

**INFORMATION AVAILABLE TO PATIENTS DIAGNOSED WITH
DEMENTIA;
INTERVIEWS WITH CAREGIVERS AND THEIR EXPERIENCES**

Honors Thesis

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By

Leigh M. Williams

Hannah E. Fraley RN MSN
Faculty Advisor
Department of Nursing

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Abstract

Purpose: Dementia is a prevalent problem for older adults and their families. Early intervention and a multidisciplinary approach for treatment have been linked to better quality of life. The primary objective of this study was to discover what information is available to patients with dementia upon diagnosis and how beneficial the information given is perceived by the primary caregivers. Secondary objectives included types of resources most utilized by the caregiver and how caregivers found out about such resources.

Methods: A qualitative study design was employed using snowball sampling methods and semi-structured interviews among primary caregivers (n= 5) of patients with Alzheimer's Disease (n= 3), Lewy Body Dementia (n= 1), and Dementia Unspecified (n= 1) respectively. Thematic coding methods were used to identify potential barriers to accessing timely information regarding disease prognosis and optimal resources.

Results: Several themes emerged from caregiver interviews. Central themes found among the caregivers include: 1.) chronic grief 2.) chronic frustrations 3.) chronic guilt 4.) total responsibility of care. Several subthemes emerged that compound upon these caregiver experiences including provider related parries such as lack of quality information, and access barriers including difficulty finding community resources.

Conclusion: Caregivers interviewed in this study perceive support from their health care team in general, yet have limited perceived support in navigating how to access community resources. Patients and their families need guidance and support from the health care team upon diagnosis, yet also need ongoing support and education while caring for a loved one with Dementia.

Keywords: Alzheimer's disease; dementia; quality of care; caregiver; education

Table of Contents

Abstract.....	2
Acknowledgements.....	4
Introduction	5
Literature Review.....	5
Dementia and the Healthcare System.....	6
Caregiver Experience.....	8
Caregiver Needs.....	9
Clinical Implications.....	11
Methods.....	13
Results.....	14
Patient Demographics.....	14
Caregiver Related Themes.....	15
Healthcare Related Subthemes.....	20
Discussion.....	21
Conclusion.....	23
References.....	25
Appendices.....	28
Appendix A (Informed Consent).....	28
Appendix B (IRB Approval).....	29

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*“Love and compassion are necessities, not luxuries. Without them
humanity cannot survive.” –Dali Lama XIV*

Introduction

Alzheimer's disease is a growing epidemic in the United States amongst seniors. One in nine people over the age of 65 suffer from Alzheimer's disease and it is the sixth leading cause of death (Alzheimer's Association, 2013). Currently, the number of people affected by Alzheimer's is approximately 5.2 million and is projected to double by 2050 (Alzheimer's Association, 2013). It has been discussed at large that the quality of care for people with this disease is often lacking. As the number of people with Alzheimer's disease increases, further understanding is needed targeting the needs of this population. Information regarding treatment (non-pharmacological and pharmacological), health care costs, and what to expect during this disease needs to be more accessible to patients and their families at time of first diagnosis. At initial diagnosis, providing patients and their families information regarding their diagnosis and disease process will allow them to begin to plan for the future ahead. Dementia is a progressive disease that puts a lot of burden on both the patient and caregiver. There has been limited research conducted on early stage interventions, with majority of research on how to guide patients and their families later in the disease process (Sorensen, Waldroff, & Waldemar, 2008). In response to lack of information available regarding the quality of information given to caregivers of people with dementia, this study looks directly at caregivers experiences. The aim was to understand the type of information given to patients and their families and the level of support and knowledge provided to this population. By understanding the quality of care being offered, suggestions can be made to better this long and emotional process.

Literature Review

Dementia is a permanent or progressive decline in several areas that interfere with a person's life socially and economically. Dementia disrupts several areas of functioning

including: memory, orientation, information processing, problem solving, judgment, sequencing of tasks, recognition of objects, writing and drawing, calculating, activities of daily living, mood and affect, perception and thinking, behaviors and sleep-wake cycle (Abraham, 2005).

According to The American Psychiatric Association (1994) clinical dementia is a progressive loss of memory and intellectual functions (as cited by Kaskie, Coddington & Abrams, 2004).

People who have dementia struggle with learning new information, retrieving memories, and behavioral issues including anger and combativeness. They may also experience hallucinations and delusions (Kaskie et al.,2004).

Dementia and the Healthcare System

An estimated 5.4 million Americans have dementia and 87% of the people live in the community according the Alzheimer's Association (2011) (as cited in Samia, Hepburn & Nichols, 2012). One in three seniors die with dementia and dementia is the sixth leading cause of death (Alzheimer's Association, 2013). Approximately 15.4 million caregivers provide 17.5 billion hours of unpaid care yearly (Alzheimer's Association, 2013). According to Nichols (2011), the majority of these caregivers do not have the training or skills necessary to meet the demands of these people (as cited in Wallis, 2011). Dementia is a progressive disease that affects the patient and their family for many years. According to the Alzheimer's Association (2013) caregivers of people with dementia provide care for longer than those who provide care to older adults with other ailments. The majority of caregivers for people with dementia provide care for 1-5 years while the majority of others provide care for less than a year (Alzheimer's Association 2013). Currently, the cost of providing care for people with dementia is 203 billion dollars a year and is projected to increase to 1.2 trillion dollars a year by 2050 (Alzheimer's Association, 2013).

With these substantial numbers that are only going to increase, it is clear that this is a group that needs attention in the medical field. The increasing numbers of people with Alzheimer's and other dementias means increased numbers of caregivers. Caregivers can potentially have their health impacted from this new role and may also have a negative impact on the economy, as they are not typically working due to their new role as care provider (Habermann, Hines & Davis, 2013).

Challenges faced by the healthcare field regarding dementia include access to service, cost of care and quality of care. (Kaskie et al., 2004). While we are making strides in research targeting dementia, including programs that caregivers require (Alzheimer's Association, 2013); there are still areas where we are lacking. To start, there is little research on caregivers early on in diagnosis (Ducharme, Levesque, Lachance, Kergoat, & Coulombe, 2011a). Part of the issue is the lack of training and diagnosis of dementia by physicians. Most patients are initially screened by their primary care physician; however, these providers fail to recognize the diagnosis frequently (Austrom et al, 2005). A study by Callahan, Hendrie and Tierney (1995) found that 75% of patients who had moderate to severe cognitive decline did not have an official dementia diagnosis on their medical history (as cited in Austrom et al., 2005). There is also a lack of access to programs and services available to patients diagnosed with dementia (Kaskie, et al., 2004). For instance, the article *A Strategic Response to the Challenges Presented by Older Patients with Alzheimer's disease and Other Types of Dementia* details this lack of care (Kaskie et al., 2004). One study discussed was conducted by Kaskie and Meedel (2002) which found that out of 34 community-based programs surveyed (20 residential care facilities and nine primary healthcare providers for elders with chronic disabilities) only six contained programs specifically for elders with dementia. They also report the results of a survey completed in 2003

by Maslow (2003) that found that few care facilities had plans to create programs for people with dementia (as cited in Kaskie et al., 2004). Another area that needs improvement is how physicians handle dementia care. An intervention completed in 2003, *Assessing Care of Vulnerable Elders-2 (ACOVE-2)*, the authors looked at care given to patients with Alzheimer's, and it was found that physicians performed better care management of the medical aspects of Alzheimer's but not the counseling aspects (Reuben et al., 2010).

Caregiver Experience

Dementia not only affects the patient. It is a disease that has a large impact on the family and the caregiver. Typically, caregivers are women (Alzheimer's Association, 2013). 36% of adult children in the United States are primary caregivers for a parent with the he majority of caregivers tending to be adult daughters (Habermann et al., 2013). Dementia caregiver's experience more burden than caregivers of older adults with physical conditions. This is due to patient psychosis and poor ADL and IADL skills (Yeager, Hyer, Hobbs, & Coyne, 2010). According to the Alzheimer's Association (2013), 61% of caregivers report very high emotional stress and 43% due to caregiving. The period of transition from moment of diagnosis to taking on the role of caregiver is essential. The caregiver has to become ready to accept the responsibility this role entails including education, taking on more responsibilities, and planning for the future. (Ducharme et al., 2011b) While transitioning into their new role, caregivers face uncertainty, instability, change, and are more prone to health risks. It is important to look at their health, physically and mentally and how they are coping with stress during this crucial time (Ducharme et al., 2011a). Some of the consequences of caregiving include: feelings of isolation anxiety, poor sleep, hospitalization and even death (Wallis 2011).

The challenges and demands caregivers face are difficult to predict, progressive and are dependent on each family situation (Samia et al., 2012). It has been shown that at time of diagnosis of dementia, caregivers are not given adequate information (Ducharme et al., 2011b). Georges and Gove (2007) found that less than one third of caregivers were informed of services given to them at this time (as cited in Ducharme et al, 2011b). Laakkonen and associates (2008) found that 50% of spousal caregivers felt uncertain about the quality of information and services provided after diagnosis (as cited in Ducharme et al., 2011b). Caregivers feel isolated due to a lack of knowledge and support (Robinson et al., 2005 as cited in Ducharme et al., 2011b).

A study done by Habberman, Hines and Davis (2013) looked at positive experiences. Interviews were conducted on 34 adult children caregivers and some of the positive experiences found were: returning and giving back care, spending time together, and appreciating each other/ becoming closer. Of the 34, six were unable to report any positive aspects. They all mentioned feeling of being hopeless, alone and not knowing how there could be any positives in the experience. This shows the overpowering burden this experience can put on a caregiver. The caregivers who were able to identify positive aspects were found to have less stress and feelings of being overwhelmed (Habermann et al., 2013).

Caregiver Needs

Knight and Kaskie (1995) found that most people are uninformed about the course of the disease and what to expect clinically (as cited in Kaskie et al., 2004). According to Gwyther (2000), patients and their caregivers need more education regarding family needs, financial support and legal planning; specifically regarding Medicare, and long term-care insurance coverage, benefits and limitations (as cited in Kaskie et al., 2004). According to Bourgeois et al.,

skill building interventions such as behavioral management, communication and general problem skills are beneficial for caregivers (as cited in Farran, Loukissa, Perraud, & Paun, 2004). In order for the caregiver to build the necessary skills, they require increasing their knowledge on dementia, goal directed behavior and emotional acceptance of the situation (Farran et al., 2004). It has been found by Mittelman et al. (1993) that caregivers are not adequately informed enough to be able to ask the most important questions or request the most useful information (as cited in Nichols, Martindale-Adams, Greene, Burns, Graney and Lummus, 2009).

A study that looked at caregiver issues and concerns found that the five main issues and concerns of caregivers are: dealing with change, managing competing responsibilities and stressors, providing a broad spectrum of care, finding and using resources and experiencing emotional and physical responses to care (Farran et al., 2004). This information is valuable because it helps identify what caregiver needs are and the different ways we can approach supporting them. Similarly, a study done by Nichols et al. (2009) found that the most common behavioral topics of concern for caregivers were combativeness, confusion and communication. They also found that the caregivers were concerned with their own healthy lifestyle, grief, relaxation techniques, and caregiver depression (Nichols et al., 2009).

It has been shown that intervention programs are implemented too late in the course of the dementia. Charlesworth (2011) and Clark, Chaston and Grant (2003) both suggest that a more proactive approach should be taken and intervention programs should be offered earlier in diagnosis (as cited in Ducharme et al., 2011b). Ducharme and associates found that caregivers were able to plan more efficiently, have more knowledge regarding dementia, and utilize more effective coping mechanisms and problem solving skills after a multidisciplinary intervention program that was tailored to the caregivers needs (Ducharme et al., 2011b).

Clinical Implications

It has been noted that simply distributing educational materials to physician's rarely changes physician behavior (Austrom et al., 2005). Physicians need to be better trained in care for dementia patients. Physicians who diagnose dementia earlier on can help keep patients out of hospitals and spend more time getting them the medication and care they need. Nurses would benefit from education programing as well because they will learn how to interact with dementia patients more appropriately such as, causing less patient agitation (McCallion et. al, 1999 as cited in Kaskie et al., 2004).

It would be beneficial for healthcare organizations to partner with the Alzheimer's organization to provide training to staff (Kaskie et al., 2004). Physicians would also benefit from partnering with community based organizations to integrate their care. The Alzheimer's Association chapters could provide patient and family education and also offer counseling and community services. However, it has been found that the medical community and the Alzheimer's association rarely work together. (Reuben et al., 2010). It has been shown to be beneficial to patients and their families when these two communities work together (Reuben et al., 2010). The Alzheimer's Association (2013) suggests that some of the components of effective caregiving programs include: being administered over long periods of time, seeing dementia care as an issue that involves the entire family and interventions that teach dementia caregivers how to manage behavioral problems. In particular multidimensional programs are effective (Alzheimer's Association, 2013). Such education programs have included components that address acknowledging the disease, accepting role transition, developing emotional tolerance, becoming assertive and proactive, establishing realistic goals, recognizing patient's abilities, and creating opportunities for caregivers to maintain satisfying social and occupational

lives (Yeager et al., 2010). Some programs to consider include REACH II and ACTIVE (Yeager et al., 2010; Alzheimer's Association, 2013).

Caregivers should receive support through community support as well as individual psychological support (Yeager et al., 2010). Future responses to the challenges brought on by dementia include public education, professional training, program development and service integration in the community (Kaskie et al., 2004). In a study conducted by Sorenson, Waldrorff and Waldemar (2008), interventions were conducted to caregivers of people with Alzheimer's which included support groups, counseling and education. After the study, it was found that caregivers found support groups to be useful. It helped with their self-esteem, and coping with the everyday challenges they faced.

Austrom et al. (2005) implemented a "Prevent Study" (providing resources early to vulnerable elders needing treatment for memory loss). The authors included a screening and diagnosis protocol and a multidisciplinary approach with a geriatric advanced practice nurse (GAPN) as coordinator. The team included an advanced practice nurse, social psychologist, geriatrician, and a geriatric psychiatrist guided treatment. The GAPN provided education and support and facilitated discussion between primary physician, family and resource team. A monthly support group was offered to participants and they were provided education and counselling for both the caregiver and the participants. At the very least, all participants received education regarding communication, coping and caregiving skills, legal and financial advice, exercise information that included a guidebook and videotape and the *Caregiver Guide* provided by the Alzheimer's Association (Austrom et al., 2005). The GAPN helped coordinate contact, make appointments, give recommendations regarding medication and make home visits to help fit caregiver and patient schedules. The caregivers were given updated handouts regarding their

specific treatment protocol. This study above relies on the GAPN to be successful. This program includes well-trained nurses who follow their patients closely. This study shows successful integration of a long term, multidisciplinary treatment plan that had beneficial consequences to patients and their families.

Resources for Enhancing Caregiver Health II (REACH II) is an intervention for family caregivers of patients with Dementia that is funded by the National Institute on Aging and National Institute of Nursing Research (Czaja et al., 2009; Alzheimer's Association 2013). It targets areas specific to caregivers of those with dementia including: depression, burden, self-care and healthy behaviors, social support and problem behaviors (Belle et al., 2006 as cited in Czaja et al., 2009). Some additional interventions to consider could include: providing homework, daily diaries, practice actives, providing verbal, written and performance feedback and offering incentives to help build skills instead of solely focusing on general concepts like preparedness and competence (Farran et al., 2003).

Methods

The key questions asked within this study includes: what information is available to patients with Alzheimer's early on in the diagnosis and how beneficial this information is to the patient and the caregiver. In response to the lack of evidence surrounding information given to patients with Alzheimer's a qualitative study was conducted. Semi structured interviews were conducted with five caregivers (n=5) of family members with dementia. The interviews were conducted one time with each caregiver and they were recorded. Interviews lasted 15-35 minutes long and took place in various locations including participants' homes, coffee shops and libraries. The participants were given a disclosure form (Appendix A) that they signed and gave back to the author. The participants were informed participants that their interviews would be

recorded and transcribed and that their participation was voluntary and would remain anonymous in the report. This research study was approved by the Salem State University institutional review board prior to commencing the study (Appendix B). Questions asked to the patients included: how their loved one got diagnosed and when, what information was available to them by their neurologist and when they received it, the quality of the information they received, did they have to research on their own, did they feel supported by their neurologist, and would having information more readily available and helpful make a difference in their experience and what types of treatments/resources such as support groups do they utilize. The interviews were transcribed verbatim and checked for accuracy. Interviews were then analyzed using conventional content analysis. Thematic coding was used to find various themes consistent amongst the five interviews. Several themes emerged from the research.

Sample

The sample for this study was a convenience sample found using snowball methods of recruitment. The author obtained this sample by asking friends to recommend potential participants. The author made a post on social media looking for people who were caregivers of someone with dementia. Participants were then contacted and they agreed to take part in the study.

Results

Participant Demographics

The participants were all female ranging from 50-80 years old. One participant was the spouse of someone diagnosed with dementia and the rest were children. Three participants were caregivers of family members diagnosed with Alzheimer's Dementia, one was the caregiver of a

loved one diagnosed with Lewy Body Dementia and one was the caregiver of a loved one with unspecified dementia. All of the participants were from the greater Boston area. None of the participants saw the same doctors, but some utilized the same resources. The caregivers were caring for people in various stages of dementia. Three had already expired, one was in the late stages of dementia and was fully dependent, and one was still living independently with moderate supervision.

Through thematic analysis it became evident that many of the themes found could be categorized into four categories centered on the caregiver's experience through the course of the disease. Several sub-themes regarding the health care they received compounded these caregiver focused themes. The caregiver related themes found include chronic grief, chronic guilt, chronic frustration, and total responsibility of care for the patient.

Caregiver Related Themes

Chronic Grief

All of the participants expressed feelings of grief throughout the process. The majority of reported grief stems from watching loved ones become ill. Every one of the participants discussed what it feels like to watch their loved one become progressively more neurologically impaired. One described the process as "tough to see them fall away to nothing. It's like watching a flower bloom and then seeing it die off little by little". A second participant said, "it is like seeing her go back to being a baby". Another participant became very emotional when discussing seeing her mother become ill stating "we started living with a mother who slowly started falling apart. But we grew to understand it."

Three of the participants have a strong family history of dementia. One participant explains this history,

He is one of nine, one died in World War II one died of a heart attack, of the rest three have passed away of Alzheimer's and three currently have it so there is only one living who isn't diagnosed.

Another participant expresses her fears for the future because of her family history: "It's very sad and it's scary because my father had it and my mother had it so what's left for me?" One of the participants whose mother is still in the early stage of dementia expressed fear for what the future has in store describing that she is afraid that one day her mother is going to go for a walk and never come home and that she is "waiting for the bomb to drop".

Chronic Guilt

Feelings of guilt and helplessness were evident. One participant summarized her feelings by stating

"...and the guilt. Feeling like you can't do anything for this person. Guilt might not be the right word. Not lack of control but, inability. Hopelessness like your hands are tied. Tied every which way: with the patient themselves, if you're not poor enough you can't get any help, the help is so expensive then you would be poor."

This particular participant also expressed feeling guilty for some of the things she would have to do to keep her father happy such as lying.

Some of the participants also expressed guilt and grief regarding things they went through with their loved one during their illness. A particular participant was explaining that it was hard to deal with some of her mother's delusions stating "she would call and say someone was breaking into her house or stealing the car. You had to treat it like it was real but it wasn't. and what if it was real? Because you don't know what is real and what is fake unless you're there

and that was hard.” She then shared a story in which her mother wandered alone at night and was robbed on the street. She continued to wander until she eventually made her way home.

Additionally, one participant shared a story about her mother when she was in the hospital,

One time she was in the hospital disoriented and she kept getting her and telling her where’s my daughter, put her in a chair which I understand they have to because patient safety and they strapped her down. But when I saw her she was beside herself and she was mortified because it came back a little. I understand they were busy but they should have called me. They told her they called me but they never did and that wasn’t right.

This participant also conveyed feeling afraid of bringing her mother to the hospital because of the consequences she thought might come of it: “we knew if we took her in an ambulance once we put her in a facility we would not get her back...they’re not going to help the patient, she would end up in a locked psych ward and that was not going to happen to my mom”. She detailed being yelled at and threatened by her mother and how hard it was to watch the frustration her mother was going through.

Chronic Frustration

The most apparent theme which emerged was frustration. The caregivers expressed being frustrated by their physicians, insurance companies and availability of resources. The entire process including the nature of the disease was a burden to these participants. One participant explained this encompassing frustration:

It’s a frustrating disease. And if you don’t understand it you can get frustrated with that person. You will be shocked how many friends step away because they don’t like to see that person that way. You lose family and friends—siblings of the patient. There just seems like there should be more done and you feel bad for the staff, I don’t know there should be something else. I know it’s costly and frustrating.

Regarding insurance, all of the participants who utilized, or tried to utilize community resources had difficulties and frustrations with coverage. Participants expressed having a hard time getting covered for services in the community and medications as one caregiver stated: “I was really frustrated by the system and I didn’t understand why insurance wouldn’t cover anything. It was like are you kidding me?” Another stated that trying to get VNA “was horrific” and that they would have had to pay for everything out of pocket. The participants also mentioned getting help when it was too late. Two of the participants expressed getting hospice weeks before their loved one died; “we could have had more help. We finally got hospice a week before he died”. Another participant recalls “and then she probably died three weeks after we started hospice. By the time they were starting services she had already passed away.”

Overall, the participants reported frustrations with the quality of care they were receiving from their healthcare team. One participant stated, “I didn’t feel like anyone was going out of their way to help us.” The participants unanimously stated that they found the majority of resources on their own. They expressed feelings of trudging through the treatment plan alone. One participant stopped seeing their neurologist completely and others started going less frequently. One participant described:

*I think they (neurologist) realize it only last so long
before they pass away.. I don't feel like they were very invested
in her. They pass you down from people to people, you get
diagnosed and then referred and then from there it's all downhill.
You're trying to get them settled but you're never going to get them settled*

Another stated “then we reached a certain point we weren’t going because there was nothing they could do...it feels like you’re doing that the whole time, trying to catch up, the time you

know what you needed to know it's too late." This participant went on to say "they should at least provide a case manager".

Responsibility of Care

These caregivers assumed the role of doctor, nurse, nursing assistant, advocate, and loved one for these patients. It became evident that the caregivers were their own case managers. They found resources and made connections. All five participants mentioned having to completely alter their life schedules in order to care for their loved one. The disease process involved the entire family for these participants. One caregiver showed the author a calendar her family made that planned out every single hour someone from her family would be with her mother. This family also created an extremely detailed outline of the patient's medical history. It was clear this family felt as though they needed to advocate for themselves.

There were plenty of tears. But we would call each other and said mom did this and that. We started it saying we needed to think about what we're going to do. That's why we needed to know her meds, her history, who would be with her. Only resources we used was each other... We all worked together as a family to bring her places... When we realized my mom couldn't be by herself anymore we put an email out to all the grandchildren and asked if they would stay with grandma.

Another participant stated "we did all the work ourselves". And another participant who has yet to require services said that she will have to quit her job to care for her mother and maybe eventually put her in a nursing home. Many of the participants expressed want for change in their treatment. "The family shouldn't have to have this big burden of caring for someone and trying to keep them comfortable". Another participant expressed an interest in becoming involved in research/care for families touched by dementia because she felt so strongly that there needs to be a change in care.

*Health Care Related Subthemes***Provider-Related Barriers**

All five participants reported receiving vague information upon diagnosis and did not know what to expect over the course of the disease. One participant stated, “they put him on a medication and they said just to watch him” where another recalled, “it was all general”. The participant whose mother is still early on in the process of her dementia shared that she did not receive a lot of information. She reported:

We took her to the doctor and the neurologist said she's just getting older and that she was just forgetting. But it was getting to be too much. So then we took her to another guy who really seemed to know what he was doing... (Interviewer: What information did he offer you?) She wasn't as bad then as she is now so I didn't really need information... He answers every question I ask but I'm not sure if I'm really asking enough questions.

The participant with the extensive family history stated that she felt her doctor assumed she knew what to expect due to her exposure with dementia in the past.

Every participant also answered yes to the question “Do you feel supported by your neurologist?” One participant felt supported by a subsequent physician they say but not the first assigned. She stated:

The person we worked with before her primary care would say 'I don't think you can continue this with your mom. And I said yes we will we are not putting her anywhere'. But we as a family supported each other.

Others described their relationship with their neurologist by saying “I did like him...If I had questions he was always willing to answer. But I didn't get a lot of info” and “I think they would help but we had to do a lot of research on our own, hard to get a hold of the help”. Two of the

participants stated they were not connected with a case manager. While two others stated they had one but did not get a lot of help with services from them.

Access Barriers

All five participants did research on their own and found resources through word of mouth. One participant stated “We did everything online. We understood that more than going to the doctor”. They all shared experiences of speaking to friends and family members who went through the same experience and finding resources such as the senior center and support groups offered through them. Not one of the participants found a support group or found out about a senior center through their doctor’s office. One participant shared:

As primary caregiver I was trying to figure out how to help him as opposed to the symptoms. Until he had a symptom I never realized he was gonna have that. Knowing those things like delusions would help. And then I would look them up and I would see. I would talk to my family, talk to my cousins whose parents had it.

As stated above, many participants had a hard time getting the help they needed for resources due to issues with insurance of the case managers. The participants expressed feelings of having no treatment plan. One patient stated: “we had no long term plan. We were flying by the seat of our pants. It was like ok now what do we do?”

Discussion

This rich, qualitative data tells us that patients and their families are not getting integrated, supportive nor community based care. The areas reported in which health care is lacking include receiving vague information from the physicians, not knowing what to expect with the course of the disease, doing a lot of research on their own, finding community resources through word of mouth, and not being supported by a case manager. The participants also

struggled with finding useful community resources that were not only covered by insurance but were presented to them in a timely manner and were beneficial for both patient and caregiver. It is this lack of quality of resources and education that compile and lead to decreased quality of life for both the patient and caregiver. Some of the experiences felt by the caregivers include chronic frustration, guilt, grief and total responsibility of care.

These findings support previous research. As found by Ducharme et al. (2011a) caregivers are faced with uncertainty, instability and change. Samia et al. (2012) suggests caregiver needs and demands vary depending on each family situation. All participants within this study report different needs, different stories, and different perspectives, yet share the common themes identified. Previous researchers found that caregivers are not given adequate information regarding services, the course of the disease, and felt a lack of knowledge and support (Ducharme et al., 2011b)

Reuben et al., (2010) highlights that physicians performed better handling of the medical aspects of dementia but not the counseling aspects. Most participants here report they felt supported by their neurologist and felt comfortable asking questions, however they did not receive the emotional or community support they felt they needed. According to Knight and Kaskie (1995), most people are uninformed about the course of the disease, and what to expect clinically. Gwyther (2000) reports that caregivers require information regarding family needs, financial and legal planning (as cited in Kaskie et al., 2004).

Previous research as well as the findings from this study can provide insight into changes needed for this type of patient population and their caregivers. Previous studies include interventions that are multidisciplinary and are implemented early on have proven to be successful. Sorenson, Waldroff and Waldemar (2008) used an intervention containing support

groups, counselling and education strategies that helped caregivers self-esteem and daily challenges. Similarly, Austrom et al. (2005) used their “prevent study” that utilized a Geriatric Advanced Nurse Practitioner that worked as the care coordinator. The GPN facilitated communication with the physician, social psychologist, geriatrician and geriatric psychiatrist as well as the patient. The intervention included education, support groups and counseling. The nurse’s role here is invaluable; the RN is the primary educator, facilitator, and advocate for the patient. By implementing a specialized nurse practitioner to care for the patient and family, a holistic approach can be taken to ensure that the entire family is getting the care necessary to prevent barriers that were found in this study, and supported by previous studies.

Conclusion

This study aimed to uncover the experiences felt by patients and their caregivers early on and during the course of dementia. It aimed to highlight the highs and lows of the process and ways to make improvements. It was found that caregivers are not receiving enough thorough information and do not have adequate access to community resources for various reasons. Nurses should take ownership of creating new roles that allow for integrated, multidisciplinary, and community based care.

The limitations of this study must be noted. By the nature of qualitative design, this study included self-reported data and the findings cannot be generalized to the entire population. This study contained a small sample size within a limited geographic location. There were also differences among the participants as to who were the primary caregivers, knowledge of the disease and disease stage. The caregivers were caregivers to those with different forms of dementia including Alzheimer’s and Lewy Body Dementia. Participants also had provider differences; i.e. NP, MD, Specialist. Some had access to case management while others did not. Despite this small sample size, data saturation was reached. It should be stated that the

knowledge gained through this study is important as a foundation for future study with this population. Also, this study provides a view into the lived experiences of caregivers of dementia which will provide insight into future intervention development. If given more resources, the author would have focused on a much larger sample size throughout New England with consistent perimeters including diagnosis, stage of disease, and relationship of caregiver.

Suggestions for future research include expanding the study to include caregivers from across the region. It would be beneficial to see if there are areas in New England that seem to have successful community programs for patients with dementia and their families. The author also suggests research that implements a nurse as the care coordinator/ team leader offering monthly support programs, as well as services and ongoing communication and collaboration with the physician and see results from such an intervention. Future research activities should focus on intervention development with this high risk group- i.e. nurse navigator or case manager, family centered care intervention. This study and future research aids to improve the quality of life for not only patients with dementia but their families as well. It further offers in the emergence of a new potential role for nursing in care of the older adult and ways the healthcare system can improve.

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Appendix A

Salem State University
Institutional Review Board (IRB)

Consent Form

My name is Leigh Williams. This interview is for a research paper I am doing for school. I will ask you questions about your experience in the diagnostic process of the person you care for with Alzheimer’s disease.

Participation is completely voluntary. There are no right or wrong answers. You may stop at any time. All answers will remain completely anonymous. You do not have to answer any questions that make you feel uncomfortable.

The risks and benefits are that the information I gather from this case study will help show the information available, or perhaps lack of, to patients with Alzheimer’s and their caregivers. From this case study, actual caregiver experience will expose where the diagnostic and teaching processes of Alzheimer’s disease is lacking. However you may get upset thinking about your experience with your loved one when I ask you some questions.

If you have any questions about this research you can contact me through my email l_williams14@salemstate.edu or through my faculty sponsor Victoria Morrison’s email at vmorrison@salemstate.edu. You can also feel free to call me at 781 507 3158.

I understand that my name or identity will not be used in reports or presentations of the findings of this research. The information provided to the researchers will be kept confidential with the exception of information which must be reported under Massachusetts’s law including cases of child or elder abuse.

For questions or concerns about the research, please contact Leigh Williams (l_williams14@salemstate.edu) or Hannah Fraley (hfraley@salemstate.edu).

Name of Participant _____

Signature of Participant _____

Date _____

This research project has been approved by the Institutional Review Board at Salem State University. Thank you for your help.

For concerns about your treatment as a research participant, please contact:
Institutional Review Board (IRB)
Sponsored Programs and Research Administration
Salem State University
352 Lafayette Street,
Salem, MA 01970

(978) 542-7556 or (978) 542-7177 or irb@salemstate.edu

A copy of this signed form is as good as the original.

This research project has been reviewed by the Institutional Review Board at Salem State University in accordance with US Department of Health and Human Services Office of Human Research Protections 45 CFR part 46 and does not constitute approval by the host institution.

Appendix B

Notice of Expedited Review {45 CFR 46.110 and 21 CFR 56.110}

The Office of Sponsored Programs and Research Administration has evaluated the project named above. According to the information provided, you intend to study Information Available to Patients Diagnosed with Alzheimer's; Interviews of Caregivers. This study presents no more than minimal risk to human subjects, and involve only procedures listed in one or more of the following categories as authorized by 45 CFR 46.110 and 21 CFR 56.110 (*Department of Human Services, Part 46: Protection of Human Subjects; effective 7/14/2009; <http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.htm>*).

The activities listed should not be deemed of minimal risk simply because they are included on this list. Inclusion on this list merely means that the activity is eligible for review through the expedited review procedure when the specific circumstances of the proposed research involve no more than minimal risk to human subjects.

1. Clinical studies of drugs and medical devices only when condition (a) or (b) is met.
 - a. Research on drugs for which an investigational new drug application (21 CFR Part 312) is not required.
 - b. Research on medical devices for which (i) an investigational device application (21 CFR Part 812) is not required; or (ii) the medical device is cleared/approved for marketing and the medical device is being used in accordance with its cleared/approved labeling.
2. Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture as follows:
 - a. from healthy, nonpregnant adults who weigh less than 110 pounds. For these subjects, the amounts drawn may not exceed 550 ml in an 8 week period and collection may not occur more frequently than 2 times per week; or
 - b. from other adults and children (45 CFR 46.402(a)), considering the age, weight, and health of the subjects, the collection procedure, the amount of blood to be collected, and the frequency with which it will be collected. For those subjects, the amount drawn may not exceed the lesser of 50 ml or 3 ml per kg in an 8 week period and collection may not occur more frequently than 2 times per week.
3. Prospective collection of biological specimens for research purposes by noninvasive means.
4. Collection of data through noninvasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice, excluding procedures involving x-rays or microwaves. Where medical devices are employed, they must be cleared/approved for marketing. (Studies intended to evaluate the safety and effectiveness of the medical device are not generally eligible for expedited review, including studies of cleared medical devices for new indications.)
5. Research involving materials (data, documents, records, or specimens) that have been collected or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis). (NOTE: Some research in this category may be exempt from HHS regulations for the protection of human subjects 45 CFR 46.101(b)(4). This listing refers only to research that is not exempt).
6. Collection of data from voice, video, digital, or image recordings made for research purposes.
7. Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, or quality assurance methodologies. (NOTE: Some research in this category may be exempt from HHS regulations for the protection of human subjects 45 CFR 46.101(b)(4). This listing refers only to research that is not exempt).
8. Continuing review of research previously approved by the IRB as follows:
 - a. where (i) the research is permanently closed to the enrollment of new subjects; (ii) all subjects have completed all research related interventions; and (iii) the research remains active only for long-term follow-up of subjects; or
 - b. where no subjects have been enrolled and no additional risks have been identified; or
 - c. where the remaining research activities are limited to data analysis.
9. Continuing review of research, not conducted under an investigational new drug application or investigational device exemption where categories two through eight do not apply but the IRB has determined and documented at a convened meeting that the research involves no greater than minimal risk and no additional risks have been identified.

Date of Expedited Approval: June 18, 2014

**Date of Salem State University IRB
Approval:** June 18, 2014

If you are conducting research using an online survey such as Survey Monkey, the IRB requires that the approval dates appear on the online consent page of your survey.

This research project has been reviewed by the Institutional Review Board at Salem State University in accordance with US Department of Health and Human Services Office of Human Research Protections 45 CFR part 46 and does not constitute approval by the host institution