# ENHANCING HEALTH AND QUALITY OF LIFE FOR PERSONS WITH DEMENTIA AND THEIR CAREGIVERS THROUGH A BIOPSYCHOSOCIAL APPROACH TO MEALTIME MANAGEMENT

by

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### A DISSERTATION

Presented to the Department of Special Education and Clinical Sciences and the Division of Graduate Studies of the University of Oregon in partial fulfillment of the requirements for the degree of Doctor of Philosophy

September 2023

### DISSERTATION APPROVAL PAGE

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Title: Enhancing Health and Quality of Life for Persons with Dementia and Their Caregivers Through a Biopsychosocial Approach to Mealtime Management

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Degree awarded: September 2023

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#### DISSERTATION ABSTRACT

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Doctor of Philosophy

Department of Special Education and Clinical Sciences

September 2023

Title: Enhancing Health and Quality of Life for Persons with Dementia and Their Caregivers Through a Biopsychosocial Approach to Mealtime Management

Dementia is a progressive neurodegenerative disease characterized by sensorimotor, psychosocial, and physiological deficits. As a result of this neurological damage, persons with dementia (PWD) often experience difficulty with memory, attention, cognition, sensation, and motor functioning (Gordon et al., 2018; Heßmann et al., 2016; Jack et al., 2009). As neurological damage progresses, PWD require greater reliance on caregivers for completion of activities of daily living (ADLs) like showering, clothing, and eating (Isik et al., 2019; Petersen et al., 2018).

One major contributor to the deaths associated with dementia progression is the development of swallowing disorders (dysphagia), with nearly all PWD developing some form of eating or swallowing impairment (Affoo et al., 2013; Ranier Wirth et al., 2017). Associated with these mealtime deficits, individuals with cognitive impairment are at increased risk for malnutrition, dehydration, and the development of pneumonia (Namasivayam & Steele, 2015; Rainer Wirth et al., 2016).

The following study utilized a person-centered, holistic model of patient care to identify areas for caregivers to support PWD during mealtimes. Person-centered care, as opposed to disease-centered care, shifts the perspective away from disease management to treat the PWD as a whole person. A person-centered, holistic model of mealtime management addresses the cognitive, social, psychological, and physiological domains that effect mealtime performance. Utilizing a person-centered model of patient care for mealtime management leads to improved patient outcomes, increased quality of life, and increased satisfaction with care (Bangerter et al., 2017; Cartwright et al., 2022; Gallant, 2019; Han et al., 2016; Reimer & Keller, 2009). The following study utilized the Biopsychosocial Model of Mealtime Management in Persons with Dementia (Bayne & Shune, 2022), as a framework to create individualized caregiver training sessions that address the multifactorial issues leading to deficits in mealtime performance for PWD. Individualized caregiver training was provided with the goal of increasing mealtime performance in PWD, decreasing caregiver burden, and optimizing the dyadic relationship of caregiver/care recipient surrounding mealtime management.

Participants with dementia in this study demonstrated increased intake, better quality of life, and mealtime related impairment and their caregivers demonstrated increase quality of life, increased confidence, and decreased difficulty with provision of mealtime assistance. The findings of this study provide further support for multicomponent intervention to best support mealtimes for persons with dementia and their caregivers.

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- Bayne, D. F., Barewal, R., & Shune, S. E. (2020). Sensory-Enhanced, Fortified Snacks for Improved Nutritional Intake Among Nursing Home Residents. *Journal of Nutrition and Geriatrics*, 41(1), 92-101.
- Burdick, R., Bayne, D. F., Shune, S. E., Hitchcock, M., Gilmore-Bykovskyi, A., & Rogus-Pulia, N., (submitted). The Impact of Preoral Factors on Swallowing and Nutritional Outcomes: A Scoping Review. *Journal of Speech, Language, and Hearing Research*

#### ACKNOWLEDGMENTS

I wish to express my sincere appreciation to my advisor, Dr. Samantha E. Shune, whose wisdom, leadership, and passionate investigation into elements of mealtime support have guided me throughout my doctoral studies. Additionally, I would like to thank all past and present members of the Optimizing Swallowing and Eating for the Elderly (O-SEE) Lab. Members of the O-SEE lab were crucial for brainstorming ideas and overcoming roadblocks in many of my research related activities at the University of Oregon. I was particularly lucky to have the assistance of Jenn Jones as a research assistant. Jenn's passion for dementia related research proved crucial to the completion of this dissertation study. I would also like to thank my committee members, Drs. Khurana, McIntosh, and Seeley for their indispensable counsel and guidance throughout the course of this study.

I would also like to thank my fellow doctoral students, Dr. Aaron Rothbart, Dr. Ting-Fen Lin, and doctoral candidate Bedoor Nagshabandi for taking me under their collective wing and supporting me throughout the completion of this degree. I so appreciated the opportunity to work closely with members of the Clinic for Adult Acquired Language and Motor Speech disorders, Elise Peltier, Amanda Montoya, Amanda Thompson, Sierra Corbin, and Jess Baltrán Robinson. Additionally, I am incredibly grateful to the research participants who made this project possible and gave this work meaning.

A special thanks goes to Jen Meyer, Jayme Sloan, Kate Mierzwa, Dr. James & Angela Sadighian, Dr. Bryce LeFoya, and Julia Ngo who made Oregon feel like home.

Lastly, I would like to thank my fiancé, Dr. Michael Lynch, Pierogi, and our family for bringing love and light into my life.

This dissertation is dedicated to my gramma, Joyce Elaine Bayne, who taught me that memories are our most precious possessions.

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#### **Chapter I: Introduction**

Dementia is a progressive neurodegenerative disease characterized by sensorimotor, psychosocial, and physiological deficits. As a result of this neurological damage, persons with dementia (PWD) often experience difficulty with memory, attention, cognition, sensation, and motor functioning (Gordon et al., 2018; Heßmann et al., 2016; Jack et al., 2009). Over time, more neurons will become damaged representing larger and more diffuse portions of the brain. As this diffuse continues to progress, PWD will experience increased difficulty with more and more activities; eventually PWD may rely more on caregivers for completion of activities of daily living (Isik et al., 2019; Petersen et al., 2018). As the disease progresses, the portions of the brain that are responsible for basic physiological functioning, like swallowing and breathing, become impacted (Ganguli et al., 2005; Petersen et al., 2018). Ultimately, dementia is a fatal disease; in 2019 it was listed as the fifth leading cause of death in the United States (Centers for Disease Control and Prevention, 2020; Ganguli et al., 2005).

One major contributor to the deaths associated with dementia progression is the development of swallowing disorders (dysphagia), with nearly all PWD developing some form of eating or swallowing impairment (Affoo et al., 2013; Ranier Wirth et al., 2017). Associated with these mealtime deficits, individuals with cognitive impairment are at increased risk for malnutrition, dehydration, and the development of pneumonia (Namasivayam & Steele, 2015; Rainer Wirth et al., 2016). In addition to increased risk of the above state physiological consequences of dementia progression, PWD are at increased risk for social isolation, institutionalization, and, ultimately, mortality (Clavé & Shaker, 2015; Espinosa-Val et al., 2020; Sørensen et al., 2008; Vemuri et al., 2017).

Approximately 83% of assistance provided to PWD comes from informal caregivers (e.g., unpaid family members, friends) who provide assistance with completion of ADLs (Friedman et al., 2015; Spillman et al., 2014). Unfortunately, this high level of reliance on informal caregivers for assistance with activities like mealtime performance places the caregiver at increased risk for caregiver burden (Namasivayam-MacDonald & Shune, 2018, 2020; Nund et al., 2014; Patterson et al., 2012). High levels of caregiver burden are associated with negative outcomes for both the caregiver and the care recipient. Caregivers who are experiencing high levels of caregiver burden are at increased risk of depression, anxiety, immune disfunction, and mortality (Liu et al., 2015; Nichols et al., 2022; Schulz et al., 1995). Caregiver burden negatively affects the care recipient as well, with recipients experiencing decreased quality of life, increased risk of institutionalization, and decreased physical and psychological health (Amjad et al., 2021; Bilotta et al., 2010; Stall et al., 2019). Feeling inadequately prepared to provide mealtime assistance often increases levels of caregiver burden, which is often due to lack of adequate education surrounding care related activities (Funk et al., 2010; Schumacher et al., 2007; Stajduhar et al., 2010). Due to the complex and changing deficits surrounding mealtimes in individuals with neurodegenerative diseases (e.g., dementia), and the negative consequences associated with mealtime deficits, there is a great need to address caregiver education surrounding mealtime management (Shinagawa et al., 2009).

The purpose of the current study was to utilize a person-centered, holistic model of patient care to identify areas where caregivers can support PWD in order to lead to improved mealtime performance. Person-centered care, as opposed to disease-centered care, shifts the perspective away from disease management to treat the PWD as a whole person. A personcentered, holistic model of mealtime management addresses the cognitive, social, psychological,

and physiological domains that effect mealtime performance. Utilizing a person-centered model of patient care for mealtime management leads to improved patient outcomes, increased quality of life, and increased satisfaction with care (Bangerter et al., 2017; Cartwright et al., 2022; Gallant, 2019; Han et al., 2016; Reimer & Keller, 2009). The study utilized the Biopsychosocial Model of Mealtime Management in Persons with Dementia (Bayne & Shune, 2022) as a framework to create individualized caregiver training sessions that address the multifactorial issues leading to deficits in mealtime performance for PWD. Individualized caregiver training was provided with the goal of increasing mealtime performance in PWD, decreasing caregiver burden, and optimizing the dyadic relationship of caregiver/care recipient surrounding mealtime management.

Chapter II provides a review of the current literature surrounding dementia, dysphagia, and dementia-related dysphagia concerns. Following the review of dementia and dysphagia, the chapter provides a historical perspective of models of patient care, particularly as relevant to the mealtime process. These models of patient care were amalgamated to create the Biopsychosocial Model of Mealtime Management in Persons with Dementia. Chapter II continues with a review of this person-centered holistic model of patient care and potential interventions that was used to inform individualized caregiver education sessions. The chapter closes with a statement of purpose and presentation of research questions that were addressed in the proposed study. Chapter III presents a description of the research methods, procedures, and proposed method of analysis for the proposed study. This methods section describes the proposed participants that were recruited for the study, followed by a description of the experimental design and intervention. Chapter III closes by describing the outcome measures, procedures, and analyses to

answer the research questions. Chapter IV presents study results, and Chapter V presents a discussion of the results along with study limitations and directions for future investigation.

#### **Chapter II: Review of Literature**

The following literature review consists of several sections. The first two sections present information about Alzheimer's disease and associated dementias along with the characteristics of this cluster of diseases, including those that may contribute to difficulty with mealtime participation. The third section describes three theoretical models that can be used to inform mealtime management in this population. The fourth section describes a Biopsychosocial Model of Mealtime Management (Bayne & Shune, 2022) that builds on the presented theoretical models and that was used to guide the caregiver education intervention in the current study. The fifth section describes potential areas for intervention that informed the individualized caregiver education. The final section provides the statement of purpose and research questions for the current study.

### **Alzheimer's Disease and Associated Dementias**

#### **Current Scope of Dementia**

Increasing age is the single largest contributing factor to the development of Alzheimer's disease and related dementias (Alzheimer's Association, 2022). In 2019, 16% of the American population was 65 years or older, representing more than 1:7 Americans (Administration of Community Living, 2020). By the year 2040, the number of individuals in America over the age of 85 is expected to increase from 6.6 million to 14.4 million, a 118% increase. An increasingly aging population generally reflects positive developments in healthcare leading to increased life-expectancy; however, this is accompanied by inevitable increases in biological and neurological decline seen in aging bodies. The natural degenerative aging process is the largest contributing factor to the development of non-communicable diseases (Jin et al., 2015). Currently in the United States, one in nine people over the age of 65 are living with dementia, and this figure

increases to one in three for people over the age of 85 (Rajan et al., 2021). Worldwide, the number of persons with dementia (PWD) is estimated to be 47 million, a number expected to increase to 131 million by the year 2050 (Prince et al., 2016), representing a number greater than the population of Australia (Australian Bureau of Statistics, 2020).

Dementia, one of the most prevalent non-communicable diseases, is a term used to describe a cluster of symptoms that results from various neurodegenerative diseases. There are over 100 types of dementia, most commonly presenting as Alzheimer's disease which accounts for upwards of 80% of dementia cases (Alzheimer's Association, 2022). Alzheimer's dementia is caused by two neuropathologies (neuronal changes) including the buildup of beta-amyloid plaques outside of neurons and accumulation of abnormal formations of tau proteins within neurons (Alzheimer's Association, 2022). Together, these two neuropathologies alter the flow of chemical information from one neuron to another. This flow of chemical information is what creates the basis for memory creation/recall, sensory motor processing/control, emotion, and thought regulation (Alzheimer's Association, 2022).

### Dementia Symptomatology

Typically, dementia progression follows a predictable pattern from no clinical symptomatology to severe impairment that impacts everyday life. Figure 1 provides a visual example of disease progression from preclinical dementia to severe dementia. There are a number of risk factors that may contribute to development of dementia, including biological sex (women are on average more likely to develop dementia symptoms), age (older age is the largest single risk factor for developing dementia symptoms), and genetics (a previous family history of dementia increases odds of dementia diagnosis) (Vermunt et al., 2019). Typically, total disease duration lasts between 12 and 25 years, with pre-clinical dementia lasting on average 2 to 15

years, MCI due to dementia lasting on average 3 to 7 years, and mild to severe dementia lasting on average 1 to 7 years (Vermunt et al., 2019). Additionally, there are a number of factors that play into the duration an individual may spend in each of the categories of dementia classification presented in Figure 1. Younger individuals typically spend longer in each stage of dementia progression, with older individuals progressing through each stage at a quicker rate due to reduced resilience to neuropathology and higher rates of comorbidity in older individuals (Vemuri et al., 2017; Vermunt et al., 2019). Females tend to spend a longer period of time in in the mild to severe dementia stage than males across all ages due to lower mortality rates in females compared to males (Vermunt et al., 2019). Typically, individuals with certain genetic markers associated with family history of dementia progress more quickly through the preclinical stage and spend more time in the clinically symptomatic dementia stage (van der Lee et al., 2018; Vermunt et al., 2019).



Figure 1. Dementia Continuum from preclinical to severe dementia presentation. Adapted from Alzheimer's Association (2022).

*Note*. ADL = Activities of daily living, MCI = Mild cognitive impairment.

During the preclinical dementia stage, individuals may exhibit neurobiological changes without any clinical symptomatology associated with dementia. Longitudinal and post mortem studies have shown neurological changes such as abnormal beta-amyloid plaque and tau-protein levels through position emission tomography scans and cerebrospinal fluid analysis prior to the onset of clinical symptoms (Olsson et al., 2016; Sperling et al., 2020). Typically, neural connections that are responsible for language, thought, and memory formation recall exhibit damage first (Gordon et al., 2018; Jack et al., 2009). Oftentimes, however, individuals will display neuronal changes up to 20 years before displaying any clinical symptoms (e.g., deficits in language, thought, and memory recall) (Gordon et al., 2018).

As the disease progresses into the mild cognitive impairment stage, individuals may begin to develop mild changes in cognition; approximately one-third of individuals exhibiting mild cognitive impairment will develop dementia within five years (Nichols et al., 2022; Petersen et al., 2018). Individuals with mild cognitive impairment due to dementia may not experience impacts on activities of daily living due to the brain's ability to compensate for the neurobiological changes and associated cognitive impairment, but oftentimes those closest to the PWD (e.g., family members and close friends) may notice subtle changes in memory, thought, and language functioning (Alzheimer's Association, 2022).

As dementia severity increases, individuals may experience increased difficulty with memory formation, recall, and language. While cognitive decline is the hallmark characteristic of dementia, motor changes as well behavioral and psychiatric symptoms (BPSD) oftentimes fall into the cluster of symptoms that hallmark the neurodegenerative disorder (Alzheimer's Association, 2022; Ismail et al., 2016, 2022). As an individual begins to move into the stage of moderate and severe dementia, they may experience increased difficulty with multi-step

activities like bathing, cooking, or dressing (N. Evans et al., 2020). This increased difficulty with activities of daily living (ADLs) ultimately requires that PWD rely on caregivers to provide support. In fact, 83% of help provided to older adults comes from unpaid/informal caregivers (e.g., family members, friends) with nearly half of all informal caregivers reporting that they provide assistance with ADLs such as medication management and mealtime assistance (Friedman et al., 2015; Spillman et al., 2014).

Unfortunately, Alzheimer's dementia ultimately leads to death as PWD continue to experience neurological decline associated with the disease's progression. In 2019, Alzheimer's dementia was listed as the fifth leading cause of death; this was moved back to the seventh leading cause of death in 2020 following the emergence of the COVID-19 pandemic despite a 10% increase in Alzheimer's related deaths from 2019-2020 (Centers for Disease Control and Prevention, 2020). The actual number of deaths associated with Alzheimer's dementia is likely underreported, however, as the Centers for Disease Control and Prevention uses acute cause of death for reporting (Stokes et al., 2020). Oftentimes, though, the acute cause of death is secondary to Alzheimer's symptomatology which makes it difficult to determine the actual levels of mortality associated with Alzheimer's dementia. As the dementia progresses, PWD often experience increased difficulty with motor control and difficulty participating in mealtimes resulting in malnutrition and increased risk of pneumonia development, both of which are often listed as the acute cause of death (Alzheimer's Association, 2022; Brunnström & Englund, 2009). In fact, multiple investigations into leading causes of death associated with a dementia diagnosis revealed pneumonia as the most common acute cause of death in PWD (Brunnström & Englund, 2009; Romero et al., 2014). Thus, in order to maximize health and quality of life for PWD, it may be crucial to consider factors that impact mealtime safety which can ultimately

increase mortality (e.g., malnutrition and aspiration pneumonia). However, contributors to deficits in mealtime performance in PWD are multifaceted including potential cognitive, biological, and psychosocial deficits seen during disease progression. In the following sections I discuss these contributors, including the prevalence of swallowing impairment, the multifactorial nature of mealtime management, and the consequences associated with impaired mealtime performance in PWD.

### **Dysphagia and Dementia**

### Prevalence of Dysphagia in PWD

One primary area of management in dementia care relates to nutritional intake, which is often complicated by the presence of oropharyngeal dysphagia (OD). OD refers to a disordered swallowing process involving some aspect of the swallowing process. OD is commonly seen in PWD, with 57%-93% experiencing swallowing-related deficits (Alagiakrishnan et al., 2013a; Espinosa-Val et al., 2020). Given the number of individuals expected to develop dementia, these statistics represent a potential 26.8 million individuals with dementia who will experience some degree of swallowing-related deficit. Yet, despite the high potential of OD in PWD, there lacks a consensus on the functional impact of swallowing-related deficits in this population; this may be in part due to the high levels of heterogeneity in dementia presentation.

In order to understand disordered swallowing, we must first consider what is known about non-disordered swallowing. Traditionally, the swallowing process has been divided into four distinct categories (Logemann, 1998). The oral preparatory phase involves manipulation of food in the oral cavity as well as chewing. The oral phase of the swallow involves using lingual musculature to move the chewed food (bolus) from the mouth posteriorly into the pharynx where the swallowing reflex is triggered. The pharyngeal phase of the swallow involves the use of

pharyngeal musculature to transport the bolus through the pharynx (throat) to the superior portion of the esophagus. Finally, the esophageal phase of the swallow involves esophageal peristalsis that carries the bolus through the cervical and thoracic esophagus into the stomach.

### Characteristics of Dysphagia and Mealtime Management in PWD

OD, itself, is a symptom of an underlying disease process and, as such, the cause for OD among all populations differs widely. OD among PWD likely results from many different factors that accompany the biological, cognitive, and psychosocial decline during the disease's progression. OD results from disturbances in motor control, changes in cognition, and/or sensory issues, all of which are common in individuals with progressive neurological diseases (White et al., 2008). The physiological causes of OD in PWD are varied, but likely related to age-related decline in motor and sensory functioning that is exacerbated by the progressive neurological decline decline characteristic of dementia (Easterling & Robbins, 2008).

The cause of specific mealtime deficits in PWD is secondary to the kind of sensory, cognitive, or motor impairment that PWD experience. For example, PWD who are experiencing sensory deficits may experience prolonged oral transit time (Suh et al., 2009). Alternatively, PWD who are experiencing motor deficits may experience difficulty with mastication, formation of a cohesive bolus (ball of food in the mouth), or movement of laryngeal musculature, which is needed to move the bolus through the pharynx into the esophagus (Humbert et al., 2010; Suh et al., 2009). PWD experiencing cognitive deficits may be at increased risk for rapid intake, large bite sizes, and premature movement of the bolus into the pharynx prior to swallowing initiation (Alagiakrishnan et al., 2013b). Importantly, it needs to be recognized that these symptoms are oftentimes not happening in isolation and PWD experience many of these symptoms seen in PWD are often

combined with additional sensory, motor, and cognitive deficits external to swallowing (as described further below), necessitating consideration of more holistic treatment.

### Consequences of Dysphagia in PWD

Unfortunately, the consequences of OD can be severe. Even in otherwise healthy older adults, aging cognitive and neuromuscular processes increase the risk for malnutrition and the development of aspiration pneumonia, which puts these individuals at higher risk of mortality (Ebihara et al., 2016; Namasivayam & Steele, 2015). During the course of dementia progression, most PWD will develop dysphagia putting them at increased risk of aspiration and subsequent pneumonia when compared to aged-matched peers without dementia (Ranier Wirth et al., 2017). In addition to the physiological effects of dysphagia, including malnutrition, weight loss, and dehydration, OD can impact psychosocial domains, resulting in reduced social participation and quality of life (QoL) (Chen et al., 2009b; Jones et al., 2018; Namasivayam & Steele, 2015; Plowman-Prine et al., 2009a). PWD, in particular, face a wide range of symptomology congruent with the deleterious effects of OD, including reduced sensory and motor function resulting in altered feeding ability (Alagiakrishnan et al., 2013a; White et al., 2008), which may further reduce social participation and quality of life in PWD. Treatment consideration, then, must address both biological and psychosocial changes that are seen in PWD. Crucially, consequences of dysphagia extend beyond the PWD and impacts the caregiver as well. OD has been found to contribute to increased caregiver burden across populations, often resulting from the increased demands related to dysphagia-care provision and negative impact OD has on social participation (Ekberg et al., 2002; Lloyd et al., 2019; Nund et al., 2014). Caregiver burden Further, mealtime deficits seen in PWD often evolve with the disease progression. It may be difficult for caregivers to understand the complexity of mealtime related deficits seen in neurodegenerative disorders,

highlighting the need for increased caregiver education surrounding mealtime management (Shinagawa et al., 2009).

## *Current Treatment Approaches for Dysphagia Management and Considerations for a Person-Centered Approach to Mealtime Management*

Given the degenerative nature of the disease, dysphagia management in PWD is often viewed as a palliative approach to minimize the symptoms and consequences of OD as opposed to addressing the underlying cause of the mealtime deficits (Rogus-Pulia & Plowman, 2020). Oftentimes the goals surrounding dysphagia intervention are to minimize the symptoms of dysphagia as opposed to consideration of the cause of the swallowing impairment (Rogus-Pulia & Plowman, 2020).

This approach to intervention is more diseased based, where the clinician is identifying deficits and attempting to mitigate the symptoms of the deficit. In the case of dysphagia management, a disease-based approach to patient care may be placing a patient on a pureed diet due to jaw weakness despite the patient's wishes to have a less restrictive diet. Unfortunately, placing the patient on a pureed diet against their wish's limits the patient's diet and ultimately may put the patient at increased risk of muscle deterioration, malnutrition, and reduced quality of life all based on a reactionary, risk-mitigation approach to disease management (Beck et al., 2018; Gellrich et al., 2015; Jones et al., 2018; Swan et al., 2015; Wirth et al., 2017).

Alternatively, a person-centered approach is one where intervention is individualized and reflective of the person as a whole as opposed to the care task (e.g., mealtime assistance) (Edvardsson et al., 2008). Previous research has shown that there is a reduction in risk of aspiration when caregivers are providing person-centered care in PWD (e.g., adjusting the patient's pace, showing approval regarding appropriate mealtime performance, making direct eye

contact, providing choices, and asking the patient for cooperation) as compared to when caregivers are providing largely diseased-based care (e.g., outpacing to increase amount of food in oral cavity, interrupting the patient, ignoring the patient, and verbally or physically controlling the patients actions) (Coleman & Medvene, 2013; Gilmore-Bykovskyi et al., 2018; Lann-Wolcott et al., 2011). Provision of person-centered care also has implications beyond the physiological domain (e.g., reduced aspiration risk); PWD treated with person-centered care have been shown to exhibit fewer instances of BPSD, have an increased sense of autonomy, and have better overall quality of life (Edvardsson et al., 2008; Zingmark et al., 2002).

When designing an approach to dysphagia management for an individual with a neurodegenerative disease and their caregiver, special consideration needs to be taken to address a number of factors beyond the four phases of the swallow stated previously. Focusing solely on the four stages of the swallow sets intervention up in a disease-based context that aims to solely minimize risk in response to physiologic impairment. Yet, as discussed previously, deficits related to dementia progression are multifactorial. PWD experience functional impairments (e.g., decreased sensorimotor function), cognitive impairments (e.g., increased level of difficulty with participation in multi-step tasks), and psychosocial impairments (e.g., decreased social participation and decreased quality of life); each of these impairments can lead to increased difficulty with mealtime participation and ultimately put PWD at increased risk of malnutrition (Alagiakrishnan et al., 2013c; Jones et al., 2018; Plowman-Prine et al., 2009b; Rogus-Pulia & Plowman, 2020). In order to ensure a truly person-centered approach to mealtime management, it is crucial to balance domains such as the PWD's goals of care, QoL, the care environment, caregiver burden, and course of disease progression (Rogus-Pulia & Plowman, 2020).

Moving beyond the four traditional phases of dysphagia to create a holistic model of dysphagia management makes room for the introduction of a fifth phase, the pre-oral phase. The pre-oral phase of mealtime management considers the context in which an individual is consuming food or liquid. Contextual factors that occur prior to the introduction of food or liquid to the oral cavity are present in every mealtime scenario and may have the capacity to be modified to assist in successful mealtimes. With the addition of contextual factors (e.g., patient preferences, mealtime environment, caregiver interaction style), the caregiver is better positioned to provide truly person-centered care when providing mealtime assistance to PWD.

Several models of disease classification have attempted to capture these contextual factors, but to date there has not been a comprehensive model that addresses contextual, biological, and psychosocial factors that may color the mealtime process.

### **Current Models That Can Inform Mealtime Management**

Prior to considering plans for mealtime management in PWD, it is crucial to consider what is already known about mealtime management across both clinical and non-clinical populations. A number of current theoretical models of mealtime management exist that can help inform a new conceptualization of mealtime management for PWD, as is described below.

### World Health Organization's International Classification of Function, Disability, and Health

The World Health Organization's International Classification of Function, Disability, and Health (WHO-ICF) offers a conceptual model for describing an individual's functional status within the context of disease or disorder (Kostanjsek, 2011). Approved by all member states of the World Health Organization, the WHO-ICF model is one of the most widely accepted models for classification of disfunction within the context of health. The health condition (a disease or disorder) may impact functioning at three mutually interacting levels: in relation to the body,

activity, and participatory capability within the context of an individual's environmental and personal factors (Kostanjsek, 2011). Significantly, the model explicitly recognizes, and draws attention to, the important role of contextual factors on functional outcomes given the presence of disease.

As applied to mealtimes in dementia, the relationship between dementia (disease) and the eating process (activity) is multifaceted. Successful or unsuccessful mealtimes cannot be attributed to any one factor and, as the WHO-ICF model stipulates, multiple contextual factors, such as reliance on others for feeding assistance and altered cognitive functioning, affect the functional outcome. Using the WHO-ICF model, caregivers and health professionals can view the mealtime experience as one that relies on a complex interplay of physiological, psychosocial, and environmental factors. Figure 2 presents a visual model for the WHO-ICF which can support a broader approach to mealtime management by more fully understanding the impact of impaired mealtime participation.



Figure 2. WHO-ICF Model outlining interconnected factors that can be mapped onto a disease or disorder (World Health Organization, 2013).

The WHO-ICF model provides a framework for understanding factors that can influence a mealtime experience. Many of these factors can be impacted by a diagnosis of dementia. The pre-oral, oral preparatory, and oral phases of the swallow are under voluntary control and as such require cognitive input for successful completion. As dementia progresses PWD typically experience increased cognitive decline resulting in issues with memory, attention, and problem solving all of which present increased risk of breakdown in the first three phases of the swallow (Threats, 2007). Breakdown in any of these phases may contribute to increased risk of aspiration, development of pneumonia, choking, and nutrition maintenance (Threats, 2007). Activities and participation domains that may influence mealtime performance in PWD include the preparation of meals, socialization during mealtimes, and participation in events such as religious activities or celebrations, all of which may be impacted by a PWD's reduced cognition and/or neuromuscular control (Aliev et al., 2013; de Paula et al., 2016; Gitlin et al., 2016). Environmental factors that may act as facilitators or barriers to successful mealtime performance include items such as food presentation, lighting, sound levels, presence of friends or family, or reliance on others to assist in mealtimes. Manipulation of these environmental factors have the potential to help (decreased distractions at mealtime) or hinder (eating in isolation) a PWD's ability to participate in mealtime activities (Bisogni et al., 2007; Nell et al., 2016). Lastly, the personal domain includes items such as eating preferences, motivation, and ability to follow recommendations, all of which may be impacted by a diagnosis of dementia (Han et al., 2016; van der Wardt et al., 2017).

The WHO-ICF model highlights the importance of environmental, contextual, and biological functioning on mealtime performance allowing for a more holistic view of mealtime management. However, it must be recognized that this model of classification is born out of the

identification of disability within the context of the person's diagnosis and environment as opposed to an individual's preserved abilities. The 2013 WHO Practical Manual for using the ICF framework mentions the word "disability" 270 times, and mentions the word "enable" in the context of human performance twice; the word "ability" is mentioned in the same context just once (World Health Organization, 2013). This deficit-based terminology may contribute to furthered disease-based treatment approaches that respond to a patient's dysfunction as opposed to a patient-centered approach which leverages the patient's retained abilities for mealtime success.

**Implications for Mealtime Management.** The WHO-ICF model of disease, function, and health classification delivers a framework for caregivers to consider diseases or disorders not in isolation, but in the context of physiology, participation, activities of daily living, and environmental and personal factors. Recognizing that the disease or disorder does not exist in isolation allows for a wider scope of intervention by asking caregivers to consider the multifactorial effects of contextual factors on the individual who is experiencing the disease or disorder. However, when working with an individual who is navigating a neurodegenerative disease, it may be beneficial to flip the narrative from a deficit-based approach to an approach that identifies retained assets (Hopkins et al., 2015). Instead of asking, "What deficits are present in the PWD that inhibit them from participating in mealtimes?" clinicians and caregivers can investigate, "What abilities does the PWD retain that will allow them to participate in mealtimes?". An asset based approach focuses on leveraging the PWD's retained assets to prevent future problems as opposed to a deficit based model of care which is reactive to problems that arise from complications of disease progression (Rahman & Swaffer, 2018).

Combining the WHO-ICF, which highlights the importance of the interconnected nature of disease, function, and environment, with an asset-based approach to dementia management, which aims to leverage those retained abilities, may better encourage patient-centered care that frames PWD and caregivers as co-producers of positive health outcomes (Hopkins et al., 2015).

### Bisogni et al.'s Framework of Typical Mealtime Processes

Moving toward a more asset-based approach to mealtime management for PWD requires a clear understanding of the environmental factors related to mealtimes. Exploration of environmental and contextual factors that are present in a typical mealtime experience may lead to better understanding of how these factors influence mealtime performance within the context of a disease/disorder (e.g., dementia). A thorough understanding of these environmental and contextual factors within the context of non-disordered mealtimes will provide an expanded understanding of the domains highlighted by the WHO-ICF and allow better identification of retained assets that can lead to successful participation in mealtimes for PWD.

A 2007 review of eating habits in healthy adults revealed an intricate series of interconnected dimensions that form a framework to describe the typical mealtime process (Bisogni et al., 2007). These dimensions include social setting, food and drink, time, recurrence, physical condition, location, activities, and mental processes (see Figure 3). Social setting describes the people present and their relationship to the participant. The food and drink domain details the type of material consumed, amount consumed, and how the food or drink was prepared (e.g., homemade or pre-prepared). The dimension of time is described as the time of day the meal was consumed, the chronological relation to other daily experiences (e.g., after exercise or before work), and the subjective experience of time (e.g., participants reported "I was in a rush"). The domain of recurrence is used to describe how repetitious the mealtime

experience was (e.g., a meal eaten once a week versus once a year on special occasions). Physical condition refers to two main components, the appetite and hydration needs of the participant and the physical state of the participant such as presence of fatigue, illness, or disease. The location domain describes both the general location (e.g., at home vs. at a restaurant) as well as positionality within that location (e.g., at the dining room table versus in front of the television). Activities include anything that was happening during the mealtime (e.g., parental tasks) and how disruptive they were to the mealtime experience. Lastly, the mental processes domain includes two main features, food-related goals (e.g., eating so the food does not go bad) and associated emotions (e.g., stressed versus at ease).

Within Bisogni et al.'s (2007) conceptual model, these dimensions come together to characterize a mealtime episode with each dimension describing a particular aspect of the mealtime. For example, mapping a typical dinnertime using this framework may include location (at home), people (with family), and time (after work and picking up children); each of these aspects color the eating experience and converge to define its success or failure. Mapping the mealtime experience of a PWD in a long-term care (LTC) facility may include location (in an isolated room), social setting (alone, without peers), and mental processes (confusion, frustration). Each of these dimensions influences the others, and the interconnected nature of these dimensions affects the ultimate mealtime experience.


Figure 3. The eight interacting dimensions and features of eating and drinking episodes that characterize situational food and beverage consumption among working adults. Adapted from (Bisogni et al., 2007).

**Implications for Mealtime Management.** Bisogni et al.'s (2007) conceptual model provides a deeper understanding of the physiological, environmental, personal, and contextual factors that influence a typical mealtime experience. Recognition of the factors that influence mealtime performance in non-disordered mealtimes allows caregivers and practitioners the ability to identify areas where retained abilities can be leveraged to promote success during mealtimes. Recognition of biological, contextual, psychosocial, and personal factors that can be leveraged for improved mealtimes is only the first step, however. In order to create a holistic

model of mealtime management, the next step is to identify factors that can in fact be modified as opposed to fixed factors that may not be modifiable.

#### Historical Perspectives of the Biopsychosocial Model of Patient Care

Bisogni et al.'s (2007) description of the mealtime experience as a dynamic process of environmental-social-personal interactions supports a more holistic approach to patient care, which is often framed within a biopsychosocial model. The biopsychosocial model of patient care was introduced as an alternative to the biomedical model of illness classification (Engel, 1977). Engel's Biopsychosocial model argued that a patient's biological, social, psychological, and behavioral domains must be considered together in order to fully understand a patient's diagnosis and prognosis (Engel, 1977). Adaptation of the biopsychosocial model to describe dementia was first by described by Cohen-Mansfield, who proposed that the manifestation of dementia is the result of the convergence of biological, psychological, and environmental factors (Cohen-Mansfield, 2000).

Considering the progressive nature of dementia, Spector & Orrell (2010) expanded on Cohen-Mansfield's (2000) model by proposing that the impact of biological, psychological, social, and environmental domains change throughout disease progression (Spector & Orrell, 2010). In addition to highlighting the progressive nature of dementia related symptomatology, the Spector-Orrell model identifies fixed and tractable biopsychosocial characteristics that a PWD experiences. Fixed characteristics are those that are not able to be altered. For example, fixed biological characteristics may be diagnosis or past medical history and fixed psychosocial characteristics are those that can be changed. For example, a tractable biological characteristic may be sensory impairment, and a tractable psychosocial characteristic may be environment or levels of mental

stimulation. Identification of tractable biological and psychosocial characteristics may allow caregivers to better highlight modifiable personal and contextual factors that impact functional outcomes and leverage the PWD's retained assets to enhance mealtime participation. Patient-centered treatment requires consideration of both tractable biological and psychosocial characteristics when managing feeding and swallowing impairments in PWD to ensure that the mealtime is as successful as possible. Central to a biopsychosocial approach is patient-centered, as opposed to, disease-centered care. For example, consider a patient with dementia in an isolated room who is exhibiting heightened levels of agitation. As they throw their lunch tray off the table, is this truly an example of BPSD? Or perhaps the patient is full, and the caregiver did not recognize cues to stop feeding? The caregiver's response to this behavior may depend on the caregiver's view of the behavior (Gitlin et al., 2016). Coming from a disease-based perspective, the caregiver may view these behaviors as a result of the neurodegenerative disease process and disregard this attempted communication, potentially resulting in increased frustration for both the caregiver and the PWD (Duxbury et al., 2012). Alternatively, by utilizing a person-centered approach, the caregiver can better recognize this behavior as a reaction to the interplay between biological, social, and environmental factors resulting in an attempt to communicate an unmet need (Bisogni et al., 2007; Kitwood, 1997). By utilizing a person-centered perspective, the PWD's needs may be better met thereby alleviating further frustration for both the PWD and the caregiver. It is crucial for caregivers to look at how these individuals are attempting communication, both with verbal cues and non-verbal behavior. To view the patient and their retained abilities holistically, clinicians must consider how PWD are framed within the context of a degenerative disease.

Implications for Mealtime Management. The Spector & Orrell (2010) model of dementia management does not explicitly address areas associated with mealtime management, however they do provide context for clinicians and caregivers to consider tractable and fixed biopsychosocial characteristics. Identification of tractable characteristics associated with dementia that may impact mealtime success in PWD allows clinicians and caregivers the opportunity to identify areas in which intervention can be employed to promote successful mealtimes.

By combining aspects of the three theoretical models described above (WHO-ICF, Bisogni's conceptual model of mealtime management, and the tractable characteristics of the Spector-Orrell model biopsychosocial model of dementia management) caregivers can utilize a person-centered biopsychosocial model of mealtime management for PWD that views patients' actions as a result of not only the disease, but also the social and environmental processes.

#### A Biopsychosocial Model of Mealtime Management in PWD

Through a combination of components from the three theoretical models described above, a novel framework for mealtime management in PWD can be considered. The WHO-ICF outlines the importance of considering contextual factors, and how these factors intermingle to create disfunction in the context of disease/disorder. Bisogni et al.'s conceptual model of mealtime management provides evidence for specific characteristics present in mealtimes for non-disordered persons. The identification of characteristics that lead to successful mealtimes provides a framework for clinicians and caregivers to identify areas in which PWD may maintain skills. Further, identification of these retained skills allows for implementation of a personcentered, asset-based approach to patient care that emphasizes working with remaining cognitive and functional skills to promote mealtime success. The Spector-Orrell model of biopsychosocial

management of PWD further promotes a person-centered, asset-based approach to patient care by highlighting tractable characteristics which are amenable to intervention. Identification of personal, biological, and contextual factors (WHO-ICF) pertaining to retained mealtime skills (Bisogni et al.) which are amenable to intervention (Spector-Orrell) ultimately led to the creation of the Biopsychosocial Model of Mealtime Management in PWD (Bayne & Shune, 2022).

The Biopsychosocial Model of Mealtime Management in PWD provides a framework for caregivers to identify retained capabilities, and leverage these capabilities for more successful mealtimes, as opposed to compensating for the disabilities associated with dementia. Figure 4 illustrates tractable characteristics commonly seen in PWD across two domains, biological and psychosocial. Addressing both domains allows for exploration of mealtime management with a focus on promoting success in mealtimes as opposed to mitigating the effects of mealtime breakdown.

In addition to addressing the biological and the psychosocial processes often seen in PWD, the Biopsychosocial Model of Mealtime Management in PWD also introduces dysphagia management interventions that target both domains and explores feeding related outcomes. The model described below focuses on the tractable characteristics seen in PWD as these are the characteristics that caregivers can identify and manage as areas for intervention. Of note, these are commonly seen features around mealtime management in PWD and are commonly represented in the literature (Batchelor-Murphy et al., 2017; Bayne et al., 2022; Caplin & Saunders, 2015b; Curle & Keller, 2010a; Dunne et al., 2004; Gitlin et al., 2016; Keller et al., 2015; Milte et al., 2017; Nijs et al., 2006; Prochnow et al., 2019; Schillinger et al., 2003; Shune & Barewal, 2022; Tamura-Lis, 2013; Wegner et al., 2004; Wright et al., 2006).



Figure 4. Dysphagia management in PWD utilizing a biopsychosocial model as an asset-based approach to patient-centered care (Bayne & Shune, 2022).

### **Tractable Characteristics**

The left boxes in the model describe the tractable, or modifiable, biological and psychosocial changes that occur as a consequence of dementia. These characteristics are important to delineate given their potentially negative impact on the mealtime experience and the opportunity they provide for intervention.

**Tractable Biological Characteristics.** The top left box in this model describes modifiable biological changes that can be addressed to best support mealtime management in PWD throughout the progression of their disease. Tractable biological characteristics related to mealtime management in PWD are varied and, if not addressed, may result in innumerable downstream deficiencies. Risk for nutrition deficiencies begin in the early stages of dementia with changes in the sensory system including reduced gustatory and olfactory senses (Aliev et al., 2013). Due to changes in motor control, PWD face reduced ability to participate in activities of daily living (ADLs), such as feeding and other mealtime related tasks, which may be a result of reduced fine motor control commonly seen as the disease progresses (de Paula et al., 2016). Changes in gross motor control may be a result of paratonic rigidity seen in dementia which can place the patient at increased risk of postural difficulties and reduced oropharyngeal swallow control (Bautmans et al., 2008; Drenth et al., 2020). Combined with other biological and psychosocial features related to cognitive decline, malnutrition is a significant risk for PWD (Espinosa-Val et al., 2020; Namasivayam & Steele, 2015).

**Tractable Psychosocial Characteristics.** The bottom left box of the proposed model provides modifiable psychosocial changes that can be addressed to help support mealtime management in PWD. Tractable psychosocial characteristics related to mealtime management include the psychological changes seen in PWD and the way their social environments shape their participation in ADLs. Emotional and behavioral dysregulation have long been an identified as characteristics associated with emotional lability across many subtypes of dementia (Taragano et al., 2009). Identifying and effectively addressing emotional lability in PWD may be a crucial component in promoting mealtime engagement. Altered social interaction is a result of a confluence of factors associated with the dementias including altered cognitive status, communicative ability, or changes in sensory and motor ability (Kolanowski & Litaker, 2006; Lee et al., 2017; Resnick et al., 1997). The ability to engage in mealtime tasks is another psychosocial characteristic that may be altered in PWD, and successful mealtime engagement results from a variety of factors. Mealtime engagement can come in the form of direct attention from caregivers, social engagement with others who are participating in the mealtime, as well as engagement in tasks related to mealtime preparation (Cohen-Mansfield et al., 2009; Gitlin et al.,

2016; Keller et al., 2015; Liu et al., 2020). Altered ability to socially participate across a wide variety of tasks is a known correlate of dementia progression (Nell et al., 2016; Smits et al., 2015), which may put PWD at increased risk of disengagement during mealtimes. Although caregiver preparedness is not a direct psychosocial domain of the person with dementia, it is included here because the caregiver directly manipulates the environment in which the PWD is receiving care.

#### **Biopsychosocial Interventions and Outcomes**

The middle box of the proposed model provides potential interventions that have been described previously in the literature. The righthand box provides associated mealtime outcomes that were described in the literature reviewed to create this model and suggest an improved mealtime experience for PWD.

The following section describes potential areas where informal caregivers of PWD can modify either biological or psychosocial domains in order to support successfully assisted mealtimes. In each subsection, mealtime related outcomes are detailed in relation to each topic. In the first section, I will discuss the importance of caregiver education, how this education is achieved, and the outcomes associated with increased caregiver education. Each of the following sections are areas in which the caregiver can provide direct support to the PWD during mealtimes as well as the outcomes associated successful utilization of each of these interventions.

**Caregiver Education.** Caregiver education, as well as accessibility of caregiver education, is an important component when designing appropriate care for PWD. Availability of education is crucial for caregivers to meet the changing needs of PWD; however, there currently exists minimal to no standardized nutrition education for community-dwelling PWD and their

caregivers (Anderson et al., 2016). Informal caregivers have expressed need for the availability of nutrition-based education in four main domains: meal preparation/food choices; addressing the PWD's lack of appetite and altered eating behaviors; interpreting and synthesizing existing nutrition information; and identifying *reliable* nutrition information (Anderson et al., 2016). Through consistent education addressing the changing nutritional needs and capabilities of PWD, healthcare professionals may play an integral role in alleviating caregiver burden that is associated with lack of education surrounding mealtime management (Salva et al., 2011).

Mitigating caregiver burden is a crucial component to holistic model of care for PWD and their caregivers. Although 45% of caregivers of PWD report that providing care has been very rewarding, they also report higher levels of stress and burden associated with caregiving (Riffin et al., 2017). The burden associated with caregiving is multidimensional with physical, social, and emotional hardships leading to serious complications involving overall health, immune functioning, and longevity on the part of the caregiver (Pinquart & Sörensen, 2003, 2007). The effects of increased caregiver burden and distress often extend beyond the caregiver and effect the PWD as well. Care recipients whose caregivers experience increased stress and burden are at increased risk for institutionalization, higher levels of BPSD, and are at higher risk of being abused (Amjad et al., 2021).

One common factor that caregivers report leads to increased levels of care-related stress is feeling unprepared to provide care due to lack of adequate education (Funk et al., 2010; Schumacher et al., 2007; Stajduhar et al., 2010). Feelings of adequate preparedness have been correlated with positive outcomes for both the caregiver and the care recipient. Caregivers who feel better prepared to provide care for PWD report reduced care related burden, less stress, increased feelings of emotional well-being and better overall health (Alvariza et al., 2020). When

caregivers participate in formal education regarding the caregiving process, care recipients report positive outcomes as well, including reduced stress, better communication with their caregiver, and feeling that their needs were better met by the caregiver (Norinder et al., 2017).

Given high levels of heterogeneity within the dementia population as well as within the caregiver care-recipient dyad, education and intervention programs that are responsive to this heterogeneity will lead to better outcomes surrounding mealtime participation and performance (Anderson et al., 2016; Cohen-Mansfield, 2000). Implementation of a multicomponent caregiver education program addressing modifiable/contextual factors to decrease agitation in PWD can lead to decreased negative caregiver attitudes toward care provision, increased caregiver confidence, and improved patient outcomes such as increased nutrition maintenance and improved social participation (Anderson et al., 2016; Murphy et al., 2017; Staedtler & Nunez, 2015). Participation in educational programs by both formal and informal caregivers and psychological interventions geared at caregivers' mindfulness have been shown to lead to a reduction in caregiver burden and an improvement in both QoL and depression scores for the caregiver and PWD (Fischer et al., 2012; Paller et al., 2015). Additionally, previous research has found that when individuals dine with a caregiver who has been trained to engage appropriately with PWD, there is an increase in dietary intake by 20% of total volume, which offers increased opportunity for weight gain and monetary savings as compared to nutritional supplements that are a costly alternative to food intake (Wright et al., 2006). Reduced care depression and burden as well as improved QoL could position caregivers to provide higher levels of care for the PWD while ensuring the health and wellbeing of the caregiver is maintained. A 2022 review of education models for caregivers and individuals with dysphagia revealed that participation in education programs surrounding mealtime management resulted in decreased instances of

pneumonia development, increased dysphagia related knowledge, and increased caregiver confidence (Reddacliff et al., 2022).

Crucially, however, we need to consider the mechanism of action for education of caregivers. That is, how do we effectively provide education to caregivers in order to support successfully assisted mealtime activities? The teach-back method has long been used in healthcare settings, and involves patients and caregivers repeating back what they have heard, in their own words, so healthcare providers can confirm comprehension and correct any misunderstandings (Slater et al., 2017). The teach-back method (also known as "closing the loop") is a communication and educational method where patients and caregivers are asked to demonstrate their understanding of educational material by paraphrasing the information and reporting back to the healthcare provider their impressions of learned material. The teach-back method has been shown to increase information retention and understanding, especially in populations with low health literacy (Caplin & Saunders, 2015a). In healthcare settings, teachback has been used to increase caregiver and care recipient confidence and compliance with recommendations (Prochnow et al., 2019). When utilized by healthcare providers, teach-back has increased patient and caregiver understanding of recommendations, level of trust in healthcare providers and overall patient satisfaction (Schillinger et al., 2003; Tamura-Lis, 2013). Furthermore, teach-back has demonstrated positive patient and caregiver outcomes in the emergency department, outpatient settings and home-based care, indicating this is an effective method to deliver healthcare education to patients and caregiver across a wide range of settings (Caplin & Saunders, 2015a; Prochnow et al., 2019; Schillinger et al., 2003; Tamura-Lis, 2013).

**Sensory Stimulation.** The risk for nutritional deficiencies begins in the early stages of dementia alongside early changes in the sensory system, including reduced gustatory and

olfactory senses (Aliev et al., 2013). Meeting the needs of the PWD is an evolving process as the disease progresses and requires scaffolding support during feeding activities. By utilizing an asset-based approach, caregivers can support PWD to participate in mealtimes despite changes in sensory functioning (Gitlin et al., 2016). The level of scaffolding support should maximize retained strengths and capabilities of the PWD and will look different dependent on the progression of the disease process.

*Tactile Support.* Tactile support can be provided in the form of hand feeding assistance. Individuals with advanced dementia may benefit from feeding assistance through the use of assistive feeding utilizing tactile cues from the caregiver (Batchelor-Murphy, 2016). Batchelor-Murphy describes three distinct manners in which a caregiver can assist with movement of food or liquid from the table to the mouth: hand-under-hand, hand-over-hand, and direct hand feeding. During hand-under-hand feeding, the caregiver holds the utensil or cup and places their hand under the care recipient's thereby allowing the care recipient to feel as though they have initiated the movement and are in control of the movement. Additionally, utilizing hand-under-hand as a feeding assistance technique allows the PWD greater control over the direction and speed of movement, which may allow for greater feelings of autonomy (Batchelor-Murphy, 2016; Batchelor-Murphy et al., 2017; Wegner et al., 2004; Wright et al., 2006). Hand-over-hand relies on the caregiver placing their hand over the care recipient's hand in an effort to support the care recipient's movement from plate to mouth (Batchelor-Murphy et al., 2017). Finally, in direct hand feeding, the caregiver holds the utensil or cup and feeds the care recipient without any active involvement from the care recipient (Batchelor-Murphy et al., 2017). The hand-underhand feeding technique has been shown to reduce BPSD and increase intake, likely related, at

least in part, to the PWD utilizing the preserved ability to provide cues for force and speed of movement (Batchelor-Murphy, 2016; Batchelor-Murphy et al., 2017).

*Auditory Support.* Individuals with mild to moderate dementia may not necessitate tactile support and may benefit from less invasive sensory stimulation such as increased auditory cues. Individuals with moderate dementia tend to benefit from auditory cues with an emphasis on procedural repetition (e.g., "follow each bite with a drink"). In cases of more mild dementia, promotion of increased sense of self, socialization, and belonging has been achieved through participation in guided, goal-directed activities that increase sensory awareness of mealtimes (e.g., assisting in basic meal preparation or discussing menu options) (Gitlin et al., 2016). Supported meal-centric activities increase engagement of both the caregiver and the PWD while promoting increased sense of self, belonging, and identity during progression of the disease (Gitlin et al., 2016). Auditory stimulation is not limited to conversational auditory support, however. Caregivers can provide auditory stimulation through the introduction of relaxing music played during mealtimes to decrease adverse mealtime behaviors while simultaneously increasing caloric intake in PWD (Hicks-Moore, 2005; Thomas & Smith, 2009).

*Visual Support.* Visual stimulation is known to play a role in caloric intake and weight management in PWD as well. Simple visual enhancement, such as increasing the contrast of crockery, has also been shown to increase intake of both food and liquid in PWD (Dunne et al., 2004). For example, participants were found to increase food intake by 25% and liquid intake by 84% when they were provided high contrast (red) tableware and flatware as opposed to low contrast (white) tableware and flatware (Dunne et al., 2004). The authors suggest that high contrast crockery may increase attention to food and liquid during mealtimes resulting in increased intake.

In addition to high contrast crockery to draw attention to food and liquid, environmental visual manipulations have been shown to impact intake during mealtimes. By creating a pleasant and visually stimulating environment with the use of an aquarium in dining rooms, PWD who were previously at risk for malnutrition increased in weight by 2.2 pounds, on average, in a period of ten weeks (Edwards & Beck, 2013). During the ten-week intervention period where researchers placed the aquarium in the dining room, PWD increased daily food intake, on average, by 25% (measured in grams) compared to daily intake prior to introduction of the aquarium (Edwards & Beck, 2013). In addition to having direct benefits on mealtime performance, increased visual stimulation through the use of brightly colored (high contrast) table cloths and table decorations (vase with flowers) increased memory of the mealtime throughout the day and perceived quality of the meal in PWD (Tanaka & Hoshiyama, 2014).

*Olfactory Support.* Information on olfactory stimulation to increase mealtime performance in PWD is lacking; however, there is limited evidence to suggest that olfactory priming may increase caloric intake and sleep duration as well as increase balance in PWD (D'Andrea et al., 2022). A recent rapid review identified only one study that assessed the impact that olfactory stimulation has on food intake in PWD (D'Andrea et al., 2022). Researchers in this study increased olfactory stimulation by infusing dining rooms with food smells prior to mealtime which led to increased caloric intake in PWD. Through olfactory priming with food smells prior to actual intake PWD increased caloric intake by 25% during primed meals (Sulmont-Rossé et al., 2018). Additionally, the PWD displayed increased interest and attention to food during primed meals compared to meals where olfactory priming did not occur. Unfortunately, Sulmont-Rossé et al. repeated the experiment two weeks after initial olfactory priming and there was no significant increase in intake when PWD were primed using the same scent.

Ultimately, increasing sensory stimulation (tactile, auditory, visual, olfactory) with PWD may provide a simple, non-pharmacological intervention that caregivers can employ with little to no increased risk to the PWD. Positive mealtime outcomes are varied; however, evidence supports that providing increased sensory stimulation can increase nutritive intake and decrease instances of BPSD resulting in overall increased mealtime success for PWD. However, sensory stimulation is only one portion of the environment that caregivers can manipulate to increase mealtime success.

**Social Environment Manipulation.** The environment in which a mealtime is taking place consists of a dynamic interplay between socialization and sensory stimulation. Environmental manipulation should extend beyond the physical environment to the social environment as well, which includes the individuals in the dining vicinity and the interactions that they have with the PWD (Liu et al., 2020; Liu et al., 2019). Fostering a social dining environment that supports successful mealtimes may lead to increased nutritive intake. Specifically, intake is associated with the dyadic verbal interactions between PWD and their caregivers. When caregivers offer positive verbal support (e.g., providing verbal instruction, providing mealtime choices, asking for cooperation, and expressing approval), PWD demonstrate increased intake of food and liquid (Liu et al., 2020). The association between mealtime intake and positive caregiver support indicates that despite cognitive decline, social interaction remains a key component of mealtime success for PWD as identified in Bisogni et al.'s (2007) conceptual model.

Social roles between all individuals who are participating in a shared mealtime may also influence mealtime performance for PWD. Individuals experiencing more severe dementia may not display overt social interaction (e.g., verbal communication or overt engagement with others) however, they may display increased engagement in mealtimes and consumption of more food when observing visual cues from mealtime partners that model appropriate mealtime behaviors (Curle & Keller, 2010a). Providing PWD with increased opportunity to socialize during mealtimes and encouraging socialization may encourage healthy food consumption for individuals that are less likely to participate in mealtimes by modeling appropriate mealtime behaviors and providing increased opportunity to communicate with tablemates (Curle & Keller, 2010b). Despite potential reductions in social interaction, for some PWD, when they eat in the presence of others who are also eating, they tend to increase the quantity of their intake (Burdick et al., 2021).

Designing a mealtime environment that is conducive to nutritive intake is a multifaceted process, even more so in a dining room where there are multiple individuals engaging in mealtimes simultaneously. In addition to increasing nutritive intake, designing a mealtime environment that allows for socialization can lead to increased quality of life for PWD. By providing meals in a family style manner that allows for self-serving and socialization during mealtimes, PWD have reported increased quality of life, display increased fine motor functioning, and experience increased body weight (Nijs et al., 2006). These results support utilizing person-centered, asset-based principles of patient care by allowing the PWD to capitalize on their retained ability to serve themselves may increase intake as well as improve autonomy during mealtime tasks.

Although dementia is, by its progressive nature, a disease that results in an ever-changing set of symptomologies, PWD also benefit from consistency during mealtimes (Nell et al., 2016). Maintaining a consistent and recognizable mealtime environment allows for the reduction of anxiety and distraction and can decrease cognitive load, allowing for increased attention to the mealtime task and increased nutritive intake (Nell et al., 2016). Ultimately, socialization and companionship during mealtimes remains an important component to increasing intake of food during mealtimes (Curle & Keller, 2010b; Nijs et al., 2006; Wright et al., 2006).

**Patient Preferences.** Sensory stimulation and social environment manipulation clearly have potential to increase nutritive intake, decrease BPSD, and increase QoL in PWD. However, for person-centered care to be truly person-centered, patient preference must also be a salient feature of a biopsychosocial model of mealtime management. Unfortunately, discovering and honoring the preferences of a PWD can be difficult in light of the cognitive decline that accompanies a dementia diagnosis (Reimer & Keller, 2009). Due to the difficulty some PWD have with communicating their preferences, the responsibility to interpret attempts at communication falls to the caregiver. Despite communication difficulties, honoring the mealtime assistance by individualizing the mealtime experience is central to enhancing mealtimes (Shune & Linville, 2019).

The traditional biomedical model often results in PWD becoming passive participants in their care, whereas allowing opportunities for choice aligns with a biopsychosocial model of mealtime management. In order to make a choice, however, the PWD must have the capacity to choose (Mol, 2008). Certainly, as cognitive decline progresses, the complexity of choice may need to be scaffolded to meet the abilities of the PWD. In the early stages of cognitive decline, a PWD may be able to verbalize their choice from a menu of options. Conversely, PWD with more

severe cognitive decline may point to a desired food item or assert choice simply by closing their mouth to a food they are not interested in. In order to individualize the mealtime experience, caregivers may consider providing increased food variety (Shune & Barewal, 2022).

Choice and ability to assert individual preferences surrounding food and drink remains a dominant concern in PWD (Milte et al., 2017) Caregivers can improve mealtime quality of life and overall perception of the dining experience in PWD by including PWD in the decision-making process regarding when, where, and what they would like to eat. By providing greater variety of flavor, texture, temperature, and quantity during mealtimes, and increasing frequency of mealtimes offered, caregivers can provide PWD greater ability to choose what and how they would like to eat, thereby increasing mealtime autonomy and the likelihood of consumption (Milte et al., 2017). Ultimately, caregivers can utilize an asset-based biopsychosocial model to support person-centered care by providing multiple options, honoring preferences of PWD, and aiming to increase mealtime autonomy.

**Cognitive Stimulation.** Although it is well established that cognitive decline is the hallmark symptom of dementia, PWD may be able to learn and/or regain some level of cognitive functioning in order to better participate in mealtimes (Brush & Camp, 1998; Lin et al., 2010). One method which has been shown to increase learning and retention of behavior in PWD is spaced retrieval (Bourgeois et al., 2003). Spaced retrieval is a method of learning that requires the individual to recall newly learned information over progressively longer periods of time and has been shown to increase learning and retention in PWD (Bourgeois et al., 2003). With use of this technique, PWD have demonstrated significantly increased mealtime independence following training to recognize when mealtime was, masticate effectively, and generally required less assistance from caregivers during mealtimes (Lin et al., 2010).

Montessori-based programs that focus on breakdown of tasks, guided repetition, sequencing, and provision of feedback from caregivers have also been used to increase cognitive stimulation to facilitate learning of new skills in PWD (Booth et al., 2018). Utilization of Montessori principles for mealtime management has been shown to lead to improvements in procedural skills needed for independent eating such as pouring, hand-eye-coordination, scooping, and discrimination of edible versus non-edible items (Lin et al., 2011). Montessoribased principals have also been applied specifically to enhance person-centered mealtime practices by encouraging PWD to make more choices related to menu selections, increasing engagement, and increasing socialization during mealtime activities (Cartwright et al., 2022).

Increased engagement in mealtimes may also be achieved through practices that enhance attention to the mealtime task. Participation in a mindfulness program has demonstrated improvements in cognitive control, attention, and task switching tasks in PWD (Paller et al., 2015). Mindfulness exercises that encourage attention to breathing, bodily sensations, body movement, and acceptance of thoughts have been shown to increase QoL, decrease depressive symptoms, and increase recall in PWD (Paller et al., 2015). Improved cognitive and psychological performance may be seen in mealtimes for PWD following participation in mindfulness training; however, the potential mealtime benefits remain unknown and are currently under investigation (Aguirre et al., 2017).

In addition to relearning and/or regaining skills, capitalizing on retained cognitive assets may increase participation in and success of mealtimes. The field of neuropsychology has provided evidence that implicit memory (memory that relies on past experiences) remains intact even in people experiencing severe dementia (Sabat, 2006). Two specific techniques have been found to capitalize on retained implicit memory which may have direct implications in mealtime

support, bridging and mirroring. Bridging entails utilizing objects that connect actions with implicit memory of the use of the object (Jack-Waugh et al., 2020). For example, the PWD may hold a toothbrush while the caregiver provides oral care or the PWD may hold a utensil while the caregiver provides feeding assistance. Mirroring capitalizes on retained implicit memory through the mirror neuron network, a system that has been found to be relatively preserved in PWD (Farina et al., 2017, 2020). Healthy adults have been shown to increase rate and duration of consumption when they are in the presence of another who is consuming at a higher rate as compared to the presence of another who is not consuming at a higher rate, which suggests that behavior mirroring may extend to activities such as eating and drinking (Long et al., 2011; Nam & Shune, 2020; Shune & Foster, 2017). With the preserved mirror neuron network seen in PWD, caregivers may increase consumption in PWD by providing a visual cue in the form of eating/drinking themselves during the mealtime.

Adaptive Motor Support. Successful eating and swallowing requires appropriate cognitive, sensory, and motor functioning (Rogus-Pulia et al., 2015). The process of eating and swallowing is often affected in PWD due to changes in cognition, sensory abilities and motor control in this population (White et al., 2008). Functional upper-limb motor skills are required for effective self-feeding. Unfortunately, PWD often experience changes in upper-limb functioning is associated with reduced ability to participate in ADLs such as eating and dressing, autonomy is also reduced (Carmeli et al., 2003; Ranganathan et al., 2001). In part due to this loss of autonomy and reduced motor ability, PWD often experience reduction in food intake and have poor nutritional status (Chang & Roberts, 2008). Reduced motor ability to move food from the plate to the mouth and/or reduced oral control result in PWD relying on caregivers for feeding assistance, which

may increase risk of malnutrition, aspiration, and weight loss (Chang & Roberts, 2008; Ranganathan et al., 2001; H. D. Reimer & Keller, 2009). Thus, motor support may also be an important component of mealtime management to reduce risk of further decline associated with reduced motor functioning.

Management of motor changes in PWD has been addressed broadly in two categories, rehabilitative and compensatory. Acquisition, as well as long-term retention, of fine motor skills have been found in PWD through various means of training. Learning of fine motor hand movements that require hand-eye coordination have been found in PWD following repeated practice with a rotary pursuit task (Dick et al., 1995). The rotary pursuit task involves using a pointer to follow a moving target across a screen. As applied to mealtimes, the finding that such a skill could be acquired even by individuals with severe dementia raises the possibility that repeated practice of functional skills (e.g., movement of utensil from plate to mouth) may be used to increase fine motor skills in PWD during mealtimes. Interestingly, acquisition of one fine-motor skill through the use of continuous repeated practice has also been shown to transfer to non-practiced fine motor movements in PWD (Dick et al., 2003). Transfer of fine motor ability from practiced to non-practiced tasks further supports that continuous repeated practice of functional motor skills may increase ability to participate in mealtimes. Acquisition of new skills, however, requires training of these skills, which may not be possible given the myriad of responsibilities burdening caregivers of PWD.

When acquisition of new skills is not a feasible intervention, compensatory strategies may be more appropriate to support retained motor abilities in PWD. In addition to providing additional sensory stimulation as discussed previously, hand-over-hand feeding techniques have also been utilized to support changes in the motor control in PWD as well (Batchelor-Murphy,

2016; Batchelor-Murphy et al., 2017). Another widely used compensatory strategy to address swallowing difficulties due to changes in motor control is the modification of food textures (Carnaby & Harenberg, 2013; Sura et al., 2012). The use of texture modified foods may provide a number of potential benefits, including reduction in the risk of choking, supporting nutrition maintenance in PWD, and increasing independence by enabling the PWD to self-feed more effectively (Austbø Holteng et al., 2017).

However, there is conflicting support demonstrating the effectiveness of texture modified food on safe intake (Beck et al., 2018; Wirth et al., 2017). Recommendation for consumption of texture modified foods is associated with decreased energy and fluid intake in PWD, which may increase risk of malnutrition in this population (Wirth et al., 2017). Additionally, individuals who have been placed on a texture modified diet tend to report reduced quality of life (Jones et al., 2018; Swan et al., 2015). Despite lack of empirical support for the use of texture modified foods in PWD, recommendations for texture modification remains common in clinical practice. Increasing access to nutrient dense food items for between meal supplementation may be one means of increasing nutrition maintenance. Utilization of nutrient-enhanced between meal supplements has been shown to increase nutrient intake and weight in both nursing home residents as well as PWD (Bayne et al., 2022; Hanson et al., 2011). By increasing access to nutrient dense foods that are safe for individuals requiring texture modified diets, caregivers can provide means for care recipients to maintain caloric intake even when smaller amounts of food are consumed, which may reduce the repercussions associated with texture-modified diets and PWD who are already at risk for malnutrition (Bayne et al., 2022; Morley, 2020; Payne & Morley, 2018).

Changes in cognitive functioning and motor control may result in PWD displaying difficulty with utensil use as well as difficulty with transit of food from plate to mouth (Papachristou et al., 2013). Interventions investigating the use of foods that are easily picked up, or "finger foods", have sought to circumvent the use of utensils. The use of finger foods has been shown to increase intake of fruits and vegetables in PWD when compared to provision of meals that do not include finger foods (Visscher et al., 2020). In addition to being easier to pick up and transport to the mouth, finger foods may provide an additional opportunity for increased tactile and visual stimulation. Similar to findings that high visual contrast crockery leads to increased nutritive intake, finger foods that were of high visual contrast were consumed in a larger quantity than finger foods with low visual contrast (Pouyet et al., 2014a). When finger foods were placed in multiple layers to increase visual contrast, PWD consumed more of the finger foods than when they were placed in a single layer on the plate (Pouyet et al., 2014b). Pouyet et al. (2014) additionally investigated choice in PWD by providing a sauce as an additional option to the finger foods. PWD demonstrated significantly increased choice of the finger food with the provision of a sauce versus finger foods provided alone (Pouyet et al., 2014b). These findings support previous findings that high contrast items (crockery, table setting, food items) lead to increased consumption of food during mealtimes, perhaps in the context of increased attention being paid to the food and drink items (Dunne et al., 2004; Pouyet et al., 2014b; Tanaka & Hoshiyama, 2014). Ultimately, both compensatory and rehabilitative interventions demonstrate the ability to capitalize on the retained motor assets of PWD despite changes in motor function in order to increase nutritive intake.

#### **Discussion of Biopsychosocial Interventions**

The global prevalence of people with dementia is expected to approach nearly 156 million PWD by the year 2050, which is more than double the current prevalence (Nichols et al., 2022). This projected rapid increase in PWD highlights the importance of reflecting on current practices and investigating novel models of intervention to support this vulnerable population.

One common deficit associated with dementia progression is difficulty with successful participation in mealtimes. Difficulty participating in mealtimes in PWD is not the result of one factor, but rather a confluence of biological, psychological, and social characteristics common in dementia. Factors leading to mealtime difficulties for PWD may include changes in cognitive status, altered sensorimotor functioning, and increased reliance on caregiver support. The complex nature of biological, psychological, and social factors leading to mealtime difficulty emphasizes the need for a pragmatic model that caregivers can utilize to successfully support PWD during mealtimes. Existing models that inform dementia and mealtime management (WHO-ICF, Spector-Orrell's model of dementia management, and Bisogni et al.'s Framework of Typical Mealtime Processes) come together to support the Biopsychososcial Model of Mealtime Management in Persons with Dementia. The Biopsychosocial Model of Mealtime Management in Persons with Dementia builds on past research around patient-centered care and introduces areas for intervention that can capitalize on PWD's retained capabilities (Bayne & Shune, 2022). Significantly, this model highlights areas where caregivers of PWD can actively intervene in the mealtime process to increase the potential for positive mealtime outcomes (e.g., increased nutritive intake, decrease in BPSD). This model was utilized to, in part, create individualized caregiver training sessions that addresses the multifactorial issues leading to deficits in mealtime performance for PWD.

Successfully assisted mealtimes are a critical component of caring for PWD as mealtimes have large impacts on QoL, maintenance of nutrition, feelings of autonomy, and socialization (Chang & Roberts, 2008; Chen et al., 2009a; Jones et al., 2018; Mitchell et al., 2009; Namasivayam & Steele, 2015; Plowman-Prine et al., 2009a). Additionally, considerations for mealtime management must reflect the dynamic relationship between the biological and psychosocial characteristics that impact the ability of PWD to participate in mealtimes. Biopsychosocial interventions that utilize an asset-based approach to mealtime management have been shown to increase nutritive intake, increase QoL, and decrease BPSD in PWD (Cartwright et al., 2022; Curle & Keller, 2010a; Dick et al., 1995; Paller et al., 2015; Pouyet et al., 2014b; Wright et al., 2006).

The Biopsychosocial Model of Mealtime Management utilized in this study may be a crucial component in designing person-centered, individualized education to assist caregivers provide mealtime assistance for PWD.

#### **Statement of Purpose and Research Questions**

The purpose of the present study was to investigate the impact of targeted, individualized caregiver training via telehealth with the teach-back method on mealtime management for PWD on care recipient outcomes including mealtime intake (research question 1) and occurrences of BPSD (research question 2). Additional caregiver outcomes were explored (research question 3 - 5), including measurements of caregiver burden, caregiver confidence, perception of ease of mealtime assistance provision, quality of life, and levels of preparedness to provide mealtime assistance. Additional care recipient outcomes were also explored (research question 6) involving degree of swallowing impairment and degree of assistance needed during mealtimes.

This study investigated the following four experimental questions with two additional descriptive research questions:

 Is there a functional relation between the provision of individualized biopsychosocial mealtime management training to caregivers of PWD and the level of nutritive intake in the care recipient?

Hypothesis: Participation in individualized biopsychosocial training will result in increased nutritive intake in the care recipient.

2. Is there a functional relation between the provision of individualized biopsychosocial mealtime management training to caregivers of PWD and occurrences of BPSD in the care recipient?

Hypothesis: Participation in individualized biopsychosocial training will decrease occurrences of BPSD displayed by the care recipient during mealtimes.

3. Is there a functional relation between the provision of individualized biopsychosocial mealtime management training to caregivers of PWD and perceived level of difficulty with provision of mealtime assistance?

Hypothesis: Participation in individualized biopsychosocial mealtime management training will decrease perceived level of difficulty with provision of mealtime assistance.

4. Is there a functional relation between the provision of individualized biopsychosocial mealtime management training to caregivers of PWD and perceived level of confidence with provision of mealtime assistance?

Hypothesis: Participation in individualized biopsychosocial mealtime management training will increase perceived level of confidence with provision of mealtime assistance.

5. What are the effects of participation in individualized mealtime education management on caregiver burden, confidence, quality of life, and levels of preparedness to provide mealtime assistance?

Hypothesis: Participation in individualized biopsychosocial mealtime management training will positively affect caregiver factors by decreasing mealtime burden, increasing quality of life, and increase preparedness to provide mealtime assistance.

6. What are the effects of participation in individualized mealtime education management on degree of care recipient's perceived swallowing impairment and care recipient's degree of assistance needed during mealtimes?

Hypothesis: Participation in individualized biopsychosocial mealtime management training will positively affect care recipient outcome measures by decreasing care recipient's perceived swallowing impairment and degree of assistance needed during mealtimes.

## **Chapter III: Methods**

# **Participants**

Three informal caregiver/care recipient dyads were recruited to participate in mealtime management training via telehealth. This represents a total of six participants with three informal caregivers and three PWD. In order to participate in this study, caregivers of PWD were required to meet four criteria for inclusion: (1) be 18 years of age or older; (2) be an informal (e.g., unpaid) caregiver of a person with dementia; (3) have been acting as an informal caregiver for a minimum of two months; and (4) be assisting in some capacity with mealtime activities. The study was open to dyads that include PWD with a range of dementia severity, and severity was not used as inclusion or exclusion criteria. Additionally, as this study was completed via telehealth, participants were required to have stable internet access and a device to connect to Zoom video and audio features. Table 1 provides demographic information for the care recipients and Table 2 provides demographic information for the caregivers who participated in the study.

Table 1.

	Participant Care Recipient	Participant Care Recipient	Participant Care Recipient
	1 "Elizabeth"	2 "Jon"	3 "Ellery"
Gender	Female	Male	Female
Race/Ethnicity	White	Black	Black
Age Bracket	85 +	25-34	75-84
Year of Dementia	2008	2022	2016
Diagnosis			

Participant	care	recipient	demograph	hics
			···· ··· · · · · · · · · · · · · · · ·	

#### Table 2.

	Elizabeth's Caregiver	Jon's Caregiver	Ellery's Caregiver
Gender	Female	Male	Female
Race/Ethnicity	White	Black	Black
Age Bracket	45-54	25-34	55-64
Employment Status	Working Full-Time	Working Full-Time	Working Full-Time
Hours Per Week	20	32	63
Providing Care			
Highest Level of	Master's, Professional, or	Bachelor's Degree	Master's, Professional, or
Education Completed	Doctoral Degree		Doctoral Degree
Relationship to Care	Child of Care Recipient	Nephew of Care	Child of Care Recipient
Recipient		Recipient	

## Participant caregiver demographics

Participants were recruited via word-of-mouth, social media posts, physical flyers posted in healthcare settings (e.g., doctor's offices) and community spaces (e.g., libraries), as well as flyers distributed electronically (e.g., mailing lists, caregiver support forums, Craigslist). Since this study was completed via telehealth using Zoom, participants were welcomed from any geographical location.

# **Study Design**

The study utilized a multi-method design including both single subject and quantitative descriptive methodologies. Utilizing this mix of methodologies allowed for a more comprehensive investigation of the effects of participating in individualized biopsychosocial mealtime education for caregivers of PWD and on both caregiver and care recipient outcomes.

#### Single-Case Design

Single-case methodology was used to determine the functional relation between the education program (independent variable; IV) and caregiver and PWD outcomes (dependent variables; DVs). Single case methodology is a rigorous methodological design that allows for a small number of participants where each participant serves as their own experimental control when measured over multiple periods of time (Horner et al., 2005). In order to serve as their own control, each participant is exposed to a baseline, or "control", condition followed by an intervention, or "experimental", condition. Single-case research design (SCRD) utilizes several different research designs to control for threats to internal validity where the baseline phase (phase A) and intervention phase (phase B) are altered over time or introduced in a "timelagged" fashion across participants (Gast & Ledford, 2014). The current study utilized an A-B multiple baseline across participants non-concurrent SCRD in order to examine the relation between caregiver training and outcome behaviors in both the PWD and caregiver. Origionally, this study was designed to be completed concurrently, however switched to a somewhat nonconcurrent multiple baseline design during the baseline collection phase. The switch from concurrent to non-concurrent baseline data collection was made following an illness in one participant resulting in inability to collect baseline data points on the days that the participant was ill. The use of an A-B SCRD through a multiple-baseline design enabled systematic replication of effects across participants, effectively eliminating potential bias from confounding variables such as small sample sizes and clinically heterogeneous populations (Smith, 2012; Gast et al., 2014). Additionally, single case methodology works well for establishing precedent in novel interventions prior to large-scale intervention styles, such as randomized control trials (Horner et al., 2005).

# **Descriptive Design**

Quantitative methodologies were utilized to assess changes in both caregiver and care recipient outcomes following the intervention. For the caregiver, quantitative data were utilized to further describe caregiver burden and quality of life prior to and following participation in the study. For the care recipient, quantitative information was utilized to describe the degree of perceived swallowing impairment and degree of assistance needed during mealtimes prior to and following participation in the study. Quantitative data were collected via completion of selfreport questionnaires at the beginning and end of the study to compare pre- and post-treatment metrics.

## **Procedure and Analysis**

### **Procedures**

This research project was conducted with the approval from the University of Oregon Institutional Review Board. Table 3 outlines the procedures and data collection process across all study timepoints.

Table 3.

Time	Task	
Time 0	a. Screen Participants	
(Pre- Intervention)	b. Complete Consent	
	c. Assign to groups	
	d. Collect questionnaires	
	e. Complete intake interview to determine	
	self-identified areas of need	
Time 1	a. Begin baseline data collection for single	
(5 days pre-intervention)	case	
Intervention	a. Provision of individualized	
	biopsychosocial caregiver training	

#### Procedures and data collection schedule

Table 3., continued

Time	Task
Time 2	a. End data collection for single case
(post intervention)	Collect questionnaires

Individuals who were interested in participating in the study completed a short Qualtrics survey which could be accessed via a QR code or web address from the recruitment flyer. The purpose of this Qualtrics survey was to determine initial eligibility. If the respondent met initial eligibility, they were asked to provide contact information for the research team to contact them for study enrollment. For participants that met criteria for study inclusion and agreed to participate, informed consent material was explained during a phone or Zoom interview and an additional Qualtrics form was sent to document informed consent. These components comprised enrollment of the study. Once enrolled in the study, demographic information was collected regarding both caregiver and care recipient factors. Caregiver demographic information included gender, age, race/ethnicity, relationship to care recipient, level of education, employment status, and hours of care provided per week. Care recipient demographic information included gender, age, race/ethnicity, and length of dementia diagnosis.

The following section includes a brief review of the relevant components of the Biopsychosocial Model of Mealtime Management that were employed to create the individualized caregiver education intervention in the current study. Following the description of the proposed intervention is a discussion on the data collection procedures for the single-case and quantitative portions of the study.

**Intervention.** The intervention in the current study was based on the Biopsychosocial Model of Mealtime Management in Persons with Dementia (Bayne & Shune, 2022). Literature

has repeatedly supported the need for multicomponent interventions to address the multifactorial concerns caregivers confront when supporting PWD for successful mealtimes (Anderson et al., 2016; Bayne & Shune, 2022; Murphy et al., 2017; Staedtler & Nunez, 2015). Table 4 provides a brief synopsis and outline of the broad categories for intervention and potential specific strategies associated with the implementation of each. These interventions are based on the literature review used to create the Biopsychosocial Model of Mealtime Management introduced in Chapter 2. The interventions and associated strategies in Table 4 were used to guide the creation of the individualized caregiver education programs used in the current study.

Table 4.

Intervention	Specific Strategy
Increased Sensory Stimulation	Provide increased sensory stimulation via tactile support (hand feeding), provide visual stimulation via increased contrast of crockery, provide auditory stimulation by playing familiar music in the background, increase olfactory stimulation by allowing the PWD to be in the vicinity during mealtime preparation
Social Environmental Manipulation	Create a social environment that encourages positive mealtime performance by ensuring the PWD is not eating in isolation, providing verbal cues to maintain attention to mealtime tasks, provide words of encouragement and support during mealtimes, maintain consistent and recognizable mealtime settings, consider modeling appropriate intake of food and liquid
Consideration of PWD Preferences	Include PWD in the decision-making process by providing choice in meal timing, providing options for meals, honoring the preferences of PWD

Mealtime interventions and specific strategies for implementation

Table 4., continued

Intervention	Specific Strategy
Increase Levels of Cognitive Stimulation	Provide increased opportunity for PWD to participate in mealtime preparation via Montessori-based tasks and participate in mindfulness tasks to increase awareness of mealtimes. Provide opportunities for mirroring and bridging during mealtimes
Ensure Appropriate Motor Support	Adaptive motor support recommendations will differ based on the retained motor abilities of the PWD. Ensuring the PWD is sitting upright at a 90-degree angle from lap to torso when able, providing hand-over-hand feeding support, utilization of finger foods, and utilization of adaptive utensils (e.g., leak- free cups) may increase access to food and liquid for PWD.

Of note, mealtime interventions and outcomes do not share a 1:1 relationship. For example, increasing sensory stimulation during the mealtime (e.g., providing tactile support, increasing color contrast of food items on the plate) has been shown to increase feelings of autonomy in PWD, increase nutritive intake, reduce BPSD, and promote mealtime engagement in both the PWD and their caregiver (M. K. Batchelor-Murphy et al., 2017; Dunne et al., 2004; Gitlin et al., 2016; Wegner et al., 2004). In the current study, all of the above intervention components were considered when designing the individualized mealtime education programs for caregivers of PWD, but it must be noted that both PWD and caregiver/care recipient dyads are highly heterogenous populations. In order to address this level of heterogeneity, the process of determining which intervention components were relevant for each dyad was determined through a two-step process.

The first step to determining which intervention components were included in the caregiver education session included an interview with the caregiver. Clinical interviewing is

standard practice when providing intervention in the field of Speech-Language Pathology. Typically, clinical interviewing is completed to collect information that may not be available in the patient's medical chart. Clinical interviews with the patient and their caregiver provided important information to help the clinician better understand the client, their impairment, and their goals for therapy. Clinical interviewing provided a more holistic view of the patient's experience with their deficits, as well as course and severity of the deficit. In the present study, the clinical interview with the PWD's caregiver (as well as the PWD if they were able to participate) was of particular importance as the research team did not have access to past medical history. These interviews took place at Time 0 in Table 3, prior to collection of baseline phase data. Following these interviews, concerns and goals that were reported by the caregiver and PWD were utilized to assist in determining components in the individualized multicomponent caregiver education program. For example, if the caregiver reported that they are uncomfortable with how to appropriately thicken liquids, the PI included a section on methods to thicken liquids and test for appropriate level of viscosity. Table 5 provides examples of questions that were used to guide these semi-structured interviews; this list is not all inclusive as follow-up questions were asked depending on the participants' responses.

Table 5.

# Interview Questions

Clinical Interview Questions - to be adapted based on audience (Caregiver or PWD)

- What are some typical foods and drinks that you/your loved one enjoy? Avoid?
- How often do you/your loved one have meals? Do you/your loved one typically eat three larger meals or snack throughout the day?
- Does your loved one have any texture modification requirements (e.g., thickened liquids or pureed solids)?
- Has your loved one experienced any unintended weight loss?
- Since the dementia diagnosis, have you/your loved one experienced any changes in your typical mealtimes?

### Table 5., continued

Clinical	Interview Questions - to be adapted based on audience (Caregiver or PWD)
- W	Vhat kind of changes have you noticed during mealtimes? How does that make you
fe	eel?
- W	Where do you/your loved one typically have meals (e.g., in front of a TV, at the
k	itchen table)?
- H	lave you noticed any changes in your loved one's posture when they are sitting pright?
u] 11	pright:
- H	low often and to what degree are you providing assistance during mealtimes?
- V	Vhat kind of assistance are you providing?
- W	Vhat is your loved one's response to getting assistance during mealtimes?
- W	Vhat barrier(s) have you noticed that get in the way of successful mealtimes?
- H	Iow do you define mealtime success?

Responses from the semi-structured interviews were used to assist in identifying components that were included in the individualized caregiver education. The second step to determining which intervention components were included in the caregiver education program involved a review of the baseline phase video samples. Additional opportunities for education were identified by the PI and included in the individualized education programs. Education components that were identified during steps one and two were integrated to create an individualized multi-component education program. In Table 6 below, the specific components for each participant's individualized biopsychosocial training session are listed.

The delivery of the individualized education session took place over Zoom during a 30– 90-minute session in which the PI addressed concerns brought up during the initial interview, provided education regarding mealtime changes in PWD, and provided suggestions for modifications to the mealtime environment based on the initial interview and baseline meal observations.
#### Table 6.

Participant	Biopsychosocial Mealtime Training Components
Caregiver/Care Recipient Dyad 1	-Skilled motor movement (reduce frequency of
	alternating utensil presentations (e.g., spoon vs. straw),
	provide oral care prior to meals) to assist with suspected
	oral motor apraxia
	-Fine motor control (offering fine motor support via
	hand-over-hand feeding, encourage self-feeding)
	-Sensory stimulation (increasing contrast in temperature,
	taste, and texture)
	-Gross motor support (ensure comfortable upright sitting position as tolerated)
	Cultural considerations (discuss home country for
	-Cultural considerations (discuss nonic country for
Caragivar/Cara Paginiant Duad 2	Gross motor support (onsure online meal is within visual
Caregiver/Care Recipient Dyad 2	field with supported upright posture)
	Fine motor control (encourage self feeding)
	Propertive muscle training (Improve physiclegical
	reserve with strength training)
	Environmental manipulation (reduce distractions)
	Social environment (ast with enother individual in the
	-social environment (eat with another individual in the
	Cultural considerations (ansura gross motor support
	despite not sitting upright in chair with the use of
	nillows)
Caregiver/Care Recipient Dvad 3	-Environmental Manipulation (Create well lit room
	position care recipient so they are not distracted by outside movement)
	-Fine motor support (reduce need for multiple utensils by
	cutting food for care recipient, encourage self-feeding)
	-Social support (consume meals simultaneously with care
	recipient cut food prior to presenting to care recipient)
	-Sensory stimulation (provide extra seasoning to increase
	palatability of food and drink)
	-Cultural considerations (provide the use of finger-foods
	where able)
	-Proactive muscle training (Improve physiological
	reserve with strength training)

Individualized biopsychosocial mealtime training components used for each participant

Throughout the caregiver education intervention, the PI utilized a health-literacy tool known as "teach-back" to reinforce caregiver education. Teach-back has been shown to be an

effective method reinforcing patient education independently of demographic background (e.g., race, ethnicity, age, education) (Caplin & Saunders, 2015a). Teach-back utilizes four stages to reinforce patient (caregiver) education: explaining, assessing, clarifying, and understanding (DeWalt et al., 2010). In this study, the first stage was completed by explaining strategies to increase mealtime performance to the caregiver (and potentially the PWD if they are able to participate). The second stage, assessment, allowed for assessing the caregivers understanding of the information that has been provided. Stage 2 required asking the caregiver to take the position of educator by paraphrasing the information back to the PI. The PI elicited this paraphrasing by prompting the caregiver to paraphrase information through teach-back questioning (e.g., the PI might prompt, "So that I know that I have explained this correctly, can you tell me in your own words about..."). If the caregiver's explanation of the information indicates that the material was misunderstood, the PI initiated the third stage. In Stage 3, clarification, the PI reviewed the information and encourage the caregiver to ask questions. The PI then repeated the second stage to re-assess for comprehension of education material. Once the caregiver effectively taught-back the educational information without any misunderstandings, this was an indication that Stage 4, comprehension, has been achieved (DeWalt et al., 2010). None of the care recipient PWDs opted to participate in the education sessions.

**Single-Case Data Collection.** A single-case, multiple baseline across participant design was utilized in this study. Participants received the individualized biopsychosocial caregiver education intervention at one of three different points in time, and the order in which they received the intervention was be determined via case randomization. The single subject portion of the study consisted of two phases: baseline (Phase A), and experimental (Phase B). Baseline data collection began simultaneously for all participants across all groups (Time 1 in Table 1),

and at least five baseline data points were collected before the first participant caregiver received the caregiver education intervention. Initiation of intervention was randomized with participants receiving intervention on after six, seven, or eight days of baseline data collection. Details of the individualized intervention packages are available in Table 6. On each day of baseline data collection, caregivers logged into a pre-setup Zoom meeting where the mealtime interaction between caregiver and care recipient was recorded for later review by the research team in order to analyze caregiver and care recipient behaviors. All Zoom meetings had their own unique ID and allowed the caregiver to log into the meeting and record the mealtime interaction independently of research personnel. The caregiver also weighed the plate of food prior to and after consumption for the calculation of meal intake by weight. During a designated period of time (e.g., daily at 6:00 PM), the PI or a member of the research team contacted the caregiver via email or phone to record the caregiver's perceived level of difficulty and confidence in providing mealtime assistance and support. This procedure was followed in the both the baseline and experimental phases. Data collection was terminated following collection of six data points after the third group has participated in intervention (Time 2 in Table 1).

The current study assessed the functional relation of individualized biopsychosocial mealtime training for caregivers (IV) on mealtime performance and caregiver perceptions of mealtime assistance across three DVs: dietary intake measured in grams (DV1), occurrences of behavioral and psychiatric behaviors (BPSD) (DV2), and two caregiver report measures including perceived difficulty providing mealtime assistance and confidence with provision of mealtime assistance (DV3). Primary unit of analysis for DV1 was the difference between pre-and post- mealtime intake in weight via grams (g), primary unit of analysis for DV2 was count of occurrences of BPSD (n), and primary unit of analysis for DV3 included caregiver perceived

level of difficulty and confidence in providing mealtime support quantified using a 0-6 Likerttype scale (Table 7 below). To collect DV3 data, caregivers were asked to respond to two questions "How much difficulty did you experience with providing mealtime assistance today?" and "How confident were you with providing mealtime assistance today?"

Table 7.

Six-point Likert Scale for Difficulty and Confidence Questions

0	Not at all
1	Very slightly
2	Somewhat
3	Moderate
4	Very much
5	Maximal

Quantitative/Descriptive Data Collection. Quantitative data were collected on both caregiver and care recipient characteristics. Data were collected to determine caregiver quality of life and perceptions of burden associated with providing mealtime assistance. Care recipient data were collected to determine degree of swallowing impairment and degree of assistance needed during mealtimes. The caregiver and care recipient outcome measures are described further below. Data on these quantitative metrics were collected online via a Qualtrics survey. Because there was no restriction on dementia severity, there was the possibility that some care recipients may not have been able to participate in survey completion. To allow for study participation of individuals across a wide range of dementia severity, all survey metrics were designed to be completed by proxy (via the caregiver). While generally completed by patients themselves, previous research has suggested that proxies can reliably report on observable symptoms related to swallow function (e.g., weight loss, ability to eat outside the home, pain, increased effort). Caregivers completed the survey at two times during study participation: prior to initiation of

single-subject participation and following completion of participation in the intervention/single subject portion of the study. The link to the Qualtrics survey was shared via email allowing participants to complete the survey independently.

Caregiver burden was measured utilizing a pre- and post-intervention comparison of scores on the Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES; Shune et al., 2020). The CARES is a validated 26-item questionnaire consisting of two subscales: Part A, which examines caregiver response to behavioral and functional changes in the person with dysphagia (10 items), and Part B, which examines subjective reports of caregiver stress (16 items). Subscale A allows for a maximum score of 10 points, and subscale B allows for a maximum of 16 points, with each yes response receiving one point. In both subscales, a higher score is indicative of a higher degree of caregiver burden related to dysphagia care.

Caregiver quality of life was measured utilizing a pre- and post- intervention comparison of responses to the Caregiver Quality of Life Scale (Caregiver QoL Scale; Thomas, 2006). The Caregiver Quality of Life Scale is a validated 20-item questionnaire that characterizes quality of life of caregivers of PWD (Thomas, 2006). The Caregiver QoL scale investigates four major domains as they relate to QoL: the capacity to deal with difficulties associated with a diagnosis of dementia, participation in daily activities, the caregiver's psychological status, and the caregiver's feelings of distress. Caregivers can score a maximum of 100 points with a score of 0 indicating poor QoL and a score of 100 indicating good QoL.

Care recipient's degree of perceived swallowing impairment was measured utilizing a pre- and post-intervention comparison of scores on the 10-Item Eating Assessment Tool (EAT-10; Belafsky et al., 2008). The EAT-10 is a validated, 10-item tool designed to quantify perceived swallowing impairment. Using Likert-type scale responses, the goal of the EAT-10 is

to identify the extent to which patients experience eating-related problems, such as coughing when eating, pain when swallowing, and weight loss due to swallowing impairment. Caregivers were asked to determine if each eating-related problem results in "no problem" (score of 0) up to "severe problem" (score of 4) for a potential total score of 40 points. A score of three or higher is suggestive of increased risk of dysphagia.

Care recipient's degree of assistance needed during mealtimes was measured utilizing a pre- and post-intervention comparison of scores on the Edinburgh Feeding Evaluation in Dementia Scale (EdFed; 1994). The EdFED is used to measure feeding related behaviors to assess the degree of feeding assistance needed in PWD. The EdFED is a ten-item scale where seven items relate to mealtime behaviors in PWD including refusal to eat, turning head away, refusal to open mouth, spitting food out, leaving mouth open allowing food to fall out, leaving food on the plate, and refusal to swallow. An additional three items assess level of assistance PWD require during mealtimes. All items were scored by the caregiver as 0 (never observed during meal), 1 (sometimes observed during meal), and 2 (often observed during meal). Total EdFED scores can range from 0 - 20, with higher scores indicating more observed feeding related behaviors and greater mealtime assistance required (Watson, 1994).

#### **Data Analysis**

**Single-Subject data analysis.** The single case multiple baseline design data first analyzed through visual analysis. Visual analysis was completed for all DVs. The level, trend, variability, immediacy of effect, and consistency of data across both phases and between all participant groups was observed (Gast & Ledford, 2014). Typically, immediacy of effect is a crucial component of establishing a functional relation in single case research design. However,

in the case of severe behavioral conditions or in the case of progressive disease, like dementia, delay in immediacy of effect can be expected (Gast & Ledford, 2014; Ledford et al., 2018).

Further statistical analysis was completed through two additional metrics, Tau-U and D-CES. Tau-U was used to calculate the effect size of the intervention. Tau-U incorporates nonoverlap between baseline and intervention phases while controlling for monotonic trend within the data (Parker et al., 2011). Tau-U was completed using a publicly available calculator at https://jepusto.shinyapps.io/SCD-effect-sizes/. The interpretation of the Tau-U scores used the following values: .65 or lower: weak or small effect; .66 to .92: medium to high effect; and .93 to 1: large or strong effect (Parker et al., 2011).

Design comparable effect size (D-CES) was an additional metric used to calculate effect size that is appropriate for use with multiple baseline single-subject research design. D-CES a statistical measure used to compare the magnitude of an effect across cases in a multiple baseline between subjects design (Pustejovsky et al., 2023). In order to calculate the D-CES, researchers typically use a common metric or formula that takes into account the specific characteristics of the study design and the outcome measure being assessed. This ensures that the effect sizes from different studies can be compared and interpreted meaningfully (Valentine et al., 2016). D-CES calculations were made using the publicly available software at

<u>https://jepusto.shinyapps.io/scdhlm</u> and through *r* statistical computing software (Pustejovsky et al., 2023). D-CES power was interpreted using the following framework: d = 0.2 or lower: small effect; d = 0.5: medium effect; and d = 0.8: large effect (Cohen, 1988).

Calculating effect sizes to augment visual analysis allowed evaluation of the relative impact or effectiveness of individualized biopsychosocial education on caregiver and care recipient outcomes across participants, leading to a more comprehensive understanding of the overall effect.

**Descriptive Data.** Raw scores were calculated via the standard procedures that have been established for each questionnaire including CARES, Caregiver QOL Scale, EAT-10, and EdFED. Pre- and post-intervention raw scores were compared via RCI, paired *t*-tests, and Cohen's *d* (effect size) to augment the SCRD data.

#### **Chapter IV: Results**

The following chapter presents data analyzed to answer the above stated research questions in two main sections: (a) determining a functional relation between the provision of targeted, individualized biopsychosocial mealtime management training and level of nutritive intake, occurrences of BPSD during mealtimes, caregiver confidence, and perceived difficulty of care provision; and (b) determining the effects of participation in individualized biopsychosocial mealtime management on caregiver and care recipient outcomes including perceived swallowing impairment, degree of assistance required during mealtimes, caregiver burden, confidence, quality of life and levels of mealtime related distress.

Determining the Functional Relation Between Individualized Biopsychosocial Mealtime Management Training and Nutritive Intake, Occurrences of BPSD, Caregiver Confidence, and Perceived Difficulty of Care Provision.

This section discusses results for the primary research question as well as secondary research questions which utilized a multiple baseline, between subjects single-case experimental design.

Research Question 1: Is there a functional relation between the provision of individualized biopsychosocial mealtime management training to caregivers of PWD and the level of nutritive intake in the care recipient.

For the first research question, it was hypothesized that care recipient intake (measured in grams (g)) would increase following the caregiver's participation in an individualized biopsychosocial education session. Figure 5 displays the intake grams (g) during mealtimes across baseline and intervention phases for care recipients.

#### Figure 5.





Intake Visual Analysis. Level, or the magnitude of data as indicated by the ordinate scale value, was assessed across all three participants. Baseline stability was not anticipated across all participants, and visual analysis reveals the anticipated variability in intake across all three participant care recipients during the baseline phase. Participant 1 demonstrated the highest level of variability during the baseline phase with varying levels of intake throughout the entire baseline period. Participant 2 demonstrated relative consistency in intake during the baseline

phase with sessions 1, 3, 5, 6, and 7 all between the range of 120 - 140 g. However, in session 2, Participant 2 demonstrated reduced intake of 50 g, and in session 4, Participant 2 consumed 300 g. Participant 3 demonstrated consistent intake between 350 - 470 g for the first six sessions, and a reduction to 214 g in session 8. Participants 2 and 3 demonstrated appropriate stability in baseline condition with approximately 80% of values within  $\pm 25\%$  of the respective median values.

Relative level change was assessed by calculating the median value of the first and second half of the data series in each condition for each participant. For Participant 1, relative level change in the baseline condition is countertherapeutic/deteriorating indicating reduced nutritive intake (g) during the baseline condition. For Participant 1, relative level change in the intervention condition is therapeutic/improving indicating increased nutritive intake (g) during the intervention condition. For Participant 2, relative level change in both the baseline and intervention conditions is therapeutic/improving indicating increased/stable nutritive intake (g) during the baseline and intervention condition. For Participant 3, relative level change in the baseline condition is neither therapeutic/nor countertherapeutic indicating stable nutritive intake (g) during the baseline condition. For Participant 3, relative level change in the intervention condition. For Participant 3, relative level change in the intervention condition. For Participant 3, relative level change in the baseline condition. For Participant 3, relative level change in the intervention condition. For Participant 3, relative level change in the intervention condition. For Participant 3, relative level change in the intervention condition. For Participant 3, relative level change in the intervention condition. For Participant 3, relative level change in the intervention condition. However, across all three participants, there was overlap between baseline and intervention conditions.

Percent of non-overlapping data (PND), established as the percent of non-overlapping data points between two adjacent conditions, was calculated for all three participants to better understand the impact that the intervention had on outcome behavior. Generally speaking, the higher the PND, the more impact the intervention has had on a target behavior. PND between

baseline and intervention phases was found to be 22% for Participant 1, 0% for Participant 2, and 22% for Participant 3 indicating the strongest impact was found for Participants 1 and 3 in terms of increasing nutritive intake (g).

Trend, or slope, was assessed for all participants across both baseline and intervention phases; trend direction and trend stability is detailed below. Trend direction is established as accelerating, decelerating, or zero-celerating, with trend stability established if 80% of data points fall within 25% of the median value for each phase (the stability envelope) (Evans et al., 2014). The following paragraph describes change in trend within phases. For Participant 1, decelerating trend is observed in the baseline condition indicating reduced nutritive intake (g) during the baseline condition, however stability of this trend cannot be established as only 33.3% data points are within the stability envelope. For Participant 1, zero-celerating trend is observed in the intervention condition indicating stability in nutritive intake (g) during the intervention condition; trend stability is established with 80% of data points in the stability envelope. For Participant 2, accelerating trend is observed in both the baseline and intervention conditions which is therapeutic/improving indicating increasing nutritive intake (g) during the baseline and intervention conditions; trend stability is established with 80% of baseline data points and 100% of intervention data points falling within the stability envelope. For Participant 3, decelerating trend is observed in the baseline condition indicating decreasing nutritive intake (g) during the baseline condition; trend stability is established with 88% of data points falling within the stability envelope. For Participant 3, accelerating trend is observed in the intervention condition indicating increased nutritive intake (g) during the intervention condition; trend stability is established with 80% of data points within the stability envelope.

The following paragraph describes relative level change between adjacent conditions. Relative change between two adjacent conditions assists in indicating whether there was a change in behavior in the initial phase after the introduction of the IV (defined here as individualized biopsychosocial caregiver education). Relative level change between adjacent phases does not reveal the immediacy of effect, however a delayed effect is anticipated in the targeted population due to the presence of cognitive impairment associated with dementia. Relative level change between adjacent phases revealed a 145 g improvement in Participant 1, a zero-sum stable intake in Participant 2, and a 106 g deterioration in Participant 3. Delay in immediacy of effect was predicted *a priori*, and this is supported via visual analysis. Therefore, results of visual analysis of immediacy of effect, trend, and level do not suggest demonstration of treatment effect across participants which was supported via effect size calculations as follows.

**Intake (g) Tau-UAnalysis.** In addition to visual analysis, Tau-U calculated to determine the statistical difference in intake between the two phases of the study. Table 8 displays the results of the *Tau-U* analysis, which yielded a weighted score of .033 suggesting a small treatment effect. Although effect size does not imply causation and are independent of experimenter control, (Carter, 2013), results of the *Tau-U* analysis reinforces the visual analysis that we cannot support the existence of a functional relation across three points in time.

Intake (g) D-CES Analysis. In an effort to further augment visual analysis of intake (g) & Tau-U effect sizes, D-CES provided an additional effect size calculation in which data is averaged across participants to estimate an across-participant average effect for MBL designs (Kratochwill et al., 2021). An online web application with r companion was utilized to calculate D-CES for the current study (Pustejovsky et al., 2023; Valentine et al., 2016). D-CES power was interpreted using the following framework: d = 0.2 or lower: *small effect*; d = 0.5: *medium effect*;

and d = 0.8: *large effect* (Cohen, 1988). The analyses yielded an overall weighted score of 0.1025, indicating a *small* treatment effect. Additionally, D-CES provided a standard error score of .2193 and an autocorrelation estimate of .1293. The D-CES scores support the intake (g) visual analysis findings. D-CES intake results can be found in Table 9.

# Research Question 2: Is there a functional relation between the provision of individualized biopsychosocial mealtime management training to caregivers of PWD and occurrences of BPSD in the care recipient?

For the second research question, it was hypothesized that care recipient behavioral and psychiatric symptoms of dementia (BPSD) (measured in number per minute (n/min) via the Edinburgh Feeding Evaluation in Dementia Scale (EdFED)) would decrease following the caregiver's participation in an individualized biopsychosocial education session. The EdFED consists of 10 items that identify mealtime related BPSD. The EdFED consists of two sections; section 1 identifies level of assistance required from caregivers during mealtimes, and section 2 identifies behaviors reflecting functional or cognitive decline related to mealtimes. Because there are two distinct sets of behaviors that are identified in the EdFED, the following section consists of two visual analyses to determine functional relation between the provision of individualized biopsychosocial mealtime management training to caregivers of PWD and occurrences of BPSD in the care recipient. Figure 6 (below) displays the count of BPSD indicating level of assistance needed during mealtimes across baseline and intervention phases for care recipients.

**BPSD Level of Assistance Visual Analysis.** Level, or the magnitude of data as indicated by the ordinate scale value, was assessed across all three participants. Baseline stability was not anticipated across all participants, and visual analysis reveals the anticipated variability in intake

#### Figure 6.



Count of level of assistance BPSD (n/min) across baseline and intervention sessions

across participant care recipients one and two. Participant 2 demonstrated the highest level of variability during the baseline phase with varying levels of BPSD throughout the entire baseline period. Participant 3 demonstrated relatively consistent BPSD ranging from 0.08 to 0.36 BPSD/min. Participants 1 and 3 demonstrated appropriate stability in baseline condition with approximately 80% of values within  $\pm 25\%$  of the respective median values.

Relative level change was assessed by calculating the median value of the first and second half of the data series in each condition for each participant. For Participants 1 and 2, relative level change in the baseline condition is countertherapeutic/deteriorating indicating increased BPSD/min during the baseline condition. For Participants 1 and 2, relative level change in the intervention condition is therapeutic/improving indicating decreased BPSD/min during the intervention condition. For Participant 3, relative level change in the baseline condition is therapeutic/improving indicating both the baseline condition is therapeutic/improving both the baseline and intervention conditions. However, across all three participants, there was overlap between baseline and intervention conditions.

Percent of non-overlapping data, established as the percent of non-overlapping data points between two adjacent conditions, was calculated for all three participants to better understand the impact that the intervention had on outcome behavior. Generally speaking, the higher the PND, the more impact the intervention has had on a target behavior. PND between baseline and intervention phases was found to be 56% for Participant 1, 80% for Participant 2, and 88% for Participant 3 indicating the strongest impact was found for Participant 3 in terms of decreasing BPSD/minute.

Trend, or slope, was assessed for all participants across both baseline and intervention phases; trend direction and trend stability is detailed below. Trend direction is established as accelerating, decelerating, or zero-celerating, with trend stability established if 80% of data points fall within 25% of the median value for each phase (the stability envelope) (Evans et al., 2014). The following paragraph describes change in trend within phases.

For Participant 2, decelerating trend is observed in the baseline condition indicating decreased BPSD/min during the baseline condition; however, stability of this trend cannot be

established as only 40% data points are within the stability envelope. For Participant 2, decelerating trend is observed in the intervention condition indicating decreased BPSD/min during the baseline condition; however, stability of this trend cannot be established as only 60% data points are within the stability envelope. For Participant 1, decelerating trend is observed in both the baseline and intervention conditions which is therapeutic/improving indicating decreased BPSD/min during the baseline and intervention conditions and 56% of intervention data points falling within the stability envelope. For Participant 3, decelerating trend is observed in both the baseline and intervention conditions which is therapeutic/improving indicating decreased BPSD/min during the baseline data points and 56% of intervention data points falling within the stability envelope. For Participant 3, decelerating trend is observed in both the baseline and intervention conditions; trend stability is not able to be established with 71% of baseline data points and 63% of intervention data points falling within the stability envelope.

The following paragraph describes relative level change between adjacent conditions. Relative change between two adjacent conditions assists in indicating whether there was a change in behavior in the initial phase after the introduction of the IV (individualized biopsychosocial caregiver education). Relative level change between adjacent phases does not reveal the immediacy of effect, however a delayed effect is anticipated in the targeted population due to the presence of cognitive impairment associated with dementia (Gast & Ledford, 2014). Relative level change between adjacent phases revealed a 0.24 BPSD/min decrease/improvement in Participant 1, a 0.92 BPSD/min decrease/improvement in Participant 2, and a 0.19 BPSD/min decrease/improvement in Participant 3. Delay in immediacy of effect was predicted *a priori*, and this is supported via visual analysis. Therefore, results of visual analysis of immediacy of effect, trend, and level does suggest demonstration of treatment effect across participant care recipients which is further supported by effect size analysis.

**BPSD Level of Assistance Tau-U Analysis.** In addition to visual analysis, Tau-U was calculated to determine the statistical difference in BPSD between the two phases of the study. Table 8 displays the results of the *Tau-U* analysis, which yielded a weighted score of -.77 suggesting a medium-large treatment effect (Parker et al., 2011). Although effect size does not imply causation and is independent of experimenter control (Carter, 2013), results of the *Tau-U* analysis reinforces the visual analysis that we can support the existence of a functional relation across three points in time.

**BPSD Level of Assistance D-CES Analysis.** In an effort to further augment the visual analysis of BPSD & Tau-U effect sizes, D-CES provided an additional effect size calculation in which data is averaged across participants to estimate an across-participant average effect for MBL designs (Kratochwill et al., 2021). An online web application with r companion, which was utilized to calculate D-CES for the current study (Pustejovsky et al., 2023; Valentine et al., 2016). D-CES power was interpreted using the following framework: d = 0.2 or lower: *small effect*; d = 0.21 - 0.5: *medium effect*; and d = 0.8: *large effect* (Cohen, 1988). The participants yielded an overall weighted score of -0.3647, indicating a *medium* treatment effect. Additionally, D-CES provided a standard error score of .2875 and an autocorrelation estimate of -0.1525. The D-CES scores support BPSD visual analysis findings. D-CES BPSD results can be found in Table 9.

The following section addresses the second portion of the EdFED, which identifies functional and cognitive impairment. Visual analysis for the second portion of BPSD is detailed below. Figure 7 (below) displays the occurrence of BPSD indicating functional or cognitive impairment across baseline and intervention phases for care recipients.

Figure 7.

Occurrence of BPSD (n/min) indicating functional or cognitive impairment across baseline and



intervention phases for care recipients



demonstrated relatively consistent BPSD/minute in the baseline condition with approximately 80% of values within  $\pm$  25% of the respective median values.

Relative level change was assessed by calculating the median value of the first and second half of the data series in each condition for each participant. For Participant 1, relative level change in the baseline condition is countertherapeutic/deteriorating, indicating increased BPSD/min during the baseline condition. For Participant 1, relative level change in the intervention condition is therapeutic/improving indicating decreased BPSD/min during the intervention condition. For Participants 2 and 3, relative level change in the baseline condition is therapeutic/improving the baseline condition is therapeutic/improving indicating the baseline condition. For Participants 2 and 3, relative level change in the baseline condition. For Participants 2 and 3, relative level change in the intervention conditions. For Participants 2 and 3, relative level change in the intervention condition is stable at 0 BPSD/min, indicating no BPSD/min during the intervention conditions. However, across Participants 2 and 3, there was overlap between baseline and intervention conditions.

Percent of non-overlapping data, established as the percent of non-overlapping data points between two adjacent conditions, was calculated for all three participants to better understand the impact that the intervention had on outcome behavior. Generally speaking, the higher the PND, the more impact the intervention has had on a target behavior. PND between baseline and intervention phases was found to be 33% for Participant 1, 100% for Participant 2, and 0% for Participant 3 indicating the strongest impact was found for Participant 1 in terms of decreasing BPSD/minute.

Trend, or slope, was assessed for all participants across both baseline and intervention phases; trend direction and trend stability is detailed below. Trend direction is established as accelerating, decelerating, or zero-celerating, with trend stability established if 80% of data points fall within 25% of the median value for each phase (the stability envelope) (Evans et al.,

2014). The following paragraph describes change in trend within phases.

For Participant 1, accelerating trend is observed in the baseline condition indicating increasing BPSD/min during the baseline condition; trend stability is not able to be established with 67% of baseline data points in the stability envelope. For Participant 1, decelerating trend is observed in the intervention condition indicating decreased BPSD/min during the intervention condition; stability of this trend is not able to be established with 44% data points within the stability envelope. For Participant 2, decelerating trend is observed in the baseline condition indicating decreased BPSD/min during the baseline condition; stability of this trend is established with 100% data points within the stability envelope. For Participant 2, zero-celerating trend is observed in the intervention condition indicating stability of zero BPSD/min; additionally, stability of this trend is established with 100% data points within the stability envelope. For Participant 3, decelerating trend is observed in the baseline and condition indicating decreased BPSD/min during the baseline condition; trend stability is not established with 71% of baseline data points in the stability envelope. For Participant 3, zero-celerating trend is observed in the intervention condition indicating stability of zero BPSD/min; stability of this trend is established with 100% data points within the stability envelope.

The following paragraph describes relative level change between adjacent conditions. Relative change between two adjacent conditions assists in indicating whether there was a change in behavior in the initial phase after the introduction of the IV (individualized biopsychosocial caregiver education). Relative level change between adjacent phases does not reveal the immediacy of effect, however a delayed effect is anticipated in the targeted population due to the presence of cognitive impairment associated with dementia (Gast & Ledford, 2014). Relative level change between adjacent phases revealed a 0.07 BPSD/min decrease/improvement

in Participant 1, a 0.29 BPSD/min decrease/improvement in Participant 2, and a 0.04 BPSD/min decrease/improvement in Participant 3. Delay in immediacy of effect was predicted *a priori*, and this is supported via visual analysis, however, in this circumstance immediacy of effect was apparent for all three participant care recipients. Therefore, results of visual analysis of both BPSD/min outcomes through interpretation of immediacy of effect, trend, and level change suggest demonstration of treatment effect across participants.

**BPSD Functional or Cognitive Impairment Tau-U Analysis.** In addition to visual analysis, Tau-U was calculated to determine the statistical difference in BPSD between the two phases of the study. Table 8 displays the results of the *Tau-U* analysis, which yielded a weighted score of -.75 suggesting a medium-large treatment effect. Although effect size does not imply causation and is independent of experimenter control (Carter, 2013), results of the *Tau-U* analysis reinforces the visual analysis that we can support the existence of a functional relation across three points in time.

**BPSD Functional or Cognitive Impairment D-CES Analysis.** In an effort to further augment the visual analysis of BPSD & Tau-U effect sizes, D-CES provided an additional effect size calculation in which data is averaged across participants to estimate an across-participant average effect for MBL designs (Kratochwill et al., 2021). An online web application with r companion, which was utilized to calculate D-CES for the current study (Pustejovsky et al., 2023; Valentine et al., 2016). D-CES power was interpreted using the following framework: d =0.2 or lower: *small effect*; d = 0.21 - 0.5: *medium effect*; and d = 0.8: *large effect* (Cohen, 1988). The participants yielded an overall weighted score of -1.0809, indicating a *large* treatment effect. Additionally, D-CES provided a standard error score of .3920 and an autocorrelation estimate of 0.1913. The D-CES scores support BPSD visual analysis findings (see Table 9).

Research question 3: Is there a functional relation between the provision of individualized biopsychosocial mealtime management training to caregivers of PWD and perceived level of difficulty with provision of mealtime assistance?

For the third research question, I hypothesized that there would be a reduction in the level of perceived difficulty with provision of mealtime assistance following participation in individualized biopsychosocial mealtime education. The following section will explore this relation with visual analysis of caregiver response to the question "How much difficulty did you experience with providing mealtime assistance today?". Caregivers responded using a likert-type scale with possible responses of "0 Not at all; 1 Very Slightly; 2 Somewhat; 3 Moderate; 4 Very Much; 5 Maximal". Figure 8 (below) displays the caregiver perceived level of difficulty with mealtime provision across baseline and intervention phases.

**Care Difficulty Visual Analysis.** Level, or the magnitude of data as indicated by the ordinate scale value, was assessed across all three participants. Baseline stability was not anticipated across all participants, and visual analysis supports this anticipated lack of baseline stability in participants 2 and 3. Participant 1 is the only caregiver who demonstrates stability in the baseline condition with approximately 80% of values within  $\pm$  25% of the respective median values.

#### Figure 8.

Caregiver perceived level of difficulty with mealtime provision across baseline and intervention

phases



Relative level change was assessed by calculating the median value of the first and second half of the data series in each condition for each participant. For Participant Caregiver 1, relative level change in the baseline condition is countertherapeutic/deteriorating indicating increased difficulty with mealtime provision during the baseline condition. For Participant Caregiver 1, relative level change in the intervention condition is therapeutic/improving indicating decreased difficulty with mealtime provision during the intervention condition. For Participant Caregiver 2, relative level change in the baseline condition is countertherapeutic/deteriorating indicating increased difficulty with mealtime provision during the baseline condition. For Participant Caregiver 2, relative level change in the intervention condition is stable indicating consistent levels of perceived difficulty with mealtime provision during the intervention condition. For Participant Caregiver 3, relative level change in the baseline condition is countertherapeutic/deteriorating indicating increased difficulty with mealtime provision during the baseline condition. For Participant Caregiver 3, relative level change in the baseline provision during the baseline condition. For Participant Caregiver 3, relative level change in the intervention condition is therapeutic/improving indicating decreased difficulty with mealtime provision during the intervention condition. However, across all participant caregivers, there was overlap between baseline and intervention conditions.

Percent of non-overlapping data, established as the percent of non-overlapping data points between two adjacent conditions, was calculated for all three participants to better understand the impact that the intervention had on outcome behavior. Generally speaking, the higher the PND, the more impact the intervention has had on a target behavior. PND between baseline and intervention phases was found to be 50% for Participant Caregiver 1, 0% for Participant Caregiver 2, and 0% for Participant Caregiver 3 indicating the strongest impact was found for Participant Caregiver 1 in terms of decreasing perceived difficulty with mealtime provision.

Trend, or slope, was assessed for all participant caregivers across both baseline and intervention phases; trend direction and trend stability is detailed below. Trend direction is established as accelerating, decelerating, or zero-celerating, with trend stability established if 80% of data points fall within 25% of the median value for each phase (the stability envelope)

(Evans et al., 2014). The following paragraph describes change in trend within phases.

For Participant Caregiver 1, accelerating trend is observed in the baseline condition indicating increasing difficulty with mealtime provision during the baseline condition; trend stability is not able to be established with 67% of baseline data points in the stability envelope. For Participant Caregiver 1, decelerating trend is observed in the intervention condition indicating decreased difficulty with mealtime provision during the intervention condition; stability of this trend is not able to be established with 70% data points within the stability envelope. For Participant Caregiver 2, accelerating trend is observed in the baseline condition indicating increasing difficulty with mealtime provision during the baseline condition; trend stability is not able to be established with 43% of baseline data points in the stability envelope. For Participant Caregiver 2, a zero-celerating trend is observed in the intervention condition indicating stability with perceived level of difficulty with mealtime provision during the intervention condition; stability of this trend is established with 100% data points within the stability envelope. For Participant Caregiver 3, accelerating trend is observed in the baseline condition indicating increasing difficulty with mealtime provision during the baseline condition; trend stability is not able to be established with 50% of baseline data points in the stability envelope. For Participant Caregiver 3, decelerating trend is observed in the intervention condition indicating decreased difficulty with mealtime provision during the intervention condition; stability of this trend is not able to be established with 63% data points within the stability envelope.

The following paragraph describes relative level change between adjacent conditions. Relative change between two adjacent conditions assists in indicating whether there was a change in behavior in the initial phase after the introduction of the IV (individualized

biopsychosocial caregiver education). Relative level change between adjacent phases does not reveal the immediacy of effect, however a delayed effect is anticipated in the targeted population due to the presence of cognitive impairment associated with dementia (Gast & Ledford, 2014). Given the presence of cognitive impairment, it is expected that there would be a delay in treatment effects for both care recipient and caregiver outcomes as a result of the increased level of complexity associated with the neurodegenerative diagnosis. Relative level change between adjacent phases revealed a 1-point decrease/improvement in Participant Caregiver 1, a 1-point decrease/improvement in Participant Caregiver 2, and a 0-point change between baseline and intervention phases in Participant Caregiver 3. Delay in immediacy of effect was predicted *a priori*, and this is supported via visual analysis with all participants. Participants one and three demonstrated decreased difficult ratings after three sessions and participant two demonstrated stability across the entire intervention session.

Therefore, results of visual analysis of caregiver confidence outcomes through interpretation of immediacy of effect, trend, and level change suggest demonstration of treatment effect across participants.

**Care Difficulty Tau-U Analysis.** In addition to visual analysis, Tau-U was calculated to determine the statistical difference in difficulty with mealtime assistance between the two phases of the study. Table 8 displays the results of the *Tau-U* analysis, which yielded a weighted score of -.39 suggesting a small treatment effect. Although effect size does not imply causation and is independent of experimenter control (Carter, 2013), results of the *Tau-U* analysis reinforces the visual analysis that we cannot support the existence of a functional relation across three points in time.

Care Difficulty D-CES Analysis. In an effort to further augment the visual analysis of

Care Difficulty & Tau-U effect sizes, D-CES provided an additional effect size calculation in which data is averaged across participants to estimate an across-participant average effect for MBL designs (Kratochwill et al., 2021). An online web application with r companion, which was utilized to calculate D-CES for the current study (Pustejovsky et al., 2023; Valentine et al., 2016). D-CES power was interpreted using the following framework: d = 0.2 or lower: *small effect*; d = 0.21 - 0.5: *medium effect*; and d = 0.8: *large effect* (Cohen, 1988). The participants yielded an overall weighted score of -0.3604, indicating a *medium* treatment effect. Additionally, D-CES provided a standard error score of .2572 and an autocorrelation estimate of -0.1139. The D-CES scores support Care Difficulty visual analysis findings. D-CES care difficulty results can be found in Table 9.

### Research Question 4: Is there a functional relation between the provision of individualized biopsychosocial mealtime management training to caregivers of PWD and perceived level of confidence with provision of mealtime assistance?

For the fourth research question, I hypothesized that there would be an increase in the level of perceived confidence with provision of mealtime assistance following participation in individualized biopsychosocial mealtime education. The following section will explore this relation with visual analysis of caregiver response to the question "How confident were you with providing mealtime assistance today?". Caregivers responded using a likert-type scale with possible responses of "0 Not at all; 1 Very Slightly; 2 Somewhat; 3 Moderate; 4 Very Much; 5 Maximal". Figure 9 (below) displays the caregiver perceived level of confidence during mealtime provision across baseline and intervention phases.

#### Figure 9.

Caregiver perceived level of confidence during mealtime provision across baseline and

intervention phases



**Caregiver Confidence Visual Analysis.** Level, or the magnitude of data as indicated by the ordinate scale value, was assessed across all three participants. Baseline stability was not anticipated across all participants, and visual analysis supports this anticipated lack of baseline stability in Participant 2. Participant Caregivers 1 and 3 both demonstrated stability in the baseline condition with approximately 80% of values within  $\pm$  25% of the respective median values.

Relative level change was assessed by calculating the median value of the first and second half of the data series in each condition for each participant. For Participant Caregiver 1, relative level change in the baseline condition is countertherapeutic/deteriorating indicating decreasing confidence with mealtime provision during the baseline condition. For Participant Caregiver 1, relative level change in the intervention condition is therapeutic/improving indicating increasing confidence with mealtime provision during the intervention condition. For Participant Caregiver 2, relative level change in the baseline condition is therapeutic/improving indicating increased confidence with mealtime provision during the baseline condition. For Participant Caregiver 2, relative level change in the intervention condition is contratherapeutic/declining indicating decreased levels of perceived difficulty with mealtime provision during the intervention condition. For Participant Caregiver 3, relative level change in the baseline condition is countertherapeutic/deteriorating indicating decreasing confidence with mealtime provision during the baseline condition. For Participant Caregiver 3, relative level change in the intervention condition is therapeutic/improving indicating increased confidence with mealtime provision during the intervention condition. However, across all participant caregivers, there was overlap between baseline and intervention conditions.

Percent of non-overlapping data, established as the percent of non-overlapping data points between two adjacent conditions, was calculated for all three participants to better understand the impact that the intervention had on outcome behavior. Generally speaking, the higher the PND, the more impact the intervention has had on a target behavior. PND between baseline and intervention phases was found to be 70% for Participant Caregiver 1, 38% for Participant Caregiver 2, and 38% for Participant Caregiver 3 indicating the strongest impact was found for Participant 1 in terms of increasing confidence during mealtime provision.

Trend, or slope, was assessed for all participants across both baseline and intervention phases, trend direction and trend stability is detailed below. Trend direction is established as accelerating, decelerating, or zero-celerating, with trend stability established if 80% of data points fall within 25% of the median value for each phase (the stability envelope) (Evans et al., 2014). The following paragraph describes change in trend within phases.

For Participant Caregiver 1, decelerating trend is observed in the baseline condition indicating decreasing confidence with mealtime provision during the baseline condition; trend stability is established with 83% of baseline data points in the stability envelope. For Participant Caregiver 1, accelerating trend is observed in the intervention condition indicating increased confidence with mealtime provision during the intervention condition; stability of this trend is established with 100% data points within the stability envelope. For Participant Caregiver 2, accelerating trend is observed in the baseline condition indicating increasing confidence with mealtime provision during the baseline condition; trend stability is not able to be established with 57% of baseline data points in the stability envelope. For Participant Caregiver 2, a decelerating trend is observed in the intervention condition indicating decreasing confidence with mealtime provision during the intervention condition; stability of this trend is established with 100% data points within the stability envelope. For Participant Caregiver 3, decelerating trend is observed in the baseline condition indicating decreasing confidence with mealtime provision during the baseline condition, trend stability is established with 100% of baseline data points in the stability envelope. For Participant Caregiver 3, accelerating trend is observed in the intervention condition indicating increased confidence with mealtime provision during the intervention condition; stability of this trend is established with 100% data points within the stability envelope.

The following paragraph describes relative level change between adjacent conditions. Relative change between two adjacent conditions assists in indicating whether there was a change in behavior in the initial phase after the introduction of the IV (individualized biopsychosocial caregiver education). Relative level change between adjacent phases does not reveal the immediacy of effect, however a delayed effect is anticipated in the targeted population due to the presence of cognitive impairment associated with dementia (Gast & Ledford, 2014). Relative level change between adjacent phases revealed a 1-point increase/improvement in Participant Caregiver 1, a 1-point increase/improvement in Participant Caregiver 2, and a 0-point change between baseline and intervention phases in Participant Caregiver 3. Delay in immediacy of effect was predicted *a priori*, and this is supported via visual analysis. However, in this circumstance, immediacy of effect, trend, and level change suggest demonstration of treatment effect across participants.

**Caregiver Confidence Tau-U Analysis.** In addition to visual analysis, Tau-U was calculated to determine the statistical difference in intake between the two phases of the study. Table 8 displays the results of the *Tau-U* analysis, which yielded a weighted score of .70 suggesting a medium to high treatment effect (Parker et al., 2011). Although effect size does not imply causation and is independent of experimenter control (Carter, 2013), results of the *Tau-U* analysis reinforces the visual analysis that we can support the existence of a functional relation across three points in time.

**Caregiver Confidence D-CES Analysis** In an effort to further augment the visual analysis of Caregiver Confidence & Tau-U effect sizes, D-CES provided an additional effect size

calculation in which data is averaged across participants to estimate an across-participant average effect for MBL designs (Kratochwill et al., 2021). An online web application with r companion, which was utilized to calculate D-CES for the current study (Pustejovsky et al., 2023; Valentine et al., 2016). D-CES power was interpreted using the following framework: d = 0.2 or lower: *small effect*; d = 0.21 - 0.5: *medium effect*; and d = 0.8: *large effect* (Cohen, 1988). The participants yielded an overall weighted score of 1.3010, indicating a *large* treatment effect. Additionally, D-CES provided a standard error score of 0.4540 and an autocorrelation estimate of 0.3984. The D-CES scores support Caregiver Confidence visual analysis findings. D-CES Caregiver Confidence results can be found in Table 9.

Table 8.

	<b>*</b> * 1	~	
Metric	Value	Score	
Intake (g)			
	Tau-U	0.033	
	z-Score	0.186	
	<i>p</i> -Value	0.853	
BPSD-Level of Assistance	e		
	Tau-U	-0.77	
	z-Score	-3.98	
	<i>p</i> -Value	<.001	
BPSD-			
Functional/Cognitive			
Impairment			
	Tau-U	-0.75	
	z-Score	-3.95	
	<i>p</i> -Value	<.001	
Caregiver's Perception of	f		
Difficulty			

Tau-U results

	Tau-U	-0.75
	z-Score	-3.95
	<i>p</i> -Value	<.001
egiver's Perception of		
iculty		
	Tau-U	-0.39
	z-Score	-2.22
	<i>p</i> -Value	0.02

#### Table 8., continued

Metric	Value	Score
Caregiver's Perception of		
Confidence		
	Tau-U	0.70
	z-Score	3.98
	<i>p</i> -Value	< 0.001

*Note.* The Single Case Research free calculator (<u>http://www.singlecaseresearch.org/</u>) was used to calculate Tau-U effect size value.

#### Table 9.

#### **D-CES** results

Metric	Value	Score
Intake (g)		
	D-CES	0.1025
	Standard Error	0.2193
	Autocorrelation Estimate	0.1293
BPSD-Level of Assistance		
	D-CES	-0.3647
	Standard Error	0.2875
	Autocorrelation Estimate	-0.1525
BPSD-		
Functional/Cognitive		
Impairment		
	D-CES	-1.0809
	Standard Error	0.3920
	Autocorrelation Estimate	0.1913
Caregiver's Perception of		
Difficulty		
	D-CES	-0.3604
	Standard Error	0.2572
	Autocorrelation Estimate	-0.1139
Caregiver's Perception of		
Confidence		
	D-CES	1.3010
	Standard Error	0.4540
	Autocorrelation Estimate	0.3984

#### **Treatment Fidelity**

In order to evaluate the level of agreement between the two independent observers, a

weighted Cohen's Kappa was calculated to assess the level of agreement between both observers on the application of caregiver-directed mealtime management strategies. Two trained members of the research team served as the independent observers of the study. A total of 25% of baseline sessions (six sessions) and 25% of intervention sessions (six sessions) were rated for fidelity. Procedural fidelity was rated on a binary scale of "present = 1 and absent = 0". The decision to use a binary rating was made as not all caregiver-directed mealtime management strategies were able to be assessed via total count (e.g., cutting up solids to be bite-sized prior to initiation of mealtime). Baseline sessions were rated to ensure absence of caregiver-directed mealtime management strategies, and experimental sessions were rated to ensure inclusion of caregiverdirected mealtime management strategies. For Participant 1, the caregiver demonstrated use of caregiver-directed mealtime management strategies in 0% of baseline sessions as compared to 100% of intervention sessions. For Participant 2, the caregiver demonstrated use of caregiverdirected mealtime management strategies in 0% of baseline sessions compared to 85% of intervention sessions. For Participant 3, the caregiver demonstrated use of caregiver-directed mealtime management strategies in 0% of baseline sessions compared to 100% of intervention sessions. Results indicated acceptable treatment fidelity, k = 1.0, p < 0.001.

#### **Descriptive Data**

A dependent measures *t*-test was conducted to compare pre-post outcome measures utilizing participant responses from pre- and post-participation questionnaires. An additional measurement was completed to further elucidate whether change in the participants' pre- and post-intervention scores are statistically significant, the Reliable Change Index (RCI). RCI is calculated by assessing change in the participant score divided by the standard error for the respective test; an RCI score of 1.96 or greater is considered statistically significant (Jacobson & Truax, 1991). Data for each portion of the questionnaire were analyzed independently.

## Research question 5: What are the effects of participation in individualized mealtime education management on caregiver burden, confidence, quality of life, and levels of distress?

Results of the paired *t*-test indicated that there is a significant improvement between Caregiver QoL pre-intervention (M = 53.3, SD = 20.2) and Caregiver QoL post-intervention (M= 61.7, SD = 17.6; t(2) = 5, p = .038). The effect size, as measured by Cohen's d, was d = 2.88, indicating a large effect size. RCI calculations support this significance finding with a score of 16.82, indicating reliable clinically significant change. Results of the paired *t*-test indicated that there is a non-significant difference between CARES-A pre-intervention (M = 6.7, SD = 2.1) and CARES-A post-intervention (M = 4.7, SD = 4.5; t(2) = 1.3, p = .321). The effect size, as measured by Cohen's d, was d = 0.75, indicating a medium effect size. RCI calculations support this significance finding with a score of 1.03 indicating no reliable change. Results of the paired *t*-test indicated that there is a non-significant difference between CARES-B pre-intervention (M = 8, SD = 4.4) and CARES-B post-intervention (M = 7.7, SD = 3.1; t (2) = 0.3, p = .808). The effect size, as measured by Cohen's d, was d = 0.16, indicating a very small effect size. RCI calculations support this significance finding with a score of 0.13 indicating no reliable change. Results of the paired *t*-test indicated that there is a significant improvement between caregiver's perceived difficulty with providing assistance pre-intervention (M = 7.3, SD = 0.6) and caregiver caregiver's perceived difficulty while providing assistance post-intervention (M = 9, SD = 0; t(2)) = 5, p = .038). The effect size, as measured by Cohen's d, was d = 2.89, indicating a large effect size. Results of the paired-t test indicated that there is a significant difference between caregiver ratings of confidence while providing assistance pre-intervention (M = 7, SD = 1) and caregiver
ratings of confidence while providing assistance post-intervention (M = 9.3, SD = 0.6; t(2) = 7, p = .020). The effect size, as measured by Cohen's d, was d = 4.04, indicating a large effect size.

# Research question 6: What are the effects of participation in individualized mealtime education management on degree of care recipient's perceived swallowing impairment, care recipient's quality of life, and care recipient's degree of assistance needed during mealtimes?

Results of the paired *t*-test indicated that there is a non-significant difference between EAT-10 pre-intervention (M = 22.3, SD = 19.3) and EAT-10 post-intervention (M = 19.7, SD = 17; t(2) = 1.8, p = .208). The effect size, as measured by Cohen's d, was d = 1.06, indicating a large effect size. RCI calculations, additionally, support a clinically significant change with a score of 8.84 indicating clinically meaningful change has occurred. Results of the paired *t*-test indicated that there is a non-significant difference between EdFED pre-intervention (M = 10.7, SD = 4.9) and EdFED post-intervention (M = 9.7, SD = 3.2; t(2) = 0.9, p = .478). The effect size, as measured by Cohen's d, was d = 0.50, indicating a medium effect size. RCI was not able to be calculated for EdFED responses as standard deviation and Cronbach's alpha of the normative sample is not published (Watson, 1994). Results of the paired *t*-test indicated that there is a nonsignificant difference between QoL AD pre-intervention (M = 26.5, SD = 3.5) and QoL AD postintervention (M = 30, SD = 4.2), t(1) = 7, p = .09). The effect size, as measured by Cohen's d, was d = 2.80, indicating a large effect size. RCI calculations, support a clinically significant change with a score of 8.94 indicating clinically meaningful change has occurred.

#### **Appraisal of Research Design**

Within SCED it is essential that designs are evaluated to ensure that they adhere with established single-case criteria. To confirm sufficient methodological SCED adherence to published standards an evaluation tool was selected, the Risk of Bias in N-of-1 Trials (ROBiNT) scale (Tate et al., 2015). ROBiNT uses a 15-item scale that evaluates the rigor with which the design meets single-case parameters. Items are classified into two subscales: (1) internal validity and (2) external validity. Items are rated on a 3-point scale (0, 1, 2). Evaluation can result in a maximum score of 30 points, suggesting all criteria are met fully.

Table 10 presents the scores for items on the scale, subscale, and a summative score. The design for the current study received a total score of 24 out of 30 possible points. On the internal validity subscale, the design received a total score on of 12 out of 14 possible points. Four items of the subscale fully met criteria (design, sampling of behavior, blind assessors, inter-rater reliability, and treatment adherence), and the remaining two items partially met criteria (randomization and participant/therapist blinding). On the external validity subscale, the design scored 12 out of 16 possible points. Five items of the subscale fully met criteria (baseline characteristics, therapeutic setting, dependent variable, raw data record, and data analysis), two items partially met criteria (independent variable and generalization), and one item did not meet criteria (replication).

Table 10.

Item	Score	Rationale
Internal validity		
Design	2	At least three demonstrations of effect
Randomization	1	Entry into the intervention phase was randomized
Sampling of behavior	2	Less than five data points, but a minimum of three data points in the baseline phase; five data points in the treatment phase
Blinding (participant/therapist)	2	Only the patient was blinded to condition
Blinding assessors	1	Raters were blinded to conditions
Inter-rater reliability	2	25% of recordings in each phase sampled for inter-rater agreement with at least 80% agreement
Treatment adherence	2	minimum of 20% of sessions were rated in each condition; demonstration of strong adherence to intervention
External validity		
Baseline characteristics	2	Provided a description of inclusionary participant characteristics and baseline clinical variables

## ROBiNT Scale for Design Appraisal

# Table 10., continued

Item	Score	Rationale
Therapeutic setting	2	Sessions were conducted online via a telehealth platform with participation occurring within the home setting for each participant
Dependent variable	2	Precise and repeatable measures used with operational definitions, including specification of correct/incorrect criteria
Independent variable	1	Training was described; type of intervention applications varied
Raw data record	2	Performance data presented in an aggregated format
Data analysis	2	Systematic visual analysis completed in conjunction with quantitative calculations of effect size
Replication	0	No replication was incorporated into the study
Generalization	1	Generalization was measured via post intervention validated survey completion
<u>Scores</u>		
Internal validity	12 (86%)	
External validity	12 (75%)	
Total	24 (80%)	

#### **Chapter V: Discussion**

The purpose of the present study was to evaluate the impact of individualized biopsychosocial intervention on clinical and subjective outcomes associated with dysphagia/mealtime management in the dementia community. The current literature base surrounding mealtime management largely comprises singular interventions for rehabilitation of dementia's deleterious mealtime effects. However, research has supported the need for multicomponent interventions to address the multifactorial concerns caregivers confront when supporting PWD for successful mealtimes (Anderson et al., 2016; Bayne & Shune, 2022; Murphy et al., 2017; Staedtler & Nunez, 2015). Despite this identification of need for multifaceted treatments, research supporting the implementation of multifaceted treatment approaches for mealtime management in dementia is deficient. To address this research-topractice gap, the present study explored a variety of evidence-based mealtime management strategies that targeted factors for both the caregiver and care recipient.

It was hypothesized that the provision of individualized biopsychosocial mealtime management education would improve both care recipient (i.e., BPSD, nutritive intake, QoL, degree of swallowing impairment, degree of assistance required) and caregiver (i.e., burden, confidence, quality of life, levels of preparedness to provide mealtime assistance) factors. The following chapter provides an interpretation of the primary findings of the present study, followed by a discussion of limitations, and concludes with an exploration of clinical implications and future lines of research.

#### **Primary Findings**

The primary research question sought to identify if the delivery of individualized biopsychosocial education results in increased nutritive intake via measurement in (g). For all

participants, findings showed that following the caregiver's participation in the education session, care-recipient intake either increased or stabilized. Both visual and quantitative analyses support a small effect for participants in this study. Visual analysis revealed an immediate increase in intake for Participant 1 and a delay in increase of intake for Participant 3; intake for both participants was trending toward increased intake following intervention. Participant 2 did not show immediacy of effect and demonstrated stability of intake level with a zero-celerating trend. Despite the lack of increased intake in Participants 2 and as was also observed in Participant 3, these care recipients were noted to consume the entirety of all meals that were provided post-intervention in the majority of sessions; with 100% of provided meal consumed, these participants may not have had the opportunity for further increased intake.

A secondary research question was established to determine whether participation in individualized biopsychosocial education results in a reduction in behavioral and psychiatric symptoms of dementia (BPSD). Findings revealed that following caregivers' participation in individualized biopsychosocial education care recipients demonstrated a significant treatment effect. This treatment effect was supported by both visual analysis and effect size calculations. Measurement of BPSD was operationalized by the Edinburgh Feeding Evaluation in Dementia Scale (EdFED). The EdFED is divided into two parts; (1) quantifying the level of assistance required through counts of instances requiring physical assistance and instances of spilling food, and (2) quantifying instances of behaviors that reflect functional or cognitive decline through counts of turning head away, refusal to open mouth, spitting food out, and leaving mouth open.

Visual analysis and effect size calculation revealed that for the first portion of the EdFED, level of assistance required by the care recipient, there was a medium-large effect and functional relation between provision of individualized biopsychosocial education and level of

assistance required by the care recipient. Immediacy of effect was observed for all three care recipients, along with change and level and overall downward trend indicating decreased assistance required. For Care Recipient 1, this was due to increased independence during mealtimes via self-feeding. Although frequency of self-feeding was not an original part of the research plan, during the baseline phase the caregiver was noted to provide direct feeds for all intake (caregiver feeds all food and drink without care recipient participating in upper extremity movement). Following intervention, Care Recipient 1 regularly self-feed allowing for increased independence with feeding and decreased reliance on the caregiver to provide assistance.

Care Recipients 2 and 3 both demonstrated independence with feeding in the baseline phase, however both demonstrated multiple instances of food spilling during transit from plate to mouth. Reduced motor ability to move food from the plate to the mouth and/or reduced oral control can result in PWD relying on caregivers for feeding assistance, which may increase risk of malnutrition, aspiration, and weight loss (Chang & Roberts, 2008; Ranganathan et al., 2001; H. D. Reimer & Keller, 2009). Care Recipient 2 demonstrated an immediate reduction in food spillage in the intervention phase with overall reduced level and trend. This reduction in degree of assistance required indicates that Care Recipient 2 benefitted from instruction on gross motor control and thereby demonstrated better control of the food/drink from plate to mouth. Like Care Recipient 2, Care Recipient 3 also demonstrated an immediate reduction in food spillage following individualized biopsychosocial instruction. Care Recipient 3 required assistance with fine motor control and demonstrated increased control of the utensil following the education session.

Visual analysis and effect size calculation revealed that for the second portion, quantifying instances of behaviors characteristic of functional or cognitive decline, there was a

medium-large effect and functional relation between provision of individualized biopsychosocial education and instances of behaviors characteristic of functional or cognitive decline. Immediacy of effect was observed for all three care recipients, along with change and level and overall downward trend indicating decreased assistance required. For Care Recipient 1, this was due to reduction in turning head away and refusal to open mouth during mealtimes. It is not within the scope of this study to interpret the behavior of the care recipient, and refusal of mouth opening has a multitude of potential causes. However, Care Recipient 1 demonstrated many instances of non-mouth opening, which may be non-verbal communication, or it may be a manifestation of a physiological difficulty. Of note, this behavior was noticed to increase following the switch from a straw to a spoon presentation. Straw presentations require narrow labial closure around the utensil while spoon presentations require a wider labial opening to accommodate the increased size of the utensil. It is impossible to confirm, but it was hypothesized that switching between the straw and spoon created confusion for the care recipient's motor plan. During the individualized biopsychosocial education session, Caregiver 1 was instructed on management of the mouth closure behavior.

Visual analysis and effect size calculation revealed that for the second portion of the EdFED, quantifying instances of behaviors characteristic of functional or cognitive decline, there was a medium-large effect and functional relation between provision of individualized biopsychosocial education and instances of behaviors characteristic of functional or cognitive decline. Immediacy of effect was observed for all three care recipients, along with change and level and overall downward trend indicating decreased assistance required. For care recipient 1, this was due to reduction in turning head away and refusal to open mouth during mealtimes. It is not within the scope of this study to interpret the behavior of the care recipient, and refusal of

mouth opening has a multitude of potential causes. However, care recipient 1 demonstrated many instances of non-mouth opening, which may be non-verbal communication or it may be a manifestation of a physiological difficulty. Of note, this behavior was noticed to increase following the switch from a straw to a spoon presentation. Straw presentations require narrow labial closure around the utensil while spoon presentations require a wider labial opening to accommodate the increased size of the utensil.

Loss of skilled movement is commonly observed in moderate or severe disease stages of dementia, as individuals have difficulties with limb movements, handling utensils, and eating (Yliranta et al., 2023). It is impossible to confirm, but it was hypothesized that switching between the straw and spoon created confusion for the care recipient's motor plan. During the individualized biopsychosocial education session, Caregiver 1 was instructed on management of the mouth closure behavior. Caregiver 1 was instructed that mouth closure may be a communication attempt, but it could be the result of an interrupted motor plan. Following this instruction, Care Recipient 1 demonstrated an immediate reduction in instances of mouth opening refusal as well as reduction in head turning away from food presentation resulting in better acceptance of food trials. Care recipients 2 and 3 both showed immediate reduction in behaviors indicative of functional or cognitive decline to zero. In the baseline phase, both care recipients demonstrated instances of food falling out of the mouth and leaving the mouth open. The caregivers were instructed on strategies to increase retention of food in the mouth including co-eating (caregivers were encouraged to eat with the care recipient to provide a visual cue for appropriate mouth closure) and postural support strategies for increased food retention (e.g., sitting upright at 90-degrees, ensuring the food was in bite size pieces, ensuring food and drink was within reach from a seated position).

Research questions three and four were established to determine if there was a functional relation between the provision of individualized biopsychosocial mealtime management education and the caregivers' reported level of difficulty and confidence in providing mealtime assistance. None of the participants demonstrated immediacy of effect with perceived level of difficulty. Despite this, there was an overall medium effect size indicating that there was decreased perception of difficulty with mealtime provision. Complimenting this reduced level of difficulty is an increase in level of confidence. Immediacy of effect for Participant 1's perceived level of confidence. Although there was not immediacy of effect across all three participants, there was an increase in the overall level and trend for all three participants.

Supporting the visual analysis, effect size calculations demonstrated a large effect on degree of caregiver confidence with mealtime management following individualized biopsychosocial instruction. Although there was not an observed immediacy of effect for Caregiver 1, this was not at all a surprise due to the severity and complexity of the symptoms demonstrated by Care Recipient 1 (Gast & Ledford, 2014; Ryan-Madonna et al., 2019). Confidence is typically not a characteristic that is established immediately following intervention (Ryan-Madonna et al., 2019). Although Care Recipient 1 demonstrated increased complexity of symptoms, following a period of two sessions of successful implementation of biopsychosocial strategies, Caregiver 1's confidence increased and this level of confidence was largely maintained throughout the intervention phase.

Research questions five and six sought to determine the effect of participation in individualized mealtime education on both caregiver and care recipient factors. Research question five examined caregiver burden related to swallowing/eating, confidence with providing

mealtime assistance, quality of life, and perceived difficulty with mealtime delivery, and preparedness to provide mealtime assistance. Descriptive statistics revealed a significant increase in caregiver QoL and confidence following participation in biopsychosocial education surrounding mealtime management. There was not, however, a significant reduction in caregiver burden. This finding is not altogether surprising, as dementia is a progressive neurodegenerative disease and a patient's condition will ultimately continue to deteriorate over time. However, despite consistent ratings of caregiver burden, caregivers displayed increased confidence and quality of life indicating the caregiver may be better equipped to deal with burden associated with care delivery to a terminally ill patient. Research question six examined care recipient quality of life, degree of assistance needed and degree of swallowing impairment. Descriptive statistics revealed that there was not a significant difference between care-recipient degree of swallowing impairment or degree of assistance required following participation in this study. Additionally, there was not a significant difference established in *t*-test calculation of caregiver QoL, but there was a clinically significant increase in quality of life as indicated by RCI. Although this study is likely underpowered for use of *t*-test calculation, clinically significant increased quality of life is a promising result and provides support for further investigation.

#### **Discussion of Treatment Fidelity**

A high level of treatment fidelity was noted among both observers in this study. This level of treatment fidelity indicates that with a single education session with a trained provider, caregivers of PWD can reliably and consistently deliver clinically meaningful care for their care recipients. In addition to provision of clinically meaningful care, quality of life increased for both the caregivers and care recipients. This increase in quality of life is in congruence with consistent levels of burden level of swallowing impairment which indicates that despite the progressive and persistent symptomatology associated with dementia, caregivers and care recipients may expect increased wellbeing.

#### Limitations

Although the findings of this study offer compelling evidence for the effect of biopsychosocial education sessions on caregiver/care recipient factors, findings should be interpreted with caution. The following section describes limitations and challenges that impacted this study. Limitations are described in terms of (1) contextual factors, (2) methodological factors, and (3) measurement factors. It is important to note that these factors can ultimately weaken the overall strength and generalizability of the results.

#### **Contextual Factors**

Although this study was designed to be completed via telehealth, it must be acknowledged that this study was completed during the COVID-19 pandemic. While an evaluation of treatment delivery model is beyond the scope of this study, clinically significant findings and good measures of treatment fidelity indicate that treatment via telehealth is a feasible mode of intervention. Despite this, it must be acknowledged that the ongoing pandemic does hold certain implications for this study. For example, participants in this study may have been drawn to this study because they were not receiving the same level of in-person care that they may have under a non-pandemic environment. Additionally, it must be acknowledged that several participant illnesses impacted this study. One caregiver needed to delay care to their care recipient due to a suspected COVID-19 diagnosis. In another instance of illness impacting the study, one care recipient was hospitalized with a suspected COVID-19 diagnosis. Two additional participants unenrolled in the study secondary to hospitalizations. However, despite

complications posed by the pandemic, this population is medically fragile, and illness related complications are inevitable.

#### Methodological Factors

Although multiple baseline between subjects single case designs stipulate demonstration of effect across three separate baselines to confirm the existence of a functional relation (Kratochwill et al., 2021), utilization of SCED brings into question generalizability of findings to the larger population. However, an advantage of this study design, especially in the context of a medically fragile population with highly variable presentations, is that each participant acts as their own control (Gast & Ledford, 2014). An additional limitation of this study was the need to switch to a somewhat non-concurrent multiple baseline design during the baseline collection phase. The switch from concurrent to non-concurrent baseline data collection was made following an illness in one participant resulting in inability to collect baseline data points on the days that the participant was ill. Despite this limitation, threats to internal validity were mitigated by randomizing initiation of the intervention phase following baseline session six, seven, or eight. Although this decision was made as a result of a participant's illness, experimental flexibility in SCED allowed for appropriate measurement of all data points in a reasonable time frame (May-June of 2023).

#### **Measurement Factors**

The primary research question was whether participation in individualized biopsychosocial mealtime management training increased intake in PWD. A functional relation was not able to be established, and examination into the influence of biopsychosocial mealtime management on intake during mealtimes may have been limited by measurement tools. The decision to measure intake via grams (g) was made to get the clearest picture of intake. However,

as in the case of Participants 2 and 3, these participants consumed 100% of the food and liquid provided. Unfortunately, this did not reflect functional change as the caregivers were providing similar amounts of food/drink in both the baseline and experimental phases. In lieu of measurement of intake via grams, this study may have benefitted from calculation of percentage of total meal consumed. Calculating percentage of consumption may have provided a clearer picture of successfully assisted mealtimes. Unfortunately, this study is constrained to measurements of intake measurement in grams which limits interpretation of mealtime success. As a result, this study may not have been able to establish a functional relation between PWD mealtime intake and biopsychosocial caregiver education.

#### **Clinical Implications**

To the best of this writer's knowledge, this dissertation study provides some of the first data to support the widely held theoretical belief that intervention to support mealtimes for PWD must be multicomponent in nature. A primary goal of this study was to evaluate the impact of individualized biopsychosocial education on the caregiver/care-recipient dyad as a whole. This study demonstrated positive functional relations between provision of individualized multicomponent mealtime education on both participants in the dyad. As a result, this study provides preliminary evidence that both caregivers and care recipients must be a part of the care plan and intervention. Further, this study supports the idea that holistic mealtime management, which encompasses an understanding of the interplay between biological, psychological, and social factors, requires multicomponent intervention that is individualized to the needs of the caregiver/care recipient dyad. Each person with dementia is unique, with varying needs, preferences, and challenges. Biopsychosocial consideration may better allow caregiver recognition of the individual needs of their care recipient and help them tailor mealtime support

accordingly. Through consideration of the biological, psychological, and social aspects of mealtime support, caregivers can provide personalized care that respect the person's dignity, autonomy, and cultural background.

By incorporating biopsychosocial considerations into their caregiving approach, caregivers of persons with dementia can optimize mealtimes. These implications may result in improved nutritional intake, decrease behavioral and psychiatric symptoms associated with dementia, enhanced confidence with mealtime provision, decrease mealtime difficulty, and increased overall quality of life for both the caregiver and the individual with dementia.

Overall, the results of this study suggest a positive response to intervention which is strengthened by participant endorsement of the intervention revealed by social validity and subjective feedback from participant caregivers. During the baseline phase, one participant was in discussions of end-of-life care due to a result of limited intake and weight loss. Following participation in this study, this care recipient's weight increased from 94 lbs. to 97 lbs. End-oflife considerations were also not discussed since the patient has increased in weight.

Additionally, caregivers reported that their loved ones' intake has "increased to 100%" and "time is cut in half" indicating better intake in a shorter period. Lastly, subjective increase in mood and energy level was reported in all participant care recipients following intervention. One caregiver reported that since participating in this study, the care recipient "is able to open her mouth better, she is taking her meds better and getting the benefit from them [the medication]. She is talking and initiating [conversation] more. The progress is amazing!".

#### **Future Directions**

The study benefited from using a multi-method design, incorporating both single subject and quantitative data to establish functional relation, effect size, and clinically relevant

improvement. Future studies should expand upon this multi-method design, incorporating qualitative data to further elucidate the impact of multicomponent, individualized, biopsychosocial education for mealtime management in persons with dementia and their caregivers.

This study provided preliminary evidence that the Biopsychosocial Model of Mealtime Management a crucial component in designing person-centered mealtime interventions that positively impact the caregiver and care-recipient dyad. The capacity for an individual with decreased cognitive ability to participate in research may be difficult to ascertain, often resulting in clinical practices that position the PWD as a passive participant of intervention (Alsawy et al., 2017; Davis & Museus, 2019; Davis et al., 2009) This "default view" needs to be re-examined. Future research must challenge this deficit-based perspective to identify areas where PWD can be integrated into research and clinical practice to better understand where mealtimes can be enhanced. The first step to ensuring truly person-centered care is to consider the perspective of, and minimize compromises to, the dignity of PWD (Mckeown et al., 2015). Utilization of an individualized biopsychosocial framework may have guided the caregiver's perspective away from one that highlights areas of breakdown in mealtime and instead asks the caregiver to consider capitalizing on retained assets to promote successful mealtimes.

#### Conclusion

Mealtime management is a crucial component in considering care for PWD. The multifaceted nature of the mealtime experience for PWD, including increased reliance on caregivers, decreased opportunities for socialization, and changes in sensorimotor function, highlight the need for a dynamic approach to mealtime care. Moreover, these interconnected features of eating and drinking episodes suggest that single-component interventions, such as

increasing the contrast of food or assisting gross motor functioning may not be enough to fully support PWD during mealtimes. Literature has repeatedly supported the need for multicomponent interventions to address the multifactorial concerns caregivers confront when supporting PWD for successful mealtimes (Anderson et al., 2016; Bayne & Shune, 2022; Murphy et al., 2017; Staedtler & Nunez, 2015). As evidenced in this study, successfully assisted mealtimes are reliant on explicit targeting of biological and psychosocial factors seen in dementia. Utilizing an individualized biopsychosocial model of mealtime management can improve clinical and lifestyle outcomes for both the person with dementia and their caregiver.

Successfully assisted mealtimes are a critical component of caring for PWD as mealtimes have large impacts on QoL, maintenance of nutrition, feelings of autonomy, and socialization (Chang & Roberts, 2008; Chen et al., 2009a; Jones et al., 2018; Mitchell et al., 2009; Namasivayam & Steele, 2015; Plowman-Prine et al., 2009a). Additionally, considerations for mealtime management must reflect the dynamic relationship between the biological and psychosocial characteristics that impact the ability of PWD to participate in mealtimes. Biopsychosocial interventions that utilize an asset-based approach to mealtime management have been shown to increase nutritive intake, increase QoL, and decrease BPSD in PWD (Burdick et al., 2021; Cartwright et al., 2022; Dick et al., 2003; Paller et al., 2015; Pouyet et al., 2014b; Wright et al., 2006). Utilizing an individualized biopsychosocial model of mealtime management, that requires centering on the unique needs of each PWD, yields the potential to improve a broad range of mealtime outcomes more effectively.

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