cultural and value systems in relation to one's goals, expectations, standards, and concerns (Dewitte, Vandenbulcke, & Dezutter, 2018). Specifically, for IWDs, quality of life can be conceptualized as the integration of cognitive functioning, physical functioning, social interactions, mental well-being, and mood (Stites, Karlawish, Harkins, Rubright, & Wolk, 2017). Research has found several different factors that are associated with lower or deteriorating quality of life, one of which includes unmet needs (Conde-Sala, et al., 2016; Gaugler, Kane, Kane, & Newcomer, 2005; Hancock, Woods, Challis, & Orrell, 2006; Orrell, Hancock, Liyanage, Woods, Challis, & Hoe, 2008; Martyr et al., 2018).

Martyr et al. (2018) recently conducted a systematic review and meta-analysis of self-reported quality of life for IWDs in order to extend the literature on the illness experience. This analysis found several factors that were associated with poor self-reported quality of life including anxiety, pain, depression, neuropsychiatric symptoms, and unmet needs. Additionally, NDBs have been found to increase levels of distress for IWDs as well as affect their quality of life (Norton, Allen, Snow, Hardin, & Burgio, 2009). Hence, it is apparent that the constructs of unmet needs and NDBs could have major implications for these outcomes of well-being and will be addressed in the current study.

Once the key variables predictive of increased quality of life and decreased depressive symptoms are identified, the goal eventually would be to create nonpharmacological interventions. This would allow an individual's unmet needs to be addressed before the needs become an issue, providing IWDs with the skills to communicate the needs they have in such a way that caregivers can understand, as well as provide caregivers with the knowledge and skills to be able to notice, acknowledge, and address the unmet needs in order to improve quality of life for IWDs (Cohen-Mansfield, 2001). However, before these interventions can be implemented, preliminary studies need to be conducted that assess the self-reported unmet needs from an IWD perspective in order to understand psychosocial well-being outcomes and increase our awareness of the illness experience.

The Present Study

The care needs of IWDs living in the community are complex and depend on the severity of dementia symptoms (Park et al., 2018). These symptoms could include cognitive impairment, behavioral difficulties, and psychological symptoms (Park et al., 2018). With a focus on these symptoms specifically, the present study attempted to understand the possible relationship between unmet needs and NDBs. Research on the unmet needs among IWDs postulates that the dementia process includes a decrease in the ability to meet one's needs because of increased difficulty with communication, physical functioning, and cognitive impairment (Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015). These needs could be related to physical discomfort, mental discomfort, the need for social contact, the discomfort of an uncomfortable environment. or inadequate levels of stimulation (Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015). Additionally, the current literature on NDBs suggest that when using a PCC approach, there is the ability to look for meaning in the behaviors exhibited by IWDs, and an understanding that these behaviors are possibly an attempt to communicate an unmet need or are a result from experiencing an unmet need (Clifford & Doody, 2017).

Research has not yet able to solidify the connection between self-reported unmet needs and NDBs due to issues such as not having accurate psychometric measures. However, as both of these constructs have been shown to have major implications for outcomes of well-being, the present study was the first step in extending the literature on these constructs while also examining the relationships between these constructs and outcomes of well-being. Furthermore, there is a growing body of research that examines the dementia illness experience from the IWD's perspective. However, most previous research conducted on unmet needs of IWDs is examined from a caregiver's perspective, not an IWD's perspective. This creates a possible issue, as previous research in other proxy-report domains (such as quality of life and depression) have found that caregiver's reported quality of life for IWDs is lower than IWDs' self-reported quality of life (Moon, Townsend, Dilworth-Anderson, & Whitlatch, 2016; Breland et al., 2014). More importantly, current research exclusively uses proxy-report measures of behavior symptoms, such as NDBs, rather than self-reported IWDs measures. To date, no published studies have assessed the self-reported NDBs from an IWD's perspective.

The current study was a first attempt to answer the 2017 NIA Research Summit on Dementia Care call for future research including, "increase the collection of self-reported data from persons living with dementia …" (Gitlin, Maslow, & Khillan, 2018), by assessing the self-reported unmet needs and NDBs of IWDs by utilizing the SPM for IWDs. The SPM for IWDs includes five theoretical domains: background and contextual characteristics, objective and subjective primary stressors, role and intrapsychic secondary strains, internal and external mediators, and outcomes of well-being (Judge, Menne, & Whitlatch, 2010). For this research, objective primary stressors (cognitive status and behavior frequency) and subjective primary stressor (distress from behaviors or NDBs) were assessed in order to determine their direct impact on outcomes of well-being: quality of life, as well as an indirect effect on depression when mediated by unmet needs and values and preferences. The aim of this research was to assess self-reported unmet needs and NDBs of IWDs with mild to moderate dementia.

Objectives and Hypotheses

The three main objectives for this research study included: (1) to better understand the illness experience by having individuals with mild to moderate dementia self-report their unmet needs and NDBs, (2) to understand the possible connection between unmet needs and NDBs and (3) to understand how unmet needs and NDBs are related to outcomes of well-being. These three objectives help provide more information on the illness experiences of IWDs, as well as ways in which to use a PCC approach and ensure IWDs are ‘living well.’ From these objectives, several hypotheses were developed.

Hypothesis 1:

Individuals with dementia who self-report more unmet needs will have more NDBs.

Hypothesis 2:

Individuals with dementia who express more unmet needs will have lower quality of life and more symptoms of depression.

Hypothesis 3:

Individuals with dementia who express more NDBs will have lower quality of life and more symptoms of depression.

Hypothesis 4:

Individuals with more cognitive impairment will have more unmet needs and more NDBs.

Hypothesis 5:

Care values and preferences will be related to unmet needs and NDBs.

Hypothesis 6:

It is hypothesized that the set of predictors of unmet needs, NDBs, and values and preferences will predict significant variance in each of the outcome measures of depression and quality of life.

Hypothesis 7:

A mediation hypothesis is considered whereby unmet needs will have a mediating effect on the relationship between objective primary stressors (NDBs) and outcomes of well-being (depressive symptoms and quality of life) within the SPM for IWDs.

CHAPTER II

METHODS

Participants

Participants were recruited from Altenheim Senior Living Facility, which is a non-profit organization located in Strongsville, Ohio offering assisted and independent living, skilled nursing and rehabilitation, outpatient physical therapy, long-term care, memory care, and home healthcare. A total of 39 potentially eligible participants were referred and screened for eligibility (see *Figure 2*). Of these 39 IWDs, four were determined ineligible by the Activities Director at Altenheim Senior Living. Of these four, two were on end-stage hospice care and two were currently hospitalized. The remaining 35 potentially eligible participants were contacted for participation through a sign-up sheet at an informational meeting held at Altenheim Senior Living (*n*=4) as well as approached in-person at the facility (*n*=30) or through a mailed flyer (*n*=1) coming directly from the facility Activities Director.

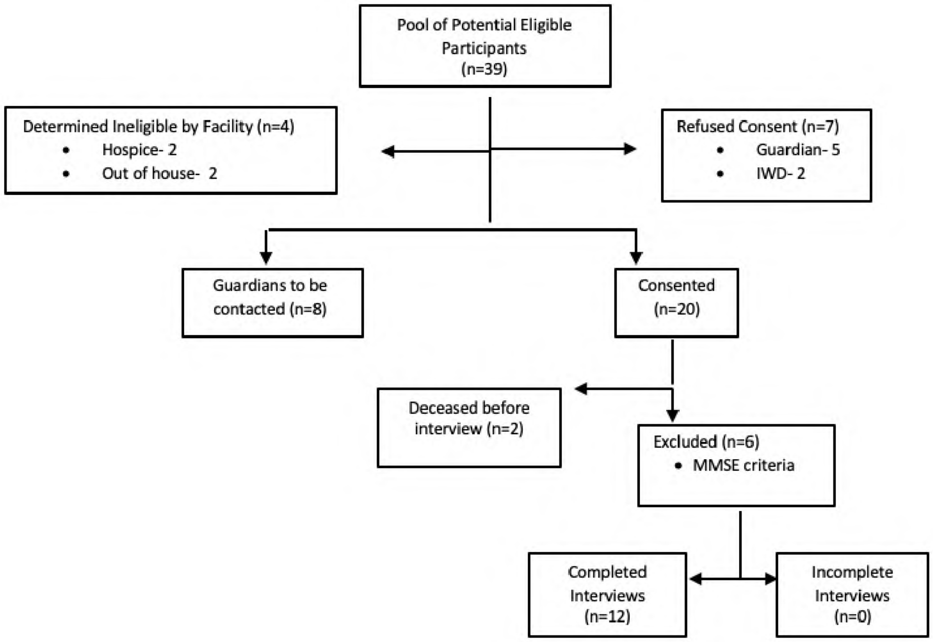
Inclusion and Exclusion Criteria

Participants were residents of Altenheim Senior Living Facility and had to score at least an 11 or higher on the Mini-Mental State Examination (MMSE) as this is the cut off for moderate dementia (Folstein, Folstein, & McHugh, 1975), as well as a range determined to be suitable for individuals to reliably self-report (Krestar, Looman, Powers, Dawson, & Judge, 2012). Additionally, all participants were required to have a guardian consent form completed, as well as verbal/written assent in order to move on to the structured interview portion of the study.

Of the 35 potentially eligible participants, seven refused to participate (five legal guardian refusals and two refusals from IWDs). Twenty legal guardian consent forms were obtained, two participants died between obtaining consent and the structured interview portion, leaving 18 potential participants for inclusion criteria screening. Of these 18, six were excluded for scoring below an 11 on the MMSE, leaving a total n=12 for the final analyses.

A statistical power analysis was performed for the present exploratory study to determine sample size estimation. Through an a priori analysis with an alpha = .05 and power = 0.80, the projected sample size needed for an effect size of 0.25, which is considered a medium effect according to Cohen's (1988) criteria, was approximately N = 53. However, due to unforeseeable circumstances this sample size was not obtained. During the data collection process, the current study's recruitment site shut down visitation during the global COVID-19 pandemic for the safety of its residents and staff. Therefore, the subsequent small sample size was taken into consideration when analyzing and interpreting the proceeding results.

Figure 2. Recruitment Consort Diagram



Materials

Cognitive Impairment: Participants completed The Mini-Mental State Examination (MMSE), which is a screening tool for cognitive impairment. This test covers a variety of cognitive domains including orientation to time and place, short and long-term memory, registration, recall, constructional ability, language and the ability to understand and follow commands (Molloy & Standish, 1997). The possible score range for this test is 0-30; lower scores indicate higher levels of cognitive impairment. Within this range of scores, 25-30 is an indication of modestly normal cognitive function with the possibility of issues with some IADLs; 21-24 is an indication of mild cognitive impairment; 11-20 is an indication of moderate cognitive impairment; and 0-10 is an indicator of severe cognitive impairment (Folstein, Folstein, & McHugh, 1975). The original MMSE had high test retest reliability (*r* = .83; Folstein, Folstein, & McHugh, 1975).

Unmet Needs: The unmet needs measure used in the current study was adapted from a previously published measure (Bass et al., 2012) which has been tested on populations of IWDs and caregivers of IWDs (Bejjani et al., 2015; Bass et al., 2012; Bass et al., 2014; Menne et al., 2014). This unmet needs measure includes 43 dichotomous 'yes/no' questions that are summed to measure an individual's perception of unmet needs across the following eight domains: (1) understanding dementia, (2) daily living tasks, (3) accessing services, (4) legal and financial issues, (5) organizing family care, (6) alternative living arrangements, (7) emotional support, and (8) activity level. Higher summed scores indicate more unmet needs. Previous studies using this measure have observed good structural validity, with factor loadings from .62 to .83 (Bass et al., 2014), 0.63 to 0.84 (Bass et al., 2012; Bejjani et al., 2015) as well as good reliability (∝= .93) (Bass et al., 2012). Within the current study sample, the unmet needs measure exhibited good reliability (∝ = 0.96). Additionally, a subsequent 'distress' scale was added to this measure, also containing dichotomous 'yes/no' responses, assessing if any of the measure domains not only were or were not an unmet need but whether that topic caused the IWD any distress. Higher summed scores indicated higher levels of distress. The distress portion of the unmet needs measure also displayed good reliability within the study sample (∝= 0.98).

To illustrate adaptations that were made to this measure, domains one through seven are consistent with the original measure. The addition of "activity level" as a subscale was developed for the present study, along with the exclusion of a previously used domain, "access to VA services." These adaptations were made in order to modify the measure so as to accurately assess our conceptualization of unmet needs. Additional modifications and adaptations were made to this measure based on the literature, which suggested topics such as socialization, purposeful activity, and psychological distress areas related to unmet needs IWDs identify. Thus, various questions were added to encompass these possible unmet needs (i.e. items d, f, g, h, i, mm, nn, oo, pp, and qq). Finally, various questions detailing access and utilization of VA services, which were critical questions in the original studies, were deleted or modified within this study as this was not the focus of the present research questions.

Need-Driven Behaviors: The BRIA Measure of Behavioral Difficulty and Distress was used to measure IWDs' NDBs. The measure assessed two key components of IWDs' behaviors: the frequency of a behavior and the resulting distress of experiencing the behavior. For the purpose of this study, the entire measure was administered, but only the distress scale was used for hypothesis testing and to represent the NDBs construct. The BRIA Measure of Difficulty and Distress comprises 13 items that assess the frequency of behaviors (e.g., repeat the same word over and over again; yell or swear at people; act restless or agitated; act fearful without good reason; wandering) and the resulting distress experienced. Frequency is assessed using a 4-point Likert scale ranging 'from none of the time' to 'all of the time,' with higher scores indicating more frequent and difficult behaviors. Behavioral distress is assessed using a 4-point Likert scale ranging from 'not distressing' to 'very distressing,' with higher scores indicating greater behavioral distress or NDBs. All items can be dichotomized to 'yes/no' responses to facilitate IWDs' participation. The BRIA Measure of Difficulty and Distress has been used in previous research with family caregivers of IWDs and has demonstrated good reliability and structural validity (Bass et al, 2012 (0.79); Bass et al., 2013; Judge et al 2012). The measure has only recently been used with IWDs using self-report data collection methods (Judge, 2017).

Cronbach's alpha could not be conducted for the BRIA Behavioral Difficulty and Distress Scale (i.e. NDBs). By nature of the scale, participants were only asked the distress portion of the measure if they indicated experiencing that behavior within the previous frequency portion of the measure. Therefore, because of the discrete missing values associated with this scale, reliabilities could not be determined. However, the frequency portion of the BRIA Behavioral Frequency and Distress Scale did demonstrate good reliability (∝= 0.91).

Values and Preferences: The Values and Preferences Scale (VPS) assesses aspects of everyday life that persons with cognitive impairment consider important (Whitlatch, Piiparinen, & Feinberg, 2009). The VPS describes seven concepts/items describing values and preferences in everyday care that persons with cognitive impairment feel are important, including (a) maintaining personal privacy, (b) organizing daily routines, (c) participating in activities, (d) involving particular family or friends in care, (e) not involving particular family in care, (f) coming and going as the individual pleases, and (g) accepting some restrictions in order to be safe (Whitlatch, Feinberg, & Tucke, 2005). These seven concepts are rated on a 3-point scale: 3 = very important, 2 = somewhat important, or 1 = not at all important. The VPS has shown good reliability with caregivers' environment and social networks (∝=.81) and personal autonomy (∝=.82), as well as IWDs' environment and social networks (∝=.81) and personal autonomy (∝=.70) (Whitlatch, Feinberg, & Tucke, 2005). Consistent with previous research, the current study also found good reliability within the study sample (∝= 0.76).

Depression: The Center for Epidemiological Studies Depression Scale (CES-D) was originally designed to measure depressive symptoms in the general population (Radloff, 1977). This original 20-item scale assesses perceived mood and level of functioning during the past week, representing four factors, including depressed affect, positive affect, somatic problems, and interpersonal relationship problems (Smarr & Keefer, 2011). An adapted 11-item scale has been utilized with cognitively impaired participants in order to understand the illness experience of IWDs (Dawson et al., 2012; Krestar et al., 2012; Menne et al., 2009) and this short form has found good reliability (0.86; Miller, Anton, & Townson, 2008). With a 3-point response scale, where 0=hardly ever (<1 day), 1= sometimes (1-3 days), 2= often (4-7 days), scoring ranges from 0-22, with higher scores indicating more significant depressive symptoms (Smarr & Keefer, 2011). The CES-D has high acceptability in both general and clinical populations and high reliability, with Coefficient ∝ 's ranging from 0.85 in the general population to 0.90 in psychiatric populations (Radloff, 1977). Similarly, the present study found good reliability within the sample (∝= .89).

Quality of Life: The Quality of Life-Alzheimer's Disease measure (QoL-AD) was specifically used to obtain a rating of quality of life for IWDs and has been approved for individuals scoring at least a 10 or above on the MMSE (Logdson, Gibbons, McCurry, & Teri, 1999). This 12-item test is rated on a 4-point scale, where 1 = poor, 2 = fair, 3 = good, and 4 = excellent. The total score range for this test is 13-52, with higher scores representing higher quality of life (Logdson, Gibbons, McCurry, & Teri, 1999). The 13-items include physical health, energy, mood, living situation, memory, family, marriage, friends, self, ability to do chores, ability to do things for fun, money, and life as a whole. The reliability of this test is high with a Coefficient ∝ = .88 in the original study (Logdson, Gibbons, McCurry, & Teri, 1999). In the current study, good reliability for the QoL-AD was also found with the present sample (∝= .93).

Demographic Information: A brief self-report questionnaire was given to participants in order to obtain demographic information such as age, gender, race, socioeconomic status and marital status. These demographic variables, along with cognitive impairment, were assessed as possible covariates within the study. All demographic variables were deemed unnecessary to include as covariates based on the small samples size and variability within the study sample. Cognitive impairment was considered as a covariate and subsequently controlled for during the analyses.

Procedure

As part of the training process, the co-investigator was trained and observed by the principle investigator on proper protocol administration, including: (1) how to administer the MMSE assessment, (2) how to interact and collect data from IWDs, (3) how to redirect the respondent should the individual get off topic or become confused, (4) how to look for signs of fatigue and distress and implement the proper response, and (5) how to de-escalate signs of agitation and/or aggression. The principle investigator completed the first participant interview and half of a second participant interview while the co-investigator observed. The remaining participant interviews were completed by the co-investigator.

Once participants were recruited and guardian consent forms were obtained, the co-investigator worked with the Altenheim Activities Director to schedule appropriate times to meet with each participant for the structured interview. All interviews took place in a private, comfortable room located at Altenheim Senior Living Facility and lasted between 20-60 minutes. Before the interview was conducted, informed consent (for IWDs without a legal guardian) and/or verbal/written assent was received from the participant (for IWDs with a legal guardian). If the caregiver was present, he/she was asked to leave the room until the completion of the interview. Once consent was obtained, the co-investigator began with collecting the demographic information followed by administering the standardized MMSE to determine if the participant met the inclusion criterion of a score of at least a 11 or above.

If the participant met the inclusion criteria, the co-investigator guided the participant through a series of self-report measures. Each question was read aloud to the participant and index cards with large print response options for each measure was available for each participant. Dichotomized response options for each study measure were also available should any of the participants be unable to use the full scale response options. In total, six measures were completed including a demographic survey, Unmet Needs measure, the BRIA Behavioral Distress scale, the Value and Preferences Scale, and finally the CES-D and the QoL-AD. If the participant did not meet the inclusion criteria, he/she completed 10 brief open-ended questions and then thanked for his/her time.

Design

The present study utilized a correlational research design by employing survey data in an attempt to understand the role of individuals differences between participants and the relationship between the independent and dependent variables.

Analyses

In the present study, data analyses were conducted in the following three steps in order to address the survey data and hypotheses: preliminary analyses, descriptive analyses, and primary analyses.

Preliminary Analyses: The preliminary analyses were conducted in order to prepare the raw data for the descriptive and primary analyses. The study's raw data were entered and assessed through SPSS statistical software. The raw data were analyzed for outliers and missing data in order to understand the variability of the sample and/or assessed for any possible data entry errors that needed to be addressed. For each of the measures, including the Unmet Needs measure, The BRIA Behavioral Difficulty and Distress scale, VPS, CES-D, and QoL-AD, Cronbach's alpha tests were run, and measures with alphas at .70 or higher were deemed reliable measures.

Descriptive Analyses: Means, standard deviations, and frequencies of the sample were assessed along with the demographics in order to understand the sample, as well as the connections between the demographic variables and the independent and dependent variables. Cognitive impairment was analyzed as a covariate.

Correlation Analyses: In order to analyze Hypotheses 1 through 5, a series of correlation analyses were conducted. Hypothesis 1 examined the relationship between unmet needs and NDBs. Hypothesis 2 examined the relationship between unmet needs and the well-being outcomes of depressive symptoms and quality of life. Hypothesis 3 examined the relationship between NDBs and the well-being outcomes of depressive symptoms and quality of life. Hypothesis 4 examined the relationship between cognitive severity and the two constructs of unmet needs and NDBs. Finally, hypothesis 5 examined the relationship between values and preferences and unmet needs and NDBs.

Regression Analyses: To understand the possible predictive values of the study's independent variables, specifically addressed in Hypothesis 6, two multiple regression analyses were conducted. The multiple regression analyses regressed various dependent variables (i.e., depressive symptoms, quality of life) on the variables of unmet needs, NDBs, and values and preferences in order to understand the interrelationships among variables as well as the unique contribution of each independent variable. MMSE scores were also included within the multiple regression analyses to control for cognitive impairment. Finally, two mediation analyses were conducted for Hypothesis 7, which examined how unmet needs may mediate the relationships between NDBs and both well-being outcomes.

CHAPTER III

RESULTS

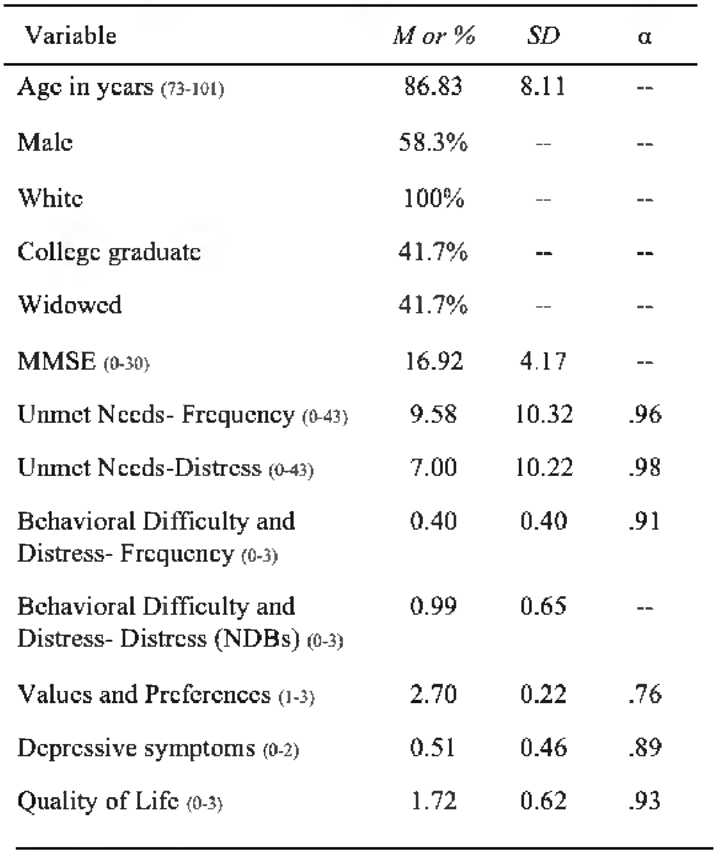
Due to limitations with data collection and the low sample size that the current study faced, the investigators are aware and proceed to the analysis portion of this document with caution regarding the statistical findings and implications of these findings. Many of the proceeding results for the main hypothesis tests do not have sufficient power or meaningful significance due to an insufficient sample size. However, there are important and insightful results at the item and descriptive level that further extend the current literature on many new constructs, including unmet needs, distress, and NDBs that are reported from the IWD's perspective.

Means, standard deviations, and scale reliabilities for all five measures, as well as sample characteristics, are shown in Table 1. Participants' ages ranged from 73 to 101 (*M* = 86.83, *SD* = 8.11), with the sample fairly evenly split between males (58.3%) and females (41.7%). All participants were white, not of Hispanic origin (100%), with a majority of participants stating they were widowed (41.7%), and the remaining identified as married (25.0%), single (26.7%) or other (16.7%). All participants completed high school, with some attending but did not graduating college (16.7%), were college graduates (16.7%), completed a Master's degree (16.7%), and some completed a doctoral/ MD/JD degree (8.3%). MMSE scores ranged between 12 and 22 (*M*= 16.92, *SD*= 4.17), indicating individuals with mild to moderate dementia (Folstein, Folstein, & McHugh, 1975).

Cronbach's alphas statistics were conducted for each measure to assess reliability, and all study measures met reliability qualifications (Table 1). Though this study had a small sample size, it is important to note that these self-report measures, both new and established, did show reliabilities within acceptable ranges. This adds to the existing literature, providing a rationale and evidence that IWDs' self-report scales can have reliable psychometric properties, and IWDs should be self-reporting their own data whenever possible.

When conducting research with IWDs, certain situations result in the need for the participant to switch to dichotomized 'yes/no' response options as opposed to full scale response options. Of the 12 participants, only one participant had to use the dichotomized response options. Specifically, the dichotomized response options were only used for one scale: the BRIA Behavioral Difficulty and Distress assessing NDBs. This participant was able to use full scale response options for all other measures. The full response options for the BRIA Behavioral Difficulty and Distress scale included a 4-point Likert scale ranging from 'from none of the time' with a score of '0' to 'all of the time" with a score of '3,' while the dichotomized form scores a 'no' responses as '0' and a 'yes' response as a score of '1.' Due to the conservative weight of this dichotomized score for the BRIA Behavioral Difficulty and Distress scale, and that this dichotomized scoring was only used for one participant, the investigators have decided to leave this one participant's scores as dichotomized, and all other participant responses were left in the full scale response format for further analyses.

Table 1. Sample Characteristics of Participants who Completed the Study



Variable	*M or %*	*SD*	α
Age in years (73-101)	86.83	8.11	--
Male	58.3%	--	--
White	100%	--	--
College graduate	41.7%	--	--
Widowed	41.7%	--	--
MMSE (0-30)	16.92	4.17	--
Unmet Needs- Frequency (0-43)	9.58	10.32	.96
Unmet Needs-Distress (0-43)	7.00	10.22	.98
Behavioral Difficulty and Distress- Frequency (0-3)	0.40	0.40	.91
Behavioral Difficulty and Distress- Distress (NDBs) (0-3)	0.99	0.65	--
Values and Preferences (1-3)	2.70	0.22	.76
Depressive symptoms (0-2)	0.51	0.46	.89
Quality of Life (0-3)	1.72	0.62	.93

Note. All score ranges for study measures are reported in parentheses. Both Unmet Needs measures were summed scores.

Of the 12 study participants, six had item-level missing data, which accounted for a total of 10.7% of the missing data across the main study variables. One participant had a moderate amount of missing data due to a refusal to answer various questions (19.7% of this participant's data was missing). A Little's MCAR test was conducted to determine if the missing data were missing completely at random. Results concluded a non-significant *p*-value (X_2 (1456, N=12) = 68.39, p = 1.00), suggesting that the null hypothesis can be accepted; the data were missing completely at random. Therefore, with the small amount of missing data at the item level, available item analyses (AIA; Parent, 2013) were used for this data set.

The current study provides many interesting findings in relation to IWDs' self-reported item and descriptive level data that both coincide with and differ from current literature findings. Therefore, frequencies of IWDs' self-reported unmet needs and resultant distress were broken down by the measure subscales: (1) family concerns, (2) health information, (3) daily living tasks, (4) legal and financial issues, (5) emotional support and counseling, (6) finding/arranging services, and (7) living arrangements and activities (see Appendix A). Within these findings, not only was there a range of variability among the items within this measure for both the frequency portion and distress portions of the scale but a majority of IWDs identified at least one unmet need (74.8%). Additionally, these results do not necessary align. For instance, an unmet need did not always coincide with related distress from said unmet need(s). However, if an unmet need was reported as distressing, it most likely also had a higher frequency.

The top reported unmet needs among IWDs were all within the 'Health Information' subscale, with one of the top five reported unmet needs also being within the 'Finding/Arranging Services' subscale. The highest reported unmet need among IWDs was "getting information about your memory issues" (58.3% unmet) followed by "Trying things that may prevent your memory issues from getting worse" (41.7% unmet), "tests for diagnosing memory issues" (41.7% unmet), "knowing the future course of your memory issues" (41.7% unmet), and "getting service providers to work together" (41.7%

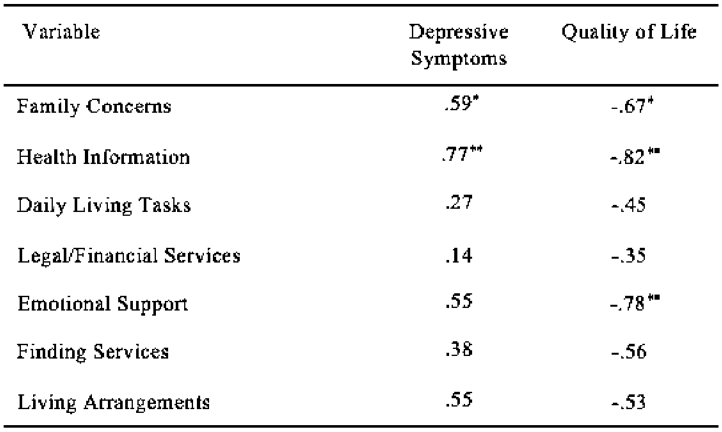
unmet). On the contrary, the lowest reported unmet needs IWDs identified were within the ‘Family Concerns’ and ‘Living Arrangement and Activities’ subscales for needs such as “getting family members or friends to help you because of your memory issues” (8.3% unmet) and “making yourself comfortable with your current living arrangement” (8.3% unmet).

The distress portion of the Unmet Needs scale was a subsequent question concerning the amount of distress IWDs felt concerning the unmet need item and was asked for every item, irrespective of how the IWD answered the frequency portion. As mentioned, the distress from the unmet needs portion of the measure did not always align with the reports of an unmet need’s frequency. For instance, one of the top reported distressing unmet needs was “scheduling follow-up visits with doctors.” This need was only reported to be unmet by 8.3% of IWDs; however, this need was distressing for 33.3.% of IWDs. Another example can be seen with the top reported unmet need mentioned earlier, “Trying things that may prevent your memory issues from getting worse,” which was reported as unmet by 41.7% of IWDs but only distressing for 8.3% of IWDs. These findings suggest that while some unmet needs align with similar levels of resultant distress, such as “How to manage your feelings when you feel confused or upset,” which was reported as unmet need by 25.0% of IWDs and was distressing for 33.3% of IWDs, this is not the majority pattern for unmet and met needs. The subscales with the most reported distressing items included ‘Health Information,’ ‘Emotional Support,’ ‘Finding/Arranging Services,’ and ‘Living Arrangements and Activities,’ with the least distressing items resulting from the subscales ‘Legal and Financial Issues,’ ‘Daily Living Tasks,’ and ‘Family Concerns.’

Previous research suggests that some unmet needs, such as memory, daily activities, company, and communication problems, are more related to outcomes of well-being (Hancock, Woods, Challis, & Orrell, 2006). The present study assessed the seven Unmet Needs subscales in order to determine which specific unmet needs categories could be more or less related to outcomes of well-being. As seen in Table 2, the subscales 'Health Information' ($r = .77$, $p <.01$) and 'Family Concerns' ($r = .59$, $p = .04$) were positively related to depressive symptoms, and 'Health Information' ($r = -.82$, $p = <.01$), 'Family Concerns' ($r = -.67$, $p = .02$) and 'Emotional Support' ($r = -.78$, $p <.01$) were negatively related to quality of life. This suggests that within the present study's sample, unmet needs concerning health, family, and emotional support were more related to outcomes of well-being.

Similar to the unmet needs descriptives, the item-level frequencies exhibited from the BRIA Behavioral Difficulty and Distress scale provides new information to the behavior literature as there are currently no published studies that include self-reported behaviors from IWDs. While the distress portion of this measure was used for the main hypothesis tests, interesting patterns are apparent within the frequency portion of this measure as well. First, it can be seen that IWDs are, in fact, identifying behaviors and reporting these behaviors to an extent that there is variability among behaviors. As can be seen in Table 3, the top reported behaviors that IWDs report experiencing in the past four weeks included "acting restless or agitated" (66.7%) and "complaining about or criticizing things" (58.3%), with other behaviors such as "act confused" (41.6%) and

Table 2. Correlations Examining the Relationships Between Unmet Needs Subscales, Depressive Symptoms, and Quality of Life



Variable	Depressive Symptoms	Quality of Life
Family Concerns	.59*	-.67*
Health Information	.77**	-.82**
Daily Living Tasks	.27	-.45
Legal/Financial Services	.14	-.35
Emotional Support	.55	-.78**
Finding Services	.38	-.56
Living Arrangements	.55	-.53

Note. N = 12. Analyses used were Biserial correlations.
$^*p \leq .05$, $^{**}p \leq .01$.

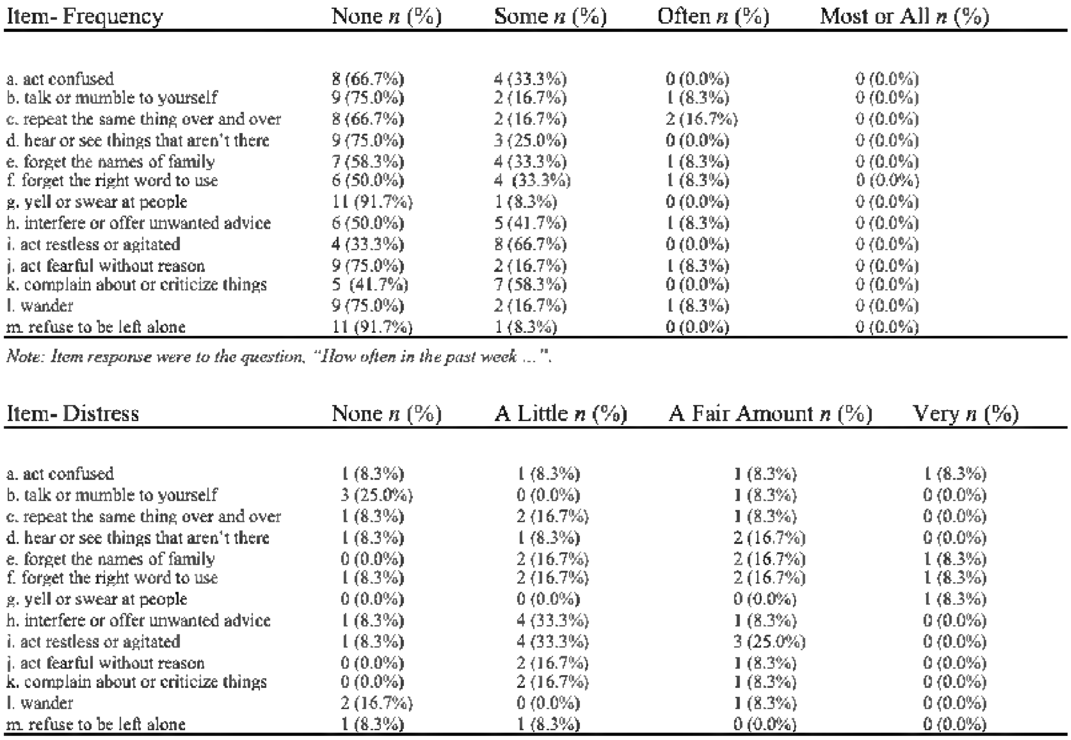
"forgetting the names of family or friends" (41.6%) also adding variance. Additionally, when taking into consideration the distress portion of this measure, while some of the behaviors are reported infrequently, such as "acting fearful without good reason" (25.0%) and "yell or swear at people" (8.3%), when an IWD does report these behaviors, he/she reports a higher level of distress. These behaviors were identified as "a fair amount distressing" and "very distressing," respectively, on a 4 point-Likert scale.

Correlational Analyses

As previously mentioned, due to the low sample size, the investigators acknowledge limitations with reporting and interpreting the proceeding correlational analyses. We advise readers to consider these limitation when interpreting results.

Correlational analyses were used to examine the relationships between the independent and dependent variables outlined within Hypotheses 1 through 5 (Table 4). Hypothesis 1 was not supported: there was not a significant relationship between unmet needs and NDBs (r = .36, p = .28). Hypothesis 2 was supported, with a significant

Table 3. Frequencies of BRIA Behavioral Difficulty and Distress (NDBs)



Item- Frequency	None *n* (%)	Some *n* (%)	Often *n* (%)	Most or All *n* (%)
a. act confused	8 (66.7%)	4 (33.3%)	0 (0.0%)	0 (0.0%)
b. talk or mumble to yourself	9 (75.0%)	2 (16.7%)	1 (8.3%)	0 (0.0%)
c. repeat the same thing over and over	8 (66.7%)	2 (16.7%)	2 (16.7%)	0 (0.0%)
d. hear or see things that aren't there	9 (75.0%)	3 (25.0%)	0 (0.0%)	0 (0.0%)
e. forget the names of family	7 (58.3%)	4 (33.3%)	1 (8.3%)	0 (0.0%)
f. forget the right word to use	6 (50.0%)	4 (33.3%)	1 (8.3%)	0 (0.0%)
g. yell or swear at people	11 (91.7%)	1 (8.3%)	0 (0.0%)	0 (0.0%)
h. interfere or offer unwanted advice	6 (50.0%)	5 (41.7%)	1 (8.3%)	0 (0.0%)
i. act restless or agitated	4 (33.3%)	8 (66.7%)	0 (0.0%)	0 (0.0%)
j. act fearful without reason	9 (75.0%)	2 (16.7%)	1 (8.3%)	0 (0.0%)
k. complain about or criticize things	5 (41.7%)	7 (58.3%)	0 (0.0%)	0 (0.0%)
l. wander	9 (75.0%)	2 (16.7%)	1 (8.3%)	0 (0.0%)
m. refuse to be left alone	11 (91.7%)	1 (8.3%)	0 (0.0%)	0 (0.0%)

Note: Item response were to the question, "How often in the past week ...".

Item- Distress	None *n* (%)	A Little *n* (%)	A Fair Amount *n* (%)	Very *n* (%)
a. act confused	1 (8.3%)	1 (8.3%)	1 (8.3%)	1 (8.3%)
b. talk or mumble to yourself	3 (25.0%)	0 (0.0%)	1 (8.3%)	0 (0.0%)
c. repeat the same thing over and over	1 (8.3%)	2 (16.7%)	1 (8.3%)	0 (0.0%)
d. hear or see things that aren't there	1 (8.3%)	1 (8.3%)	2 (16.7%)	0 (0.0%)
e. forget the names of family	0 (0.0%)	2 (16.7%)	2 (16.7%)	1 (8.3%)
f. forget the right word to use	1 (8.3%)	2 (16.7%)	2 (16.7%)	1 (8.3%)
g. yell or swear at people	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (8.3%)
h. interfere or offer unwanted advice	1 (8.3%)	4 (33.3%)	1 (8.3%)	0 (0.0%)
i. act restless or agitated	1 (8.3%)	4 (33.3%)	3 (25.0%)	0 (0.0%)
j. act fearful without reason	0 (0.0%)	2 (16.7%)	1 (8.3%)	0 (0.0%)
k. complain about or criticize things	0 (0.0%)	2 (16.7%)	1 (8.3%)	0 (0.0%)
l. wander	2 (16.7%)	0 (0.0%)	1 (8.3%)	0 (0.0%)
m. refuse to be left alone	1 (8.3%)	1 (8.3%)	0 (0.0%)	0 (0.0%)

Note: Item response were to the question, "and distress is that for you …" if the participant experienced the behavior in the "frequency" portion.

negative relationship between unmet needs and quality of life ($r = -.83$, $p < .01$), as well as a significant positive relationship between unmet needs and depressive symptoms ($r = .69$, $p < .01$), observed. Altogether, these results suggest that more unmet needs reported by IWDs is related to lower quality of life and more depressive symptoms. Similarly, there was a significant positive relationship between unmet needs distress and depressive symptoms ($r = .76$, $p < .01$) and a negative relationship between unmet needs distress and quality of life ($r = -.74$, $p < .01$), indicating that more unmet needs distress is related to more depressive symptoms and lower quality of life. Additionally, there was a significant positive relationship between the frequency of unmet needs and subsequent unmet needs distress ($r = .67$, $p = .02$), suggesting that more unmet needs are related to more distress.

Table 4. Correlations Examining the Relationships between Unmet Needs, NDBs, Values and Preferences, Depressive symptoms, and Quality of Life.

Variables	Unmet Needs-Frequency	Unmet Needs-Distress	NDBs-Frequency	NDBs-Distress	Mean (SD)
Unmet Needs-Frequency	--	.67*	.33	.36	9.58(10.32)
Unmet Needs-Distress	.67*	--	.37	.55	7.00(10.22)
NDBs-Frequency	.33	-.22	--	.52	0.40(0.40)
NDBs-Distress	.36	.55	.52	--	0.99(0.65)
Values and Preferences	-.16	.20	.27	.68*	2.70(0.22)
Depressive Symptoms	.69*	.76**	.76**	.78**	0.51(0.46)
Quality of Life	-.83**	-.74**	-.65**	-.56	1.72(0.62)

Note. N = 12. Analyses used were Biserial and Pearson's r correlations. Both Unmet Needs frequency and distress are summed scores.
$^{*}p \leq .05$, $^{**}p \leq .01$.

Hypothesis 3 was supported in that NDBs were positively related to depressive symptoms (r = .78, p < .01); however, no significant relationship was found between NDBs and quality of life (r = -.56, p = .07). Additionally, Hypothesis 4 was not supported, as cognitive impairment was not related to unmet needs (r = -.13, p = .68) or NDBs (r = .43, p = .19). Results show support for Hypothesis 5: care values and preferences were positively related to NDBs (r = .68, p =.02). Specifically, having more care preferences were related to more NDBs. However, care values and preferences were not significantly related to unmet needs (r = .39, p = .21). Additionally, when looking at the frequency portion of the BRIA Behavioral Frequency and Distress Scale, results indicated a significant and positive relationship between the frequency of behaviors and depressive symptoms (r = .76, p < .01), as well as a significant negative relationship with quality of life (r = -.65, p = .02), such that IWDs identifying more behaviors was related to more depressive symptoms and lower quality of life.

Regression Analyses

For the following regression analyses, the investigators again make note of the current study's low sample size and resultant low power; thus these limitations should be considered when interpreting the following regression analyses. With these violations of power and adequate sample size comes bias within the standard errors of the model and subsequent bias with the corresponding test statistics and associated significance value (Fields, 2017). As such, the following regression analyses have no meaningful significance.

In order to assess Hypothesis 6, two multiple regressions were conducted in which all study variables were entered together at the same time. Cognitive impairment (i.e. MMSE) was also included within the regression models as cognitive impairment is a typical variable that has to be controlled in dementia research. However, cognitive impairment is also a part of the SPM for IWDs theoretical conceptualization as a primary objective stressors; therefore, the investigators were also interested in how this variable interacted within other predictors variables within the model.

As seen in Table 5, results suggests that Hypothesis 6 was supported, as unmet needs, NDBs, and values and preferences significantly predicted depressive symptoms (R_2= .85, F (4,6) = 8.61, p = .01), accounting for 85.2% of the total variance when controlling for cognitive impairment. Additionally, unmet needs (B = .02, p = .05) was a unique and significant predictor of depressive symptoms while NDBs (B = .43, p = .07) and values and preferences (*B* = .30 , *p* =.57) were not. Results suggest that IWDs with more unmet needs report more depressive symptoms.

Finally, the set of predictor variables also significantly predicted quality of life (R_2 = .84 , *F* (4,6) = 8.36, *p* = .01), accounting for 84.8% of the total variance when controlling for cognitive impairment. Both unmet needs (*B* = -.03, *p* = .04) and NDBs (*B* =-.72, *p* = .04), were unique and significant predictors of quality of life; however, values and preference were not (*B* = 1.12, *p* = .16). Results suggest that IWDs with fewer unmet needs and fewer NDBs are predicted to have a higher quality of life.

Table 5. Regression Analyses for Predicting General Well-Being Outcomes (N=10)

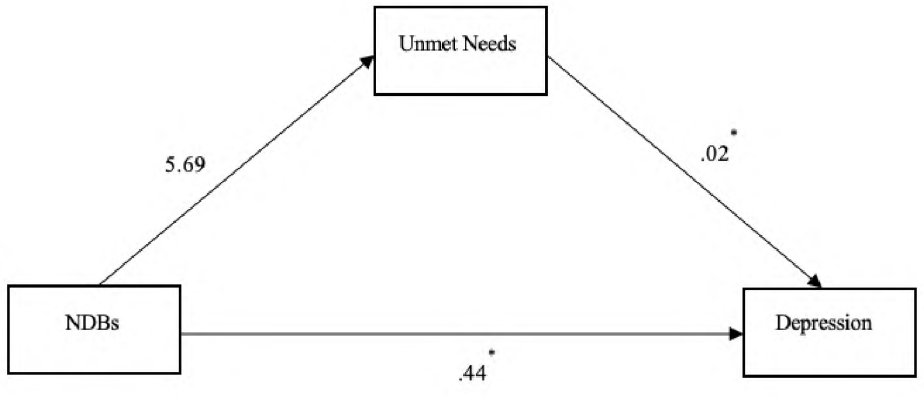
Psychosocial well-being outcomes	Depression		Quality of Life	
Independent variable	*B*	*β*	*B*	*β*
Unmet Needs	.02*	.51*	-.03*	-.53*
NDBs	.43	.62	-.72*	-.76*
Values and Preferences	.30	.16	1.12	.42

$^{*}p \le .05$, $^{**}p \le .01$.

Mediation Analysis

Utilizing the PROCESS macro in SPSS (namely Model 4; Hayes, 2019), a simple mediation analysis was conducted using an ordinal least square path analysis. Hypothesis 7 was not supported (*see Figure 3*), as NDBs did not indirectly influence depressive symptoms through its effect on unmet needs. NDBs were not significantly related to unmet needs (*a* = 5.69 , *p*=.28); however, unmet needs were positively related to depressive symptoms while controlling for NDBs (*b*= .02, *p*= .05). Even so, a bootstrapped confidence interval for the indirect effect of NDBs (*ab*) using 5,000 bootstrap samples was -0.17 to 0.72, indicating there was no evidence of a significant indirect effect of NDBs on depressive symptoms through unmet needs.

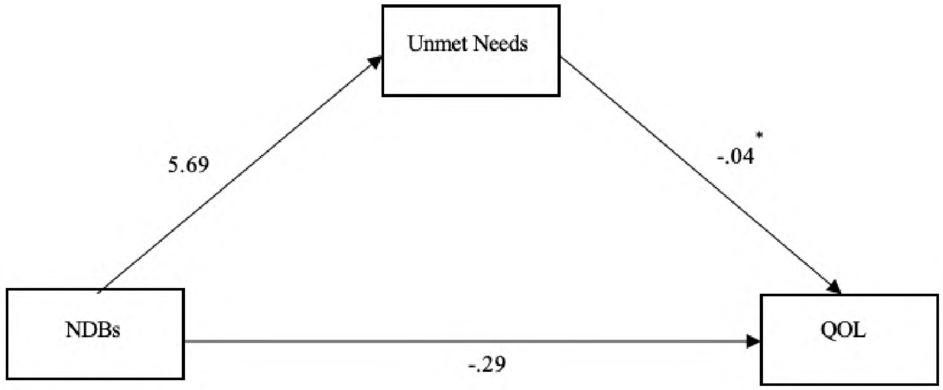
Figure 3. Model Coefficients for Depressive Symptoms Mediation Model



Note. Unstandardized regression coefficients for the relationship between NDBs and depressive symptoms as mediated by unmet needs.
* $p < .05$

A second mediation analysis (*see Figure 4)* was conducted on quality of life. Again, Hypothesis 7 was not supported: NDBs did not indirectly influence quality of life through its effect on unmet needs. Again, NDBs were not significantly related to unmet needs ($a = 5.69$, $p = .29$); however, unmet needs were negatively related to quality of life while controlling for NDBs ($b = -.04$., $p < .01$). According to a bootstrapped confidence interval for the indirect effect of NDBs (*ab*) using 5,000 bootstrap samples was -0.92 to 0.33, again indicating no evidence of a significant indirect effect of NDBs on quality of life through unmet needs.

Figure 4. Model Coefficients for Quality of Life Mediation Model



Note. Unstandardized regression coefficients for the relationship between NDBs and depressive symptoms as mediated by unmet needs.
* p <.05

Though the aforementioned mediation analyses utilized a bootstrapping technique, the investigators recognize and take into consideration the limitation of a low sample size and resultant low power when interpreting these results. No broad generalizations or conclusions concerning these analyses can be made.

CHAPTER IV

DISCUSSION

Previous research has suggested that the dementia process includes a decrease in the IWDs' ability to meet their own needs (Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015) as well as an increase in behavioral symptoms (Desai & Grossberg, 2001). More recently, the literature has begun discussing behavioral symptoms experienced by IWDs as expressions of unmet needs (i.e. NDBs), as such behaviors may be an attempt to express a goal or need (Algase et al., 1996; Cohen-Mansfield, 2001). This is a rather unique and novel perspective in viewing behaviors, as it places behaviors as not a central symptom of a dementing illness but rather the result of complex social, emotional, and physical needs that are not being met due to cognitive impairment. Despite the fact that there is considerable research on both the behaviors and unmet needs of IWDs, there is still a substantial theoretical gap within the current literature. Specifically, this gap includes assessing the constructs of unmet needs, NDBs, and their connections to one another, as well as outcomes of well-being through a PCC approach by understanding the perspectives of an IWD rather than a caregiver proxy-report. In fact, this research gap was identified in the 2020 NIA Research Summit on Dementia Care and called for future research to “develop and implement person-centered and broader conceptualizations of outcomes that are informed by the person living with dementia…” (Zimmerman & Stone, 2020).

Though some previous studies have identified behavioral symptoms as NDBs and are, therefore, an attempt to communicate a need (Norton, Allen, Snow, Hardin, & Burgio, 2010; Cohen-Mansfield, Marx, Dakheel-Ali, Reiger, Thein, & Freedman, 2010), no published study to date has examined behaviors or NDBs from the perspective of IWDs. Researchers are unaware if IWDs can in fact self-report their own behaviors and resulting distress. Similarly, unmet needs have been extensively studied within the dementia population; however, most of these studies have also utilized a proxy-report data collection method or include self-reported assessments but only alongside a proxy-report. For the latter, the researcher makes the final decision whether a need is met or unmet (Banerjee, Samsi, Petrie, Alvir, Treglia, Schwam, & Del Valle, 2009; Norton, Allen, Snow, Hardin, & Burgio, 2009; Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015; Clifford, & Doody, 2017; Hancock, Woods, Challis, & Orrell, 2006). Previous studies that have included self-reported unmet needs of IWDs reveal inconsistencies between the unmet needs identified by IWDs and unmet needs identified by proxy-reports (Orrell et al., 2008; Schölzel-Dorenbos, Meeuwsen, & Rikkert, 2010). Furthermore, there have been no published studies to date that have addressed a potential connection between unmet needs and NDBs from an IWD’s own perspective. This lack of self-report data for both constructs illustrates a limitation that should be addressed in order for researchers, caregivers, and clinicians to gain a better perspective on the illness experience of IWDs.

The current study intended to address this gap through providing an increased understanding of the illness experience by having individuals with mild to moderate dementia self-report their own unmet needs and NDBs in an attempt to explain a possible connection between unmet needs, NDBs, and outcomes of well-being. The SPM for IWDs (Judge, Menne, & Whitlatch, 2010) was used as the guiding theoretical model, as it was adapted and developed to understand the illness experience of living with dementia. This model includes an understanding of the stress process, specifically for IWDs. Objective primary stressors (cognitive status and frequency of behaviors) and subjective primary stressors (distress from behaviors or NDBs) were assessed in order to determine their potential direct impact on quality of life, as well as an indirect effect on depression (i.e. general well-being outcomes) when mediated by unmet needs and values and preferences (i.e. internal and external mediators).

The present study demonstrated several findings that are novel within the dementia literature. First, one of the major theoretical implications of this study includes the fact that individuals with mild to moderate dementia were able to self-report their own unmet needs, NDBs, distress, values and preferences, quality of life, depressive symptoms, and there was variability in responses. This is a valuable finding, as it challenges prior assumptions about IWDs' ability to provide insightful and meaningful information concerning their experience of living with dementia. Several previous studies have utilized self-report data collection methods for quality of life and depressive symptoms (Conde-Sala et al., 2016; Gitlin, Winter, Burke, Chernett, Dennis, & Hauck, 2008; Dewitte, Vandenbulcke & Dezutter, 2017; Dawson, Powers, Krestar, Yarry, & Judge, 2012; Moon, Townsend, Dilworth-Anderson & Whitlatch, 2016; Menne, Judge, &Whitlatch, 2010). While these studies have provided evidence that IWDs can reliably and accurately self-report outcomes of well-being, very few studies have had IWDs self-report their unmet needs and related distress (Orrell et. al., 2008; Hancock, Woods, Challis, & Orrell, 2006; Orrell, Hancock, Hoe, Woods, Livingson, & Challis, 2007). Additionally, no published studies to date have shown evidence that IWDs can self-report their behavioral frequencies and related distress.

Of considerable importance to theoretical development lies within the psychometric evidence of specific measures and methodologies that makes the inclusion of IWDs within the research process possible. For instance, though the current sample size was small, all of the study measures had high reliabilities. While measures such as the QoL-AD and CES-D have been shown to be reliable for populations of individuals with cognitive impairment in previous studies (Logsdon, Gibbons, McCurry, & Teri, 1999; Gitlin et al., 2008; Dewitte, Vandenbulcke & Dezutter, 2017; Moon, Townsend, Dilworth-Anderson & Whitlatch, 2016; Menne, Judge, & Whitlatch, 2010), the current study also provides psychometric evidence for the use of the Unmet Needs scale, which has previously been used for caregivers of IWDs, and this scale is only in its early stages of use for IWD self-reports (Bejjani et al., 2015; Bass et al., 2012; Bass et al., 2014; Menne et al., 2014). Furthermore, the BRIA Behavioral Difficulty and Distress scale has only been used as a caregiver proxy-report in previous research (Bass et al, 2012; Bass et al., 2013; Judge et al 2012). Interestingly, participants, no matter their cognitive impairment level, could use the full scale response options for these measure, except for one participant who had to use dichotomize response options for just one measure (BRIA Behavioral Difficulty and Distress). Additionally, the current sample were all IWDs living in an assisted living memory care facility, suggesting that the current sample potentially had more functional impairment and, therefore, only strengthens the rationale that IWDs, despite cognitive and functional impairment, are able to participant in the research process.

Key Findings of Unmet Needs and Related Distress

Examining the present study's findings in relation to frequency of unmet needs and distress, results showed that almost all of participants were experiencing some form of unmet need. The majority of unmet needs identified by IWDs fell within the 'Health Information' subscale, which addressed topics concerning education about memory loss, progression of the illness, understanding causes of memory loss, medications, and appointments with physicians. The highest reported unmet need among IWDs, by a little over half of the sample, was "getting information about your memory issues." Other unmet need subscales that had a higher frequency of reports fell within the "Emotional Support" subscale, including managing feelings of confusion, knowing what to do if the IWD felt uncomfortable accepting help, and feeling isolated from others. The most common unmet needs related to depressive symptoms were unmet needs within the 'Family Concerns' and 'Health Information' subscales. For quality of life, the most common unmet needs were within the 'Family Concerns,' 'Health Information,' and 'Emotional Support' subscales. This information provides context for the development of intervention protocols that could address outcomes of well-being, as future interventions need to provide a specific focus on needs within these three subscales.

Interestingly, the distress portion of the Unmet Needs scale did not always align with the frequency of reported unmet needs, such that an unmet need did not always lead to a report of related distress. However, most items that were reported as distressing had corresponding high frequencies of that need being unmet. For instance, as previously mentioned, four of the top five reported unmet needs fell within the 'Health Information' subscale. Despite this, IWDs reported hardly any distress concerning these unmet needs. Whereas other unmet needs within 'Emotional Support,' 'Arranging Services,' and 'Living Arrangements' subscales showed more equal reports of higher frequencies and higher levels of related distress.

The distress portion of the Unmet Needs measure provides new insight into dementia research concerning those areas of life that IWDs experience feelings of distress, whether or not they are also experiencing an unmet need. This is interesting to consider from an intervention perspective, as previous research has developed protocols to address IWDs' unmet needs when identified by a proxy-report. With continued data collection on both the self-reported frequency and distress of unmet needs, researchers have the ability to design new intervention protocols that potentially address not only IWDs' unmet needs but also address needs, met or unmet, that cause IWDs distress. This form of intervention could be displayed in various ways. Take for instance this present study's finding concerning the high frequency of IWDs reporting unmet needs regarding health information. During the early stages of a dementia diagnosis, a participant was most likely informed of the causes, tests, and progression of dementia. Despite this, IWDs do not feel this is a need met. Therefore, interventions designed to increase education early on in the diagnostic process, as well as continued education for IWDs concerning their illness and the associated changes as the disease progresses, could help IWDs feel as though these health concerns are no longer an unmet need. Additionally, the distress from unmet needs could be a comparable intervention protocol; however, instead of focusing on needs that are unmet, researchers should focus on the needs/topics that are most distressing to IWDs. This likely would have an influence on IWDs quality of life and depressive symptoms. Altogether, this study is only the first step for additional research that could inform both theoretical avenues, as well as intervention work, in order to address self-reported unmet needs and distress among IWDs.

The unmet needs findings from the present study align in some ways with previous research by Hancock, Woods, Challis, and Orrell (2006) who found that memory (i.e. content within the Health Information subscale) and communication problems (i.e. content within the Family Concerns subscale) were most commonly related to depression. However, this study did not find that other unmet needs related to daytime activities and company were related to depressive symptoms (Hancock, Woods, Challis, & Orrell, 2006). Furthermore, Orrell and colleagues (2008) stated that IWDs' unmet needs were associated with psychological problems, including anxiety, depression, and distress. This is also consistent with the present study's findings, as both the total score of unmet needs (as well as the previously mentioned unmet needs subscales) were related to depressive symptoms and quality of life. Additionally, more reported unmet needs was related to more distress from those unmet needs.

It is vital to note that the current study aligns with a growing body of research that suggests a proxy-report does not always coordinate with a self-report. Specifically, previous research demonstrates that caregivers typically report unmet needs related to mobility and incontinence as most significant/frequent for their loved one (Orrell et al., 2008). The present study included these unmet needs within the 'Daily Living Tasks' subscale and found that these needs were reported as adequately met and non-distressing by a vast majority of the sample. Findings such as these not only expand the current theoretical literature on the illness experience but subsequently provide information for the development of new interventions that can be refined and implemented to address the unmet needs which are self-identified as important by IWDs.

Key Findings of Need-Driven Behaviors

This study contributed unique and innovative findings in relation to IWDs' self-reported behaviors, these results help provide new insight into the perspective and experiences of IWDs. Of importance with relation to the findings on behaviors, IWDs were able to recognize and self-report various behaviors that they identified in themselves, as well as express the associating distress or lack thereof. Though the topic of behaviors could be sensitive for individuals to identify and report (i.e. yelling or swearing at others, forgetting family members names, offering unwanted advice), participants in the current study reported their behaviors and did not object or become upset when asked these questions. While this may seem a minor discovery, details such as these bolster the evidence and rationale that IWDs can be included within the research process despite cognitive impairment.

Since there is no previous research to compare concerning self-report data on behaviors, the caregiver proxy-report literature has suggested that behavioral excesses, or the addition of a behavior as the problem (i.e. agitation, wandering, repeating the same questions), are more distressing to formal and informal caregivers (Banerjee, Samsi, Petrie, Alvir, Treglia, Schwam, & Del Valle, 2009). IWDs within the present study reported similar results to caregiver proxy-reports, as behavioral excesses such as "acting restless or agitated" and "interfering/offering unwanted advice" and were rated as distressing to those IWDs who self-identified these behaviors. On the other hand, IWDs also reported a consistent number of behavioral deficits, or the non-occurrence of a behavior as a problem, as distressing as well. Behaviors such as "forgetting the right word to use" or "forgetting the name of your family or close friends" are behavioral deficits that were also rated as distressing by those IWDs who identified experiencing these behaviors. Understanding these details ultimately provides a level of justification for developing intervention protocols with an adjustment to the underlying mechanisms targeted. Rather than focusing on decreasing the level of behaviors IWDs exhibit, and the related distress these behaviors incite on caregivers, new protocols could address the behaviors that are also distressing for IWDs, as it has been found in this study that distressing behaviors (i.e. NDBs) are related to IWDs' depressive symptoms. When an intervention takes both perspectives and aspects of distress into consideration, researchers may not only be able to improve IWDs' and caregivers' outcomes of well-being but also provide caregivers with the knowledge of how their loved one is experiencing their illness and create an understanding between care partners.

While previous research has reported connections between unmet needs and NDBs (Hancock, Woods, Challis, & Orrell, 2006), as well as NDBs and quality of life (Orrell et al., 2008), the current study did not find any relationship between unmet needs and NDBs. This lack of connection could be due to the current study's low sample size; therefore, more data collection is imperative to determine this possible connection.

However, another possible explanation concerns the current measures utilized for NDBs and unmet needs constructs. The measure used may not be capturing the true conceptualization of NDBs and unmet needs, as current measures have been developed with a clinical lens with the goal of decreasing symptoms. However, unmet needs and NDBs have been theorized with a PCC approach so as to evoke an understanding of the underlying meaning behind behaviors rather than simply discussing behaviors as symptoms. Therefore, a misalignment in theoretical conceptualization and current measurement techniques becomes apparent, highlighting the need for more research to develop and psychometrically test appropriate measures.

Theoretical Support for the SPM for IWDs

Though the current study did not find any relationships between self-reported unmet needs and NDBs, both unmet needs and NDBs were related to outcomes of well-being. Specifically, more unmet needs were related to more depressive symptoms and lower quality of life, and NDBs were suggested to be related to depressive symptoms. When looking at the frequency portion of the BRIA Behavioral Difficulty and Distress Scale, behavioral frequency was related to both depressive symptoms and quality of life. These relationships between unmet needs, NDBs, behavioral frequency, and outcomes of well-being theoretically supports and aligns with the SPM for IWDs (Judge, Menne, & Whitlatch, 2010). To clarify, NDBs (i.e. primary subjective stressors) were directly related to depressive symptoms (i.e. outcomes of well-being), and behavioral frequency (i.e. primary objective stressors) was also related to both depressive symptoms and quality of life. While the mediation models within this study did not demonstrate an indirect relationship between NDBs and these outcomes of well-being through unmet needs, unmet needs were related to both depressive symptoms and quality of life. It could be that unmet needs simply do not mediate the relationship between NDBs and outcomes of well-being, as previously suggested by the caregiving literature (Park et al., 2018) or the current study's low sample size. Additionally, the measures used to conceptualize the constructs of unmet needs and NDBs need to be addressed in future research. As more data is collected to provide the current study a larger sample size and increased power, other theoretical connections within the SPM for IWDs for the placement of unmet needs may need to be considered.

As previously discussed, due to limitations with data collection and the low sample size that the current study faced, the investigators acknowledge that some of the results, while statistically significant, do not have meaningful significance and do not meet necessary statistical assumptions. With this in mind, the regression analyses suggested that IWDs with more unmet needs and NDBs have more symptoms of depression. IWDs who self-report a greater importance on care values and preferences may have more symptoms of depression. Finally, IWDs with fewer unmet needs and fewer NDBs may have higher quality of life. These trends suggest support for the SPM for IWDs illustrating a connection between subjective primary stressors and potential mediators (both internal and external) when predicting outcomes of well-being; these need to be further addressed in future research.

The trends that were evident within the current study align with previous research conducted by Dawson, Powers, Krestar, Yarry, and Judge (2014) who also utilized the SPM for IWDs found that IWDs with more embarrassment about memory problems (i.e. secondary roles and intrapsychic strains) had more symptoms of anxiety; IWDs with higher feelings of physical health strain (i.e. secondary roles and intrapsychic strains) and higher perceptions of role captivity (i.e. subjective stressors) and more depressive symptoms; and IWDs who perceived less difficulty with IADLs (i.e. primary objective stressors) and higher levels of inner strength and personal growth (i.e. secondary roles and intrapsychic strains) had higher levels of quality of life. However, these investigators did not find any relationships between caregiver proxy-reported behaviors and outcomes of well-being (Dawson, Powers, Krestar, Yarry, & Judge, 2014). Seeing as the current study was able to find a relationship between NDBs and outcomes of well-being by utilizing the SPM for IWDs, there is a need to collect more data in order to test the predictive powers of behaviors on outcomes of well-being when behaviors are self-reported.

Though the construct of care values and preferences (i.e. those aspects of everyday life that an individual considers important) were found to be related to NDBs, these were not related to unmet needs or any outcomes of well-being. Furthermore, values and preferences were only a significant predictor when included within the model containing both unmet needs and NDBs for predicting depressive symptoms. Previous literature has demonstrated that discussions about daily preferences contributes to increased quality of life for IWDs by providing the opportunity for autonomy and decision-making preferences (Menne & Whitlatch, 2007). Though no connections between care values and preferences and outcomes of well-being or unmet needs were demonstrated in the current sample, this could be due to the small sample size. However, another possible explanation could be related to the context in which this measure was first designed.

The Values and Preferences Scale was first developed as a means to increase researchers', clinicians', and caregivers' understanding of the decision-making process of older adults regarding their own health, as well as the level of involvement older adults had in decision-making about end-of-life care while acknowledging how these preferences of care may change over time (Whitlatch, Piiparinen, & Feinberg, 2009). Specifically, this measure was created for IWDs living within the community, and these individuals were typically in the very mild stages of dementia. These characteristics are very different from the current study's sample, and the values and preferences listed may not pertain to IWDs residing in assisted living who are experiencing more progressive stages of the illness. Furthermore, the Values and Preferences scale appeared to suffer from ceiling effects within the current sample, as many of the IWDs identified all items and topics within the measure as "very important" to them, with very little variability across the measure.

This suggests that future research utilizing this measure may need to reassess the items and subscales in order to tap into the care values that are relevant for various dementia populations. While previous research has identified care values and preferences as a central tenets of a PCC approach, there still remains a significant gap in the literature as to how these values and preferences change over time and across contexts (Van Haitsma et al., 2014). Future research could benefit by altering the measure in order to develop more appropriate items that are designed for the specific context of an assisted living facility, as well as potential intervention protocols that address IWDs' distress levels. For example, a preference can be described as the appeal of an option that serves to fulfill an individual's needs and is determined by the level of value an individual places on said need (Van Haitsma et al., 2019). These preferences, based on needs, can transform over time depending on varying circumstances. With this in mind, it could be suggested that the development of new values and preferences items should closely resemble possible needs of IWDs and are sensitive to the heterogeneity of IWDs. This includes values and preferences for IWDs living in the community (i.e. how important is it for you to stay in your own home?) vs. long-term care facilities (i.e. how important is it for you to have someone to talk to when you feel uncomfortable accepting help?) or IWDs in early stages (i.e. how important is it for understand the cause of memory problems?) vs. later stages (i.e. how important is it for you to have meaningful visits with loved ones?). Refining the items and ideals within the Values and Preferences scale could help future research formulate and test the mechanism(s) through which values and preferences affect psychological outcomes.

Limitations and Future Directions

There are limitations within the current study that need to be addressed and taken into consideration. One of the major limitations discussed throughout is the low sample size. Due to unforeseeable circumstances, an appropriate sample size was not obtained, as the current study's data collection site had to shut down visitation during the global COVID-19 pandemic for the safety of its residents and staff. With this low sample size came subsequent low power and lack of meaningful significance, which limited the implications and interpretability of the current studies results. Therefore, future research needs to continue to collect data, which will not only help improve theoretical support for the SPM for IWDs and the connections between IWDs self-reported unmet needs, behaviors, distress and outcomes of well-being, but will also allow the investigators to conduct predictive models that could potentially show meaningful significance. Additionally, this will continue to validate psychometrics of the study's measures and help aid the development of psychometrically sound measures designed for populations of cognitively impaired individuals.

Another limitation of this study is the design of the BRIA Behavioral Difficulty and Distress. While this was the best measure within the current literature to use for the construct of NDBs, the design of this measure includes asking the IWD to first state the frequency of a given behavior in the past week. If the IWD identified exhibiting said behavior, the investigator then asked the IWD how much distress he/she had from exhibiting that behavior. However, if the IWD stated they had not exhibited a behavior, the investigator does not then ask the subsequent distress portion of the scale. This limitation of the measure is challenging for studies with small sample sizes and conceptually warrants further examination. Overall, there is a lack of research examining how IWDs perceive their own behaviors, the resulting distress they identify and the necessary mechanics to help IWDs cope with and manage their behaviors (Minyo & Judge, 2020). As such, future research is needed to develop a more nuanced measure of behavioral distress and how this is related to the actual experience of different behaviors. Following these same lines, another limitation with the current study which ultimately demonstrates a significant gap within current research, concerns the lack of specific methodologies that accurately measure the constructs of unmet needs and NDBs.

Within the literature, the measures that have been utilized for the construct of unmet needs consist of clinical assessment tools conducted either by a trained clinician or researcher that take into consideration a caregiver proxy-report and IWD self-report.

Typically, the clinician or researcher makes a final determination of a met or unmet need. Measures such as the Camberwell Assessment of Need for the Elderly (CANE; Reynolds et al., 2000), Care Needs Assessment Pack for Dementia (CARENAPD; McWalter, Toner, McWalter, Eastwood, & Marshall, 1998), Johns Hopkins Dementia Care Needs Assessment (Black et al., 2008), and the Type of Unmet Needs Assessment (TUNA; Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Reiger, 2015) all concern topics of living accommodations, access to adequate food, and incontinence and mobility, with only minor assessments of daily activities and psychological distress. While these are important aspects of life, it does not provide detail into the specifics of an IWD's unmet needs and does not tap into the illness experience. In particular, unmet needs are conceptualized as "needs important to the IWD that are not currently being met" such as inadequate daytime activities, lack of company, failing memory, lack of information, and psychological distress. This conceptualization does not align with current measurements within the literature. Additionally, how do we know that these items within the measures are what "IWDs deem important"? Taking into consideration the lack of early qualitative research on unmet needs by IWDs, and the fact that a caregiver proxy-report or a clinician are determining the topics and making the final decision of met or unmet needs, these current measures do not appropriately align with theory.

Furthermore, needs can vary depending on an individual's background and care context, leading to various trajectories and aspects of unmet needs depending on an IWD's living situation, stage of dementia, care partner, health history, race and ethnicity, gender, and more. Therefore, needs assessments should take these individual differences into consideration and provide measurement scales that are specific to certain contexts, allowing for the heterogeneity of unmet needs to be fully understood from each person's perspective. It may be, like other areas of research, that there are common overall themes concerning unmet needs and distress such as the connection with general outcomes of well-being. However, there also could be individual differences that need to be analyzed in order for an intervention to be tailored, incorporating the appropriate aspects of life that are unmet or are distressing for an IWD in order to have an overall effective intervention.

Similarly, the construct of NDBs has been assessed through clinical assessment measures, either researcher-observation based or a caregiver proxy-report, as to the frequency of behaviors that IWDs exhibit. Measures, including the Neuropsychiatric Inventory (NPI; Cummings, Mega, Gray, Rosenberg-Thompson, Carusi, & Gornbein, 1994), Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, 1996), and the Revised Memory and Behavior Problem Checklist (RMBPC; Teri, Truaz, Logsdon, Uomoto, Zarit, & Vitaliano, 1992), have been used to assess behaviors of IWDs while also being extended to assess NDBs. However, NDBs are a strictly theoretical construct at this point as a specific measure of NDBs has not yet been developed. Having a researcher observe behavior or caregiver proxy-report behavioral frequency does not measure a construct conceptualized as "those dementia-related behaviors that occur due to the inability of the caregiver to comprehend needs and the inability for the IWD to make his or her needs known" (Algase et al., 1996; Kovach, Noonan, Schlidt, & Wells, 2005). Therefore, there is a misalignment at the construct level as to how these two constructs are theoretically related and adequately captured with current measures. This, in part, is due to a lack of early research detailing a theoretical understanding for how

IWDs perceive their own behaviors, the resulting distress they identify, and the necessary mechanics to help IWDs cope with and manage their behaviors (Minyo & Judge, 2020).

This measurement and theoretical limitation sheds light on another major gap in dementia research that requires future research. While there is a rationale and evidence for the reliable and consistent self-reports from IWDs through both qualitative and quantitative studies (Powers, Dawson, Krestar, Yarry, & Judge, 2014; Harmen & Clare, 2006; Clare, Rowlands, Bruce, Surr, & Downs, 2008; Clark, Tucke, & Whitlatch, 2008; Feinberg & Whitlatch, 2001), there are still no clear guidelines for determining a priori the IWDs who will be able to self-report and who will not. Historically, research has largely utilized clinical cognitive status examinations to evaluate an IWD's level of cognitive impairment in order to determine inclusion and exclusion criteria for who is eligible to participate. These cognitive status examinations, such as the Mini Mental State Examination (Folstein, Folestein, & McHugh, 1975), Clinical Dementia Rating Scale (Morris, 1993), and The Global Deterioration Scale (Reisberg, Ferris, de Leon, & Crook, 1982) evaluate cognitive domains including short-term memory, attention, orientation, language, and the ability to understand and follow commands. While these cognitive status measures were designed to determine levels of cognitive impairment, the measures were not designed to determine whether IWDs can participate in research studies and/or whether IWDs can provide self-report information about their subjective illness experience. While a majority of mild to moderate IWDs can self-report, not all do, and there are some IWDs within the severe stages that are able to self-report but often are excluded because they fail clinical cognitive screening tools. These tools were designed to assess the subtle and mild changes associated with dementia and, thus assess key cognitive processes that are negatively impacted early on in the illness. However, remaining cognitive processes that are spared well into the progression of the illness and support the ability to self-report one's subjective illness experience are not assessed. As such, many researchers are calling for the "… development of standards for determining which individuals can self-report about which outcomes, at which stages of dementia…" (Gitlin, Maslow, & Khillan, 2018). Future research should focus on the development of measures that specifically assess cognitive processes related to participating in research and in self-reporting one's subjective illness experience. For example, a measure that assesses whether an individual understands different feelings and emotions would be more appropriate than whether an individual can correctly perform a short-term memory task.

The current study is just a first step in uncovering new information about the illness experience that includes "the development of research measures that are important for studying dementia care, services, and support… include measures of the livid experience of dementia for persons with the condition…" and "identify determinants of behavioral and psychological symptoms, ascertain how persons living with dementia experience these symptoms… conduct quantitative and qualitative studies to ascertain how persons living with dementia experience and cope with different behavioral symptoms…" (Gitlin, Maslow, & Khillan, 2018) both of which were considered future research recommendations at the 2017 and 2020 NIA Research Summits for Dementia Care. Taking the results of the current study along with these recommendations, qualitative and quantitative pilot studies on both unmet needs and NBDs are a necessary next step. Specifically, the following are vital research areas for further understanding the illness experience of IWDs: 1) developing appropriate measures that align with theory; 2) understanding what unmet needs IWDs identify; 3) what unmet needs and behaviors are distressing for IWDs; and 4) how IWDs might anticipate these unmet needs and behaviors changing over time. Information gleaned from these types of studies would be instrumental for developing, implementing, and testing efficacious interventions for IWDs that directly target and address key aspects of their illness experience such as feelings of embarrassment about their illness, feelings of role captivity, and symptoms of anxiety and depression.

Future research is needed to further understand the illness experience of living with dementia. Specifically, key areas that warrant investigation include: 1) developing appropriate measure of the illness experience (i.e., unmet needs, NDB, and behavioral distress); 2) incorporating key individual differences in understanding the impact of one's background and care context; 3) recruitment and retention of larger samples of IWDs from diverse settings (i.e., community living, assisted living, nursing home); and 4) development of an appropriate tool for determining whether IWDs can participate in research and/or provide self-report data about their subjective illness experience. These next steps will be essential in furthering our theoretical understanding of living with dementia along with developing nuanced intervention protocols that directly address the illness experience and increase the well-being of those living with dementia. Finally, as further research is conducted from IWDs' perspectives, the more researchers, clinicians, and caregivers will be able to understand how subjective and objective, biological and psychosocial constructs, self-report and proxy-report, all play a role within the multidimensional experience of living with dementia.

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Appendix

Frequencies of Unmet Needs and Unmet Needs Distress

Item	Sub-Scale	*n* (%) unmet	*n* (%)distress
a. getting family to help	FC	1 (8.3%)	3 (25.0%)
b. how to discuss memory with family	FC	2 (16.7%)	3 (25.0%)
c. who could provide your care	FC	1 (8.3%)	1 (8.3%)
d. who you prefer to provide care	FC	2 (16.7%)	1 (8.3%)
e. future course of illness	FC	3 (25.0%)	2 (16.7%)
f. getting family to cooperate	FC	2 (16.7%)	1 (8.3%)
g. dealing with family disagreements	FC	2 (16.7%)	2 (16.7%)
h. getting family to accept memory	FC	4 (33.3%)	2 (16.7%)
i. getting treatment	HI	2 (16.7%)	1 (8.3%)
j. prevent memory from worsening	HI	5 (41.7%)	1 (8.3%)
k. things to do to stay healthy	HI	2 (16.7%)	0 (0.0%)
l. tests for diagnosing memory	HI	5 (41.7%)	1 (8.3%)
m. getting information about memory	HI	7 (58.3%)	2 (16.7%)
n. understanding the causes of memory	HI	2 (16.7%)	2 (16.7%)
o. dealing with other health conditions	HI	2 (16.7%)	2 (16.7%)
p. making plans for future changes	HI	4 (33.3%)	1 (8.3%)
q. taking medications	HI	2 (16.7%)	2 (16.7%)
r. how medication help	HI	3 (25.0%)	1 (8.3%)
s. side effects of medications	HI	2 (16.7%)	3 (25.0%)
t. knowing future course of memory	HI	5 (41.7%)	1 (8.3%)
u. keep written notes	HI	3 (25.0%)	2 (16.7%)
v. scheduling follow-up visits	HI	1 (8.3%)	4 (33.3%)
w. managing daily tasks	DL	2 (16.7%)	1 (8.3%)
x. managing personal care	DL	2 (16.7%)	1 (8.3%)
y. making the place you live safe	DL	2 (16.7%)	2 (16.7%)
z. letting other know what you want	LF	2 (16.7%)	0 (0.0%)
aa. living will, advanced directive	LF	3 (25.0%)	0 (0.0%)
bb. help for legal issues	LF	3 (25.0%)	1 (8.3%)
cc. paying for services not covered by insurance	LF	2 (16.7%)	2 (16.7%)
dd. someone to talk to who understands	ES	1 (8.3%)	2 (16.7%)
ee. getting emotional support	ES	4 (33.3%)	3 (25.0%)
ff. managing feelings of confusion and upset	ES	3 (25.0%)	4 (33.3%)
gg. if you feel uncomfortable accepting help	ES	3 (25.0%)	2 (16.7%)
hh. feeling isolated from others	ES	3 (25.0%)	3 (25.0%)
ii. staying happy with your social life	ES	2 (16.7%)	2 (16.7%)
jj. knowing service providers	AS	3 (33.3%)	4 (33.3%)
kk. service providers working together	AS	5 (41.7%)	4 (33.3%)
ll. findings services	AS	2 (16.7%)	2 (16.7%)
mm. comfortable with living situation	LA	1 (8.3%)	2 (16.7%)
nn. activities, games, and hobbies	LA	2 (16.7%)	2 (16.7%)
oo. involved in activities	LA	1 (8.3%)	2 (16.7%)
pp. doings things you enjoy	LA	4 (33.3%)	4 (33.3%)
qq. staying independent	LA	2 (16.7%)	3 (25.0%)

Note: subscale abbreviations FC = Family Concerns; HI= Health Information; DL = Daily Living Tasks; LF= Legal/ Financial Services; ES = Emotional Support; AS = Arranging Services; LA = Living Arrangements/ Activities