International Journal of Education and Social Science; Vol. 8 No. 4; August 2021
ISSN 2410-5171 (Online), 2415-1246 (Print)
Published by Research Institute for Progression of Knowledge

The Relationship Between Food-Related Activities, Dementia and Alzheimer’s Disease

Jackson de Carvalho, PhD
Associate Professor & Interim MSW Program Director
Brailsford College of Arts and Sciences
Prairie View A & M University
Prairie View, Texas 77446
United States of America

Beverly Spears, PhD
Assistant Professor
Brailsford College of Arts and Sciences
Prairie View A&M University
Prairie View, Texas
United States of America

Abstract

*This study explores the phenomenon of dementia and some of the subtypes, followed by a review of the progression of the illness and how it affects activities of daily living. Dementia is described in the relevant literature as a syndrome whereby a person loses their cognitive ability, affecting their memory and everyday activities***.** *Dementia is a broad (“umbrella”) term, as there are many different subtypes of this disease. Other subtypes are caused by various disease processes and are often named after the condition that causes dementia. Furthermore, this study addresses the gap in research regarding food-related care for people with dementia and Alzheimer's by focusing on caregivers from a wide range of relationships. Investigating the caregivers' experiences of dementia and food-related life from diagnosis time will be examined on all facets of food-related processes, including food shopping, preparation, and eating. Lastly, this study aims to explore an in-depth account of caregivers' opinions on food-related support services available.*

Keywords: Dementia, prevalence, predictors, treatment, food, and research.

1.0. Introduction

This study explores the phenomenon of dementia progression and its effect on food-related activities from caregivers' perspectives. Historically, dementia has been known as a form of permanent brain damage (Agronin 2008). There are many different definitions of dementia; however, it is mostly described in the current literature as a syndrome whereby a person loses their cognitive ability, affecting their memory and everyday activities (Bunch, Weiss, Crandall, May, Bair, Osborn, Anderson, Muhlestein, Home, Lappe, & Day, 2010; Gure, 2010). One of the main definitions of dementia is by the DSM-5 that defines it as, 'The clinical syndrome of dementia refers to a pattern of cognitive deficits characterized by impairment in memory and a least one other cognitive domain (e.g., language, executive functions, visuospatial abilities) that is sufficiently severe to impact · behavior and interfere with social or occupational functioning (American Psychiatric Association, 2013, pp.147).

Dementia is an umbrella term since there are many different subtypes of this disease. Other subtypes are caused by various disease processes and are often named after the condition that causes dementia (Agronin, 2008). Alzheimer's disease, however, is the most common type of dementia followed by Vascular dementia and subsequently by frontal, temporal dementia (Dubois & Hebert, 2001). Other sub-types of dementia commonly mentioned are Creutzfeldt-Jakob disease, alcohol-related dementia, Parkinson's dementia, and HIV dementia (Gitlin & Earland, 2010). The combinations of these sub-types of dementias often occur. For example, many may have both Alzheimer's disease and vascular disease. A study conducted by Grinberg and Hiensen (2010) indicated that these two sub-types of dementia have shown to overlap by up to 76% in most studies (Agronin, 2008; Bunch et al., 2010).

Alzheimer's Disease (AD) is by far the most common disease of dementia; with US studies, as well as European studies indicating that 50 to 70% of dementia cases are affected by AD. The studies of Hoozemans, Haastert, Nijholt, Rozemuller, Eikelenboom, & Scheper, (2009) found that Alzheimer's disease is a progressive neurodegenerative disease that affects cognitive functions and episodic memory, such as amnesia, aphasia, and agnosia (Hoozemans et al., 2009). Genetic factors are said to cause AD. However, Rapport, Pettigrew, and Schapiro (1991) reported that monozygotic twins do not necessarily develop AD. Therefore, suggesting that environmental factors also influence AD. A large US study of 23,000 participants found that the median survival of people with AD from initial Diagnosis was 4.2 years for males and 5.7 years for females (Larson, Shadlen, Wang, McCormick, Bowen, & Kukull, 2004). Furthermore, Larson et al. (2004) indicated that the length of survival might differ depending on the person's age or region, but overall, females with AD lived longer than males with AD (Larson et al., 2004; Hoozemans et al., 2009).

According to Jellinger & Attems (2009), the second most common type of dementia is Vascular Dementia (VaD). In Western Europe, clinical studies VaD have shown to vary and account for up to 20% of all dementia cases. The prevalence ranged from 2.2% in females and 16.3% in males Many epidemiological studies have shown various definitions and diagnoses (Attems, & Jellinger, 2014; Grinberg & Hiensen, 2010; Hoozemans et al., 2009, Larson et al., 2004). However, the main diagnostic criteria for VaD are a progressive neurodegenerative disease that affects cognitive decline, and in tum affects memory loss and other cognitive abilities, such as language and praxis. The studies of O’Brien, & Thomas (2015) found the leading causes of VaD to be hypertension, diabetes, heart disease, and stroke (Attems, & Jellinger, 2014; Grinberg & Hiensen, 2010).

The average survival rate from the initial Diagnosis for VaD is less than AD (Strand, Knapskog, Persson, Edwin, Amland, Mjørud, & Selbæk (2018). Knopman, Rocca, Cha, Edland, & Kokmen (2003) studies supported the survival rate differences between VaD and AD, indicating that the median survival for VaD is 3.3 years compared to 6.1 years for AD. The current literature might show a variation in survival rate due to how the data was monitored; for example, some had started their evaluation from the study time and others from when they were diagnosed (Wolfston et al., 2001). A Canadian study by Wolfson and colleagues (2001) measured the length of AD and VaD survival rate and found that the average length of survival was 3.17 for males and 3.36 for females. Although this study looked at AD and VaD combined and not separately, it does support previous findings that females live longer than males (Larson et al., 2004; Strand et al., 2018).

2.0. Literature Review

An extensive literature review shows that most studies have focused on people with dementia, their food-related activities, and behavioral patterns during mealtimes in intuitional settings. Fjellstrom, Starkenberg, Wesslen, Licentiate, Backstrom, Faxen-Irving & The Omeg AD Study Group (2010) studied weight loss, behavioral difficulties, and malnutrition using observational methods from the formal caregivers' perspectives. According to Keller, Martin, Dupuis, Genoe, Edward, and Cassolato (2010), it is essential to investigate eating habits and all aspects of food-related activities (i.e., shopping, meal preparation, and eating) when caring for dementia recipients. Recently, more interest has emerged in the relevant literature in investigating other areas linked to food-related activities, such as food preparation and, most recently, the process of food shopping. Nevertheless, studies in this area are still scarce (Keller et al., 2010; Fjellstrom et al., 2010).

The current literature showed a lacuna regarding research studies focusing specifically on all food-related processes (shopping, preparation, and eating) or from a range of caregivers' perspectives. Other areas limited in research, aside from managing food processes, are food-related information and support services (Keller et al., 2010).

Food-related focused information (i.e., written materials) and support services are more beneficial than general services, yet more needs to be available to caregivers (Keller et al., 2010). By focusing on all food-related processes, a broader understanding can be developed of how caregivers can cope and manage these activities. By raising awareness and knowledge about food-related information and support services, further improvements can be made, such as maintaining their nutritional status with dementia, maintaining their weight, food intake, and reducing challenging behaviors. The overall results should lead to positive outcomes and satisfaction with food-related experiences for caregivers and persons with dementia (Fjellstrom et al., 2010; Keller et al., 2010).

This study addresses the gap in the relevant literature regarding food-related care for people with dementia and Alzheimer's by focusing on caregivers from a wide range of relationships. Investigating the caregivers' experiences of dementia and food-related life from diagnosis time will be examined on all facets of food-related processes, including food shopping, preparation, and eating. Lastly, this study aims to explore an in-depth account of caregivers' opinions on food-related support services available (Andrieu, Reynish, Nourhashemi, Gusset, Grandjean, Grand, Albarede, & Vellas, 2001).

3.0. The Role Food Plays in Our Lives

It is undeniable the role food plays in our lives, from birth to childhood through adult life (Atta-Konadu, Keller, & Daly, 2011). Food is often described as one of the main drivers of a person's cultural identity, and it provides a solid link to social interactions and psychological well-being (Barr & Schumaker, 2003). The relevant indicated limited studies exist in the role of food in everyday lives. However, research studies in this area have increased over the past decade (Ogden, 2010). A definition to explain the role of food has been described as food is essential for life. It provides subsistence, nutrients, and energy. Food is critical to our physiological "well-being, but what, when, and how we eat also contributes to our social, cultural, and psychological quality of life. In many ways, food defines who we are. It is entwined with our sense of self" (Barr & Schumacher, 2003b, pp.177).

Cultural identity plays a vital role in food and enjoyment; for example, Atta-Konadu et al. (2011) examined the context of everyday life, and the role food plays in four different countries using a 25-item American questionnaire on the meaning of health and food. The countries chosen were the US, France, Japan, and Belgium. Although Japan did not have enough participants to show a statistically significant outcome, the results significantly correlated a healthy diet and pleasure. The study results also indicated that France had a much more relaxed and positive attitude towards food, followed by Belgium and the USA (Atta-Konadu et al. (2011; Fjellstrom et al., 2010).

Berg (2006) concluded that the psychology behind food might affect the everyday view of life with food and eating, which may account for food related illnesses, such as cardiovascular disorders. Attitudes towards food may vary from country to country. Still, mealtimes for families, friends, and others getting together around the table to eat is generally seen as a social event - an enjoyable time and an opportunity to meet, discuss and form close bonds with others (Berg, 2006). Ogden (2010) described the importance of food and how social interventions revolve around it, during mealtimes and at the table. This social connectedness is due to taking the time to communicate with one another, which "create a sense of group identity" (Ogden, 2010, pp.72).

It is noteworthy that conflict may occur during meal preparation and eating time. For example, Atta-Konadu et al. (2011) found that women would prefer to feed their families natural, sample, and healthy food. Still, conflicts often arise as families tend to choose processed food. This dichotomy emphasizes the benefits of women's traditional role in the family, feeding them, preparing the meal, and making sure they are eating well. On the other hand, men traditionally remain unfamiliar with meal preparation, and the enjoyment of received meals may depend on the relationship they have with their wives (Keller et al., 2010; O’Brien & Thomas, 2015).

Furthermore, the woman's role as a meal preparer may depend on how she feels about her partner. However, generally, women have been described to take their role in preparing and providing a meal for their family as something of high value (Vesnaver & Keller, 2011). Nevertheless, modem times have changed societal values, and gender roles in food preparation are increasingly becoming equal for men and women. However, for older people, this remains traditional. This healthy matriarchal tradition influences older people as they decline psychologically or cognitively, affecting their functional status. At this point, they will depend on their social relationships as a caregiver to assist them with food-related processes, such as food shopping, meal preparation, and, in severe cases, feeding them (Vesnaver & Keller, 2011; Ogden, 2010).

Maintaining enjoyment and pleasure is essential as food activities play a vital role in the social context. Interacting with each other over a delicious meal enables people to maintain relationships and create meaning in life. Eating brings pleasure to people with dementia; however, health care providers struggle to maintain this source of enjoyment. Therefore, as dementia progresses and affects these food-related activities, the caregiver and health services must recognize the benefits that food related activities can bring to the person with dementia and their caregiver (Keller et al., 2010; Young, de Jersey, Ellick, Lewis & Banks, 2018).

4.0. Dementia Care and Food-Related Activities

Dementia progression affects cognitive and behavioral functions, particularly in food-related activities (Young et al., 2018). Many cognitive and behavioral problems arise from the beginning of dementia until the end, affecting the caregivers and causing distress for both parties According to Berg (2006), food-related activities have been found to be an enjoyable part of caring this area needs to be discussed to find ways of maintaining this pleasure. Grunerta, Deandm, Raats and Nielsena (2007) researched into ways of how caregivers provide food and drink tasks. They described these tasks as primarily revolving around eating difficulties, e.g., spitting out food or refusing to drink. These eating difficulties may cause distress for caregivers as they may feel unable to manage the role of food care. Subsequently, the person with dementia may experience a further physical and behavioral decline (Ogden, 2010; Young et al., 2018).

Thus, strategies can be developed to resolve eating problems, for example, by raising awareness of how to cope with persistent problems and addressing the adverse emotional outcomes that the caregivers experience. Eating problems have been described as inevitable in people with dementia and generally tend to occur in severe stages of dementia, and it is described as the last ADL to be lost during dementia progression (Chang, Lin, Chiu, Liao, Ho, Lin, Chou & Liu, 2017). Eating difficulties arise at different stages of dementia and are particularly difficult in severe and terminal stages (Chang et al., 2017; Grunerta et al., 2007).

4.1. Dementia Progression, Nutritional Problems and Weight Loss

Nutritional problems in most advanced dementias have a common pattern while weight loss is the most typical issue with dementia progression and eating, as this is said to occur from mild to terminal stages and may even happen before Diagnosis (Chang et al., 2017). However, caregivers are uncertain when this initially starts. Weight loss may happen due to eating difficulties, such as using utensils or forgetting to eat (Bilotta, Bergamaschini, Spreafico & Vergani, 2010). Eating habits may change; for example, people with dementia may prefer to eat sweets rather than nutritious food and may steal food or eat just the food they like, e.g., sweets, all the time. Caregivers must anticipate these behaviors and learn how to manage them to maintain a healthy balanced diet for the care recipient and maintain their diet and weight (Navratilova Jarkovsky, Ceskova, Leonard, & Sobotka, 2007). Overall, a decrease in food intake contributes significantly to weight loss and malnutrition, described as furthering cognitive decline. As a result, it decreases motivation, appetite and affects food intake (Bilotta et al., 2010; Navratilova et al., 2007).

Weight loss and malnutrition are often associated with institutionalization and increased mortality (Saka, Kaya, Ozturk, Erten & Karan, 2010). Andrieu, et al. (2001) conducted an extensive study of 318 people with AD and found a relationship between nutritional status and risk of institutionalization (2001). They measured the nutritional status by using a popular and much-used risk assessment tool. This tool is called the Mini Nutritional Assessment (MNA) (Aselage, & Amella, 2010). The MNA comprises six screening questions, and if a high risk is noted, then there are a further six questions to answer. These additional questions assess whether a person with dementia self-feed can, prepare a meal and shop for food. Other measures were Body Mass Index (BMI), which has been described as the initial physiological assessment for nutrition, and ADL scales (e.g., Aselage, & Amella, 2010; Katz, Ford & Moskowitz, 1963). The study results indicated that up to 12 % of the statistical sample had behavioral problems such as overeating or anorexia, 12.4% needed help to feed themselves, 30% required assistance shopping for food, and 25% were unable to shop at all. These factors all contributed to inadequate nutritional intake and, therefore, risk of institutionalization. They concluded that this in tum contributes to morbidity, but with the proper intervention, malnutrition can be reversed. In addition to their conclusion, food supplements were discussed as a preventative measure to reverse weight loss (Andrieu, et al. 200; Saka et al., 2010).

According to Douglas, and Lawrence (2015), clinical observations found that constant walking or pacing also contributed to nutritional problems. This type of problem often due to a large amount of energy being used, which results in metabolic imbalance (tissue building up and breaking down) and leads to a high risk of excessive weight loss. Saka et al. (2010) found that people with dementia would take food from other people, which may be because they needed the extra calories that they were burning. Furthermore, results indicated that encouragement from a carer to sit and take breaks would help dementia patients with their pacing and slow down their metabolic imbalance. Simplifying mealtimes at the table by reducing condiments was also a method to increase food intake. The study participants had Alzheimer's disease, which is noted to be physically more active than other sub-types of dementia (Navratilova et al., 2007). Therefore, studies investigating different dementia sub-types may find different pacing intensity and other eating habits while pacing. Nevertheless, it was encouraging to find that Bilotta et al. (2010) suggested supportive nutritional therapy could improve care-recipients food intake and decrease the risk of malnutrition, therefore improving their overall quality of life (Navratilova et al., 2007; Saka et al., 2010).

4.2. Caregivers' Perspective on Eating Habits.

Morris, Hope and Fairburn (1989) conducted a qualitative study to explore how caregivers manage dementia progression and food-related activities at home. The study interviewed 33 caregivers about the eating habits of people with dementia and found that the majority described the care recipient as eating less, which was also associated with weight loss, which was indicated to occur at all stages of the illness, i.e., from mild to severe. Other food habits were a preference for sweet food, eating inedible substances, and having an odd way of using cutlery. They described these changes in eating habits as one of the indicators that something was not right. The study results indicated that most caregivers had AD, which does not allow an accurate description of dementia care and food activities with all people with dementia. Although, it does indicate how caregivers observe dementia progression and the effect it has on eating habits, and in some cases, it can be an initial indicator that something is wrong. Further studies need to examine the caregivers' reactions and how they manage the changes and potential health risks. Nevertheless, this study did indicate an increase in food intake once the caregiver intervened, therefore suggesting that interventions through caregiving improve the eating habits of people with dementia (Bilotta et al., 2010; Morris et al., 1989).

5.0. Food-Related Interventions in Formal and Informal Settings

According to Douglas and Lawrence (2015) an appropriate intervention can significantly improve the nutritional status of a person with dementia. Nevertheless, interventions included in the relevant research study literature are primarily based on formal caregivers' institutions. Additionally, fewer interventions have focused on informal caregivers and people with dementia living at home (Isaia, Mondino, Germinara, Cappa, Aimonino-Ricauda, Bo, Nobili, & Massaia, 2011). As informal caregivers are the primary source of care, this area needs to be addressed as they need to learn how to manage the care recipients with their food-related activities (Navratilova et al., 2007). Nutritional interventions are needed to prevent health risks and increase enjoyment, i.e., positive outcomes for caregivers and care recipients. Therefore, it is essential to prevent malnutrition and control behavioral difficulties around mealtimes (Isaia et al., 201; Young et al., 2018).

A systematic review by Watson and Green (2006) found 13 articles that reported the effects mealtime interventions had on people with dementia. These interventions mainly focused on agitated behavior and food intake. The results showed that music was most beneficial during mealtimes, reducing difficult behavior and increasing food intake. However, these studies used a small sample and were mainly based in institutions using observational methods, for example, monitoring the behavior and food intake of the person with dementia. Only one study addressed informal caregivers living at home with care-recipients (Aselage, 2010). The study by Corcoran and Gitlin (1996) was devised of two informal caregivers and their care recipients with AD. The AD participants were observed by occupational therapists who gave them eating prompts to manage eating behavior difficulties. The study results showed that the intervention showed statistical significance below the .05 level of significance. Nevertheless, the sample was too small, which could lead to error I or error II - false negative and false positive. Future studies should recruit more participants and include other sub-types of dementia to increase external validity while generalizing the findings to the broader AD population (Aselage, 2010; Bilotta et al., 2010).

Other interventions based on institutional practices found that by organizing the mealtime environment into a 'family style' setting, dementia patients were more likely to eat more food and be calmer during the meal (Aselage, 2010). For example, all residents sat at the table during their meals at a set time. Table clothes and non-plastic plates or cutlery were used and provided cooked meals in dishes on tables instead of pre-plated trays (Young et al., 2018). In addition, providing continuous information on common meal questions, such as 'when is lunch?' limited repetitive questioning and decreased agitated behavior. Nolan and Mathews (2004) conducted a study that placed a large clock in the dining room and a large sign indicating each meal's time. These interventions indicated how the care recipient's challenging behavior and nutritional status could be modified with simple measures. In addition, these 'family style' interventions indicate how in a person's own home, making simple changes, such as placing a large clock for mealtimes or laying a tablecloth, can increase mealtime enjoyment and increase food intake and decrease challenging behavior. These studies should have taken other measures to assess the caregivers' perspectives to investigate how they manage with or without these family-style interventions. As there has been limited research on mealtimes in the care-recipients home, these measures can also be explicitly implemented in a person with dementia's home (Norfolk, 2012; Young et al., 2018).

Furthermore, recent reviews by Aselage and Amella (2010) and by Chang (2012) supported Watson and Green's review (2006), who found that mealtime interventions focused heavily on institutional settings and formal caregivers. However, in addition to this, social, cultural, and psychological aspects. These reviews highlighted the relationship between caregivers and care recipients as an essential focus during mealtimes, not just observing the care recipients' food-related behavioral difficulties or lack of food intake. Both these reviews contributed to the development of a model describing antecedents and their consequences. Antecedents were defined as methods, such as eating and communication between caregivers and people with dementia. The consequences of weight loss and an increase in burden for the caregivers, mainly when they experienced difficulties feeding the care recipient, were also included in the model. They found little research on interventions focusing on reducing eating difficulties and increasing food intake. Although, it was noted that by developing adequate eating skills and timing meals well, mealtime difficulties decreased. In addition to this, psychological aspects were included and noted that burden and stress experienced by caregivers and care recipients as dementia increases affect feeding behavior, resulting in health problems for recipients, such as malnutrition (Aselage & Amella, 2010; Chang (2012).

6.0. Adaptation to Food-Related Activities

The studies of Keller et al. (2010) showed that many studies focused on people with dementia informal care but less so at home and fewer have focused on the point of view from the informal caregiver. Although it is important to explore ways of improving care-recipients nutritional status and weight, studies must also focus on informal caregivers. This is because informal caregivers are the main source of care in dementia and manage dementia progression and food-related activities on their own and with little support (Aselage, 2010). Informal caregivers must adapt to changes in food-related activities, not only during mealtimes but also with food shopping and meal preparation, as dementia progression affects the whole process of food-related routine (Andrieu et al., 2001). As the care recipient's capacity to complete these activities declines, the caregivers need to manage all aspects of food-related activities. Otherwise, people with dementia will most likely lead to poor nutritional status, and caregivers will experience increased psychological distress (Hammar, Swall & Meranius, 2016; NICE, 2018).

Examples of studies examining the psychological impact of informal caregivers' experience during mealtimes with people with dementia have been developed by Bilotta (2010). The studies of Gillette-Guyonnett, Nourhashemi, Andrieu, Glisezinski, Gusset, and Rivière (2000) looked into the association between caregivers' burden and care-recipients' changes in nutritional status. The study was based on people with AD and their informal caregivers who lived at home. Gillette-Guyonnett et al. (2000) assessed people with AD using the Mini Nutritional Assessment (MNA), the Mini Mental-State Examination (MMSE), and Activities of Daily Living (ADL) measures (i.e., scales from Katz et al., 1963). The caregivers were assessed by using the Zarit scale measure, which is used to assess caregivers' burden. In addition, the caregivers' reaction to the care recipients' behavioral and cognitive decline was measured using a memory and behavioral checklist. The results indicated that the severity of dementia and weight loss was significant and was associated with caregivers' high scores in burden. The memory and behavioral problems checklist were a good predictor of weight loss. It indicated that overburdened caregivers were not willing to provide resources for their care recipients to receive appropriate nourishment (Bilotta, 2010; Gillette-Guyonnett et al., 2000).

A similar study by Bilotta and colleagues (2010) was conducted investigating 104 informal caregivers' burden and weight loss of care recipients. Similar measures were used as in the previous study, but the aim was to determine if a short-term burden occurs over three months. Results found that there was an association with weight loss and an increase in stress for the caregivers. Even if malnutrition did not occur, caregivers still experienced distress. They concluded that psychological help for the caregivers, as well as nutritional information, was necessary. The limitations to these studies were that they only assessed burden, and no other psychological effects were measured, such as anxiety, depression, or sleep deprivation. As a result of the Gilliet-Guyonnet et al. (2000) study, a nutritional program was developed to assist families living at home. This program was set up in three different countries in Europe, and the aim was to help caregivers prevent weight loss in the person with AD (Navratilova, 2007; Saka, 2010).

6.1. Nutritional Programs for Informal Caregivers

A nutritional program implemented by Riviere, Gillette-Guyonnet, and Voisin (2001) included 150 caregivers with care recipients with AD and a control group of 74 caregivers with non-dementia recipients. The intervention consisted of monitoring weight and physical activity, providing information on diet, and contact details of a dietician if they needed further assistance. Psychological assessments were also made, such as depression in care recipients and burden of caregivers. There was an evaluation at six months and a one-year follow-up. The results showed that weight improved in the intervention group, depressive symptoms increased in the control group, and the burden was not significant. However, caregivers showed an increase in confidence and enjoyed sharing their difficulties with others and being comfortable in asking for advice on food-related care. This study was probably biased as the caregivers recruited may have participated because they had more interest in learning and changing their behavior (Geary, 2014). The AD participants had moderate stages of dementia. Therefore, it is questionable if this would be the same for severe dementia participants. However, as there was a one-year follow-up, dementia progression was somewhat considered. In conclusion, monitoring the care recipient's nutritional status and weight and caregivers' psychological aspects and providing advice and support to informal caregivers has significant benefits, and further studies need to be developed across all food-related activities (Douglas & Lawrence, 2015; Geary, 2014).

A study by Riviere, Gillette-Guyonnet, Andrieu, Nourhashemi, Lauque, Cantet, Salva, Frisoni, and Vellas (2002), measured the aversive feeding behavior of people with AD. They recruited 224 people with AD along with their informal caregivers. A nutritional education program of nine one-hour sessions was devised to assess psychological, nutritional, and behavioral measures. They used measures, such as MNA, MMSE, and ADL scales (Katz, 1963). Most care recipients had behavioral difficulties when feeding, such as the 26% who wandered away while eating and the 19.3% who did not use cutlery. Feeding difficulties were associated with the age of caregivers and the stage of dementia, and care recipients' behavior. Furthermore, caregivers' stress was associated with preventing affective management of care-recipients' behavior and appropriate food intake. The results indicated that caregivers who experienced stress affect the recipient's negatively eating behavior. They suggested that by educating caregivers, improvements can be made. Overall, this education program to assess and monitor caregivers' and care recipients' physical and psychological aspects has proven beneficial in maintaining good food-intake behavioral difficulties during mealtimes (Geary, 2014). In addition, the interventions have assisted in reducing caregivers' distress. By investigating further into the area of food-related activities and care-management using other methods (e.g., qualitative measures), the measures mentioned in these studies, a more in depth understanding of how informal caregivers perceive dementia progression and mealtimes can be uncovered (Riviere et al., 2002; Saka, 2010).

6.2. Positive Attitudes towards Food-Related Dementia Care

Keller, Edward, and Cook (2007) conducted a study of 23 informal caregivers through qualitative interviews. Study results indicated that dementia persons appreciated the importance of social interaction and that food brought positivity to their lives. However, at the same time, these caregivers noted that mealtimes and food-related activities caused many frustrations and difficulties for them. Similarly, Keller et al. (2010) interviewed 55 informal caregivers and their care recipients. The study by Keller et al. (2007) indicated that the dementia caregiver and care recipient viewed mealtimes as an opportunity for cognitive, emotional enjoyment, and interaction. Informal caregivers described food-related activities as not just sitting at the table eating but as enjoying interconnectedness during this mealtime process, whereby they discussed additional food-related tasks, such as preparing the food and laying the table.

Caregivers found that working together with the person with dementia during food-related activities was satisfying and described their connection as increasing their self-worth and self-esteem. The relationship quality between caregiver and care recipient during food-related processes positively impacts the progression of dementia (Aselage & Amella, 2010; Chang et al., 2017).

The limitations to Keller and colleagues' (2007; 2010) are that they did not research the exact ways the abilities of a person's food-related activities decline over time or how the caregivers' process of adapting to this decline is managed. Expressing the positive side to mealtimes and food-related tasks involved around mealtimes is beneficial to successful caring. However, it is essential to understand the difficulties experienced from Diagnosis and throughout the food-related process to maintain this positivity. Thus, further research studies are needed in this area to explore these issues. For example, a recent qualitative study by Genoe, Keller, Martin, Dupuis, Reimer, Cassolato, and Edward (2012) investigated these changes and how a sample comprised of 27 people with dementia and 28 caregivers adapted to mealtimes as dementia progressed over a two-year follow-up. The results indicated that informal caregivers developed strategies to maintain their mealtime routine with the person with dementia. Changes occurred when making a transitional role in adapting as the increase of dementia impacted food-related tasks, resulting in additional stress for both parties. Further, results indicated that maintaining the relationship between caregiver and recipient is valuable to gain mealtime satisfaction and satisfaction with their life overall. Genre et al. (2012) suggested that this helps provide critical insight into supporting informal caregivers and care recipients at home and providing them with food-related information to make the transitional stage easier (Hammar et al., 2016; Keller et al., 2010).

6.3. More than Just Mealtimes

As nutritional education research with informal caregivers for people with dementia is scarce, Keller and colleagues (2008) designed an interview study to find out the nutritional education needs of informal caregivers from formal caregivers' perspectives. A second study was assembled to find food-related materials that are available for informal caregivers. Results from the interviews showed that informal caregivers were concerned about the care recipient's low food intake, gaining access to food, maintaining independence when feeding, and meal preparation (e.g., safety with a stove or with other cooking utensils). The formal caregivers would provide information mainly on topics such as healthy eating and simplifying food (Hammar et al., 2016). In addition to this, they would provide the informal caregiver with additional tips that they learned through training. From the second study, they found the quality of food- related material that was available was adequate and that most of the topics in the material were based on swallowing difficulties (Genre et al. 2012; Hammar et al., 2016).

Overall, Keller and colleagues (2008), showed that more targeted information on nutrition and dementia was needed for informal caregivers. Food preparation topics, such as safety in the kitchen and cooking, were raised as important information to give to informal caregivers, although very little was found in the literature to address this. The limitations of the study of Keller and colleagues (2008) were that they were rather small samples and that more research needs to be taken from the informal caregivers' perspectives to gain an accurate account of what they need in this area. The benefits of the Keller and colleagues' (2008) studies are that they highlight what information is needed to manage mealtimes better. This is not just about eating difficulties or nutritional tips but goes beyond this to cooking and safety in the kitchen. These elements were found to be important, but caregivers' access to this type of information is scarce (Fjellstrom et al. 2010; Keller et al., 2008).

Other recent studies that focused on informal caregivers and investigated food-related activities that went beyond the eating processes are mainly from studies exploring spouse relationships and gender differences. These studies examined the whole process of food- related care to discover changes in adapting to dementia progression and abilities to manage the food shopping, food preparing, and eating food. A study by Fjellstr6m and colleagues (2010) looked into the transitional experience of a caregiver, taking on a new role that is best suited to them and the person with dementia, while at the same time maintaining the best quality of food-related care. The results indicated that women were more likely to prepare the food and would tend to shop for food alongside their partners. Once their partners could no longer shop with them, difficulties would occur, as the female caregivers would manage alone for the first time. However, adapting to these changes and adapting to a new role was necessary (Atta-Konadu et al., 2011; Fjellstrom et al. 2010).

Furthermore, having a positive attitude to these role changes helped the caregivers maintain appropriate food-related activities. The limitations to this study were that they only used AD recipients, and therefore, other types of dementia should be accounted for. This would be because different food-related behavior during food shopping or food preparation may occur between different sub-types of dementia (Andrieu et al., 2001). In addition, other relationships aside from spouses (e.g., friends, daughters, or sons) should be accounted for to give a broader insight into how caregivers adapt to these role changes. The study uses focus groups and qualitative methods (Ritchie, Lewis, McNaughton-Nicholls & Ormston, 2014). Therefore, quantitative, and qualitative methods should be used to assess coping skills and how caregivers feel they are adapting to role changes. Overall, food-related activities were particularly burdensome for inexperienced caregivers, who were mostly men and had little previous experience in food preparation. Therefore, gender studies can provide a good example of how caregivers' food role transitions between them and the person with dementia (Nell et al., 2016; Ritchie et al., 2014).

Another transitional food role study is by Canadian researchers, Atta-Konadu and colleagues (2010). They devised a three-year study using interviews and grounded theory, asking male caregivers and their wives with dementia about their transitional journey in food-related processes. As studies on gender roles have reported leaving male caregivers as being unprepared and with little skills to adapt to food preparation, cooking, and shopping, this was a much-needed study (Fieldstream et al., 2010). For example, results indicated that wives with dementia would help the husband to prepare a meal but found that their identity was lost as they no longer could complete the meal preparation tasks. However, by assisting each other, the wife was able to maintain these food tasks. Therefore, she could continue to be active in food-related activities for as long as possible. Some husbands did not find it appropriate that they should cook; therefore, they asked for help from other family members or additional formal support, such as catering firms. Overall, these participants learned to cope with changes in dementia and adapt by cooperating, sharing, and assisting one another (Fieldstream et al., 2010; Nell et al., 2016).

In summary, discovering the relationship and role adaptations between the caregiver and the person with dementia during all food-related processes (food shopping, preparation, and eating) helps to build a better transitional understanding in this domain (Nell et al., 2016). This transitional understanding is how they adapt to dementia progression and, in turn, can maintain the care recipient's good nutritional status and limit caregiver's distress that may occur while developing new coping skills. Both these studies highlight the importance of understanding the caregiver and care recipient and how they work together through dementia increase to manage all three food-related processes to the best of their abilities (Atta-Konadu et al., 2010).

However, the studies that do address all food processes (e.g., Atta-Konado et al., 2011; Fjellstrom et al., 2010) have their limitations as they focus on the spouse caregiver. By examining the transitional food roles with other relationships, such as a friend, son, or daughter, a wide account of how informal caregivers and their individual relationship with the care recipient can be understood in more detail. Older generation females tend to be the main person in the family who shop and prepare for food. It is important to gain more insight into the male's perspective. Additionally, finding out the role of the woman can also assist informal male caregivers in managing food-related processes. These studies have suggested that relationship-focused and individual-focused approaches need interventions, such as written information, to assist the transitional food role of caregiver and care recipient (Keller et al., 2010). These interventions can also come in the form of formal social support to cater to the individual's food-related needs (Fjellstrom et al., 2010; Keller et al., 2010).

7.0. Food as Social Support in Dementia

Other forms of assisting caregivers to manage and cope better in food-related tasks are in the form of food-related social support and help from friends and families. These are formal support services, such as respite-care (e.g., lunch clubs) and home service deliveries (e.g., meals-on-wheels) (Young et al., 2018). Catering to the needs of the informal caregivers and making sure they are linked with dementia and food is most beneficial. Moreover, caregivers need to build on the experience and knowledge and gain support and assistance directly relevant to their situation (Keller et al., 2008). Therefore, proper support specializing in dementia and food-related activities are more valuable for the caregivers than general support for older adults (Keller et al., 2008).

These specialized services come in different forms, such as helping in the home, for example, meals-on-wheels services. These services deliver cooked or frozen meals to people who cannot cook for themselves, i.e., a person with dementia living at home alone, caregivers who have not got the time to cook, or those not accustomed to cooking (Ragdale, 2014). As found in Fjellstrom 's study (2010), male caregivers were most likely to use meals-on-wheels services, as they found it inappropriate or too complicated to develop these skills sufficiently. The limitations have noted with home food deliveries are that the quality of meals provided to dementia care recipients is not nutritious enough. However, at the same time, the recipients have emphasized valuing this service, therefore making it beneficial despite its lack of nutrition (Ragdale, 2014; 2010; Young et al., 2018).

Other food-related support services are in the form of lunch dubs. These lunch clubs have been designed in a cafe and have been developed across many different countries and regions: they are usually based in community centers or churches run by Alzheimer's charity organizations (NICE (2018). Caregivers can leave the care recipients there for lunch, which can be a source of respite. In addition, they can be together during social activity, i.e., eating lunch or afternoon tea. The care- recipients who attend these lunch clubs are mainly from mild to moderate stages of dementia, but all stages of dementia care are welcome (Young, 2018). These lunch clubs and cafes have been evaluated as educational, as caregivers can learn from peers, and they are also in a specialized environment with professionals and volunteers who know and are aware of how to handle people with dementia and food situations (Chang, 2017). For example, specific training on nutrition, feeding difficulties, meal preparation is offered, and offering care-recipients 'finger foods', which are easy to eat without using utensils. They encourage sharing experiences and information, which can lessen burden and anxiety (Ragdale, 2014). The evaluation of the success of these cafes has been analyzed mainly through observing the attendance rates. Further feedback through interviews or questionnaires would also be helpful to find out the exact emotional and coping skills caregivers receive from one another and from the lunch itself. Other forms of education, highlighted as the most preferred form of receiving information in food-related care, are through written materials (Keller, 2008). These studies are scarce, and more needs to be evaluated to find the exact effect of written information interventions in food-related care (Chang, 2017; Ragdale, 2014).

8. 0. Satisfaction with Food-Related Life

From the theories and studies outlined in the previous section, it has been found that many benefits occur for both parties by maintaining positive experiences that arise during food-related activities in people with dementia and their caregivers (Atta-Konadu et al., 2011). These benefits give the person with dementia the opportunity to continue having a good nutritional status for as long as possible and keeping them living at home rather than in an institution (Chang, 2017). Subsequently, the caregiver assists in maintaining a healthy amount of food intake and weight. Other areas are caregivers developing coping skills to manage care-recipients’ behavioral difficulties (e.g., wandering, repetitive questioning). Caregivers must be aware of and acknowledge the changes that occur due to dementia progression and take on the 'transitional food role' with more ease. By increasing this knowledge and awareness through specific food-related interventions (i.e., lunch clubs, food-related training, or written information), psychological distress can decrease in the caregiver, and behavioral difficulties decrease in the care recipient (Atta-Konadu et al., 2011; NICE, 2018).

A decreasing negative outcome such as caregiver burden, stress and increasing positive outcome such as pleasure and enjoyment can create satisfaction within the food-related domain of caregiving for both caregiver and recipient. This kind of positive outcome has an impact on a person's quality of life, which has recently been described more precisely as satisfaction with food-related life (Young, 2018). This area of research study is increasingly important as the quality of a person's life has a solid link to health care and, in particular, to chronic disease (Duncombe, Kitamura, Hase, Ihara, Kalaria, and Horsburgh, 2017). As life expectancy is increasing, studies in this area are growing, and researchers are interested in discovering the quality of life, particularly in current health care studies (Zhong, Yuan, Gu, Kim, Chin, Loye, … Yu, 2020). A widely generic definition for quality-of-life is:

"Quality of life is defined as an individual's perception of their position in life in the context of the culture and values systems in which they live and about their goals, expectations, standards, and concerns. It is a broad-ranging concept, affected in a complex way by a person's physical health, psychological state, personal beliefs, social relationships, and their relatio·nship to their environment" (World Health Organisation, 1997, pp.2). Nevertheless, the term quality of life has been found to have many definitions and is seen to be an umbrella of many concepts, such as happiness, functioning, and lifestyle (Zhong et al., 2020). Therefore, Duncombe and his colleagues (2017) critiqued the different concepts that have developed over time to define the quality of life. They found that satisfaction with life clearly distinguishes between the quality of life and health. Although it is not just limited to health but all aspects of life, satisfaction implies that quality of life is maintained (Grunerta et al., 2007; Young, 2018).

Life satisfaction has been defined by Shin and Johnson (1978) "as *a global assessment of a person's quality of life according to his chosen criteria"* (pp.478), and it has been referred to as a series of cognitive processes where one makes judgments of what they consider an acceptable circumstance, and different individuals have their level of standards. Satisfaction with life focuses more on positive outcomes than adverse outcomes, which is· an area lacking in dementia care research. In addition, it notably lacks in food-related tasks, where enjoyment and positivity have been noted to be high in the area of dementia care compared with other areas of activities of daily living (Zhong et al., 2020). Furthermore, Diener et al. (1985) designed a scale to measure satisfaction with life, which aimed to acquire a person's judgment about their own life. This scale consisted of five items: ' *in most ways, my life is close to my ideal.'* The benefit of this scale is that it is flexible enough to measure different domains, such as satisfaction towards one's health or relationships. Satisfaction is broken down further into different domains, such as food, money, or relationships (Diener et al., 1997). From this scale, one can measure how changes in dementia progression can affect caregivers' satisfaction and measure one particular domain, such as with food-related life (Diener et al., 1985; Zhong et al., 2020).

The term satisfaction with food-related life will be used to describe the outcome of caregivers' experience in managing care-recipient's food-related activities. The term food-related life signifies a specific domain of a person's satisfaction with life. An ideal measure to evaluate changes in food-related activities and the effects on informal caregivers' and care-recipients' lives is using a questionnaire developed by Grunerta et al. (2007) called 'the measure of satisfaction with food-related life.' This measure is unique as it focuses directly on food-related domains and satisfaction with life. It was important to them to include food shopping, food preparation, and eating with a person's quality of life and satisfaction to collect the whole process of a person's food-related experience. The benefit of this measure is that it can be used to test people's perception of their food-related life in different circumstances. In addition, it can be used as a dependent variable to find out what other various aspects affect a person's satisfaction with food. For example, this could be used with dementia caregivers who live with the care recipients and look after them occasionally with food-related activities (Grunerta et al., 2007; Young, 2018).

Other independent variables can be aspects such as stress, coping abilities, and severity of dementia. The measure was a seven-item scale influenced by Diener et al. (1985). All food-related activities were viewed as important to gain the whole picture of this domain, even though not everyone answering this questionnaire will have the same food shopping and preparation involvement. This measure was tested on older adults in eight different European countries who participated in a food project specifically for older people (Keller et al., 2008). A large sample was used to validate the scale, and it was found that it was a good measure to test the judgment of a person's experience in satisfaction with food related life. Food diaries and food-related interviews were both found to correlate with the scale, and five of the items were applicable for all European countries. In summary, this measure indicates itself to be beneficial and transferable in most scenarios. Therefore, this would be an excellent measure to implement in dementia caregiver studies as little has been done to test their quality of life, particularly their satisfaction with food-related life (Diener et al., 1985; Young, 2018).

9.0. Summary

The literature showed that most studies have focused on dementia and their eating habits and behavior during mealtimes in intuitional settings. These studies have looked at weight loss, behavioral difficulties, and malnutrition, using observational methods and looking from the formal caregivers' perspectives. Furthermore, the literature showed that it is important to investigate eating processes and all aspects of food-related processes (i.e., shopping, meal preparation, and eating) when caring for dementia recipients (Keller et al., 2007).

Recently, there has been more interest in investigating other areas of food outside eating, such as food preparation and most recently in food shopping. The existing body of research studies in this area is still scarce (Atta-Konadu et al., 2011; Fjellstrom et al., 2010).

The relevant literature is scant on research explicitly focused on all food-related processes (shopping, preparation, and eating) or from a range of informal caregivers' perspectives (Berg, 2006). Other areas limited in research, aside from looking at the abilities to manage food processes as a whole, are food-related information and support services (Keller et al., 2010). Food-related focusing information (i.e., written materials) and support services are more beneficial than general services, yet more needs to be available for informal caregivers (Genoe et al., 2012). By focusing on all food-related processes, a broader understanding of how informal caregivers cope and manage these activities can be developed. In addition, further improvements can be made by raising awareness and knowledge, such as maintaining the person's nutritional status with dementia and maintaining their weight, food intake, and reducing challenging behaviors. Thus, maintaining the person's nutritional status often results in both parties experiencing minimum distress and maintaining the connection and enjoyment around food-related activities. Therefore, the overall result will be gaining positive outcomes and satisfaction with their food-related life, which can be extended to a caregiver and person with dementia's life in general (Berg, 2006, Genoe et al., 2012).

This study addressed the gap in research on food-related care for people with dementia by focusing on informal caregivers from a wide range of relationships (i.e., not just spouses but all informal caregiver types), as well as from all dementia subtypes (i.e., not just looking at those with AD) and will include all severity groups (mild, moderate, and severe). Investigating the informal caregivers' own experiences of dementia and food-related life from the time of diagnosis will be examined and focus on all three food-related processes (shopping, preparation, and eating). This study examined an in-depth account of informal caregivers' opinions on food-related support services available. Additionally, this study aimed to develop up-to-date educational information on food-related care while discussing the benefits these tools have on informal caregivers.

References

Agronin, M. E. (2008). Alzheimer's disease and other dementias (2nd Ed). *Lippincott Williams and Wilkins.*

American Psychiatric Association, (2000). *Diagnostic and Statistical Manual of Mental Disorders (4th Ed).* Washington, DC: American Psychiatric Association. Retrieved from: http://www.minddisorders.com/De1Fi/Dementia.html#ixzz23PoCYbS7

Andrieu, S., Reynish, W., Nourhashemi, F., Gusset, P. J., Grandjean, H., Grand, A., Albarede, J. L., & Vellas, B. (2001). Nutritional risk factors for institutional placement in Alzheimer's disease after one year follow-up. *The Journal of Nutrition, Health & Aging, 5,* (2), 113-117.

Aselage MB (2010) Measuring mealtime difficulties: eating, feeding and meal behaviours in older adults with dementia. *Journal of clinical nursing* 19(5-6): 621-31.

Aselage, M. B., & Amella, E. J., (2010). An evolutionary analysis of mealtime difficulties in older adults with dementia. *Journal of clinical nursing, 19(1-2),* 33-41.

Atta-Konadu, E., Keller, H. H., & Daly, K. (2011). The food-related role shift experiences of spousal male care partners and their wives with dementia. *Journal of Aging Studies, 23,* 305-315.

Attems, J., & Jellinger, K. A. (2014). The overlap between vascular disease and Alzheimer’s disease – lessons from pathology. *BMC Medicine, 12*(1), 206. https://doi.org/10.1186/s12916-014-0206-2’

Barr, J., & Schumancher, G. (2003). Using focus groups to determine what constitutes quality of life in clients receiving medical nutrition therapy: First steps in the development of a nutrition quality-of-life survey. *The American Dietetic Association, 103(7),* 844-854.

Barr, J.T., & Schumacher, G.E. (2003b). The need for a nutrition related quality of life measure. *Journal of the American Dietetic Ass_ociation. 103(2),* 177-180.

Baskys, A., & Cheng, J. (2012a). Pharmacological prevention and treatment of vascular dementia: Approaches and perspectives. *EXG, 47*(11), 887–891. https://doi.org/10.1016/j.exger.2012.07.002

Berg, G., (2006). *The importance of food and mealtimes in dementia care. The table is set.* Jessica Kingsley Publishers: London and Philadelphia.

Bilotta, C., Bergamaschini, L., Arienti, R., Spreafico, S., & Vergani, C. (2010).

Caregiver burden as a short-term predictor of weight loss in older outpatients suffering from mild to moderate Alzheimer's disease: A three months follow- up study. *Aging & Mental Health, 14(4),* 481-488.

Bunch, T. J., Weiss, J.P., Crandall, B. G., May,~H. T., Bair, T. L, Osborn, J. S.,

Anderson, J. L., Muhlestein, J. B., Home, B. D., Lappe, D., L., & Day, J. D. (2010). A trial fibrillation is independently associated with senile, vascular, and Alzheimer's dementia. *Heart Rhythm,* 7(4), 433-437.

Chang CC (2012) Prevalence and factors associated with feeding difficulty in institutionalized elderly with dementia in Taiwan. *The Journal Of Nutrition, Health & Aging* 16(3): 258-261.

Chang C-C, Lin Y-F, Chiu C-H, Liao Y-M, Ho M-H, Lin Y-K, Chou K-R and Liu MF (2017) Prevalence and factors associated with food intake difficulties among residents with dementia. *Plos One* 12(2): e0171770-e0171770.

Corcoran, M.A. & Gitlin, L.N. (1996), Managing eating difficulties related to· dementia: a case comparison. *Topics in Geriatric Rehabilitation, 12,* 62-69.

Diener, E, Emmons, R, A., Larsem, R. J., & Griffin, S. (1985). The satisfaction with life scale. *Journal of Personality Assessment, 49(1),* 71-77.

Douglas JW and Lawrence JC (2015). Environmental Considerations for Improving Nutritional Status in Older Adults with Dementia: A Narrative Review. *Journal of the Academy of Nutrition and Dietetics.*

Dubois M. F. & Herbert R. (2001). The incidence of vascular dementia in Canada: a comparison with Europe and East Asia. *Neuroepidemiology, 20,* 179-87.

Duncombe, J., Kitamura, A., Hase, Y., Ihara, M., Kalaria, R. N., & Horsburgh, K. (2017). Chronic cerebral hypoperfusion: A key mechanism leading to vascular cognitive impairment and dementia. Closing the translational gap between rodent models and human vascular cognitive impairment and dementia. *Clinical Science*, *131*(19), 2451–2468. https://doi.org/10.1042/CS20160727.

Fjellstrom e, C., Starkenberg, A., Wesslen, A., Licentiate, M. S., Backstrom, A., T., Faxen-Irving, G., & The Omeg AD Study Group. (2010). *American Journal of Alzheimer's Disease and Other Dementias,* 25(6), 521-526.

Geary J (2014) *A Literature Review of the Negative Impact of Dementia on the Nutritional Status of Hospitalized Elderly Patients.* Unpublished Batchelor of Nursing thesis Salem State University University.

Genoe, M. R., Keller, H. H., Martin, L. S., Dupuis, S. L., Reimer, H., Cassolato, C. & Edward, G. (2012). Adjusting to Mealtime Change within the Context of Dementia. *Canadian Journal on Aging, 31*(2), 173-194.

Gillette-Guyonnett, S., Nourhashemi, F., Andrieu, S., Glisezinski, I., Gusset, P.J., & Rivière, D. (2000). Weight loss in Alzheimer disease. *American Journal o f Clinical Nutrition,* 77, 637-642.

Gitlin, L. N., & Earland, T. V. (2010). Improving quality of life in individuals with dementia: the role of nonpharmacoligic approaches in rehabilitation. International Encyclopedia of Rehabilitation. *CIRRIE publications.*

Grinberge, LT., & Heinsen, H. (2010). _Toward a pathological definition of vascular dementia. *Journal of the Neurological Sciences, 299(2),* 136-138.

Grunerta, K. G., Deandm M., Raats, M. M., & Nielsena, N. A. (2007). A measure of satisfaction with food-related life. *Appetite 49,* 486-493.

Gure, T. R. (2010). Differences in functional impairment across subtypes of dementia. The Journ-als of Gerontology. Series A, Biological sciences and medical sciences, 65A (4), *434.*

Hammar LM, Swall A and Meranius MS (2016). Ethical aspects of caregivers' experience with persons with dementia at mealtimes. *Nursing Ethics* 23(6): 624-635.

Hoozemans, J. M., Haastert, E, S., Nijholt, D., A., T., Rozemuller, A., Eikelenboom, P., & Scheper, W. (2009). The unfolded protein response is activated in pretangle neurons in Alzheimer's disease hippocampus. *The American Journal ofPathology, 174(4),* 1241-125.

Isaia, G., Mondino, S., Germinara, C., Cappa, G., Aimonino-Ricauda, N., Bo, M., Nobili, G., & Massaia, M. (2011). Malnutriton in an elderly demented population living at home. *Archives of Gerontology and Geriatrics, 53,* 249- 251.

Jellinger, K. A. & Attems, J. (2010). Is there pure vascular dementia in old age? *Journal of The Neurological Sciences, 299(1-2),* 150-154.

Keller, H. H., Edward, G., & Cook., C. (2007). Mealtime experiences of families with dementia. *American Journal of Alzheimer's disease and Other Dementias, 21(6),* 431-438.

Katz, S., Ford, A., & Moskowitz, R. (1963). The index of ADL: A standardised measure of biological and psychosocial function. *JAMA, 185,* 914-919.

Keller, H. H., Martin, L. S. Dupuis, S., Genoe, R., Edward, G., & Cassolato, C. (2010). Mealtimes and being connected in the community-based dementia context *Dementia, 9(2),* 191-213.

Knopman, D. S., Rocca, W., Cha, R. H., Edland, S. D. & Kokmen. E. (2003) Survival study of vascular dementia in Rochester, MiIB?-esota. *Archives of Neurology., 60(12),* 85-90.

Larson, E. B, Shadlen, M. F. D., Wang. L., McCormick. W. C., Bowen. J. D., & Kukull, W. A. (2004). Survival after Initial Diagnosis of Alzheimer Disease.

Annals of Internal Medicine, 140(7), 501-509.

Morris, C. H., Hope, R. A., & Fairburn, C. G. (1989). Eating habits in dementia. British Journal of Psychiatry, 154, *801-806.*

Navratilova, M., Jarkovsky, J., Ceskova, E., Leonard, B., & Sobotka, L. (2007). Alzheimer disease: Malnutrition and nutrition support. *Clinical and experimental pharmacology and physiology, 34(S*1) S11-S13.

Nell D, Neville S, Bellew R, O'Leary C and Beck KL (2016). Factors affecting optimal nutrition and hydration for people living in specialised dementia care units: A qualitative study of staff caregivers' perceptions. *Australasian journal on ageing* 35(4): E1-E6.

NICE (2018). *Dementia: assessment, management and support for people living with dementia and their carers [NG97]*. National Institute for Health and Care Excellence

Nolan, B, A., & Mathews, R. (2004). Facilitating resident information seeking regarding meals in a special care unit. *Journal of Gerontological Nursing, 30(10),* 12-16.

Norfolk NHS (2012). Dementia and Food. *NHS foundation Trust,* pp.1-3.

O’Brien, J. T., & Thomas, A. (2015). Vascular dementia. *The Lancet*, *386*(10004), 1698–1706. https://doi.org/10.1016/S0140-6736(15)00463-

Ogden, J. (2010). The psychology eating: From healthy to disordered behaviour (2nd Edition).*Wiley-Blackwell.*

Ragdale S (2014) Dementia and it's relationship with food. *Nutrition.* Mark Allen Publishing Ltd.

Rapport S. I., Pettigrew K. D., & Schapiro M. B. (1991). Discordance and concordance of dementia of the Alzheimer type (DAT) in monozygotic twinsindicate heritable and sporadic forms of Alzheimer's disease. *Neurology, 41,*1549-53.

Ritchie J, Lewis J, McNaughton-Nicholls C and Ormston R (2014) *Qualitative Research Practice* (2nd Edition). London. California. NewDelhi. Singapore.: SAGE Publications Ltd

Riviere, S., Gillette-Guyonnet, S, Andrieu, S, Nourhashemi, F., Lauque, S, Cantet, C., Salva, A., Frisoni, G., &Vellas, B. (2002). Cognitive function and caregiver burden: predictive factors for eating behaviour disorders in

Alzheimer's disease *International Journal of Geriatric Psychiatry, 17(10),*

950-955.

Riviere S, Gillette-Guyonnet S, & Voisin T. (2001). A nutritional education program could prevent weight loss and slow cognitive decline in Alzheimer's disease. *Journal of Nutrition, Health and Ageing,* 5(4), 295-299.

Saka B, Kaya O, Ozturk GB, Erten N and Karan MA (2010) Malnutrition in the elderly and its relationship with other geriatric syndromes. *Clinical nutrition* 29(6): 745-8

Shin, D., C., & Johnson, D. M. (1978). Avowed happiness as an overall assessment of the quality of life. In Diener, E, Emmons, R, A., Larsem, R. J., and Griffin, S. (1985). The satisfaction with life scale. *Journal of personality assessment, 49(1),* 71-7.

Strand, B. H., Knapskog, A. B., Persson, K., Edwin, T. H., Amland, R., Mjørud, M., … Selbæk, G. (2018). Survival and years of life lost in various aetiologies of dementia, mild cognitive impairment (MCI) and subjective cognitive decline (SCD) in Norway. *PLoS ONE*, *13*(9), 1–14. https://doi.org/10.1371/journal.pone.0204436

Vesnaver, E., & Keller, H. (2011). Social influence and eating behaviour in later life: A review. *Journal of nutrition in gerontology and geriatrics, 30(1),* 2-23.

Young AM, de Jersey SJ, Ellick J, Lewis CA and Banks M (2018) Comparison of Patient Food Intake, Satisfaction and Meal Quality Between Two Meal Service Styles in a Geriatric Inpatient Unit. *J Nutr Gerontol Geriatr*: 1-11

Watson, R., & Green, S. M. (2006). Feeding and dementia: a systematic literature review. *Journal of Advance Nursing,* 54(1), 86-93.

World Health Organization (1997). *WHOQOL -Measuring quality of life. The world health organization quality of life instruments.* THE WHOQOL-100 AND THE WHOQOL-BREF, 1-13.

Zhong, W., Yuan, Y., Gu, X., Kim, S. I., Chin, R., Loye, M., … Yu, S. P. (2020). Neuropsychological Deficits Chronically Developed after Focal Ischemic Stroke and Beneficial Effects of Pharmacological Hypothermia in the Mouse. *Aging and Disease*, *11*(1), 1. https://doi.org/10.14336/AD.2019.0507