Understanding Dementia: Metabolic and Psychosocial Risk Factors

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Abstract

Dementia is a national priority, with over six million Americans affected at an annual cost of approximately $200 billion and no available cure. As the elderly population increases exponentially, the incidence of dementia is expected to double every 20 years. Currently, the global incidence of dementia is over 9.9 million new cases every year (Alzheimer's Association, 2018a). The relevant literature often addresses dementia as a degenerative and chronic disease, the course, and the duration of which can vary. The theoretical understanding of dementia has been influenced by the historical perspective of its formulation, which focused on the neurological aspects of the disease. Interest in studying the nature of dementia outside the neuropathology has, however, allowed for additional dimensions of the disease to be explored, namely the psychosocial aspects of the dementia process. Dementia is by far the most common cognitive disorders found among the aging population, and many researchers view it as a serious and growing mental health concern in the United States and around the world. This study explores the metabolic and psychosocial risk factors associated with dementia to provide a better understanding of the mechanisms underlying this disease, which is crucial to combat its high prevalence, incidence, and burdens. To expand the understanding of factors associated with the provision of care and treatment of dementia may lead to a significant increase in the quality of life and optimized functioning in the face of this impactful disease.

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

1.0. Introduction

Dementia is by far the most common cognitive disorders found among the aging population (Alzheimer's Association, 2018b) and many researchers view it as a serious and growing mental health concern in the United States and around the world (LaMantia, Stump, Messina, Miller, & Callahan, 2016). The relevant literature often addresses dementia as a pandemic with a worldwide prevalence of approximately 35.6 million people in 2010. As the elderly population continues to increase, the incidence of dementia is expected to double every 20 years. The global incidence of dementia is over 9.9 million new cases every year (Alzheimer's Association, 2017; Prorok, Horgan, & Seitz, 2013).

It is projected that the prevalence and incidence of dementia will double approximately every five years between the ages of 65 and 85 years. According to Galvin, Valois, and Zweig (2014), over half of the elderly population will have dementia by ages 85 to 90. With the current aging population, the incidence of dementia has increased significantly in the United States, posing a challenge to health care professionals who are faced with managing the pandemic burden of dementia (Prince, Wimo, Guerchet, Ali, Wu, Prina, 2015).

Among the various types of dementia, Alzheimer's disease is the most frequent and accounts for about 72% of all dementia cases (LaMantia, et al., 2016). Those impacted by dementia often experience forgetfulness, confusion, and phases of absentmindedness over time; progressively, the disease severely impairs the brain's functions. Usually, the person will compensate for the early symptoms; neither victims nor those around them may suspect a medical problem at first. The slow but progressive damage to the brain is often not noticed until the person experiences higher than normal stresses, pressures, or losses that stretch their coping abilities to the breaking point (Galvin et al., 2014). Those with dementia gradually lose intellectual capacities, demonstrate impaired occupational functioning, become unable to perform social roles, and eventually become dependent on others for assistance with daily living (Prorok, et al., 2016; World Health Organization, 2012).
Therefore, throughout the disease process, family caregivers become responsible for the supervisory and direct care needs of the patient. In the early stages, caregivers take over higher-level functions, such as managing medications and finances.

As dementia advances, caregivers become increasingly involved with self-care tasks such as bathing, dressing, and feeding. Patient safety becomes a widening concern, and problems such as incontinence often develop. Behavioral problems, such as patient depression, agitation, and wandering, are rated as most stressful by caregivers, as they can occur unpredictably and often require continuous monitoring (La Fontaine, Jutlla, Read, Brooker, & Evans, 2016; Lee, Taylor, & Thomas, 2012).

2.0. Literature Review

An extensive review of the current literature regarding the cumulative effect of metabolic and psychosocial risk factors associated with dementia is limited. Of the available studies Postuma, Iranzo, Hogl, Arnulf, Ferini-Strambi, Manni, ... &Montplaisir (2015) summarized the findings and admitted that the influence of multiple risk factors is not often associated with the low levels of cognition generally seen in patients with dementia. Most of the epidemiological studies have methodological issues of concern. Studies on metabolic index have very loose criteria for poor performance, with some studies attributing any performance below the mean to an individual's metabolic index with others maintaining a 25th percentile cutoff (Boot, Orr, Ahlskog, Ferman, Roberts, Pankratz, ... &Boeve, 2013; Postuma et al., 2015).

The relevant literature showed that primary care providers faced challenges when dealing with individuals with dementia. Providers often lacked the knowledge and confidence in recognizing dementia symptoms and were often unsure of how to conduct a thorough cognitive screening (Spenceley, Sedgwick, & Keenan, 2015). Many home care studies have shown that informal care of the elderly at home is achieved mainly by a primary family caregiver with the assistance of other caregivers (Calabrese, 2013; Jensen, & Inker, 2015; Spenceley et al., 2015) and that older people receive assistance from a network of helpers (Zeisel, 2013). The term primary caregiver implies that there are also secondary caregivers, but this is not always the case in practice. One study documented the caregiver support network and examined its influence on the experience of the primary caregiver for a sample of caregivers of impaired older persons six weeks after they left the hospital following treatment for a stroke or a hip fracture (Athilingam, Visovský, Elliott, & Rogal, 2015; Goldmacher, & Kerwin, 2013; Prorok, et al., 2016).

Nearly 7% of the 242 primary caregiver/older person dyads reported caring for the older person without aid from anyone else, and the remaining 93% of the primary caregiver/older person dyads included one to six secondary helpers with direct care (Spenceley et al., 2015). Data drawn from the 1982 National Long-Term Care Survey has shown that approximately 70% of the 2201 subjects, which represented 2.2 million persons caring for 1.6 million disabled elders, were primary caregivers with the remainder playing a secondary role. About one-third of the primary caregivers did not receive any assistance from other informal or formal caregivers and devoted an average of 4 hours a day to caregiving activities. Another one-third of the respondents were primary caregivers with one or more unpaid helpers and provided 4.4 hours of care per day. Finally, 10% of the primary caregivers received paid help in addition to unpaid assistance and spent 5.4 hours each day to elderly care (Alzheimer's Association, 2018b; Sadak, Katon, Beck, Cochrane, &Borson, 2014). Thus, it appears that higher patient demands result in greater use of secondary caregivers.

Presently, the literature on pharmacologic treatment efficacy in a strictly Dementia sample is sparse. As beneficial as pharmacologic treatment may be in slowing disease progression and managing behavioral manifestations, prevention is ultimately the best approach to reduce the costs associated with dementia. Unfortunately, epidemiological studies have had only moderate success in identifying risk factors for developing Dementia disease. Age has consistently been identified as the primary risk factor for developing dementia. Family history, genetics, and gender have also been identified as risk factors. However, such factors provide little guidance for developing treatment options (Ballard, Kahn, & Corbett, 2011; La Fontaine et al., 2016). A growing body of literature suggests certain health predictors, and metabolic risk factors may increase the risk of developing certain forms of dementia (Booth, et al., 2013; Postuma et al., 2015).

Literature gaps were in the non-pharmacological studies; since research studies conducted did not produce rigorous high-grade evidence to support its use in clinical treatment. Many studies were of qualitative design and were not randomized controlled trials that produced enough empirical data. A significant gap in the literature was the cost comparison between using pharmacological or non-pharmacological interventions to treat dementia. Pharmacological costs were available, but very few, if any, studies were mentioned in the literature on actual costs for non-pharmacological treatments (Prince et al., 2016; Spenceley et al., 2015).

The strength of the literature for this review was the amount of data from systematic reviews and the multiple databases used for the research. Multiple databases used for literature, included Pub Med, Cumulative Index, PsychInfo, Cochrane Database of Review of Effectiveness (DARE), Cochrane Central Register of Controlled Trials (CENTRAL) and MEDLINE. Reputable governmental and private agencies conducted many of the reviews, 2
especially the pharmacological reviews. Several of the studies were extensive studies with large samples with many levels of evidence. Limitations in the literature were heavily weighed on the non-pharmacological research.

Many of the reviews spoke of the lack of high-grade evidence, problems with the scientific method of the studies and an overall lack in the literature of studies being conducted or evidence available to support non-pharmacological interventions in the treatment of dementia (Bailey, C., Clarke, Gibb, Haining, Wilkinson, & Tiplady, 2013; Cowdell, 2006).

2.1. Historical Context of Dementia

The concept of dementia has evolved as a medical diagnosis, although the condition itself has been described for thousands of years, sometimes with symptoms and etiology (Diemer & Ali, 2009). Historically, the earliest use of 'demented' in English was recorded in the Oxford English Dictionary as 1644, although Berrios & Freeman (1991) traced its origins to the Latin works of Lucretius' demens' translated as 'being out of one's mind'. The disease concept of dementia became more clearly defined throughout the 18th century and was included in the 1726 edition of Blanchard's 'Physical Dictionary' as being equivalent to 'anoea' or 'extinction of imagination or judgment' (Berrios, 1987).

With increased knowledge of anatomy and diseases, the opinion that senility was an extreme form of aging, dementia had become clinically differentiated from other psychiatric disorders by the mid-19th century (Prince et al., 2015). Furthermore, in 1894 both Emil Kraepelin and Alois Alzheimer's distinguished between senile and arteriosclerotic dementia (Mahendra, 1984). New histological techniques in the early 20th century led to Alzheimer's classical case-study of a 51-year-old woman with distinctive neuropathology (Alzheimer, 1907). Neurologically, atrophy of the brain, arteriosclerotic changes, senile plaques, and neurofibrillary tangles was found postmortem.

The clinical presentation described morbid jealousy, loss of memory, capricious behavior, spatial and temporal disorientation, persecutory ideas, and speech difficulties. Dementia was considered a chronic, irreversible, and untreatable condition until the mid-1960's when scientific advances led to the recognition that clinically reversible causes of intellectual decline (Mahendra, 1984). Of importance was the acceptance of dementia as a disease which could be researched and treated medically, and a clearer typology from senile dementia, to 'senile dementia of the Alzheimer type' to 'Alzheimer's disease' (World Health Organization, 2015). However, 21st-century dementia has continued to be used as a broadly generic term for describing the process of cognitive impairment and neuropathological disease.

2.2. Definition of Dementia

The Alzheimer’s Association, (2018b) and Lishman (1987) described dementia as an acquired global impairment of intellect, memory, and personality. The term dementia is, therefore, a collective term, which refers to a clinical syndrome instead of a specific disease entity and describes a variety of pathological processes with standard features. In brief, dementia's presence implies a global deterioration of a person's mental abilities due to underlying brain disease, which is usually progressive and chronic (LaMantia et al., 2016). Alternatively, dementia is the global impairment of higher cortical function, including memory, the capacity to solve the problems of day-to-day living, the performance of learned perception and motor skills, the ability to control emotional reactions, in the absence of gross clouding of consciousness. The condition is often irreversible and progressive (Alzheimer’s Association, 2018b; Sperling, Aisen, Beckett, Bennett, Craft, Fagan, . . . Phelps, 2011).

The classical studies of John Hughlings Jackson (1894), who was one of the pioneers of neurology, described dementia as the fourth depth of dissolution. Such persons may have a highly developed brain, but not the full use of it, although they may have many beautiful thoughts, and yet no systematic thinking process; their brain often falls out of gear when dealing with complex thinking. At the bottom, there is no person, but only a living creature (LaMantia et al., 2016; Sperling et al., 2011).

2.3. Prevalence of Dementia

Demographic changes in the older population have led to increased interest in the study of the disease as the incidence of dementia is expected to rise. Over the past century, the older population (>65) within the USA has grown from 5% to 16%. Furthermore, it is projected that 23% of the US population will be over 65 in 2031 (Tomassini, 2005). Those aged 85 and over are the fastest-growing age group in the population of many developed countries. It is worth noting that 12% of the elderly population in the US is aged over 85 (Tomassini, 2005). Dementia is present in around 1-2% of those aged 60 - 69 years, rising to approximately 20% in those aged 80 - 84 and around 50% in those aged 90 years and older (U.S. Census Bureau, 2012).

Several studies provided answers about the prevalence of dementia (Dotson, Beydoun, &Zonderman, 2010; Prince et al., 2015; Sadak et al., 2014; Yaffe, Falvey, Harris, Newman, Satterfield, Koster, . . . Simonsick, 2013). The prevalence rate of dementia was found to double every 5.1 years from the age of 65 years and with a higher
increase for vascular dementia (VaD) than for Alzheimer's disease (AD) (Katz, Lipton, Hall, Zimmerman, Sanders, Verghese, … Derby, 2012).

Similar findings were observed in the European meta-analyses (Dotson et al., 2010), and although no gender difference was found in prevalence, there were higher rates of AD in women and higher rates of VaD in men. The evaluation of disease incidence rather than prevalence is preferred when studying risk factors for dementia due to differences in duration of disease or incidence between groups (Yaffe, et al., 2013) and their meta-analysis showed that the log incidence of dementia and AD was found to rise linearly with age up to the age of 90 years. Significantly, the Alzheimer’s Association (2018b) found the incidence of dementia and AD continued to increase with age, but only in women after the age of 85 years. The differences in gender survival rates were attributed to endocrine or genetic and environmental factors, such as head trauma, occupational toxicity, and smoking (Katz et al., 2012; Prince et al., 2015).

3.0. Types of Dementia

Dementia can be differentiated into the four most common types. Alzheimer's disease (AD) is the most common cause of dementia characterized by a history of gradual onset and decline in function incorporating amnesia, apraxia, agnosia, and aphasia (Galvin et al., 2014). Vascular dementia (VaD) is characterized by cognitive impairment resulting from cerebrovascular disease defined by the presence of focal neurological signs: gait disturbance, incontinence, and emotional lability (Barnes, Yaffe, Byers, McCormick, Schaefer, & Whitmer, 2012). Lewy body dementia (DLB) is characterized by fluctuating cognition, recurrent visual hallucinations, and spontaneous features of Parkinsonism (Galvin et al., 2014; Munhoz, & Teive, 2014).

Furthermore, frontotemporal dementia (FTD) is characterized by behavioral disorder and affective symptoms: personal neglect, disinhibition, perseveration, and apathy, with intact visual and spatial abilities (Lund & Manchester Groups, 1994). These four subtypes account for the majority of total dementia cases, with AD being diagnosed in 50 - 60 % of all cases; VaD is found in 10 - 20% of cases; DLB accounts for a further 10 - 15% of cases and FTD is discovered in 8 - 15% of cases (Ferman, Arvanitakis, Fujihiro, Duara, Parfitt, Purdy, … & Dickson, 2012; Galvin et al., 2014).

4.0. Caregivers and Dementia

Most people with dementia live in residential communities and are cared for by a relative or friend (Geldmacher & Kerwin, 2013). Caregivers are a diverse group that can make investigating their needs particularly tricky. Most caregivers provide support to a relative, usually, a parent or spouse, although not all caregivers are related to the person with dementia (Spenceley et al., 2015). Caregivers are essential in supporting people with dementia to remain in the community, and lack of a caregiver is a predictor of nursing home placement (Athilingam et al., 2015). While caring takes place within the context of love, duty, and obligation, caregivers can experience adverse psychological, physical, social, and financial consequences known as caregiver burden (Athilingam et al., 2015; Wray, Wade, Beehler, Hershey, & Vair, 2014).

The non-cognitive features of dementia, such as psychotic symptoms and depression, which are associated with increased difficulty for caregivers and behavioral disturbances, are identified as the most consistent predictor of caregiver burden (Aminzadeh, Molnar, Dalziel, & Ayotte, 2012). Caregivers of people with dementia have higher stress levels than other caregivers, and their psychological well-being influences their ability to continue caring for the person with dementia (Athilingam et al., 2015). The risk of depression is higher in caregivers of people with dementia, and its prevalence is estimated at between 40-60%, with spousal caregivers and females being identified at most risk (Ferman et al., 2015; Spenceley et al., 2015).

The study of Lagomasino et al. (2015) found a higher incidence of anxiety than depression in caregivers of people with dementia and suggested this may be due to caregiver depression being inadequately targeted. Moreover, the study identified risk factors for both anxiety and depressive symptoms that included poor caregiver health, irritability in the person with dementia, and the quality of the relationship between the caregiver and care recipient. Additionally, Wray et al. (2014) studies found depression to be positively correlated with length of time caregivers live together with persons with dementia.

According to Aminzadeh et al. (2015), the availability of formal support from health and social services and informal support from family and friends can be beneficial in reducing caregiver burden. However, increased use of services is often associated with higher levels of stress in caregivers. The studies of Lee, Hillier, and Harvey (2014) investigated the reasons for non-use of community services such as home help, community nurses, meal services, transport, and respite services, in caregivers of people with dementia in Australia. The main reasons for non-use of services were a perceived lack of need for services and the person with dementia's reluctance to accept help.
Brodaty, and Donkin (2009) found that 1 in 3 caregivers was not receiving any services while 1 in 4 had only one; most caregivers denied a need for services despite the presence of caregiver burden. In addition to stresses related to caregiving, families often experience secondary stresses that proliferate because of the caregiving career. Competing demands may produce family conflict, strain on finances and employment, and changes in self-concept as caregiving spills over into all aspects of life (Wray et al., 2014). The literature on elder caregiving indicates that, typically, multiple caregivers aid frail elders. These studies report caregiving support systems averaging between two and four persons per elder, with between 21% to 33% of elders having a single caregiver (Wray et al., 2014). Many caregivers seek assistance with their caregiving duties from both formal and informal sources. The extent of this assistance is related to the gender of the primary caregiver, the structure of sibling networks, the type, and level of disability of the care receiver, employment status, living arrangement and family history (Aminzadeh et al., 2015; Wray et al., 2014).

There are few formal services specifically geared towards this population since dementia patient care is long-term care that is usually not precipitated by an acute hospital episode. With no specific skills required for this kind of care, formal services do not cover it, and the care is not reimbursed. Besides, due to the disease's progressive and irreversible nature, there is little rehabilitation potential for the patients. Furthermore, caregiving for dementia people is usually a long-drawn-out process lasting between 9 and 15 years from onset to death (Aminzadeh et al., 2015). During this time, the elderly progressively deteriorates mentally and physically imposing ever-greater psychological and physical burdens on the primary caregiver (Wray et al., 2014). With few or no formal services available, the crucial question becomes, do primary caregivers get assistance from other family members or friends to temporarily relieve them from their care burdens?

Those caregivers who have an empty caregiving network, including those who have no additional helpers to provide hands-on care to the elderly at home, are particularly vulnerable. In order to identify such primary caregivers, who are most vulnerable to negative psychological consequences as a result of inadequate support, it is essential to find the caregiver and care recipient characteristics that contribute to the lack of support from both informal and formal sources (Alzheimer’s Association (2016). This study focuses on identifying predictive factors that may yield information that enables advanced practitioners in primary care settings to assess the family's circumstances. With the assurance that some situational clues help us identify problem cases, the practitioners are more likely to be more supportive in arranging the appropriate caregiving strategies. Knowing those factors may make a difference in what the practitioner decides to do or suggest as a course of action (Geldmacher&Kerwin, 2013; Spenceley et al., 2015)

4.1. Caregiver Interventions

According to Huldgren, Mertl, Vormann, and Geiger (2015), psychosocial interventions and support for caregivers of people with dementia are paramount in reducing caregiver stress and burden, which include education, information skills training, support groups, and counseling. Peer support benefits include shared experiences and reduced isolation, which most caregivers find helpful (Lazar, Edasis, & Piper, 2017b). Nevertheless, group interventions were found less effective than individual interventions at reducing caregiver distress. Unsuccessful interventions included short educational programs, single interviews, and support groups alone. Hendrie (2006) undertook a randomized cognitive-behavioral family intervention incorporating caregiver education, stress management, and coping skills training, which was implemented over 14 sessions at two-weekly intervals. The model was useful in significantly reducing the burden in caregivers and behavioral disturbances in people with dementia. Providing information only to caregivers did not affect the burden.

Several reviews of interventions with dementia caregivers have been undertaken, and the results found to be conflicting (Huldgren et al., 2015; Lazar et al., 2017b; McNaney, Vines, Mercer, Mexter, Welsh, & Young, 2017). Methodological criticisms include design weaknesses such as small samples, limited power, and effect size; insufficient information regarding procedures and the people delivering interventions; the broad range of outcome measures and multiple statistical comparisons; definitions of a caregiver vary widely generalizing difficult, and caregiver burden measures are insensitive to change. McNaney et al. (2017) found little evidence of consistent benefits for caregiver’s except for improving caregiver knowledge of dementia, which was considered unrelated to psychological and social outcomes.

Iliffe, Koch, Jain, Lefford, Wong, Warner, and Wilcock (2012) concluded that interventions helped alleviate burden and depression with benefits to caregiver knowledge and ability, but spousal caregivers benefited less than adult children. Individual interventions are more effective at improving caregiver well-being, whereas interventions in groups help improve dementia symptoms. Hildon, Montgomery, Blane, Wiggins, and Netuveli (2010) conclude the best evidence of efficacy was interventions closest to the psychosocial intervention model of expressed emotion, stress-vulnerability model, and cognitive-behavioral approaches (Iliffe et al., 2012), most specifically problem solving and behavioral management approaches.

5.0. Diagnosing Dementia
The diagnosis of dementia demands a broad range of clinical skills and relies on accurate clinical evidence gained through personal history, medical examination, and investigation of the person (Iliffe et al., 2012).

Dementia needs to be distinguished from other conditions that may overlap or present similarly, including delirium and depression, as both conditions can improve with appropriate treatment (Munhoz, & Teive, 2014).

There are two main classification systems for the diagnosis of dementia the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V), and International Classification of Diseases (ICD-11).

The DSM-V diagnostic criteria describe dementia as the development of multiple cognitive deficits manifested through memory impairment, with one or more cognitive disturbance which cause significant impairment in social or occupational functioning - aphasia (language disturbance), apraxia (impaired ability to carry out motor activities), agnosia (failure to recognize or identify objects) and disturbance in executive functioning (i.e., planning, organizing, sequencing, abstracting). The course is characterized by gradual onset and continuing cognitive decline. The ICD-11 diagnostic criteria define dementia as a syndrome due to disease of the brain, usually chronic or progressive, with disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment. Consciousness is not clouded, and cognitive impairments are commonly accompanied by deterioration in emotional control, social behavior, or motivation, which has occurred for a period greater than six months (WHO, 2019).

6.0. Treatment for Dementia

Treatment of dementia relies primarily on limiting disease progression, reducing behavioral manifestations associated with dementia, and preventing known risk factors (Stockdale, & Miranda, 2015). Both the non-pharmaceutical and pharmacological treatment of dementia is contingent upon a comprehensive understanding of the physiological changes associated with dementia. The theoretical approach of pharmacologic treatment is to target neurochemical agents affected by the disease (Galvin, Duda, Kaufer, Lippa, Taylor, & Zarit, 2010a). Thus, recognition and conceptual understanding of the underlying pathophysiology have tremendous implications in terms of treatment and prevention and provide the basis for developing diagnostic criteria for use in clinical practice (Ballard et al., 2011; Lagomasino, Stockdale, & Miranda, 2015).

Clinical diagnosis often relies on the presentation of an individual and a description of the symptoms being experienced. The clinical diagnosis of dementia is particularly challenging because the individual afflicted with this illness has characteristic cognitive deficits that often leave them either unaware or without recollection of the types of symptoms they are experiencing. There are often other motivations for individuals to minimize or deny symptoms, such as fear of having a license to drive revoked or fear of nursing home placement. Thus, self-report is not sufficient for the accurate diagnosis of dementia (Galvin et al., 2010a; Lagomasino et al., 2015).

6.1. Non-pharmaceutical Treatment

Non-pharmaceutical interventions include the provision of therapeutic activities, education, and psychological support, and there is increasing evidence to support the benefits of psychosocial and behavioral interventions in dementia (Lagomasino et al., 2015). Therapeutic activities are undertaken in dementia to maintain or enhance cognitive functioning, promote independence, and increase self-efficacy, alongside providing enjoyment, meaningful activity, and encouraging interaction with others and the environment (Ballard et al., 2011). Three broad categories of therapeutic interventions are described, namely, social, diversional, cognitive, and alternative therapies (Lee, Taylor, & Thomas, 2012). Social and diversional activities incorporate recreational pursuits, current events, entertainment, and physical exercise.

Cognitive based therapies include reality orientation, life-review, reminiscence, and validation therapy. Alternative therapies include multi-sensory environments, drama, art, and music therapy. The literature regarding dementia’s activities has been examined (Lee et al., 2012). While the effectiveness of undertaking activities was apparent, criticism of the studies included methodological weakness such as lack of theoretical frameworks, profiling of disease diagnosis and severity, small sample size, and appropriate outcome measurement. More robustly designed studies have been undertaken, which showed the positive benefits of activities for people with dementia. Branco,Quental, and Ribeiro (2015b) conducted a randomized exercise plus behavioral management program for people with AD and their caregivers. The study results indicated that cognitive training, and preventative efforts (e.g., lifestyle changes, exercise, healthy eating, and early and efficient diagnosis) can delay cognitive decline and help individuals and their caregivers manage dementia symptoms.

6.2. Pharmacological treatment

The principal aims of dementia treatment are to improve cognition, mood, and behavior, thereby promoting optimum functional performance (Chen, Hu, Wei, Qin, McCracken, & Copeland, 2008). Several medications have been conventionally used in the treatment of AD, which includes three main Acetylcholinesterase Inhibitors (AChEI): Donepezil, Galantamine, Rivastigmine, and Memantine (BNF, 2015). AChEI helps delay the progression
of AD in people with mild to moderate dementia and reduce neuropsychiatric symptoms and functional impairment and in the UK their use is restricted to people with moderate dementia (NICE, 2006).

It is noteworthy that Memantine has shown improvements in functional ability and decreased care dependence in people with severe dementia (NICE, 2011).

The benefits of AChEI’s, however, are considered necessary as neuropsychiatric symptoms contribute to the loss of autonomy, morbidity, and the need for long-term care placement (BNF, 2015). The treatment effects observed in Donepezil have been maintained over long periods of at least two years and recommend a 3-month trial on AChEI’s for anyone diagnosed with AD, particularly as a prediction of responders/non-responders is not possible. The guidelines for prescribing of AChEI’s have recently been revised as their cost-effectiveness is questioned and improved evidence of how AChEI’s impact on QoL is needed (NICE, 2006). Simpson, Beavis, Leddy, Ball, Johnson(2005) argue that AChEI’s have shown benefits for people with dementia both within and outside of the established criteria and stopping AChEI medication increases the risk of mortality and a marked deterioration in patients.

Antipsychotic medications are a standard treatment for the reduction of behavioral disturbance in dementia and are commonly used in care homes (Simpson et al., 2005). Nonpharmacological (psychosocial) interventions are considered the preferred option, and pharmacological options should only be introduced when these prove ineffective (Overshott & Burns, 2005). The use of antipsychotic medication in non-EMI (Elderly Mentally Infirm) nursing homes were strongly linked with the presence of dementia in residents but was only prescribed for 15.3% of the population surveyed and did not seem inappropriate (Macdonald et al., 2002). Antidepressants were observed to be prescribed for 25% of the population, and the treatment of depression in dementia is encouraged. An increased risk of cerebrovascular adverse events has been associated with antipsychotic use in people with dementia, and their prescription has now become limited (Chen et al., 2008). AChEI’s are known to reduce neuropsychiatric symptoms in AD and there use as an alternative treatment for the management of behavioral disturbances is indicated (BNF, 2015; Cheng, Huang, Lanham, Cathcart, Howard, Corder, &Poduslo, 2005).

7.0. Implication for Practice

This study suggests that a holistic care approach comprised of non-pharmaceutical and anti-dementia medication may be the most effective for caregivers and dementia patients. The health care system seeks ways to transfer responsibility for continuing care from the formal system to the family system. Practitioners and researchers need to examine how the formal system can assist caregivers in managing caregiving in cost-effective ways that will promote and achieve optimal patient outcomes, especially for the primary caregiver who is not sharing care duties with others. For example, the outcomes of patients cared for by spouses who have no assistance might be compared with age and problem matched patients cared for by spouses assisted by families and formal care providers.

Upon entry into the health care system, the assessment of primary caregiver and care recipient characteristics, including caregiver's employment status, caregiver's and care recipient’s living arrangement, and care recipient’s functional status, is essential before making recommendations for change in the current caregiving situation. Recognizing these factors may make a difference to the practitioner in anticipating and identifying primary caregivers who perform the daily caregiving responsibility alone, and who are at risk for inadequate support, such as the primary caregiver who is the spouse of the care recipient, not employed, and caring for care recipient with fewer functional disabilities. This information may assist the practitioner in developing intervention strategies that are based on a family’s unique caregiving needs.

It is also essential to attempt to mobilize potential family social support networks to give the primary caregiver time out regularly to caregivers that are not employed. Alleviating the caregiver burden with time off may help them to continue their caregiving role and to relieve the burden of performing the role. Providing some amount of formal services to primary caregivers and teaching the caregivers how to do caring may be of interest to the primary working caregivers. Teaching the necessary skills in areas of weakness of the caregivers is necessary when they care for dementia care recipients with more functional disabilities.

References

Alzheimer’s Association (2016). Alzheimer’s and Dementia. Alzheimer's Association. Retrieved from http://www.alz.org/documents_custom/2016-facts-and-figures.pdf.
Alzheimer’s Association. (2017). 2017 facts and figures. Retrieved from https://www.alz.org/facts/.
Alzheimer’s Association. (2018a). Health care professionals and Alzheimer’s. Retrieved from https://www.alz.org/health-care-professionals/cognitive-tests-patientassessment.asp
Alzheimer, A. (1907). Uber eine eigenartige Erkrankung der Hirnrinde. Allgemeine Zeitschrift fur Psychiatrie und Psychisch-GerichtlichMedizin. Vol 64 pp146-148.
Alzheimer’s Association. (2018b). What is dementia? Retrieved from https://www.alz.org/what-is-dementia.asp.
Aminzadeh, F., Molnar, F. J., Dalziel, W. B., & Ayotte, D. (2012). A review of barriers and enablers to diagnosis and management of persons with dementia in primary care. Canadian Geriatrics Journal, 15(3), 85-94. doi:10.5770/cegj.15.42.

Athilangam, P., Visovsky, C., Elliott, A. F., & Rogal, P. J. (2015). Cognitive screening in persons with chronic diseases in primary care: Challenges and recommendations for practice. American Journal of Alzheimer’s Disease and Other Dementias, 3(6), 547-58. doi:10.1177/1533173515577127.

Bailey, C., Clarke, C. L., Gibb, C., Haining, S., Wilkinson, H., & Tiplady, S. (2013). Risky and resilient life with dementia: Review of and reflections on the literature. Health, Risk and Society, 15(5), 390-401.

Ballard, C., Kahn, Z., & Corbett, A. (2011). Treatment of dementia with Lewy bodies and Parkinson’s disease dementia. Drugs & Aging, 28(10), 769-777.

Barnes, D. E., Yaffe, K., Byers, A. L., McCormick, M., Schaefer, C., & Whitmer, R. A. (2012). Midlife vs late-life depressive symptoms and risk of dementia: Differential effects for Alzheimer disease and vascular dementia. JAMA Psychiatry, 69, 493-498. doi:10.1001/archgenpsychiatry.2011.1481.

Berrios, G.E. (1987). Dementia During the Seventeenth and Eighteenth Centuries: A Conceptual History. Psychological Medicine, Vol 17 Pp829-837.

Berrios, G.E. & Freeman, An, H, (1991) Dementia Before the Twentieth Century. In: Berrios, G.E. & Freeman, H. Ed. Alzheimer And The Dementias. Royal Society of Medicine Services Ltd, London.

Bruce, E., & Schweitzer, P. (2008). Working with life history. In M. Downs & B. Bowers (Eds.), Excellence in dementia care: Research into practice (1st ed., pp. 168–186). Maidenhead, Berkshire: Open University Press, McGraw-Hill International.

Booij, B. P., Orr, C., Ahlskog, J. E., Ferman, T. J., Roberts, R., Pankratz, V. S., ... & Boeve, B. F. (2013). Risk factors for dementia with Lewy bodies A case-control study. Neurology, 81(9), 833-840.

Braun, R. M., Quental, J., & Ribeiro, O. (2015b). I’m always well when we are together: Observation of institutional activities with people with dementia and its implications for a co-design research project. In K. Christer (Ed.), Proceedings of the 3rd European Conference on Design 4 Health. Sheffield: Sheffield Hallam University Art & Design Research Centre.

British National Formulary (2015) BNF 50 ed. London: British Medical Association and Royal Pharmaceutical Society of Great Britain. URL: http://www.bnf.org/bnf/.

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. Dialogues in clinical neuroscience, 11(2), 217.

Calabrese, J. D. (2013). Ethnographic approaches to health experiences research. In S. Ziebland, A. Coulter, J. D. Calabrese, & L. Locock (Eds.), Understanding and Using Health Experiences: Improving patient care (pp. 16–25). Oxford: Oxford University Press. https://doi.org/10.1093%2Facprof%3Aoso%2F978019965372.003.0003

Chen, R., Hu, Z., Wei, L., Qin, X., McCracken, C., & Copeland, J. R. (2008). Severity of depression and risk for subsequent dementia: Cohort studies in China and the UK. The British Journal of Psychiatry, 193, 373-377. doi:10.1192/bjp.bp.107.044974.

Cheng, D., Huang, R., Lanham, I. S., Cathcart, H. M., Howard, M., Corder, E. H., & Poduslo, S. E. (2005). Functional interaction between APOE4 and LDL receptor isoforms in Alzheimer’s disease. Journal of Medical Genetics, 42, 129-131. doi:10.1136/jmg.2004.024968.

Cowdell, F. (2006). Preserving personhood in dementia research: A literature review. International Journal of Older People Nursing, 1(2), 85–94. http://doi.org/10.1111/j.1748-3743.2006.00016.x

Diemer, M. A., & Ali, S. R. (2009). Integrating social class into vocational psychology: Theory and practice implications. Journal of Career Assessment, 17, 247-265. doi:10.1177/1059773508330462.

Doeleman, D. (2013). Mental status assessment of older adults: The Mini-Cog. Try this: Best practices in nursing care to older adults. The Hartford Institute for Geriatric Nursing, 3, 1-2. Retrieved from https://consultgeri.org/try-this/generalassessment/issue-3.1.pdf.

Dotson, V. M., Beydoun, M. A., & Zonderman, A. B. (2010). Recurrent depressive symptoms and the incidence of dementia and mild cognitive impairment. Neurology, 75, 27-34. doi:10.1212/WNL.0b013e3181e62124.

Ferman, T. J., Arvanitakis, Z., Fujishiro, H., Duara, R., Parfitt, F., Purdy, M., ... & Dickson, D. W. (2012). Pathology and temporal onset of visual hallucinations, misperceptions and family misidentification distinguishes dementia with Lewy bodies from Alzheimer’s disease. Parkinsonism and Related Disorders, 19(2), 227-231. doi:10.1016/j.parkreldis.2012.10.013.
Galvin, J. E., Duda, J. E., Kaufer, D. I., Lippa, C. F., Taylor, A., & Zarit, S. H. (2010a). Lewy body dementia: The caregiver experience of clinical care. *Parkinsonism and Related Disorders*, 16, 388-392. doi:10.1016/j.parkreldis.2010.03.007.

Galvin, J. E., Valois, L., & Zweig, Y. (2014). Collaborative transdisciplinary team approach for dementia care. *Neurodegenerative Disease Management*, 4(6), 455-469.

Ganguli, I., Souza, J., McWilliams, M., & Mehrrota, A. (2018). Practices caring for the underserved are less likely to adopt Medicare’s Annual Wellness Visit. *Health Affairs*, 37(2), 283-291. doi: 10.1377/hlthaff.2017.1130.

Geldmacher, D. S., & Kerwin, D. R. (2013). Practical diagnosis and management of dementia due to Alzheimer’s disease in the primary care setting: An evidence-based approach. *The Primary Care Companion for CNS Disorders*, 15(4), doi:10.4088/PCC.12r01474.

Hendrie, H. (2006). Effectiveness of collaborative care for older adults with Alzheimer Disease in primary care: A randomized controlled trial. *The Journal of the American Medical Association*, 295(18), 2148–2157.

Hildon, Z., Montgomery, S. M., Blane, D., Wiggins, R. D., & Netuveli, G. (2010). Examining resilience of quality of life in the face of health-related and psychosocial adversity at older ages: What is “right” about the way we age. *The Gerontologist*, 50(1), 36-47.

Hughlings J. (1894). A clinical study of a case of cyst of the cerebellum: Weakness of spinal muscles: Death from failure of respiration. London, British Medical Association, Reprinted from *Br Med J*, 1894, i: 393–395.

Huldtgren, A., Mertl, F., Vormann, A., & Geiger, C. (2015). Probing the Potential of Multimedia Artefacts to Support Communication of People with Dementia. In J. Abascal, S. Barbosa, M. Palanque, & M. Winckler (Eds.), *Human-Computer Interaction – INTERACT 2015* (Vol. 9298, pp. 71–79). Cham: Springer. http://doi.org/10.1007/978-3-319-22698-9_6.

Lagomasino, I. T., Stockdale, S. E., & Miranda, J. (2015). Racial-ethnic composition of providerpractices and disparities in treatment of depression and anxiety, 2003–2007. *Psychiatric Services, 62*, 1019-1025. doi:10.1176/jsp.62.9.pss6209_1019.

Lee, D. R., Taylor, J. P., & Thomas, A. J. (2012). Assessment of cognitive fluctuation in dementia: a systematic review of the literature. *International journal of geriatricpsychiatry*, 27(10), 989-998.

Lee, L., Hillier, L. M., & Harvey, D. (2014). Integrating community services into primary care: Improving the quality of dementia care. *Neurodegenerative Disease Management*, 4(1), 11-21.

Iliffe, S., Koch, T., Jain, P., Lefford, F., Wong, G., Warner, A., & Wilcock, J. (2012). Developing an educational intervention on dementia diagnosis and management in primary care for the EVIDEM-ED trial. *Trials, 13*, 142. doi: 10.1186/1745-6215-13-142.

Jensen, C. J., & Inker, J. (2015). Strengthening the dementia care triad: Identifying knowledge gaps and linking to resources. *American Journal of Alzheimer's Disease & Other Dementias*, 30(3), 268-275. doi:10.1017/1533317514545476.

Katz, M. J., Lipton, R. B., Hall, C. B., Zimmerman, M. E., Sanders, A. E., Verghese, J., . . . Derby, C. (2012). Age and sex specific prevalence and incidence of mild cognitivempaireddmentia, and Alzheimer's dementia in Blacks and Whites: A report from the Einstein Aging Study. *Alzheimer Disease and Associated Disorders*, 26, 335-343. doi:10.1097/WAD.0b013e31823dbcfc.

La Fontaine, J., Jutlla, K., Read, K., Brooker, D., & Evans, S. (2016). *The experiences, needs and outcomes for carers ofpeople with dementia: Literature Review*. Worcester: Royal Surgical Aid Society.

LaMantia, M., Stump, T., Messina, F., Miller, D., & Callahan, C. (2016). Emergency department use among older adults with Alzheimer Disease & Associated Disorders, 30(1), 35-40. doi:10.1097/WAD.0000000000000118.

Lazar, A., Edasis, C., & Piper, A. M. (2017b). Supporting people with dementia in digital social sharing. In *CHI '17 Proceedings of the CHI Conference on Human Factors in Computing Systems* (pp. 2149–2162). New York: ACM. http://doi.org/10.1145/3025453.3025586.

Lee, D. R., Taylor, J. P., & Thomas, A. J. (2012). Assessment of cognitive fluctuation in dementia: a systematic review of the literature. *International journal of geriatricpsychiatry*, 27(10), 989-998.

Lishman, W.A. (1987) *Organic psychiatry*, 2nd edition. Blackwell scientific publications: Oxford.

McNaney, R., Vines, J., Mercer, J., Mexter, L., Welsh, D., & Young, T. (2017). DemYouth: Co-designing and enacting tools to support young people’s engagement with people with dementia. In *CHI ’17 Proceedings of the CHI Conference on HumanFactors in Computing Systems* (pp. 1313–1325). New York: ACM. http://doi.org/10.1145/3025453.3025558.

Mahendra, B. (1984) *Dementia: A Brief History of The Concept*. In: Mahendra, B. Ed. *Dementia*. Mtp Press Limited: Lancaster. Pp1 -18.

Munhoz, R. P., & Teive, H. A. (2014). REM sleep behaviour disorder: How useful is it for the differential diagnosis of parkinsonism? *Clinical Neurology and Neurosurgery*, 127, 71-74.

National Institute for Clinical Excellence (2011). Guidance on the Use of Donepezil, Rivastigmine and Galantamine for the Treatment of Alzheimer’s Disease’ *Technology Appraisal Guidance - No 19*, NICE: London.
National Institute for Clinical Excellence (2006). Alzheimer’s disease-donepezil, rivastigmine, alantamine and memantine (review) - Final appraisal document. NICE: London. URL: http://www.nice.org.uk/TA111
Overshott, R. & Burns, A. (2005). Cholinesterase inhibitors: in search of cholinergic deficits. Advances in Psychiatric Treatment, Vol 11 pp321-324.
Postuma, R. B., Iranzo, A., Hogl, B., Arnulf, I., Ferini- Strambi, L., Manni, R., &Montplaisir, J. Y. (2015). Risk factors for neurodegeneration in idiopathic rapid eye movement sleep behavior disorder: a multicenter study. Annals of Neurology, 77(5), 830-839.
Prince, M., Wimo, A., Guerchet, M., Ali, G.-C., Wu, Y.-T., Prina, M., Alzheimer’s Disease International. (2015). World Alzheimer Report 2015: the global impact of dementia: an analysis of prevalence, incidence, cost and trends. London: Alzheimer’s Disease International.
Prorok, J. C., Horgan, S., & Seitz, D. P. (2013). Health care experiences of people with dementia and their caregivers: A meta-ethnographic analysis of qualitative studies. Canadian Medical Association Journal, 185(14), 669–680. doi.org/10.1503/cmaj.121795.
Sadak, T. I., Katon, J., Beck, C., Cochrane, B. B., &Borson, S. (2014). Key neuropsychiatric symptoms in common dementias: prevalence and implications for caregivers, clinicians, and health systems. Research in gerontological nursing, 7(1), 44.
Simpson, S. Beavis, D. Leddy, A. Ball, S. Johnson, I. (2005). Naturalistic audit of NICE criteria for the use of cholinesterase inhibitors. Psychiatric Bulletin, Vol 29 PP410-412.
Spenceley, S., Sedwick, N. & Keenan, J. (2015). Dementia care in the context of primary care reform: an integrative review. Aging & Mental Health, 19(2), 107-120. doi:10.1080/13607863.2014.920301
Sperling, R. A., Aisen, P. S., Beckett, L. A., Bennett, D. A., Craft, S., Fagan, A. M., . . . Phelps, C. H. (2011). Toward defining the preclinical stages of Alzheimer’s disease: recommendations from the National Institute on Aging-Alzheimer’s Association.
Tomassini, C. (2005) The demographic characteristics of the oldest old in the United Kingdom. Population Trends. Population and Demography Division Office for National Statistics: London.
U.S. Census Bureau (2012). How do we know? A snapshot of our nation’s Veterans. Retrieved from http://www.census.gov/library/infographics/veterans.html.
World Health Organization. (2012). Dementia: A public health priority. World Health Organization.
Zeisel, J. (2013). Improving Person-Centered Care Through Effective Design. Generations – Journal of the American Society on Aging, 37(3), 45–52.
Yaffe, K., Falvey, C., Harris, T. B., Newman, A., Satterfield, S., Koster, A., . . . Simonsick, E. (2013). Effect of socioeconomic disparities on incidence of dementia among biracial older adults: Prospective study. BMJ, 347, f7051. doi:10.1136/bmj.f7051
Wray, L. O., Wade, M., Beehler, G. P., Hershey, L. A., &Vair, C. L. (2014). A program to improve detection of undiagnosed dementia in primary care and its association with healthcare utilization. The American Journal of Geriatric Psychiatry, 22, 1282-1291. doi:10.1016/j.jagp.2013.04.018
World Health Organization (2015). Dementia. Retrieved from: http://www.who.int/mediacentre/factsheets/fs362/en/