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**CAREGIVER KNOWLEDGE AND PERCEPTIONS OF
DEMENTIA-SPECIFIC NUTRITIONAL APPROACHES**

BY:

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This thesis has been examined and approved by the following members of the student's committee.

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TABLE OF CONTENTS

ABSTRACT	1
INTRODUCTION	2
LITERATURE REVIEW	2
ALZHEIMER'S AND OTHER DEMENTIAS	2
CAREGIVERS	2
DEMENTIA AND NUTRITION	6
PURPOSE OF THE STUDY	8
METHODS	9
PARTICIPANTS	9
PROCEDURES AND INSTRUMENTS	9
DATA ANALYSIS	10
RESULTS	11
CURRENT DIETARY PRACTICES AND CHANGES IN EATING PATTERNS	11
CURRENT CHALLENGES REGARDING NUTRITION AND DIET	11
KNOWLEDGE ABOUT SPECIFIC DIETARY PRACTICES	13
WILLINGNESS TO ADOPT DIFFERENT DIETARY PRACTICES	14
BARRIERS TO ADOPTING DIFFERENT DIETARY PRACTICES	14
FINAL THOUGHTS	15
DISCUSSION	16
FINDING DISCUSSION	16
LIMITATIONS AND FUTURE DIRECTIONS	18
CONCLUSIONS	20
REFERENCE	21
APPENDIX	25

Abstract

Dementia is a syndrome that affects millions worldwide. The syndrome can cause great distress not only for the diagnosed individual but also for the family and friends who provide care. It is known that many caregivers for people with dementia face difficulties in planning and preparing meals, feeding, and making nutritional decisions for their loved ones. Several diets have been shown to assist with dementia-related symptoms pre and post diagnosis. However, what is unknown is whether caregivers are aware of the benefits of these diets and what the barriers are to implementing them into their nutrition regime. This study surveyed primary caregivers for people living with dementia. Data was collected using an online survey made up of 28 open and closed ended questions. Results indicated that caregivers find dementia-specific nutritional important but see challenges in implementation such as difficulties eating, inflexible food choices, or declining to eat. Findings may have implications for caregiver education programs designed to relieve caregiver stress.

Introduction

Alzheimer's & Other Dementias

Dementia is a term used to describe a variety of symptoms that impact behavioral and cognitive functioning. It affects more than 5 million individuals nationwide directly and exponentially more including family members and formal or informal caregivers (Alzheimer's Association, 2020). Rather than being characterized as a disease itself, dementia is syndrome that can be caused by several specific diseases such as Alzheimer's disease or Parkinson's disease (Gale et al., 2018:1161). Most causes of dementia are neurodegenerative, cause progressive deterioration in cognitive and behavioral functioning, and are irreversible (Gates, 2018:1161). However, other causes that are not related to neurodegeneration include vitamin deficiencies, hypothyroidism, normal pressure hydrocephalus, chronic alcohol abuse, chemotherapy-related cognitive dysfunction, infections, intracranial masses, traumatic brain injury, and psychiatric illness (Gates et al., 2018:1162).

With the variability in causes comes a variability in symptom presentation and progression. However, there are generalized symptoms that can be seen in a large number of dementia diagnoses. Some of the most significant indicators of dementia can include impairments in memory, language, reasoning and self-care that negatively impact daily life (Dickerson, 2014:488). In the early stages of most dementias, memory problems or difficulty with everyday tasks are most prominent. As the disease progresses, behaviors and judgment may become more impaired and individuals may become more dependent on others for everyday tasks such as decision-making and eventually, personal cares and feeding (Jenkins et al., 2016:11). In the later stages of the disease, an individual may become completely dependent on a caregiver.

Caregivers

Overview of dementia caregiving. There are 16 million people caring for someone with Alzheimer's disease or another form of dementia (Nikzad-Terhune, 2019:543). In 2017, these caregivers delivered over 18 billion hours of unpaid care which holds a value of nearly \$232 billion (Nikzad-Terhune, 2019:544).

The role of a primary caregiver is one that can cause an abundance of stress to both the caregiver and care receiver. While there is often a network of people aiding people with dementia, the primary caregiver holds the most responsibilities in care and decision-making. The majority of caregivers are women providing care for a parent or parent-in-law (Alzheimer's Association, 2020:34). Often, the caregiver is living with the person with dementia in the community while also providing care for their children as well (Alzheimer's Association, 2020:34). Caregiving is often seen as an unavoidable responsibility due to filial obligation. Because of the reliance on family, there are strong emotional ties and responses associated with caregiving. It is evident that there are enormous numbers of individuals putting in strenuous work on a day-to-day basis with little to no compensation.

Sources of caregiver stress. While the role of caregiver can vary across persons and is ever-changing, there are some overarching similarities in duties performed by caregivers. As the individual who is receiving care initially starts to decline, the caregiving role often begins with monitoring of the symptoms (Schulz et al.,2016:638). As the disease progresses, monitoring of the symptoms transitions into managing symptoms. Management of symptoms often comes with more responsibility for the caregiver (Schultz et al.,2016:638). Depending on the severity of comorbid health conditions, a caregiver may simply assist an individual in performing tasks or may be required to perform complex health care tasks, often with minimal training (Schultz et al.,2016:639). In addition to the monitoring or management of symptoms, a caregiver may also take on additional roles such as housework, supervision, emotional support, health and medical care, care coordination, and surrogacy in financial and legal matters (Schulz, 2016:81). The supervision domain encompasses self-care tasks such as feeding, dressing, and bathing. Additionally, tasks like managing behaviors and assisting with mobility may be required of the caregiver. Encouraging a healthy lifestyle with proper self-care, food choices, and treatment compliance is often included in the health and medical care domain. With this, caregivers are also responsible for adhering to special diets, managing prescriptions, and performing acute medical care as it arises. Care coordination incorporates advocacy by speaking to other family member, medical professionals, and insurance companies. Some caregivers may complete all these tasks, while others may only complete a handful.

Overall, there is great variability in the number and type of tasks that caregivers must complete, how caregivers manage these tasks and the consequences of the stress associated with providing care.

Caregiver burden and its consequences. Although caregivers often take on tasks out of love, it often comes with hardships. “Caregiver burden” is a term that generally describes the strain one may experience when caring for another dependent individual. Some researchers on the subject have opted for the concept of “compassion fatigue” in order to remove some of the negative connotations associated with caregiver burden (Lynch,2017:1424). Regardless of the words used to describe the experience, it undoubtedly has its challenges.

There are six main indications of caregiver burden: psychological distress, physical health, biomarkers, social relationships, work, and elder mistreatment (Schulz et al., 2016: 640-643). One of the most recognized challenges that caregivers face is psychological distress. These challenges can present themselves as depression, anxiety, chronic anger/frustration and other distressing mental health implications (Schultz et al., 2016: 640). Biomarker indicators such as measurements of stress hormones, neurotransmitters, natural killer cell activity, wound healing response, blood pressure, heart rate, insulin, transferrin, and plasma lipids can represent physical or physiological distress (Schultz et al., 2016:643). The relationship between the caregiver and the care recipient often deteriorates due to behavioral struggles, loss of physical and emotional intimacy, and overall dissatisfaction with the jobs required of a full-time caregiver (Schultz et al., 2016:642). Research has indicated that the closer the relationship of the recipient and caregiver, the higher levels of distress one experiences (Lomax et al., 2009:11). For many caregivers, especially women, the pull to leave the work force or minimize hours is strong. Evidence suggests that caregivers are often earning lower wages, being passed up or passing up opportunities for promotions, and may take on a job with fewer demands (Bittman et al., 2007:263-267). Elder mistreatment and/or neglect is another implication of caregiver burden. Research has found that nearly 25% of caregivers have engaged in behaviors that are harmful to the care recipient (Schultz et al., 2016:643). This mistreatment can be in the form of physical, emotional, sexual, or financial abuse, as well

as neglect and abandonment (Schulz et al., 2016:107). Abuse can be the result of an inability to cope with stress, poor mental health, dependence on drugs or alcohol, and isolation (Lomaz, 2009:58).

Along with the tasks that are required of a caregiver, there is also the emotional coping with the disease and its progression. “These include (1) initial recognition of the problems; (2) clarification and emotional acceptance of the diagnosis, sometimes including extensive seeking of alternate opinions and potential cures; (3) establishment of appropriate expectations; (4) grieving; (5) problem-solving and coping with respect to deteriorating behavior; and (6) decision-making regarding appropriate care” (Lomaz, 2009:49). These emotional stages are often experienced in conjunction with the stages of dementia the care recipient is experiencing.

Caregiver growth. The caregiving role is a complex and unpredictable role that can lead to heightened stress (Lynch,2017:1424). While research has shown that there are many burdensome and difficult aspects of caregiving, it is also important to highlight the positives that can come from this experience. Only 2.4% of family caregivers say that the experience of caregiving is solely negative (Lynch, 2017:1430). Caregivers of older adults can sometimes experience enhanced personal health and improved well-being as they learn to care for the health of another individual as well as become more educated (Lynch, 2017:1424). Providing care for an individual can induce a sense of confidence that the loved one is receiving adequate care and the caregiver was able to see the milestones and accomplishments (Lomaz, 2009:70). These positive outcomes function as incentives to encourage the continuation of a challenging role (Lomax et al., 2006:10).

Certain characteristics often indicate how caregivers will manage caregiving challenges. Variables such as empathy, mental health, and social isolation are good indicators of how well one will handle stressors (Lomaz et al., 2006:58). Their perceptions of the role can also aid or hinder the distress one feels (Lomax et al., 2009:9). Regardless of caregiver characteristics or perceptions, caregiving for an individual with health conditions is challenging enough. However, when one adds a diagnosis of dementia, caregiver stress and burden can increase tremendously.

Dementia & Nutrition

Caring for an individual with dementia requires important decisions to be made on a daily and often, hourly basis, including what to eat. This is often very difficult given that what an individual ate one day may not be appealing the next. Hunger and satiety cues may not be regulated which can make following a schedule strenuous (Ball et al., 2015:23). This can be especially difficult because individuals living with dementia are at a higher risk for nutritional deficiencies (Gregoria et al., 2003:305). Often, decreased appetite, dysphasia, and forgetting or refusing to eat are difficulties caregivers must overcome given that significant weight loss can occur (Ball et al., 2015:23). Overeating and weight gain can also be an issue as individuals are unable to detect feelings of satiety and forget when their last meal was.

Specific nutritional approaches. There have been a handful of diets that have demonstrated improvements in behavioral functioning for individuals with dementia. These diets include a high tryptophan diet, a vitamin D rich diet, a Mediterranean diet, and a ketogenic diet. A predominant theme of these diets is the reduction of inflammatory foods such as sugar, trans fats, omega 6 fatty acids, refined carbohydrates, mono-sodium glutamate (MSG), gluten, casein, aspartame, and alcohol. Instead, incorporating more whole foods such as a variety of fruits and vegetables, whole grains, legumes, antioxidants, and omega-3s can reduce inflammation in the body and brain (Hayden et al., 2018). Reducing inflammation assists with symptoms of dementia such as memory impairment and aggression (Lee et al., 2019:2). An additional commonality amongst these diets is increasing levels of serotonin in the brain. Decreased serotonin is correlated with symptoms such as aggressive behaviors in persons with Alzheimer's disease (Broderick, 2005:86).

Regarding high tryptophan diets, a meta-analysis of observational studies of Alzheimer's patients found a high tryptophan diet can reduce social anxiety and aggressive behaviors by increasing levels of serotonin in the brain (Volcer, 2009:2). Foods high in tryptophan include egg whites, spirulina, cod, soybeans, parmesan cheese, and sesame seeds. While incorporating these foods individually may pose difficulty, adding them into a comfortable meal may be helpful for both the caregiver and individual (Volcer, 2009:2).

Vitamin D-rich foods or vitamin D supplements have been shown to be associated with slight cognitive improvements in the general older population and those with beginning signs of Alzheimer's disease (Annweiler, 2017:2155). However, it should be noted that research indicates this association is not conclusive and has not provided evidence that vitamin D directly produces improvement. While the evidence supporting the addition of vitamin D to one's diet to prevent or slow down cognitive impairment is not irrefutable, there is evidence to suggest an association between lack of vitamin D (i.e., hypovitaminosis D) and an increase in cognitive decline (Annweiler, 2017:2155). This has been demonstrated through a meta-analysis of observational studies including 12 cross-sectional studies and 14 longitudinal (Annweiler, 2017:2155). Vitamin D rich foods that individuals can incorporate into their diet include fish liver oils, oily fish, egg yolk, wild mushrooms, and dairy.

The Mediterranean diet is high in vegetables, fruits, herbs, nuts, beans, seafood, eggs, poultry and whole grains. Researchers have followed participants without a dementia diagnosis, analyzed their adherence to the Mediterranean diet and evaluated its correlation to the development of dementia (Feart, 2008:641). Those following a Mediterranean diet have been shown to produce some improvement in overall cognitive functioning and to slow cognitive decline in persons with a diagnosis of dementia (Feart, 2009:642). Research also suggests, however, that adhering to this diet prior to a diagnosis produces the most benefits.

Another diet that had been found to produce some cognitive improvements among individuals with Alzheimer's disease is the ketogenic diet (Rusek, 2019:12). These conclusions are based on a review of experimental and clinical data on the topic (Rusek, 2019:2). A ketogenic diet has been shown to have anti-inflammatory effects which makes it a special interest of researchers regarding Alzheimer's disease. To adhere to this diet, and allow the body to be in ketosis, individuals must reduce carbohydrate intake to less than 10% and increase fat intake in order to maintain energy levels (Rusek, 2019:2). Improvements in with diet are more frequently observed during the pre-symptomatic stages of Alzheimer's disease, but it may have some benefits on cognitive performance throughout the following stages, as well (Rusek et al., 2019:12).

With the variability of diets and interventions that can provide benefits, it is important for information related to dietary practices be accessible to caregivers. In a study conducted by Ball et al., it was found that, “Family carers felt unprepared regarding feeding challenges, which resulted in family carers feeling anxious and distressed and contributed to their feelings of significant burden associated with the care of their relatives” (2015:27). Caregivers feel as though they are not provided with adequate support or information regarding nutrition (Ball et al., 2015:27). Much of the information they have acquired regarding nutrition has required trial and error and research conducted on their own time.

Purpose of the Current Study

Existing research indicates that there are dietary and nutritional interventions caregivers can utilize in hopes of alleviating some of the challenging symptoms that can occur with dementia. Finding ways to reduce inflammation, increase whole foods and limit the amount of processed food one consumes is important. However, caregivers may be left feeling unaware, uneducated, and alone in determining what to feed their loved one (Ball et al., 2015:26). The challenges faced with feeding, maintaining weight, and finding meals that are desirable are difficult. Incorporating all the dietary guidelines associated with the diets mentioned above can pose serious challenges for caregivers who are already stretched thin. There is limited research on caregiver opinions on dietary practices as well as barriers to implementing new dietary practices that may help with symptoms. Therefore, the purpose of this study was to gain a greater understanding of the knowledge caregivers have regarding these diets, how important caregivers find dietary practices, and the challenges associated with addressing the dietary needs of persons with dementia. Further understanding this topic can aid healthcare and nutrition professionals to provide useful and accessible education. It can also provide further insight into the baseline knowledge that caregivers have in regard to nutrition. Thus, offering healthcare professionals the information to assist caregivers with knowledge that could help ease some of the stressors they experience caring for a person with dementia.

Method

Participants

Sixty-nine individuals participated in the study. To be eligible for the study, participants must have been eighteen-years or older, be a caregiver living with the persons with dementia, and make the primary decisions regarding food and nutrition. For this study, “caregiver” was defined as someone who lived with the persons with dementia and was responsible for food choices. The majority of participants were 60 years of age or younger, with the most common age range being between 51 and 60 years old. Concerning gender, 37.7% of the participants were male and 62.3% were female. The mode education level of the participants was having a graduate degree (34.8%). Regarding participant relationships with the persons with dementia, most participants were adult children (43.5%) or a spouse (24.6%). The majority of participants have been providing care for 1-5 years. Table 1 provides a summary of the demographic characteristics of the participants.

Participants were recruited utilizing four main recruitment methods. The first method was to recruit via a Facebook post in three dementia support group pages that are open to any Facebook user world-wide. These groups are available to those in need of support, advice, or guidance related to the caregiving role. The second method was a post on the student investigator’s personal Facebook page and other Facebook users shared the post with their following. This included exposure to users of Facebook nation and world-wide. The third recruitment method was done via an email sent out by an adult community center in a small metropolitan area in the Midwestern United States. This community center provides services for persons with dementia and their caregivers. Finally, the fourth recruitment method was to utilize Qualtrics online recruitment which sent a recruitment message to participants nationwide who met inclusion criteria.

Procedures and Instruments

All data was collected using an online survey that could be accessed by clicking a link that was distributed via the recruitment methods described previously. Once individuals clicked on the survey link, an IRB-approved informed consent form appeared (see Appendix A). Individuals that agreed to

participate were presented with a 28-question survey that primarily included close-ended questions. Four open-ended questions were also included to allow participants to expound upon their answers to some of the close-ended questions. The survey was broken into six main sections: 1) Demographic information that included questions about age, gender, education level, relationship to the individual with dementia, and length of time serving as a caregiver. 2) Current dietary practices and changes in eating patterns since the development of dementia (4 questions). 3) Current challenges regarding nutrition and diet (2 questions). 4) Knowledge caregivers have about certain dietary practices (9 questions). 5) Willingness of caregivers to adopt different dietary practices (5 questions). 6) Barriers to adopting different dietary practices (2 questions). The entire interview can be found in Appendix B.

Data Analysis

Data analysis involved the examination of both closed and open-ended questions. Descriptive statistics were calculated for answers to close-ended questions. The frequency of each answer as well as the percentage of the sample that provided each answer was calculated. To evaluate the open-ended questions, themes were identified for each question by searching for commonalities among the responses. For two of the open-ended questions, responses were initially categorized as being either a “yes”, “no” or “maybe” answer and then were further categorized and summarized according to the explanation provided. For example, question 26 asked, “Do you see incorporating the above diets into your food choices and meal planning as beneficial? Please explain.” The answers were divided into one of the three categories based on whether the answer contained “yes,” “no,” “maybe” (or synonyms of “maybe” such as “possibly” or “sometimes”). The responses were further categorized according to the explanations provided. For instance, “no” responses were categorized as either, “no/I don’t know” or “no, calories are more important.” The “maybe or possibly” responses were categorized together as “sometimes/maybe if my loved one will accept it and its easily incorporated.” The “yes” responses were categorized as either “yes,” “yes, anything that helps is worth trying,” “yes, already following,” “yes, it can help more than just dementia,” and “yes, if I can fit it into my lifestyle.” The categories were chosen based on the most

frequently occurring themes as well as what would provide the best representation of the participants' opinions. The remaining open-ended questions were categorized in a similar fashion.

Results

Current Caregiver Understanding of Dietary Practices

Current Dietary Practices and Changes in Eating Patterns

To address the research question about what understanding caregivers currently have about dietary practices, the first segment of survey posed questions about current dietary and eating practices of the person with dementia. The opening question asked about how often the caregiver plans meals and buys groceries for the persons with dementia. The majority of participants (65.2%) reported meal planning and buying groceries *all of the time*, whereas 26.1% reported doing these things *most of the time* and 7.2% reported *some of the time*. One participant answered *none of the time*, so was brought to the end of the study as they no longer fit the inclusion criteria.

The second question asked whether the caregiver follows a specific diet plan for the person with dementia. For this question, 35% of participants reported following a specific diet plan *all of the time*, 23.8% reported *most of the time*, 22.2% reported *some of the time*, and 19.0% reported *never* doing this. Five participants did not provide an answer to this question.

The next question concerned factors that influence the food choices that caregivers make for the person with dementia. *Familiarity of food* earned the most responses with 29.6% of participants choosing this answer, followed by *price* (17.3%) and *convenience* (16.2%). Additional responses included, *diet-specific due to health issues/doctor recommendation* (10.0%), *organic* (9.5%), *diet-specific due to personal choice* (8.9%), and *diet-specific due to dementia diagnosis* (5.6%). Nearly three percent of participants chose other responses such as, “based on health needs,” “dietetic exchange based,” “those foods that are most easily self-fed,” “refusal to wear dentures – goes on hunger strikes, so what she will eat, and try to make healthy choices also tempt her to eat.”

The final question asked which factors reported in the previous question were the most influential in making food choices. Participants answered *familiarity* (50%), *price* (14.7%), *convenience* (8.8%),

diet-specific due to dementia diagnosis (8.8%), organic (5.9%), diet-specific due to personal choice (5.9%), diet-specific due to health issues/doctor recommendation (4.4%), and other (1.5%). One participant answered, “whatever she can eat” was the most important influence on food choices.

Knowledge about Specific Dietary Practices

Questions in the third section of the survey inquired about knowledge caregivers have regarding four identified dietary practices noted to help with dementia symptoms. The first question asked about whether or not caregivers have been educated about nutrition for persons with dementia. Approximately 51% said *no* and 48.5% said *yes*. Of those that responded *yes*, 37.5% were *educated by a medical provider*, 21.9% were *educated by a nutritionist*, 18.8% said they were *self-educated*, 18.8% were *educated by a registered dietician*, and 3.1% were *educated by a pharmacist*. An additional question asked whether nutrition education for persons with dementia is important. Approximately 82% of participants said *yes* and 8.8% said *no*. An additional 8.8% responded *other*, which included answers such as, “not when working with a doctor,” “unsure, advanced state,” “overall but not always realistic,” and “did not realize diet was important.” Participants were then asked if they were aware that there are diets that have been found to assist with dementia-related symptoms, with 53.7% reporting *yes* and 46.3% reporting *no*.

The remaining questions in this section asked about four diets found to have benefits regarding dementia-related symptoms. The first question asked if caregivers were familiar with a high tryptophan diets and its benefits. Approximately 67% said *no, they are not aware of the diet or its benefits*, 19.4% said *yes, they are aware of the diet and its benefits*, and 13.4% said *they are aware of the diet but not its benefits*. The next diet discussed was the Vitamin D-rich diet. Approximately 42% said *they weren't aware of the diet or its benefits*, 38.7% said *they were aware of the diet and its benefits*, and 13.4% said *they were aware of the diet but not its benefits*. The next diet was the Mediterranean diet. Approximately 62% *were aware of the diet and its benefits* and 38.9% *were not aware of the diet or its benefits*. Finally, a Ketogenic diet was discussed. Approximately 37% said *they were aware of the diet and its benefits*, 26.8% *were not aware of the diet or its benefits*, and 26.5% *were aware of the diet but not its benefits*.

Importance of Dietary Practices

Willingness to Adopt Different Dietary Practices

To gain insight on the importance of dietary practices, the fifth section discussed the willingness of caregivers to adopt the above dietary practices into the meal plans of the person with dementia. After describing what incorporating a high tryptophan diet would entail, participants were asked if they would consider incorporating the diet into the person's daily meal routine. *Yes* was reported by 54.4% of participants, *parts of the diet* by 27.9%, *no* was reported by 13.2%, and *other* by 4.4%. Those that responded *other* mentioned that "perhaps, but not stringently," "already including all of those that she will eat..." and "my loved one doesn't like fish or cheese." The next question asked about the incorporation of the Vitamin D rich diet. Approximately 64% said *yes*, 23.9% said *parts of the diet*, 9.0% responded *no*, and 3.0% responded *other*. The integration of the Mediterranean diet was discussed next. Approximately 61% said *yes*, they would consider incorporating it, 26.9% said *parts of the diet*, 10.4% said *no*, and 1.5% said *other*. The participant that answered, *other* mentioned that "we do our best to get a nutritionally balanced diet in her. However, she is an elderly Japanese woman and is unwilling to eat western foods in general." The final diet that was discussed was the Ketogenic diet. Approximately 52% said they would incorporate the diet, 26.9% said they would incorporate parts of the diet, and 22.2% said they would not. Less than 2% responded with *other* but did not provide further explanation.

The concluding question in this section asked, "the diets above incorporate foods that are known to lower inflammation, which can aid in dementia-related symptoms. Would you consider incorporating a combination of the diets above for your loved one with dementia?" Eighty-one percent responded *yes*, 14.2% said *no*, and 4.8% said *other*. Those that responded *other* mentioned that they already incorporate parts of the diet, caregiving stress prevented dietary changes, and getting the person to consume calories was more important than other nutritional concerns due to "hunger strikes."

Challenges Faced by Caregivers

Current Challenges Regarding Nutrition and Diet

The final research question looked at the challenges caregivers currently face and perceive facing if the diets are incorporated. The second section of the interview assisted with this by addressing diet and nutrition challenges that caregivers experience when providing meals for persons with dementia. The first question asked, “How has your loved one’s food choice and/or preference changed since being diagnosed with dementia? Please explain.” The answers were divided into two broad categories of, *it hasn’t changed*, (57.1%) or *it has changed* (42.9%). The two categories were then broken down according to themes identified in the data. In the *it hasn’t changed* category, subcategories were as follows, *it hasn’t changed – no explanation* (40.0%), *food choice hasn’t changed but they eat less* (7.7%), *it hasn’t changed as they won’t eat anything different* (6.2%), and *it hasn’t changed as appetite has remained constant* (2%). In the, *it has changed* category, subcategories were as follows, *it has changed as they are more specific in their food choices* (13.9%), *it has changed as their taste preferences are different than before diagnosis* (9.2%), *it has changed due to health reasons or doctor recommendations* (7.7%), *it has changed as they eat a smaller amount or fewer foods* (4.6%), *it has changed – no explanation* (3.1%), and *it has changed as they eat healthier* (3.1%). Responses that did not correspond with a given theme or did not pertain to the question were not analyzed.

The final question in the section asked, “What challenges do you face when choosing meals for your loved one with dementia? Please explain.” The responses were categorized as follows, *no challenges* (24.6%); *challenges in not wanting to eat, change in preference, and/or more picky* (19.7%); *time, availability, and/or price* (16.4%); *challenges with making food appealing, appetizing, and texture appropriate* (11.5%); *challenges in eating healthy and/or meeting dietary requirements* (11.5%); *challenges in eating difficulties such as swallowing* (13.1%); and *challenges in caregiver not enjoying cooking and/or other family obligations* (3.3%).

Barriers to Adopting Different Dietary Practices

The concluding section of the survey investigated barriers that caregivers perceive in adopting the above dietary practices. The first question asked, “Do you see incorporating the above diets into your

food choices and meal planning as beneficial? Please explain.” Responses were categorized into themes. The themes are as follows: *yes, anything that helps is worth a try (23.3%), no or I don't know (16.7%), may be beneficial or possibly beneficial if it will be easily incorporated and accepted (16.7%), already follow these dietary approaches (10.0%), yes, because its healthy or if a doctor is recommending it (10%), yes – no explanation (10.0%), yes, because it can help in other areas of life also (6.7%), yes if they can balance out other life obligations (3.3%), and maybe but calories are what is most important (3.3%).*

Participants were then asked about the barriers they perceive in incorporating any of the diets mentioned in the survey. For this question, multiple response options were provided, and participants were encouraged to select all responses they found applicable. Answers were as follows: *my loved one does not like to deviate from the current foods he/she eats (28.6%), my loved one does not have an appetite (20.0%), my loved one does not like a majority of the foods mentioned (16.2%), my loved one does not currently eat a majority of the foods mentioned (15.2%), other (14.3%), and my loved one already has a specific diet (5.7%).* “Other” responses included: “doing the best one can with limited time,” “self-feeding makes food options difficult,” and they are “...not very knowledgeable about diets and cooking, so incorporating changes would be difficult.”

Final Thoughts

Participants were given the opportunity to express any final thoughts regarding the study. While 58.2% said they did not have any comments, the remaining 41.8% of participants provided responses. Approximately 16% expressed *specific difficulties they experience in eating and nutrition*, 10.4% think *it is important and would like more information or would look into the diets*. One participant provided insight by saying, “I wish more doctors would talk about it.” 4.5% mentioned *it would be hard to start and they would need to help*. As one participant stated, “I could use help because it’s just me and my dad, and I unfortunately wouldn’t know where to start.” 4.5% provided comments that were irrelevant to the study, 3.0% mentioned that *they already are incorporating the diets*, and 3.0% provided *suggestions for further studies*.

Discussion

While specific nutritional approaches for people with dementia have been shown to have benefits, the challenges that caregivers face have also been noted in previous research such as diminished appetite, dysphasia, and refusing to eat (Ball et al., 2015:23). Caregivers may be taxed with educating themselves about the disease process, future planning, taking necessary safety measures, performing typical household tasks, and upholding the financial and legal responsibilities (Lomax, 2009:32). Whether these diets can be easily incorporated by caregivers is contentious due to changes associated with dementia such as irregular hunger and satiety cues, changes in food preferences and highly variable eating habits (Ball et al., 2015:23). Because of these changes, introducing new foods may prove difficult. However, this study provided insight into the current perceptions' caregivers have regarding nutrition.

To begin understanding if dementia-specific diets could feasibly be implemented, it was important to develop a baseline as to how caregivers approach meal planning and food choices. The caregivers in the study all reported buying groceries and following a specific diet at least most of the time. This finding is important because it suggests that caregivers have spent time thinking about the importance of diet for their loved one with dementia and developing a specific dietary plan. This finding supports recent research demonstrating that caregivers desire knowledge concerning how they should care for people with dementia (Hammar et al., 2016:631). Finding that caregivers made food decisions based on familiarity, price, and convenience suggests that caregivers and persons with dementia are comfortable with their food choices. Food familiarity has been noted to improve the mealtime experience and, deviation from normalcy may be difficult (Johansson, 2017:865). Given the high importance placed of price of food, incorporating fewer conventional foods into diets could pose difficulties due to the higher prices of specialty foods.

Most caregivers reported no change in eating habits since the person developed dementia, and several indicated that the person with dementia will not eat anything atypical, which presents an additional challenge in terms of trying to incorporate new foods in their diet. For those participants that indicated a change in dietary preferences has occurred, most caregivers said that food choices were more

particular or there was a change in amount of food consumed. Existing literature suggests that the reductions in caloric intake reported may be due to decreased appetite, lack of smell or taste, lethargy, mood changes, and difficulties preparing or eating meals (Heller, 2016). In addition, people with dementia may demonstrate changes in eating habits due to inability to accept specific textures or medication side effects (Liu et al., 2019). Regarding specific challenges, a substantial minority (25%) of caregivers indicated that they face no challenges. This is surprising given that research indicates that caregivers often feel uninformed and unsupported when deciding what to feed people with dementia (Ball et al., 2015:26). Those that do have tribulations said that change in food preferences and pickier eating was most prevalent.

It was imperative to gather information about the current knowledge caregivers have about nutrition and its importance for the people with dementia. About half of the caregivers mentioned that they have been educated by various medical and nutrition professionals and nearly all said it was important. Whether the education they received was about the diets mentioned in the study or other nutritional information such as caloric needs is unknown, however. When asked about specific diets shown to be beneficial for persons with dementia, most caregivers indicated that they were not aware of the specific diets nor their benefits. The Mediterranean diet was the most widely understood, while the high tryptophan diet was the least acknowledged. These results were not surprising given that the Mediterranean diet is commonly mentioned in dementia education resources (e.g., Alzheimer's Association, 2020).

It was expected that caregivers would be more apt to try incorporating foods that people with dementia would be willing and able to eat rather than focusing on foods noted for dementia-related benefits. This was expected given that these diets are not noted for producing significant improvements, but instead they are associated with rather small benefits post diagnosis (Hayden, et al., 2018). While participant comments indicated that they would not incorporate the diets "stringently," caregivers were willing to try and include diet-specific foods into current dietary practices. The overall goal of reducing inflammation by these diets was reported as being important by caregivers and again, they indicated that

they would attempt to incorporate as much anti-inflammatory food into their food choices as possible. Most respondents indicated that they would be willing to try new dietary practices, although an equal number of participants reported either not believing dietary changes would be beneficial or that increasing caloric intake was most important in meal planning. Participants are indicating that they are willing to consider these diets, which does not necessarily mean they will be incorporating the diets into their loved ones regular meal planning.

Participants reported that the most significant challenge regarding making dietary changes was that the person with dementia would not like to deviate from what they currently eat, or they do not like most of the foods recommended by these diets. From the additional comments offered, participants reported that they are, “doing the best one can with limited time” and that incorporating these diets would require further nutrition and cooking knowledge.

An open-ended question at the end of the survey revealed that caregivers experience conflict between wanting to incorporate the dementia-specific diets and other caregiving demands. This sentiment is nicely summarized by one participant who reported, “Taking care of my mother isn’t my job and I don’t have unlimited time to devote to her. I’m trying to live my life and we are struggling. I would love to be the perfect caregiver so I could ensure everything was geared towards improving her disease, but I’m just doing the best I can with limited funds, resources, and time.” An additional participant said that, “often times comfort foods are provided as one of the few sources of pleasure for the individual with dementia.”

Limitations and Future Directions

Due to the COVID-19 pandemic and resulting quarantine, in-person interviews were not possible, so the researcher was not able to ask follow-up questions in order to gain a more detailed and complete understanding of answers to questions. Future studies could consider utilizing in-person interviews that provide opportunities to ask follow-up questions to better understand current challenges caregivers face, their opinions on dementia-specific diets, and whether they would be willing and able to incorporate such diets into their daily routine.

The sample obtained for this study presented another limitation. For example, the education level of participants was relatively high, with most reporting being college educated and a large percentage having a graduate degree and beyond. This could indicate the participants in this study were of higher socioeconomic status and may have more resources to incorporate dementia-specific diets than those that did not participate in the study. Those outside of this socioeconomic group could also have difficulty understanding information provided or simply accessing the information. Future research should assess a broader, more representative sample of caregivers in terms of socioeconomic status in order to gain a more comprehensive opinions on the topic. In addition, the sample size for this study was relatively small. Having a large sample size, especially if conducting an online survey, could produce more variable data with a wider range of participants. In addition, the study did not ask about the stage of dementia the participants' loved ones were in which could have produced different answers especially when asking about challenges and incorporation possibility.

Finally, this study did not include any follow-up with participants. Research done in the future may consider following up with participants to determine if they utilized the information provided in the study and how successful any changes in dietary practice were. This would provide additional information about the practicality, benefits, and challenges associated with incorporating such diets.

Future studies may consider examining the implementation of the mentioned diets and their effects on dementia-related behaviors. Researchers could utilize caregiver documentation of behavior prior to diet change and post diet change to see if there is symptom improvement. While research has noted the improvements that can be made through anti-inflammatory diets, addressing this in an applicable setting could provide fascinating data.

Another direction future research could take is to assess caregiver knowledge in greater depth. This could be done via a survey that asks about the diets, the specific foods incorporated, and benefits in greater detail. A future study addressing this topic could provide knowledge through experimental studies rather than self-report.

Future researchers may also consider studying the knowledge long-term facility employees have about dementia-specific nutritional approaches. Following a similar structure to this study or utilizing in-person interviews could help gain understanding of how long-term care communities understand nutrition.

Conclusions

The current study represents one of the few investigations of dietary practices caregivers use with persons with dementia. Many of the responses provided by participants suggest that this is an important topic to caregivers of people with dementia. Caregivers in the study expressed that they face challenges with nutrition but believe it is important. They would like further information about dementia-specific nutritional approaches and despite indicating that they have received nutrition education, few knew of the benefits each diet could offer. Disseminating this information is clearly important for health care professionals when discussing the disease with caregivers and the person with dementia. Since health care professionals are often who caregivers seek for advice and assistance, it may be useful for them to discuss dementia-specific diets. This would provide caregivers with the knowledge they need to make informed decisions about food choices for people with dementia. Overall, participants in this study noted that nutrition is important, and they would like to try incorporating dementia-specific diets into the daily routine; however, participants acknowledged that many other challenges associated with caregiving may hinder their ability to make these changes.

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Appendices

Table 1. *Participant Demographics*

Variable	n (%)
Gender	
Female	43 (62.3)
Male	26 (37.7)
Age (in years)	
Younger than 40	5 (7.2)
41-50	20 (29.0)
51-60	23 (33.3)
61-70	10 (14.5)
71-80	9 (13.0)
81-90	2 (2.9)
Education	
High school	7 (10.1)
Some college	14 (20.3)
Associate degree	4 (5.8)
Bachelor's degree	20 (29.0)
Graduate degree and beyond	24 (34.8)
Relationship to Persons with Dementia	
Spouse	17 (24.6)
Adult Child	30 (43.5)
Sibling	4 (5.8)
Friend	6 (14.5)
Parent-in-law	4 (5.8)
Self	2 (2.9)
Other relative	6 (8.7)
Length of Caregiving Role (in years)	
Less than 1 year	11 (16.2)
1-5	36 (52.2)
6-10	13 (18.8)
11+	8 (11.6)

Appendix A. *Participant Survey*

Caregiver Knowledge & Perception on Dementia-Specific Nutritional Approaches

This survey will ask you a number of questions about dietary and nutritional information in reference to dementia and dementia-related symptoms. It will also ask you to provide information about the nutritional approaches you currently take for your loved one with dementia as well as your opinions on specific diets and the potential of incorporating those into your daily routine.

The survey consists of 21 questions. For questions that ask for explanation, please use the box provided to explain your answers thoroughly. If you choose “other” please explain your answer. At the end of the survey, there is an opportunity to leave any final thoughts about any of the topics discussed if you wish.

I want to express my sincere gratitude for your time, commitment, and involvement in this survey. Please use the information on the consent form provided if you have any questions or concerns.

Demographic Information

1. What is your age?
 - a. Younger than 40-years-old
 - b. 41-50
 - c. 51-60
 - d. 61-70
 - e. 71-80
 - f. 81-90
 - g. 91-100
 - h. 100+
2. What is your gender?
 - a. Male
 - b. Female
 - c. Other
 - d. Prefer not to disclose
3. What is your relationship to the individual with dementia?
 - a. Spouse
 - b. Parent
 - c. Sibling
 - d. Friend
 - e. Other (please specify)
4. How long have you been a caregiver for this individual?
 - a. Less than 1 year
 - b. 1 to 5 years
 - c. 5-10 years
 - d. 10+ years

Current Dietary Practices & Changes Since the Development of Dementia

1. Are you the primary meal planner & cook for your loved one with dementia? (If no, please refrain from finishing and submitting the survey as this is a requirement).
 - a. Yes
 - b. No
 - c. Shared responsibility
 - d. Other (please specify)
2. Do you follow a specific diet plan when choosing foods for your loved one with dementia?
 - a. Yes
 - b. No

- c. Other (please explain)
3. Which of the following factors influence the foods you choose for your loved one? (Select all that apply)
 - a. Price (whether that is high-priced or low-priced)
 - b. Organic (either in grocery stores or farmer's markets)
 - c. Familiarity (food that your loved one has enjoyed before)
 - d. Convenience (found in stores near to home)
 - e. Diet-specific due to health issues/doctor recommendation (low-sodium, low-fat, low-sugar, low FODMAP [Fermentable Oligo-, Di-, Mono-saccharides, and Polyols] etc.)
 - f. Diet-specific due to personal choice (vegan, vegetarian, low-carb, low-fat, etc.)
 - g. Diet-specific due to dementia diagnosis
 - h. Other (please specify)
 4. Of the choices in question 4, which is the most important influence (choose only one option below)?
 - a. Price (whether that is high-priced or low-priced)
 - b. Organic (either in grocery stores or farmer's markets)
 - c. Familiarity (food that your loved one has enjoyed before)
 - d. Convenience (found in stores near to home)
 - e. Diet-specific due to health issues/doctor recommendation (low-sodium, low-fat, low-sugar, low FODMAP etc.)
 - f. Diet-specific due to personal choice (vegan, vegetarian, low-carb, low-fat, etc.)
 - g. Diet-specific due to dementia diagnosis
 - h. Other (please specify)

Current Challenges Regarding Nutrition & Diet

5. Has your loved one's food choice and/or preference changed since being diagnosed with dementia? Please explain.
6. What challenges do you face when choosing meals for your loved one with dementia? Please explain.

Knowledge Caregivers Have About Certain Dietary Practices

7. Have you been educated on nutrition for your loved one with dementia?
 - a. Yes
 - b. No
 - c. If so, by whom? (self-educated, registered dietician, nutritionist, medical provider, etc.)
8. If you answered "yes" to question #7, do you feel as though you received adequate information to make nutritional decisions for your loved one?
 - a. Yes
 - b. No
9. Do you think that nutrition education for individuals with dementia and their caregivers is important?
 - a. Yes
 - b. No
 - c. Other (please explain)
10. Are you aware that there are diets that have been found to assist with dementia-related symptoms?
 - a. Yes
 - b. No
11. Are you familiar with a high tryptophan diet and its benefits?
 - a. Yes, I am aware of the diet and its benefits.
 - b. Yes, I am aware of the diet but not its benefits.
 - c. No, I am not aware of a high tryptophan diet.
12. Are you familiar with a vitamin D rich diet and its benefits?

- a. Yes, I am aware of the diet and its benefits.
 - b. Yes, I am aware of the diet but not its benefits.
 - c. No, I am not aware of a vitamin D rich diet.
13. Are you familiar with a Mediterranean diet and its benefits?
- a. Yes, I am aware of the diet and its benefits.
 - b. Yes, I am aware of the diet but not its benefits.
 - c. No, I am not aware of Mediterranean diet.
14. Are you familiar with a Ketogenic diet and its benefits?
- a. Yes, I am aware of the diet and its benefits.
 - b. Yes, I am aware of the diet but not its benefits.
 - c. No, I am not aware of Ketogenic diet.

Willingness of Caregivers to Adopt Different Dietary Practices

15. A high tryptophan diet has been shown to reduce anxiety and assist in reducing aggressive behaviors in individuals with dementia. Foods high in tryptophan include egg whites, spirulina, cod, soybeans, parmesan cheese, and sesame seeds. Would you consider utilizing this diet for your loved one with dementia?
- a. Yes
 - b. No
 - c. Parts of the diet
 - d. Other (please explain)
16. A diet high in vitamin D has been shown to have slight cognitive improvements in the older population and for those with beginning signs of Alzheimer's disease. Vitamin D rich foods include fish liver oils, oily fish, egg yolk, and wild mushroom. Would you consider utilizing this diet for your loved one with dementia?
- a. Yes
 - b. No
 - c. Parts of the diet
 - d. Other (please explain)
17. A Mediterranean diet has been shown to have some comprehensive cognitive improvements. It is high in vegetables, fruits, herbs, nuts, beans, and whole grains with additional focus on eggs, poultry, dairy, and seafood. Would you consider utilizing this diet for your loved one with dementia?
- a. Yes
 - b. No
 - c. Parts of the diet
 - d. Other (please explain)
18. A ketogenic diet has been shown to anti-inflammatory which has been shown to have some cognitive improvements. This includes reducing carbohydrate intake to less than 10% and increase fat intake. Would you consider utilizing this diet for your loved one with dementia?
- a. Yes
 - b. No
 - c. Parts of the diet
 - d. Other (please explain)
19. The diets above incorporate foods that are known to lower inflammation, which can aid in dementia-related symptoms? Would you consider incorporating a combination of the above diets for your loved one with dementia?
- a. Yes
 - b. No
 - c. Other (please explain)

Barriers to Adopting Different Dietary Practices

20. Do you see incorporating the above diets into your food choices and meal planning as beneficial? Please explain.
21. What are some possible barriers you see in incorporating the above diets in reference to your loved one with dementia? (select all that apply)
- a. My loved one does not currently eat a majority of the foods mentioned.
 - b. My loved one does not like a majority of the foods mentioned.
 - c. My loved one does not like to deviate from the current foods he/she eats.
 - d. My loved one does not have an appetite (regardless of the diet)
 - e. My loved one already has a very specific diet
 - f. Other (please explain)

Final Thoughts

22. Are there any further comments or thoughts you would like to provide regarding nutrition for your loved one with dementia?

Appendix B. *Participant Consent Form*
Minnesota State University, Mankato

Consent to Participate in a Research Study

Research on Caregiver Knowledge and Perceptions on Dementia-Specific Nutritional Approaches

Researchers

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You are invited to participate in a research study at Minnesota State University, Mankato. This research is being conducted by Danielle Freitag, a graduate student in Aging Studies and is being supervised by Jeff Buchanan, Ph.D. The purpose of this study is to learn more about how direct caregivers of individuals living with dementia understand and prioritize nutrition specific to dementia.

You are being asked to participate in this study because you are the sole caregiver of an individual living with dementia.

This study is sponsored by the Chelsea Center on Aging and the David and Darlene Janovy Award for Research on Aging.

What will happen if I take part in this research study?

If you agree to participate in this study, you will be asked to do the following:

1. Read this informed consent to ensure you understand what you are being asked to do in this study and that you acknowledge any risks that you may encounter for the duration of the study.
2. Answer a series of questions via an online survey program called Qualtrics. Participants are asked to access this survey utilizing their own computer or find access to a computer to use.
3. The survey consists of 27 questions and is estimated to take 30 minutes. Questions concerning your experience choosing food and meals for loved ones with dementia, experience in nutrition planning and education, and opinions on specific diet interventions will be asked

How long will I be in the study?

The questionnaire will be taken at a time and day convenient for you and is estimated to take 30 minutes.

Can I stop being in the study?

Participation in this research study is voluntary. You can choose to discontinue the survey at any time without penalty.

What risks can I expect from being in the study?

Risks are no more than risks experienced in everyday life. You may experience discomfort answering some of the questions. Should you experience any discomfort, you can choose not to answer the question or stop taking the survey by closing your web browser.

Are there benefits to me or others by taking part in the study?

As a result of the study, participants may experience benefits such as having their voices and opinions heard, learn additional information regarding the topics covered in the study, and have an ability to further discuss their experiences on the topic in an additional phone or e-mail interview.

Will information about me be kept private?

The survey will be anonymous. Confidentiality will be protected in that your name will not be included on any records. All information collected during this study will be used for research purposes only and will only be accessible to the principal investigator, Dr. Jeffrey Buchanan, the student investigator Danielle Freitag. Whenever one works with online technology there is always the risk of compromising privacy, confidentiality, and/or anonymity. If you would like more information about the specific privacy and anonymity posed by online surveys, please contact the Minnesota State University, Mankato Information and Technology Services Help Desk (507-389-6654) and ask to speak to the Information Security Manager).

Will I be compensated for taking part in this study?

In return for your time, participants will be eligible to win one of five \$20.00 gift cards to Amazon.com. Participants that do not complete the survey will not be eligible for compensation.

What are my rights if I take part in this study?

Taking part in this study is your choice. You may choose to take part or not take part in the study. If you take part in this study, you may leave the study at any time. Your decision whether or not to participate will not affect your relationship with Minnesota State University, Mankato, and refusal to participate will not involve a penalty. To discontinue the study, simply exit the survey.

Who will I contact if I have questions about this study?

If you have any questions you are encouraged to contact Jeff Buchanan at Minnesota State University, Mankato or Danielle Freitag. Their contact information is on the first page of this form. If you have questions about participants' rights and for research-related injuries, please contact the Administrator of the Institutional Review Board at (507) 389-1242.

Consent to Participate in the Research Study

Submitting the completed survey will indicate your informed consent to participate and indicate your assurance that you are at least 18 years of age.

Please print a copy of this consent form for your records.

MSU IRBNet LOG # 1605937