University of Nevada, Reno

Perceived Barriers to a Timely Dementia Diagnosis from the Perspective of the Caregivers

A thesis submitted in partial fulfillment of the
requirements for the degree of Master of Science in
Nursing

by

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August, 2021

THE GRADUATE SCHOOL

We recommend that the thesis
prepared under our supervision by

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entitled

**Perceived Barriers to a Timely Dementia Diagnosis
from the Perspective of the Caregivers**

be accepted in partial fulfillment of the
requirements for the degree of

Masters of Science

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Abstract

Dementia is a progressive irreversible neurocognitive disease that affects millions worldwide with an expected increase in persons effected the next decade. There is currently no cure for dementia, however a timely diagnosis may allow those who live with dementia or care for those who live with dementia time to seek support, gain community and medical resources, and increase the quality of life for the person with dementia (PWD) as well as their caregivers. Existing studies demonstrate multiple barriers that exist to seeking and obtaining a dementia diagnosis. The objective of this study is to identify the barriers to obtaining a dementia diagnosis from the perspective of the caregiver.

Methods: A qualitative phenomenology study conducted through semi-structured interviews of caregivers to PWD sourced through snowball sampling and support groups.

Results: Eight common barriers to obtaining a dementia diagnosis were identified: Denial by the PWD (85.6%), normalization of symptoms (42.9%), issues accessing medical care (42.8%), denial by extended family (25.8%), dementia symptoms masked by other medical issues (28.5%), fear of PWD's reactions (28.5%), lack of confidence in the medical diagnosis (28.5%) and being unaware of changes in the PWD (14.3%).

Conclusion: Despite the small number of participants, most of the participants (71.4%) stated that an earlier diagnosis would have benefited them or the PWD to some degree. Additional studies are needed to target the highest yielding barriers in order to implement multifaceted interventions aimed at reducing such barriers to facilitate more timely diagnoses.

Acknowledgements

The author would like to sincerely thank their faculty for their guidance and support through this process. I would like to thank Wei-Chen Tung, PhD., RN, FAAN for her outstanding leadership and mentorship on my journey though professional research. I would also like to thank Glenn Hagerstrom, Ph.D., APRN, FNP-BC and Michelle Granner, Ph. D. for their contributions as committee members on this thesis. Special acknowledgement to Stephanie S. DeBoor, PhD, APRN, ACNS-BC, CCRN and Jackie Ferdowsali DNP, AGACNP-BC, ACNPC-AG for being so supportive and understanding of my academic struggles and challenges while completing this thesis and graduate school in a global pandemic while juggling my military duties to the Nevada National Guard including multiple activations. Without their help, support, and understand I have no doubt this process would have been much more stressful.

Lastly, I want to thank my amazing Husband Matthew W. Lampson and children Moira Elaine Bloom and Desirae Leah Yamazaki for supporting me and understanding the time away from them needed to fulfill my obligations to my research, my degree, and my country. I could not have finished my research and this thesis without them.

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Chapter I

Introduction

This Master of Science thesis is a qualitative study examining the shared experiences of the perceived barriers to seeking a dementia diagnosis from the perspective of the caregivers. Additional provisions pertaining to how the timing, staging, and support related to the diagnosis effected the caregivers during the diagnostic process will be examined. The effects of dementia are not solely felt by the patients, but also by the families and communities caring for these people. The toll of caring for a patient with dementia (PWD) can be devastating emotionally, financially, socially, and mentally. Help seeking barriers are multifactorial and with the diagnosis of dementia dependent on the history of the patient, the burden of seeking a diagnosis often falls on the caregivers or the family of the PWD. This can often cause delays in the diagnostic process. As formal diagnosis is required to access support in most healthcare systems, delays in diagnosis can cause delays in treatment, issues with advanced planning, and financial hardships. This thesis seeks to better understand the perceived barriers to obtaining a timely diagnosis and how the timing affects those who care for PWD.

Background

Dementia is a progressive neurocognitive syndrome that affects more than 47 million people worldwide with a projected increase to 75 million people by 2030 according to the World Health Organization (World Health Organization [WHO], 2017). Approximately three quarters of people with dementia had not received a formal diagnosis in 2011 (Parker et al.,2020). While the benefits of an early diagnosis, meaning a diagnosis before the onset of symptoms, remains unclear it is well accepted that a formal diagnosis is required in order to access dementia specific resources and many healthcare systems (Poole et al., 2020).

There is currently no cure for dementia so the process of the diagnostics may seem futile, however, having a timey diagnosis allows the person living with dementia and their family to seek support, gain community resources, and allow family members the opportunity to adapt to the caregiver role (de Vugt & Verhey, 2013). With only 35% of Medicare beneficiaries or their caregivers aware of their diagnosis, it is truly a public health crisis (Segal-Gidan, 2017). Identifying the barriers to a pursuing a diagnosis and overcoming the barriers to arriving at one is vital to improving the health of our aging population.

How is dementia diagnosis

For clarity it is important to point out that the phrasing of "timely" diagnosis differs from "early" diagnosis. Early diagnosis would require population or targeted screening to identify people in the asymptomatic phase (DuBois et al., 2015). The phrase timely will be used and is referred to as the time when the patient or family first seeks help or begin to notice changes in cognition, behavior, or decline in the functioning necessary to maintain the same quality of life but does not necessarily result in a diagnosis of dementia (Dubois et al., 2015). While the pathological cascade can begin years or decades before symptomatic presentation the clinical deficits are often what trigger family and clinician awareness (Elahi & Miller, 2018). Visible and notable deficits arise from irreversible damage within the functional networks of the brain do to specific proteinopathy (Elahi & Miller, 2018).

Only a medical provider can make the diagnosis of dementia and is primarily based on neuropsychological testing (Tiwari et al, 2019). This can be a complex and time-consuming diagnosis to make and includes analyzing the subjective and objective data including but not limited to; confusion and memory deficits, problems with language, impaired abstract reasoning, higher cognitive functions impairment such as aphasia apraxia, agnosia, and impaired executive function (Starkweather, 2020). Neuroimaging is not necessary to make a diagnosis but is often done when investigating a treatable cause of memory impairment (Starkweather, 2021). Some patients may present with disorientation, poor judgment, loss of initiative, emotional problem such as depression, liability, or flattened affect, changes in mood, agitation, drastic personality changes, and difficulty recognizing friends and family (Elahi & Miller, 2017). Severe symptoms include loss of speech, loss of appetite, weight loss, loss of bowel and bladder control, total dependence on caregiver with clouding of consciousness and orientation typically occurring in the terminal stages (Starkweather, 2021).

The diagnostics needed to make the diagnosis of dementia include a thorough history and physical exam, preferably with family members available to give adequate history (Starkweather, 2021). It is important to note that self-reported memory loss does not usually correlate with dementia.

In order for a patient to receive a diagnosis of dementia the cognitive disfunctions must fall within the definition given by the American Psychiatric Association's (2013)

Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM–5). Per the DSM-5 dementia is defined as:

> A major neurocognitive disorder includes a decline in one or more or more cognitive domains, that interferes with the person's independence and ability to take care of their daily activities (American Psychiatric Association, 2013). The six cognitive domains defined by the DSM 5 are complex attention, language, perceptual motor function, social cognition, executive function comma and learning and memory (American Psychiatric Association, 2013).

A physical examination including a neurological examination, cognitive testing, and an attempt at a screening tool such as the Folstein mini-mental state examination (MMSE) is required for accurate diagnosis (Sanghani, 2020). In the MMSE the maximum score is 30, with a score of 24 or less indicating cognitive impairment (Sanghani, 2020). While the diagnosis can be made by most qualified providers, neuropsychiatric testing is considered the gold standard and is especially helpful when there is a difference in clinical suspicion and office test, to gauge deficits in order to make support recommendations, when present or suspected psychiatric disease complicates the diagnosis, or when a more definitive diagnosis would help the patient or family (Sanghani, 2020).

The cognitive impairments and behavioral disturbances associated with dementia can be mistaken for other maladies, therefore, it is important for the clinician to screen for reversible causes such as electrolyte dysfunction, thyroid dysfunction, low vitamin B12 levels, infectious disease, malignancy, drug use, or venereal diseases (Starkweather, 2021). Other tests, depending on the patient history and findings of the physical examination, include a CT of the head or MRI to assess for tumor, a lumbar puncture to rule out neurosyphilis, chronic meningitis, or normal pressure hydrocephalus, electroencephalography, chest x-ray to rule out congestive heart failure or chronic lung disease and an electrocardiogram (Starkweather, 2021).

It is important for the provider to identify treatable causes such as mentioned above and including depression, thyroid disorder, hypoglycemia, vitamin B12/folate deficiency or thiamine deficiency, subdural hematoma, liver failure, normal pressure hydrocephalus, stroke, CNS infection, generalized infection, cerebral neoplasm, renal failure, alcohol abuse, hypoxia, hypercalcemia, vasculitis, cardiopulmonary disorders, anemia, medication induced delirium or dementia, psychiatric disorders, and toxin exposure (Sanghani, 2020; Starkweather, 2021). It is evident that the diagnosis of dementia is complex, multifocal, and can be difficult to make. This is in part why the rate of diagnosis is so low and enforces the nihilism felt by providers when making a diagnosis that does not have a cure nor are the medications and management after diagnosis optimal (Giezendanner, 2019).

Prevalence and Epidemiology

Dementia affects an estimated 2.4 to 5.5 million people in the United States with increasing prevalence with age (US Preventive Service Task Force [USPSTF], 2020). Dementia or neurocognitive disease affects an estimated 3.2% of people between the ages 65-74 years, 9.9% of those people between 75-84 years, and 29.3% of those people over 85 years of age (USPSTF, 2020). The average dementia free 70-year-old male has an estimated 26.9% probability of developing dementia, and the average dementia-free female over 70 has an estimated 34.7% probability (Fishman, 2017).

Cost of dementia

As an increasing amount of people age, namely the "baby-boomer" generation, the number of individuals with dementia is increasing and the economic, health, and social care costs of dementia are escalating (Dubois et al., 2016). The worldwide costs of dementia in 2015 were estimated to be $818 billion, which represents an increase of 35% since 2010; 86% of the costs occur in high income countries (Wimo et al., 2017) The per person cost of dementia in 2015, according to World Alzheimer's Report, to be approximately $39,595 for high income countries (Wimo et al., 2017).

A literature review by Dubois et al. (2016) identified a cost-benefit analysis of early identification and treatment of Alzheimer's dementia with results indicating that the net benefits of savings would be highest when patients received a diagnosis at the early symptomatic stage and when caregiver interventions were combined with medication treatments. In that analysis, the average net social, state fiscal, and federal fiscal benefit of early identification in a patient who is 70 years old and had a MMSE score of 28 were estimated to be $125,000, $16,000, and $34,000 respectively (Dubois et al., 2019).

Also referenced by DuBois et al. (2019) was a British study that performed a cost benefit analysis of the Croydon Memory Service Model which takes a multi-agency and multidisciplinary approach designed to provided early diagnosis, information, and help for people with dementia and their families (Dubois et al., 2019). The cost of this service was estimated to be €220 million with an associated theoretical reduction of 20%

in-residential care home admissions by the 10th year after introduction of the service model yielded a potential annual savings to society estimated at approximately €490 million (Dubois et al., 2019). The expected number of people living with dementia will reach 131.5 million worldwide by 2050 (Elahi & Miller, 2017). In the US alone, an intervention aimed at delaying the onset of dementia could be by just five years would reduce Medicare cost by $283 billion (Elahi & Miller, 2017).

The cost of a late diagnosis is not just monetary. Quality of life, dignity, social and economic support are all effected by a late-stage diagnosis. A timely diagnosis affords the patient and the caregivers the opportunity to obtain treatment to mediate their symptoms, avoid medications that may exacerbate symptoms, and the opportunity for future access to interventions that may slow or lessen the disease process (Dubois et al., 2019; de Vugt & Verhey, 2013).

Problem and Significance

Dementia is a major global health problem costing The US millions of dollars a year, in the absence of a cure there is an increasing focus on risk reduction, timely diagnosis, and early intervention (WHO, 2017). Cost effective drugs such as acetylcholinesterase inhibitors and non-pharmacologic interventions such as cognitive stimulation therapy exists to help mediate and delay cognitive deterioration and improve quality of life (Robinson et al., 2015). These interventions are only able to be used if a diagnosis is made. Early diagnosis may also allow time for a discussion about the person's wishes at end of life and decisions and arraignments for hospice and palliative care prior to the point of lack of cognitive function (Robinson et al., 2015; De Vleminck et al., 2018). Family and care planning for those who are at risk for physical and mental illness as a consequence of caring for a PWD involves time and resources that could be made available with a timely diagnosis (Robinson et al., 2015).

Timely detection and diagnosis of dementia is important for several reasons; first, it permits effective administration of medical, behavioral and social interventions to delay cognitive and functional decline (Aigbogun, 2019). Secondly, it can allow the PWD, caregiver, and health care team to take the appropriate safety measures for events such as traffic accidents, dangerous behavioral disturbances, hospitalizations and make appropriate changes for the safety of the caregivers and the PWD (Aigbogun, 2019). Thirdly, it can ultimately reduce the total care expenditures by delaying the time to nursing home or hospital admission (Hirakawa, 2019). A timely dementia diagnosis is significant to healthcare in such that with increased awareness can come more efficient and more effective treatment for both the patient and the family holistically (Poole et al., 2020).

A timely diagnosis can offer caregivers and family the opportunity to advance through the process of becoming a competent caregiver and seek out community and family help if needed (de Vugt & Verhey, 2013). Caregivers that have more time to adapt to the changes that are characterized by dementia often feel more competent to care for a PWD and experienced less psychological problems (de Vugt & Verhey, 2013). Having time to digest, investigate emotions, and plan financially for the care of a loved one with a new dementia diagnosis may allow the family and caregivers to be more prepared for the physical and psychological changes that will happen to their loved one and to prepare themselves mentally for the task of caring for a PWD (de Vugt & Verhey, 2013).

Purpose

The purpose of this study was to explore the shared experience and perspectives of family members or caregivers who have cared for or are caring for a PWD and to investigate their perceptions regarding the barriers to seeking a diagnosis, the timeliness of the diagnosis, how the timing of the diagnosis may or may not have affected the overall care and wellbeing of the PWD, and the stressors felt while caring for a PWD. Recognition of the barriers to seeking a diagnosis and how the timing of that diagnosis affects those who care for dementia patients may empower the healthcare team to establish a better roadmap for the diagnostic process and potentially allow for better public education regarding the stigmas associated with dementia. It is the author's hope that with common barriers identified a plan of action can form to overcome such barriers and create best practices surrounding the diagnostic process in order to increase the quality of life for the PWD as well as the caregivers.

Chapter II

Review of the Literature

Systematic reviews and meta-analysis

During literature investigations several studies supported timely diagnosis and discussed barriers to obtaining a diagnosis from the perspective of the caregivers as well as from the perspective of the provider. Many of the barriers identified were complex and multifactorial including religious preferences, lack or resources, denial, social stigma, diagnostic uncertainty, and lack of education (de Vugt & Verhey, 2013; DuBois et al., 2016; Parker et al., 2020; Pool et al, 2020). Parker et al. (2020), published a systematic review of literature examining studies over 30 years pertaining to perceived barriers and facilitators to seeking help, from the perspective of the caregivers, which identified five common barriers and three facilitators to seeking help for a dementia diagnosis. The most common themes were the normalization of symptoms, lack of perceived need, denial, lack of knowledge, problems accessing help, and stigma and fear with the facilitators identified as recognition of symptoms as a problem, prior knowledge and contacts, and informal network support (Parker et al., 2020). This review concluded that barriers were often compounding, and that multiple facilitators or solutions were necessary to overcome such barriers (Parker et al., 2020)

A relevant literature review by Dubois et al., (2016) examined nine studies and found potential barriers to a timely diagnosis from the perspective of the caregiver and the providers. The identified barriers were similar to the previously referenced study by

Parker et al. (2020) in regard to the caregivers but added additional impediments to diagnosis from the provider and health team that included lack of training, diagnostic uncertainty, shortage of specialized diagnostic services, and nihilism regarding making a diagnosis when no effective disease- modifying options exist (DuBois et al., 2016).

While the aim of this study is to identify the perceived barriers to a dementia diagnosis from the caregiver perspective most, if not all, of the barriers are multifactorial. Koch et al. (2010) conducted a rapid appraisal of barriers in a primary care setting, and it was concluded that if the provider lacks confidence, that then leads to diagnostic uncertainty that can delay referrals or treatment. A shortage of specialized diagnostic services and clinicians, time constraints, practitioner confidence, therapeutic nihilism, and service support were identified as barriers from the perspective of the providers (Koch et al., 2010). Therapeutic nihilism has been implicated as a barrier for primary care diagnosis as the diagnosis is "pointless" and "not worthwhile" due to a lack of effective or available treatments and there is no benefit to making the diagnosis. Koch et al. (2010) further adds that this mindset could be contributing to why only 52% of primary care physicians stated that it was beneficial to make an early diagnosis. These type of barriers from providers can have a correlating effect on the confidence and help seeking behaviors of the caregivers and the PWD. This supports the notion that multiple barriers compound the diagnostic process and interventions aimed at reducing barriers need to be multifaceted, empowering both the caregivers, PWD, and providers (Parker et al., 2021; Koch et al., 2010).

Giezendanner et al. (2019) conducted a cross-sectional survey of general practitioners attituded toward a timely diagnosis as lack of support, time and financial constraints, stigma, diagnosis uncertainty, and general practitioners fear that the disclosure could damage the doctor patient relationship.

Literature opposing early diagnosis

Interestingly, a study done by Vugt & Verhey, (2013) found that the benefits of early diagnosis may be outweighed by risk of enhanced anxiety and fear if the family and patients are left with a diagnosis and little support (Vugt & Verhey, 2013). There is a lack of evidence that improving the possibility to diagnose people in the very early or prodromal stage, versus after neurodegenerative function has declined to the point of showing symptoms, has on overall positive patient outcome, as the technology to diagnose has increased but the ability to treat or cure has not shown significant evidence (Elahi & Miller, 2017; USPSTF, 2020). Scarcity of resources and lack of support during and post diagnosis has been echoed across many studies and without support, many families are left worse than before the diagnosis.

Disclosure preference

Literature regarding family or couple's discloser preferences who received a diagnosis of dementia included anxiety about the uncertainty of progression, economic impacts of caring for they loved one with dementia, social stigma related to the diagnosis of dementia including embarrassment and anxiety, and lack of atomic autonomy (Hellström, & Torres, 2013). Many couples and families did not inform their friends or families about their diagnosis, and some even stated that they did not want all of the information as they felt they did not have a problem at all and did not believe the diagnosis allowing themselves to continue in denial (Hellström & Torres, 2013). The stigma and fear associated with a diagnosis of dementia is a contributing factor to the barriers associated with help seeking behaviors (Parker et al., 2020).

In contrary to Hellström, & Torres' article, a systematic review by van den Dungen et al., (2014) examined 23 articles examining the disclosure preferences of those with and without cognitive impairment showed that 90.7% and 84.8% respectively were in favor of disclosure. This implies that regardless of resources the vast majority of people with cognitive impairment prefer to be informed of their dementia diagnosis in that it helps to preserve their autonomy (van den Dugen et al., 2014).

Behavior disturbances

Behavioral disturbances in patients with dementia resulted in a greater number of hospitalizations, length of stay, outpatient and clinic visits, number of skilled nursing visits and the number of patients with hospice visits following a behavioral disturbance in a patient as opposed to a patient without a behavioral disturbance (Aigbogun et al, 2019). Aigbogun et al (2019), states that costs were significantly higher ($P<0.0001$) among patients with behavioral disturbances as opposed to patients without ($42,284 vs $32,640). Recognition of exacerbating and agitating factors could help to prevent some of the concomitant behavioral disturbances associated with dementia as poly pharmacy and comorbidities were implicated in the dementia patients (Aigbogun et al, 2019; Hirakawa et al., 2019). Early detection of dementia is essential for older adults with dementia and family caregivers to ensure prompt access to non-pharmacologic treatment options and thorough medication management by appropriate health care providers (Hirakawa et al., 2019).

Chapter III

Method

Design

A qualitative, phenomenology study was conducted using a semi-structured interview technique. Initially a group panel interview was to be conducted at UNR, however, given the circumstances with the number of people allowed in the same room due to the Covid-19 pandemic this had to be moved to a Zoom meeting or recorded phone conversation. A reduced number of participants and one-on-one interviews was the most reasonable and safest option for the participants and the researcher. Demographics on the participants was gathered (see Appendix D, Table 1) to include age, level of education, occupation, relationship to the PWD, length of time the participant has been caring for or previously cared for the PWD, whether the person with dementia is living or deceased, if the participant is the sole caregiver, and what state they live in. An information sheet and demographic sheet was emailed to each participant to allow participant to make a thoughtful decision about participation.

Caregiver participants were sourced based on a snowball sampling, personal contacts, and through a Facebook support group for people caring for loved ones with dementia. Parameters of English speaking, direct care given to PWD, and official diagnosis of dementia were placed when searching for participants. Seven total participants fit these parameters and information letters were emailed out to each of them along with demographic information sheets which were filled out and returned via email.

One on one interviews were necessary and were conducted either in person, via Zoom, or phone conversation with audio recoded in a semi-structured fashion that allowed the participants to expound upon any questions as they felt inclined.

Questions were phased opened ended to allow participants to share their experiences and provide a wider understanding to the individual barriers and struggles felt while obtaining a diagnosis and feeling regarding the support after diagnosis (see Appendix C). This allowed a focus on the phenomenology as well as individual experiences and perspectives. The intent was to identify commonalties in the participants response in relation to:

a.) Feelings toward the timeliness of the diagnosis of dementia
b.) Economic, emotions and physical stress associated with the care of patient
c.) Perceived barriers or struggles related to the diagnoses process
d.) Thoughts on how an earlier diagnosis might have affected them or the patient
e.) The timeliness of the diagnosis for the PWD, and feelings regarding the socioeconomic impact the diagnosis timing had on them.

As the topic of discussion is incredibly sensitive, adequate time, verbal support and emotional support was be given when needed. Family members who were caring for a PWD, were asked questions additional questions if clarification was needed in order to extract themes in their responses (see Appendix 3).

Data Analysis

Initially, this study was intended to be conducted as a semi-structured panel interview, but for participant and researcher's safety during a global pandemic the interviews were conducted one-on-one via Zoom or audio recorded conversations. The number of participants was also reduced to seven. Due to the nature of this study, analysis and data collecting often occurred simultaneously with follow up questions (asked during the interview) aimed at narrowing down grand response to more succinct answers without limiting the expression of the participant. This resulted in authentic and candid conversations with the participants and unique and individualized answers from the participants with several major themes emerging. Then, the most overarching themes and ideas were identified through a thorough process of repeated playback of audio and visual material and rereading notes taken by the researcher. Finally, the interviewing data was coded for major themes and the frequency of similar responses were calculated by question. This was analyzed by the researcher and eight major themes resulted.

Chapter IV

Results

Demographics

Initially ten people responded or agreed to participate, however, two had to be excluded on the grounds of not having an official diagnosis at the time of participant selection. Seven individuals met inclusion criteria and participated in this study. Upon analysis of the demographics sheet (See Appendix D), all were filled out appropriately. Due to the limited number of participants few obvious demographic trends stood. The majority of participants were female (6, 85.7%), were caring for their parent (5, 71.4%), had a bachelor's degree (4, 57.14%), were not the sole caregiver (5, 71.4%), and stated that the PWD were still living at the time of the interview (5, 71.4%) (see Table 1).

Results

Each participant was asked at least nine questions (see Appendix 1) in a semi-structured format. Additional questions were asked depending on answers and for clarification of relevance to the research. After analyzing the data, eight themes emerged as barriers to a timely dementia diagnosis, with three being the most frequent (See table 4). The barriers identified were: 1. Denial by patient/PWD (85.6%), indicating that the PWD was not accepting of the potential for a cognitive impairment thus refusing to seek help; 2. Normalization of symptoms (42.8%), implying that either the patient, family or medical team felt that the initial signs and symptoms were a normal part of aging; 3. Issues accessing medical care (42.8%), inferring that there was a barrier at any stage in obtaining a diagnosis on the part of the healthcare team; 4. Denial by extended family (28.5%), meaning that there was an element of denial on the part of any family member aside from the participant (primary caregiver); 5. Masked by other issues (28.5), indicating that other medical issues either took precedent or were clouding the severity or presence of a cognitive impairment; 6. Fear of loved ones reaction (28.5%), suggesting that the participant received anger or aggression when the subject of an evaluation for cognitive impairment would be brought up or that they feared what the PWD would do if they knew about the diagnosis; 7. Lack of confidence in the medical diagnosis (28.5%), meaning that the PWD was told conflicting diagnoses regarding their condition resulting in a delay in diagnosis or distrust toward the providers; and 8. Unaware of changes (14.3%), meaning that the participant as not aware of how progressed the symptoms had gotten for their LO.

The results after analysis resulted in a rather large variety of barriers. While all of these identifies themes are important to the overall improvements needed to overcome such barriers, the three most frequently occurring were further examined for understanding. These themes are: denial by the person living with dementia, normalization of symptoms, and issues accessing medical care.

Denial by the Person Living with Dementia

Denial regarding the signs and symptoms or the diagnosis itself, by the PWD, was observed by the majority of the participant (85.6%, 6). Participant 1 (P1), participant 2 (P2), participant 3 (P3), Participant 4 (P4), participant 5 (P5), and participant 7 (P7) all identified element of denial on the part of the PWD as exemplified by the following quotes.

P1: Dad doesn't think he has any issues because he's functioning so normally. Due to his high level of functioning he isn't ready to accept the diagnosis.

P2: She was in denial because she was so emotionally stressed.

P3: She went into a rage and wrote a letter, but she couldn't even write at the time. We had to trick mom and lie to her to get her to do the MRI or else she would get crazy and throw a fit!

P4: Her short-term memory was so far gone; she would forget that she forgot things.

P5: We all suspected it years prior, but it took a long time to get Mom into a doctor as she was very good about hiding her forgetfulness. We went along with it not to upset her, plus she lived with me and still so functional. Mom would say things like "oops, did I forget that again, my silly old brain." But when she started to forget things like the oven, we sat her down.

P7: He would agree then disagree [that he had an issue], but mostly deny it and laugh it off like it was nothing

Participant 1 said that her father only went through the testing to appease her, but continued to deny it after the diagnosis. Participant 2 shared that her grandmother had been in a steady state of decline for many years but due to an element of denial from her uncle, who had passed away in 2017 and was the PWD's caregiver previously, by the time she began caring for her grandmother the PWD did not think she had any issues, however, after some issues with depression and mental health she eventually accepted her diagnosis with a flat affect. Participant 3 admitted to physical and verbal abuse when confronting her mother, putting herself and her children in danger. This participant stated that her mother would deny the diagnosis to the point of violence and aggression. Not only did this delay the diagnosis but it also complicated the treatment and subsequent placement of her mother in long-term care.

Participant 5 was able to “sweet talk” her family for years before the push for a diagnosis was finally made. The participant stated that her mother’s medical issues played a part as well, making the case for the multifactorial obstacles faced when seeking help to obtain a dementia diagnosis.

The way that the PWD would deny their symptoms and diagnoses were different for all of the participants, but the fact that they all lead to a delay in diagnosis was the same. All of the participants admitted to multiple issues and barriers faced when getting to a diagnosis.

Normalization of Symptoms

Normalization of symptoms by either the PWD, family, or healthcare team was expressed by 42.8% (3) of participant. Participant 6 stated that her father received a recent diagnosis of dementia (1/2021). This participant not only faced barriers from the PWD normalizing his short-term memory issues, but also from the PWD's primary care clinician six years ago. Even as recently as last year when she brought her father to see his primary care physician, he stated that his symptoms could very well be normal aging, but she would need to follow-up with a specialist and get an MRI to be sure. This encouraged the PLWD to further insist that his symptoms of memory loss could be more than just normal aging.

> P6: The primary care physician went as far as to say that this patient definitely doesn't have dementia or Alzheimer's. It turned out that he actually had Alzheimer's dementia and an element of vascular dementia.

From the perspective of the caregiver, the normalization of his symptoms by the PWD and the healthcare team, led to a delay in his diagnosis as much as five years. P6 stated that finally after getting the MRI and getting into a specialist, she was able to convince her father of his diagnosis, however, due to his decline he would intermittently forget accepting the diagnosis and insist again that there was nothing wrong with him.

The identified barrier of normalization of symptoms was suggested to be from lack of knowledge about dementia symptoms from the perspective of the caregiver, gaps in provider skills in differentiating cognitive impairments from normal aging or other diseases processes or a combination of both. Participant 2 took her grandmother to multiple behavioral health appointment before a clinician mentioned a potential for a cognitive decline

> P2: She said she was just depressed and that is was normal to forget things.

In the interview with P5, the caregiver stated that she took her mother to many medical appointments and the cognitive decline wasn't mentioned by the health team until a later stage in the disease process.

> P5: Mom made jokes about forgetting things and we all thought it was normal until it got bad….and the doctors never mentioned screening.

Issues accessing medical care

Issues accessing medical care, that interfered or delayed the ability to obtain a diagnosis for the PWD, effected three of the participants (28.5%). Of note, but not pertinent to this study, issues accessing care after a diagnosis as well as access to resources, effected all but one of participants.

Participant 4 lived in the UK with her mother who helped care for the PWD who was her grandmother but is now deceased. She expressed that it was a very long wait to even see a primary care provider, let alone a specialist. The time between seeing the PCP to the specialist was greater than a year. During that time, the PWD also experienced bothersome behavioral disturbances the interfered with both the participant and her mother's daily life. She went so far as to suggest an alternative way to access a specialist.

> P4: It was a long wait to see a specialist…it would have been better if someone could have come to our home. Had we been able to have a web health, they could have seen how bad Grand-mum was and gotten her into a specialist sooner. Maybe then it wouldn't have been so hard on me and my Mum…If the diagnosis had come sooner perhaps, she could have been helped with medication.

This meant that P4 and her mother had to care for the PWD in their home for two years before they were able to place her in a long-term care facility. This created a tremendous financial, emotional, and physical burden on both the participant and her mother. She also stated:

This type of insufficiency and delay in access to medical care was also felt by P7 who sought to get a diagnosis for his father in early 2020. P7 explained that due to Covid19 restrictions his father's MRI and specialist visit were changed three different times pushing it back by almost nine months.

> P7: It was hard to get a doctor’s appointment due to Covid.

This participant had his job affected out of necessity of him caring for his father. He also stated that the referral for care from the specialist was delayed and affected him being able to get his father resources such as respite, adult their daycare, and eventually a long-term care. Per the discussion with him, the delay in access to medical care cost him his job.

Participant 6 stated that she had taken her father, who is the PWD, to "many" doctors over the last 5-6 years. She said that she believed they were her father's primary care doctors, and they didn't feel that her father had and cognitive impairment. When she finally pushed for a specialist consultation, that wait time was over five months. She felt that the issues accessing competent and timely medical care affected her access to resources and further burdened her in her care of her father. When asked specifically "if she had received a dementia diagnosis earlier, would this have changed or affected the care your loved one received?" she stated:

> P6: Primary care said it might be dementia but didn't send him for testing…Had we known for sure it was dementia sooner, we might have been able to have some of Dads wishes known before he got too bad. And maybe could have planned better for long term care.

Participant 6 not only admitted to feeling the barrier of accessing timely care but also lack of confidence in the medical diagnosis. As mentioned previously, the majority of participant expressed multiple issues, identified as barriers by this researcher, that prevented them from what they felt was a timely diagnosis.

Chapter VI

Summary and Recommendations

Summary of Results and Discussion

As stated previously the intention of this study was to gather qualitative data to explore the phenomenology of the perception of the barriers to obtaining a dementia diagnosis from the perspective of those who are for them. Albeit with limited participants, that goal was accomplished. The coded themes extrapolated from the interviews with the seven participants were quite similar to those expressed in other larger studies.

The most frequently occurring barrier being denial by the PWD. The systematic review by Parker et al. (2020), cited eighteen studies, from all counties involved with their review, that supported this theme. Parker et al. (2020) stated that eleven of the studies that supported denial was denial by the caregiver regarding the diagnosis despite the PWD trying to convince the caregiver or family. Five studies that supported the PWD expressing denial and attempting to cover up symptoms were mentioned in Parker et al.'s (2020) review with persistent denial even after help had been sought and in some cases created a delay in care.

The desire to deny a cognitive impairment is driven, in part, to the associated stigma and lack of knowledge about signs and symptoms (Kock et al., 2010; Parker et al., 2020; Poole et al., 2020). In a study by Leung et al. (2011), it was noted that participants reported waiting two to four years after symptom onset to seek a diagnosis with many attributing the symptoms to other causes or simply dismissing them all together. When confronted by a family member or healthcare provider many of the participants in this study we unable or unwilling to make a connection to their memory issues and a cognitive impairment that is progressive and irreversible.

While the data collected was small in its size the impact felt by the delays in the diagnosis were felt by all of the participants interviewed. Informal caregivers, such as family, are vulnerable to "burn out" and are faced with a high level of anxiety (de Vught & Verhey, 2013). It was stated by all but one participant that an earlier diagnosis would have positively affected them in some way. The data examined by this researcher was consistent in that the barriers to a dementia diagnosis are multifactorial and necessitate intervention across the entire healthcare team to educate, empower and better utilize the existing resources to provide people with more support during and after diagnosis (Parker et al., 2020; Pool et al, 2020).

All of the interviewees were extremely candid and open with their discussions. Many became quite emotional during the conversation. While not specifically analyzed in this study it should be noted that every single participant stated that caring for a person living with dementia conveyed some level of emotional, economic, or physical stress associated with the care of their loved one (de Vugt & Verhey, 2013). All of the participants in this study admitted to some level of trauma when caring for a PWD, which is common among caregivers even in the early stated of the disease (de Vugt & Verhey, 2013. The type of trauma associated by watching a loved one decline, in many of the participants, was felt generationally as the extended family and children of many of the participants were affected by the burden of caring for a PLW (de Vugt & Verhey, 2013).

The barriers to seeking and obtaining dementia diagnosis, as well as the support given post diagnosis, are complicated and multifactorial, but they are vital to preventing and assuaging the trauma and pain felt by those caring for a PDW, as well as maintaining a quality of life for the PDW (de Vugt & Verhey, 2013; DuBois et al., 2016; Parker et al., 2020; Pool et al, 2020). Having resources in place prior to the diagnosis and educating families prior to the onset of symptoms may help to reduce the stigma and encourage more help seeking behaviors among the caregivers and the PWD (de Vugt & Verhey, 2013).

Issues accessing care was mentioned by three out of seven participant (42.8%) as well as in eight studies cited in the systematic review by Parker et al. (2020). Koch et al., (2010), identified lack of support, in any capacity, as a major barrier to seeking help. This could mean lack of support to the provider, lack of community resources pre and post diagnosis, language or transportation barriers, and financial issues when seeking care (Koch et al., 2010; Parker et al., 2020). Limited access to specialist, long wait times to see primary care, lack of diagnostic ability, diagnostic uncertainty, and a shortage of specialist have been identified as barriers to diagnosis and treatment in multiple other studies as well as in this study (DuBois et al, 2016; Koch et al., 2010; Parker et al., 2020). Unique to the participants in this study was the complication of the Covid-19 pandemic. While this was an added barrier to obtaining a diagnosis, for many, the barrier existed prior to the pandemic (Koch et al., 2010; Parker et al., 2020).

Normalization of lack of knowledge of symptoms specific to dementia was cited as a barrier in 28 studies reviewed by Parker et al., (2020). The participant in this study stated that either themselves, the PWD, or the provider attributed the delay of diagnosis to a normalization of symptoms as a normal part of aging. This could potentially be combined with dementia’s ability to be mistaken for other medical issues (Parker et al., 2020). Attributing a decline in cognition to normal aging or a similarly presenting medical condition significantly contributed to a delay in seeking a diagnosis (Parker et. Al., 2020; Poole et al., 2020). One participant particularly attributed this barrier to a delay of over five years (P6), while another stated it delayed a diagnosis by over 4 (P5). The pathway to diagnosis is complex and multifaceted with interconnected barriers and facilitators (parker et al., 2020). Advancement in awareness and knowledge regarding early signs or symptoms could reduce future delays in care (Parker et al., 2020; Koch et al., 2010).

Recommendations

In the last 30 years, some progress has been made around obtaining a dementia diagnosis, but multiple studies support that the resources post-diagnosis are severely lacking (Poole et al., 2020; Parker et al., 2020). Mass education, such as what was done with the surviving sepsis campaign, aimed at the general public knowledge of what is and isn’t a sign of normal aging, may be needed to support the facilitators to overcoming a timely diagnosis (Poole et al., 2020). A study by Robinson et al. (2015) suggested the routine screen at the age of 50, regardless of symptoms, might help to catch the early signs that the family or patient may have experiences. This could bring the screen for cognitive deficits to the same level of recognition in an annual physical as diabetes or hypertension (Robinson et al., 2015). With a baseline cognition level documented, a clinician would have a more objective way to recognize cognitive decline. This could be a potential topic for future long-term studies if implemented. This coupled with pre-appropriated community resources could decrease the anxiety and stigma associated with a dementia diagnosis (Cheng, 2017; de Vugt & Verhey, 2013).

Denial was the greatest barrier identified in this study and was interconnected with other barriers. Many of the participants stated that once a compilation of evidence was conveyed, the PWD eventually conceded to the diagnosis and was less reluctant to accept help. As suggested previously, a routine and annual cognitive screening would provide an objective baseline to which future screening could be compared to. This type of diagnostic screening might assist with the speed and frequency of primary care referral to specialized neurocognitive specialist and public awareness of dementia, thus reducing the time to appropriate and timely diagnosis (Poole et al.,2020; Robinson et al., 2015).

Parker et al. (2020) suggested multifaceted interventions including education to reduce the stigma associated with dementia and empower people with dementia and those who support them. The suggestion of the development of dementia friendly communities was mentioned in the Parker et al. systematic review as a possible option to assist those with a lower income level to still be able to retain some independence while being safe (Parker et al., 2020). While this may not be a viable option at this point, it is great to consider and could be subject to future studies.

Post diagnostic support or lack thereof was a common theme in this study. Providing relevant community resources, legal advice, prognostic information, and patient follow-up care post diagnosis as a standard could help to alleviate some of the anxiety and fear associated with the diagnosis dementia (Cheng, 2017; de Vugt & Verhey, 2013; Koch et al., 2010; Parker et al., 2020). Many participants in the study stated that they received poor follow-up care regarding resources, and that they were unknowledgeable about the next steps. Staging information or any prognostic education was lacking for many participants. Having that education might have assisted them determine what kind of needs and resources they could expect in the coming months to years to come (de Vugt & Verhey, 2013). Providing that kind of information as a standard, would likely facilitate less anxiety from the caregiver and could potentially yield economic benefits as expenditures such estate planning, medical planning, community resources, and eventually hospice or palliative care could be budgeted and plan for in advance (de Vugt & Verhey, 2013; De Vlemnick et al., 2018).

Limitations

The number of participants was a limitation as a larger number could have yielded more frequency in the barriers identified. One major barrier to a lack of participants was the number of perspective participants that did not yet have a dementia diagnosis. This was ironic as they were facing the same barriers to diagnosis as this study was aimed at uncovering. The lack the intended panel interview versus one-on-one interviews, may or may not have played a roll in the data extrapolated. English speaking participant may have limited the number of participant as this researcher was not able to source from non-English speaking networks.

The participants were very honest and emotional during the discussion, this may not have been the case is a larger group. However, a larger group may have assisted in finding more commonalities in the process of the diagnosis shared between the individuals. When people hear someone share something it can trigger a memory that they may have forgotten. Also, having a panel interview might have kept the conversations on the focus of the diagnostic process and barriers to arriving at a firm diagnosis.

Very often in the conversations, the participants would share with this researcher their current struggles and challenges of caring for their loved one. While it was helpful in gaining insight into just how deeply dementia effects the caregivers, it did not necessarily produce any data for this particular study. This type of anecdotal information could be helpful in a larger study examining the most common challenges people face when caring for a PLWD in hopes to provide more direct resources for them.

By far the largest limitation and challenge to this study was conduction research during the Covid19 pandemic. It is believed by this researcher that the extra stress placed on individuals during the pandemic was directly related to how many participants were sourced for this study. Several individuals expressed interest in participation but later either did not reply or said that they did not have the time.

Conclusion

This study aimed to identify the barriers to a timely dementia diagnosis as perceived by those people caring for a person living with dementia. Eight common themes were identified during discussions with the seven participants and in post discussion analysis, with three themes being the most frequently occurring. The three most frequently occurring themes were denial by the person living with dementia, normalization of symptoms, and issues with accessing care. The additional themes identified were a lack of confidence in the medical diagnosis, denial by extended family, fear of the PWD’s reaction, symptoms being masked by other medical issues, and being unaware of changes in the person living with dementia.

The barriers to obtaining a dementia diagnosis resulted in some degree of additional stress, delayed treatment, and financial hardships to six out of seven of the participants. Barriers to a diagnosis seldomly exist independently, therefor, a multifaced approach with interprofessional and community collaboration is needed (Parker et al., 2020).

Possible solutions including an increase focus on public education regarding what is and what is not a sign of normal aging, annual cognitive screening done by primary care providers, and pre-appropriated community and healthcare support for the caregivers and the PWD both during and post diagnosis are suggested as possible facilitators to overcoming such barriers (Cheng, 2017; de Vugt & Verhey, 2013; Koch et al., 2010; Parker et al., 2020).

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Tables

Table 1

Demographics of Participants

	Total N=7		*% of sample*
Age	< 21 years	1	14.2
	21-30 years	1	14.2
	31-40 years	1	14.2
	41-50 years	2	28.5
	51-60 years	1	14.2
	>60 years	1	14.2
Gender Identity	Male	1	14.2
	Female	6	85.7
Level of education	High school or equivalent	0	0
	Some college	1	14.2
	Associates	2	28.5
	Bachelors	4	57.14
	Masters	0	0
	Other	0	0
Occupation	Registered Nurse	1	14.2
	Teacher	1	14.2
	Unemployed	1	14.2
	Dog groomer	1	14.2
	Retired	1	14.2
	Hair dresser	1	14.2
	Contractor	1	14.2
Relationship to PWD	Son/daughter	5	71.4
	Wife/husband	0	0
	Niece/nephew	0	0
	Grandson/granddaughter	2	28.5
	No relation	0	0
	other	0	0
How long have/has care been	Less than 1 year	0	0
	Between 2-5 years	4	57.1
	Between 6-10 years	2	28.5
	Greater than 10 years	1	14.2
Is your loved one still alive	Yes	5	71.4
	No	2	57.1

Were you the sole care giver	Yes	2	28.5
	No	5	71.4
Current State of residence	NV	3	42.8
	CT	1	14.2
	NC	1	14.2
	WA	1	14.2
	OH	1	14.2

Note. PWD = Persons with dementia.

Table 2

Common Themes

Themes Identifies	Frequency	Percent of sample %
Normalization	3	42.8%
Denial by Family	2	28.5%
Denial by PWD	6	85.6%
Unaware of changes	1	14.3%
Masked	2	28.5%
Fear of Reaction	2	28.5%
Issues with care	3	42.8%
Lack of confidence	2	28.5%

Note. PWD = Persons with dementia. Normalization= Normalization of symptoms, masked= Masked by other symptoms, Fear of reaction= fear of reaction by PWD, Issues with care= Issues accessing medical care for diagnosis, Lack of confidence= Lack of confidence in medical diagnosis

Table 3

Answer to: Had you received a diagnosis earlier, would this have been of any benefit to you or your loved one?

Themes Identifies	Frequency	Percent of sample
Yes	5	71.4%
No	2	28.5%

Table 4

Quotes supporting common themes by participant

Common Theme	Participant number: Supporting Quote	Frequency, *n (%)*
Denial by patient/PWD	Participant 1: “Dad doesn’t think he has any issues because he’s functioning so normally.” Participant 2: “She was in denial because she was so emotionally stressed.” Participant 3: “She went into a rage and wrote a letter, but she couldn’t even write at the time.” Participant 4: “her short-term memory was so far gone, she would forget that she forgot things.” Participant 5: We all suspected it years prior, but it took a long time to get Mom into a doctor as she was very good about hiding her forgetfulness. We went along with it not to upset her, plus she lived with me and still so functional. Participant 7: He would agree then disagree [that he had an issue], but mostly deny it and laugh it off like it was nothing	6 (85.6%)
Normalization of symptoms	Participant 2: “she said she was just depressed and that is was normal to forget things.” Participant 5: “Mom made jokes about forgetting things and we all thought it was normal until it got bad….and the doctors never mentioned screening” Participant 6: “The primary care physician went as far as to say that this patient definitely doesn't have dementia or Alzheimer's. It turned out that he actually had Alzheimer's dementia and an element of vascular dementia.”	3 (42.8%)
Issues accessing medical care	Participant 4: “Long wait to see a specialist…it would have been better if someone could have come to our home” Participant 6: “Primary care said it might be dementia but didn’t send him for testing.” Participant 7: “It was hard to get a doctor’s appointment due to Covid.”	3 (42.8%)
Denial by extended family	Participant 2: “My uncle hid how bad it was from us…then he died, and I had to convince her she was sick.” Participant 4: “My aunts’ didn’t believe us until they saw it firsthand.”	2 (28.5%)
Masked by other issues	Participant 2: “She was so depressed we couldn’t tell at first that she was forgetting things.” Participant 5: “She also had other medical symptoms that took precedent.”	2 (28.5%)
Fear of loved one’s reaction	Participant 3:” She went into a rage whenever it was brought up…had to trick her to get an MRI.” Participant 4: “Grandma had severe outburst, sometimes involving the police…we were scared of her sometimes.”	2 (28.5%)

Lack of confidence in the medical diagnosis	Participant 6: “We sought help years prior and were told it wasn’t dementia, then were told it might be…not sent to testing right away.” Participant 7: “The doctor didn’t seem competent in making the diagnosis himself.”	2 (28.5%)
Unaware of changes	Participant 2: “We didn’t even know anything was wrong because my uncle hid it from us.”	1 (14.3%)

Note: PWD= Person with dementia

Appendices

Appendix A

Determination of Exempt Status from Research Integrity Department of the University of Nevada, Reno Institutional Review Board.

University of Nevada, Reno

Research Integrity
218 Ross Hall / 331,
Reno, Nevada 89557
775.327.2368 / 775.327.2369 fax
www.unr.edu/research-integrity

DATE: December 9, 2020
TO: Wei-Chen Tung
FROM: University of Nevada, Reno Institutional Review Board (IRB)

PROJECT TITLE: [1645144-2] Perceived Barriers to Timely Dementia Diagnosis REFERENCE #: Social Behavioral
SUBMISSION TYPE: Revision New Project
ACTION: DETERMINATION OF EXEMPT STATUS
REVIEW TYPE: Exempt
DECISION DATE: December 9, 2020
REVIEW CATEGORY: Exemption Category # 2

An IRB member has reviewed this project and has determined it is EXEMPT FROM IRB REVIEW according to federal regulations. Please note, the federal government has identified certain categories of research involving human subjects that qualify for exemption from federal regulations.

Only the IRB has been designated by the University to make a determination that a study is exempt from federal regulations. The above-referenced protocol was reviewed and the research deemed eligible to proceed in accordance with the requirements of the Code of Federal Regulations on the Protection of Human Subjects (45 CFR 46.104).

Reviewed Documents

- Advertisement - Recruitment script - thesis.docx (UPDATED: 12/4/2020)
- Application Form - Lampson. Exemption Core application-2.docx (UPDATED: 11/30/2020)
- Consent Form - INFORMATION LETTER.docx (UPDATED: 11/30/2020)
- Questionnaire/Survey - Questions for providers.docx (UPDATED: 11/30/2020)
- Questionnaire/Survey - Questions for caregivers.docx (UPDATED: 11/30/2020)
- Questionnaire/Survey - Demographic Information for Providers.docx (UPDATED: 11/30/2020)
- Questionnaire/Survey - Demographic Information for Caregivers.docx (UPDATED: 11/30/2020)

- University of Nevada, Reno - Part I, Cover Sheet - University of Nevada, Reno - Part I, Cover Sheet (UPDATED: 11/30/2020)

If you have any questions, please contact Nancy Moody at 775.327.2367 or at nmoody@unr.edu.

NOTE for VA Researchers: You are not approved to begin this research until you receive an approval letter from the VASNHCS Associate Chief of Staff for Research stating that your research has been approved by the Research and Development Committee.

Sincerelly, Richard Bjur, PhD	Janet Usinger, PhD
Co-Chair, UNR IRB	Co-Chair, UNR IRB
University of Nevada Reno	University of Nevada Reno

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of

Appendix B

INFORMATION LETTER

FOR
Perceived Barriers for Timely Dementia Diagnosis

You were being asked to participate in a research study. Marjeana H. Lampson, RN, BSN, Adult Gerontology Acute Care Nurse Practitioner student from the School of Nursing at the University of Nevada- Reno (UNR) is conducting the study. The purposes of this study are to (a) find common themes amongst the perceived barriers for a timely dementia diagnosis held by the family or loved ones caring for people with dementia or those who have cared for loved ones with dementia, (b) explore the families' and caregivers' experiences with the process of getting the diagnosis and caring for their loved one, (c) identify perceived barriers of healthcare providers to making a diagnosis of dementia, referring the patient for a dementia screening, and overall feelings toward the screening, diagnosis, and treatment of patients with dementia.

You were selected as a possible participant because you are (a) a family member or caregiver to someone who currently has or who has had dementia and are 18 years or older; (b) a medical provider who works in a capacity that may treat, diagnose, or refer for diagnostics a person with known or suspected dementia and are 18 years or older. The study will include a demographic page which should take no longer then 10 minutes to fill out as well as a semi-structured interview between the researcher, Marjeana H. Lampson, and yourself. Your answers will be recorded to enable theme and data extraction and analytics. All identifying personally identifying and/or health information will not be included aside from the information filled out on the demographic sheet.

participation is completely voluntary and confidential. You are free to withdraw from the study at any time by simply stating your wish to withdraw either verbally or in writing. The semi-structured interview may become emotionally uncomfortable to those who have a strong emotional connection to a loved one or patient with dementia. You may feel uncomfortable answering questions about your role in the care of these patients. If for any reason you feel uncomfortable, you may discontinue your participation, or skip to the next question. Your responses will be anonymous and no personal identifiable information will be collected about you. Once information has been collected for the study, your information cannot be withdrawn as there will be no subject identifiers (e.g., name, e-mail, etc.) attached to any of the information retrieved from the interview or demographics sheet. Your survey responses will be saved in a USB flash drive either in audio or typed form and stored in a locked cabinet. Only the researcher, (Marjeana H. Lampson), UNR committee chair member Wei-Chen Tung, PhD, RN, FAAN, and UNR Social Behavioral Institutional Review Board will have access to the data. Results of this study may be used for possible presentations in publications, only group data that has been analyzed will be presented. Individuals in the study will not be identified in any way.

Your participation in this study will contribute towards a better understanding of the perceived barriers to a timely dementia diagnosis, and how the timing of the diagnosis contributes to the overall care and functioning of the persons with dementia as well as those caring for those people.

There are no costs to you other than your time and effort in participation of this study. Your decision whether or not to participate will not affect your relationship with UNR, this researcher or affiliationg to any entity. If you have questions about this study, please contact Marjeana H. Lampson at (775)-400-0700 (Marjeana.lampson@nevada.unr.edu).

You may ask about your rights as a research subject or you may report (anonymously if you so choose) any comments , concerns, or complaints to the UNR Social Behavioral Institutional Review Board, telephone number (775)327-2368, or by addressing a letter to the Chair of the Board c/o UNR Office of Research Integrity, Office 205 Ross Hall/331, University of Nevada, Reno, Reno, Nevada, 89557.

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completion and return of the demographic data form implies that you have read the information in this letter and consent to take part in the research . Please keep this form for your records or future reference.

Appendix C

Questions for semi-structures interviews (caregivers)

All of you have been provided an information letter regarding this research study as well as a demographic information sheet. I am going to ask you some questions to further understand your perspective on the diagnostics and care involved with persons with dementia or suspected dementia. Please feel free to elaborate wherever you feel necessary or appropriate.

Any answers you provide are confidential and your name will not be identified with anything you say. You do not have to answer any questions you do not wish to answer.

1. Tell me about the process, if the process is known, of diagnosing your loved one with dementia?

2. Did you suspect your loved one of having dementia or was this brought to your attention somehow else? Please tell me about this.

3. How did the timing of the diagnoses affect the care your loved one received, if it did?

4. What type of care did/ does your loved one receive? For example: home health, long term care, assisted living, Memory care center, hospice, none?

5. Was/ is your loved one aware of their diagnosis? If so, what was/is their reaction?

6. What could have been better in regard to medical care during or after the diagnosis of dementia was received?

7. Had you known about the dementia earlier, would this have changed or affected the care your loved one received or is receiving, if so how?

8. Tell me about any emotional, economic, or physical stress associated with the care of your loved one.

9. Would an earlier diagnosis have affected you or your loved one’s personal, economic, emotional, or physical stress?

Appendix D

Demographic Information for Caregivers

1. Your age? _____

2. Sex?
   a. M
   b. F
3. Level of Education?
   a. High School or equivalent
   b. Some Collage/ Trade school
   c. Associate's level
   d. Bachelors
   e. Masters
   f. Doctorate
   g. Other______

4. Occupation? _________

5. Relationship to the person with dementia/ loved one?
   a. Son/Daughter
   b. Wife/ Husband
   c. Sister/ Brother
   d. Aunt/ Uncle
   e. Grandparent
   f. No relation
   g. Other________
   h.
6. How long did you/ have you been caring for the person with dementia/ loved one?
   a. Less than one year
   b. Between 2-5 years
   c. Between 6-10 years
   d. Greater than 10 years
   e. Less than 1 year

7. Is your loved one/ person with dementia still living?
   a. Yes
   b. No

8. Were you the sole care giver?
   a. Yes
   b. No

9. State of current residence? _______