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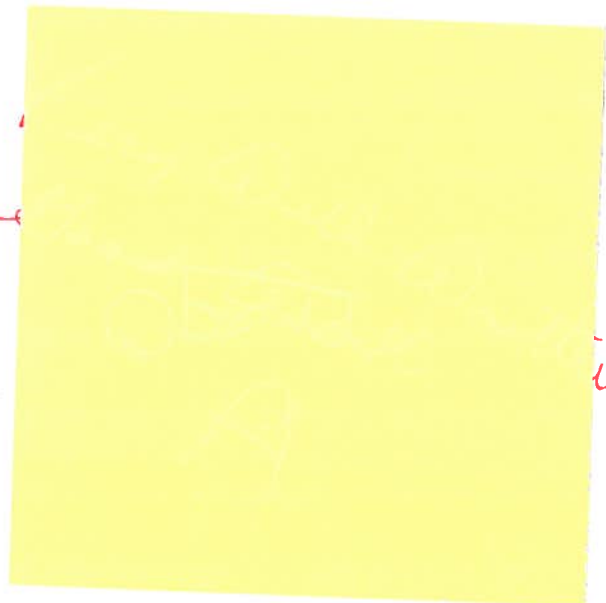
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Improving Quality of Life for Dementia Patients and Their Caregivers

HNR 499 - Senior Thesis

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Advisor: Jane Toot



-Introduction-

"...My yesterdays are disappearing, and my tomorrows are uncertain, so what do I live for? I live for each day. I live in the moment. Some tomorrow soon, I'll forget that I stood before you and gave this speech. But just because I'll forget it some tomorrow doesn't mean that I didn't live every second of it today. I will forget today, but that doesn't mean that today doesn't matter."

-Lisa Genova, Still Alice

Too often dementia care is centered only on meeting basic physical needs, and not enough attention is paid to the emotional well-being of each patient. Lisa Genova's Still Alice reminds us that dementia does not strip a person their personality, feelings, and other qualities that make them worthy of respect and love. Told from the perspective of a woman with Alzheimer's disease, the book allows readers to understand that the life and needs of an individual do not change or decline as their dementia progresses. This book, in addition to time spent being a caregiver myself inspired me to look deeper into dementia care and how it can be improved. After spending one year working as an aide in a dementia unit of an assisted living center, I found myself frustrated by the quality of life each resident appeared to be living. I found that lack of time, staff, and knowledge were barriers that kept caregivers from even considering residents' emotional needs, let alone catering to each of those needs individually. This frustration motivated me to see what can be done to provide higher quality of care for all individuals with dementia.

The number of Americans over the age of 65 is expected to more than double by the year 2060, reaching 92 million (USA Today, 2013), and within that same population, about one in nine people have dementia (Gordon, 2013). Not only will the dementia population be rising substantially, but the proportion of people who can provide care, the younger population, will be decreasing in size. Knowing this, it is important that approaches to dementia care not only

become higher quality, but also be more cost efficient and keep individuals in their home for as long as possible before moving into a long term care facility. A quickly aging population means it is important to spend more time researching strategies for caring for the elderly. That concept along with personal experience are the rationale for this paper.

-Literature Review-

(I) Dementia Overview

Dementia is a collection of several diseases that all affect brain function and lead to loss of memory, altered behavior and personality, decline in judgement and perception abilities among other varying symptoms. One in three Americans name Alzheimer's disease, the most common type of dementia, as the disease they fear most as it is devastating to not only the patient, but their family and friends as well (Gordon, 2013). Not only can dementia be traumatic, it can also lead to some extreme costs. Cognitive impairment is the strongest predicting factor in determining who will require full time long-term care within two years, and almost one half of all long-term care facility residents have some type of dementia (Neergaard, 2013). Also, in the United States and other developed countries, costs from dementia are greater than the costs from cancer, stroke, and heart disease all combined, and with the increasing elderly population these costs can only rise if nothing changes (Andrews, 2013).

With all of this in mind, it is important to find ways to keep dementia patients at home for as long as possible, and find ways to stall the problem by researching dementia prevention.

Several factors have already been associated with delaying dementia, and they include exercise of both the body and mind, working longer and retiring later, education, and keeping a healthy

weight (Fishman, 2013). Also with vascular dementia, approaches similar to those used to maintain cardiac health can slow progression (Andrews, 2013).

(II) Quality of Life with Dementia

Quality of life is a major concern when caring for dementia patients because the possibility of care providers being able to improve or change it is much greater than their ability to alter the course of the disease. It is also an important measurement that can be used to evaluate service programs, efficacy of new drugs, end of life decision making, and developing new approaches to care (Brod, 1999). The problem that researchers and caregivers face is how to go about measuring quality of life for someone with dementia. The most common method is to survey the individual's proxy which though provides helpful data, has some obvious complications. Proxy reports are likely influenced by several factors such as their relationship with the patient, the amount of time they spend with the patient, and the severity of the patient's dementia. With all of these influences, it is hard to tell whether dementia patients are truly unable to report their feelings accurately, or if the proxy reports themselves are biased. Also, proxies and patients may base their quality of life reports on very different clinical factors; what is important for one person may not have as great an influence for another (Sheehan, 2012).

Recent studies in addition to the sentiment presented in Still Alice, suggest that dementia patients are actually quite able to report on their own situation and express their feelings in support groups. These studies also suggest that lacking awareness of cognitive deficit (not knowing that you have dementia), does not mean that the individual is not aware of their feeling states and emotions (Brod, 1999). Keeping this in mind, the first step to improving

quality of life with dementia is finding an effective way to assess overall happiness and well-being of people with varying degrees of dementia.

(III) Caregiver Burden

Nearly three quarters of dementia patients are cared for at home by members of their own family, so it is extremely important to address problems and burdens associated with this type of caregiving (Tremont, 2011). A high level of caregiver burden can be detrimental both for the caregiver and care recipient. In one study, caregivers showed a 63 percent increased risk of death within four years, and spousal caregivers specifically experienced a six-fold increased risk of developing dementia, all when compared with non-caregivers (Tremont, 2011). Also for the caregiver, they often experience stress and depression, tend to neglect their own health and well-being as a result of being too concerned for that of the care recipient, and tend to withdraw from their normal activities and become socially isolated (Maslow, 2013). The care recipient may suffer because high levels of caregiver burden can lead to unsatisfactory outcomes such as mood and behavioral problems, higher mortality, and most importantly premature institutionalization (Van Mierlo, 2010 & Ming Liew, 2010). To continue, most of the time care is provided by a single individual, be it a spouse or other family member, and half of family caregivers are employed full time in addition to caregiving. This double load of work and caring responsibilities can lead to greater burden, worse outcomes for both parties, and is a major factor to be addressed as the dementia population grows (Maslow, 2013 & Schulz, 2004).

Several characteristics have been associated with higher levels of burden, and it is important to address these because as mentioned, caregiver burden can be dangerous for everyone involved. First of all, unhealthy relationships between caregiver and care-recipient

and poor family functioning prior to dementia onset are both associated with more problems and emotional reactions later on. Also when the caregiver is the spouse, female, or an older individual, they are likely to experience more stress associated with caregiving. Finally, individuals with little to no social support are highly likely to experience caregiver burden (Tremont, 2011). It is important to be aware of these factors when designing caregiver resources to make them as effective as possible.

- *Why Caregivers Don't Use Services*

It is necessary to determine reasons that caregivers do not utilize available services so that resources can be changed and designed in a way that is more accessible. One important finding is that caregivers for someone with a physical disability are much more likely to use services than those caring for someone with dementia, and also that they appear to experience less burden (Brodaty, 2005 & Schulz, 2004). This could be for several reasons, but it is important that caregivers of people with dementia be aware that it is acceptable and encouraged for them to use services.

Several barriers to using services have been identified and they include lack of knowledge of services, reluctance to use services, and lack of need for services whether real or reported. Also to be considered are inconvenient service characteristics such as costs, hours of operation, distance, etc. (Brodaty, 2005). Some of the most common reasons that individuals eventually do consult someone for help are progression of the dementia including difficulties in activities of daily living, personality changes, depression, behavior problems and safety concerns. Service providers should use this information to strategize ways to communicate effectively with caregivers and make their services more accessible.

(VI) Caregiver Gain

It is important to know ways to improve the quality of life for not only the patient, but the caregiver as well. Being a caregiver for someone with dementia can appear to be a daunting task, but there are benefits that come with the job; most caregivers do report some satisfaction with providing care. Caregiving often makes people feel useful and needed and allows people to learn new skills. Furthermore it leads people to appreciate their own life and have a more positive outlook, and it often strengthens relationships not only with the care recipient but with other family members and friends involved in the care as well. The presence of these aspects of caregiving are inversely related with burden and depression (Tremont, 2011). Also, reciprocity in the relationship between caregiver and care recipient where the two individuals become interdependent is associated with more gains. Dementia does not strip an individual of their ability to listen, sympathize, and help others with emotional and other needs. Several factors are associated with a positive caregiving experience, and they include: having a healthy relationship with the care recipient prior to dementia diagnosis, being a caregiver by choice rather than obligation, maintaining leisure and personal time, and participating in educational and support programs for caregivers (Ming Liew, 2010).

(VII) Overview of Resources for Caregivers

Since dementia can have such varying symptoms and each patient progresses through the disease in a unique way, the help that caregivers will require has a wide range. Examples of types of resources that an individual with dementia may need, as well as examples of these resources in West Michigan are as follows:

- *Caregiver Trainings and Support Groups*

Caregiving can be a daunting task for someone with no experience or training, and will likely lead to stress for both the caregiver and care-recipient. Several organizations offer various types of trainings, connections, and resources for caregivers. These can range from literature on caregiving, day to week long training in-services, in-home help and advice, to even a personal meeting with a care coordinator to help determine what the caregiver's exact needs are. An example model is Savvy Caregiver which is a 12 hour program, usually given via six two-hour group workshops. These workshops help caregivers understand what their role really is, and provides information, training, and skills they will need in order to be successful in that role.

- *Residential Respite Care*

Residential respite care can be very useful during times when the caregiver may need a range of time (usually 3-45 days) off from caregiving. It could be for any reason, be it a vacation or work trip, surgery or health problems, or even just needing a break for mental purposes. These services offer full-time care at their facility on a temporary basis. A local example is Holland Home in Grand Rapids, MI. They offer short-term respite care for people with physical disabilities or people with dementia.

- *Adult Day Care*

Adult day care centers can be a very valuable resource for caregivers who are employed. They provide care during normal business hours on weekdays. Not only do they allow the caregiver to work during the day, they can also be beneficial for the individual with dementia as they provide important social interaction. A local example is The Little Red House in Spring

Lake, MI. They provide care for people with any type of disability, including cognitive and psychosocial, and provide nutritious meals, stimulating activities, as well as basic care.

- *In-Home Assistance*

In-home care is very convenient for people who want to remain at home, and would prefer not to move into a long-term care facility. It is also convenient because it can be used for several hours a day just for help with a few tasks, or it can provide full-time assistance for an individual. A local example is Continuing Care at Home provided by Avenues by Porter Hills. They offer such a wide range of care that members often never have to live in a long-term care facility. They also assign each member a “care-coordinator” that gets to know the patient and their needs, and acts as an advocate for them throughout their disease progression.

- *Long-Term Care - Assisted Living or Nursing Homes*

Long-term care facilities are usually the last step for individuals with dementia, and are utilized after the family can no longer provide care or the dementia has progressed to a point that it is no longer practical to keep living at home. A local example is St. Ann’s Heritage of Care in Grand Rapids, MI. Residents at St. Ann’s live and receive care 24 hours a day, and their services include all meals, activities, and they also cater to emotional and spiritual needs of each resident. Family members are welcome to visit at any time. Another example is Clark Retirement Community in Grand Rapids, MI who are unique because of their new “Life Enrichment Model” used in dementia care. This model has four main focuses including: focusing on what is possible, reducing anxiety and frustration, engaging and stimulating, and educating. This model makes caregiving easier for staff, and aims to improve quality of life for all residents with dementia.

(VIII) Dementia Care Abroad

Different cultures in the world have very different opinions and habits with regard to the elderly. I was interested in three main areas of global dementia care: dementia care in Asian populations, Hispanic populations, and in developing countries.

Asians and Pacific Islanders make up about 4% of the American population, and the proportion of elderly in their population will also increase in the near future. How these cultures approach caring for their elderly may be different than what many care providers are used to. It is important to know these differences in order to make services available and encouraged for these cultures. First of all, many Asian elderly individuals may find it hard to ask for help from outside sources even if they are in need of care-coordination or other services. Additionally, traditional long-term care is often disregarded in these populations, and all dementia and elderly care is provided by family. Therefore, it may be important to come up with alternative services to help family caregivers as many of them do not see long-term care or even respite care facilities as an option (alz.org).

Hispanic individuals make up a significant and increasing proportion of the American population. In some Hispanic cultures, dementia is not recognized as a public health issue or even a disease, it is just seen as a normal part of the aging process. This means that these individuals are less likely to seek help or treatment for their family members with dementia. Also, similar to Asian populations elderly Hispanics are likely to live with and be cared for by family members, meaning more caregiver stress and more need for services that are readily available to caregivers of all cultures (aoa.gov). Overall, it is important for care-providers to be

trained in cultural competence. Different cultures will all approach care in very different ways, and services should be available to supplement these varying needs.

One study from the 10/66 Dementia Research Group looked at characteristics of caregivers, the nature of the care they provided, and the impacts that caregiving had on people in developing cultures in India, China, South East Asia, Latin America, the Caribbean, and Africa. Overall, I was surprised to find that caregiving was rather similar to the U.S., and caregivers suffer many of the same burdens. In all of the cities studied, a substantial amount of the caregivers interviewed had to cut back on their paid employment to some degree, some even had to stop working all together. In addition to working less because of care responsibilities, many families also had to pay for some amount of informal care to help further. These economic struggles are common in the U.S. as well.

In addition to common burdens, caregiver demographics are similar in developing countries as well. Most often caregivers are women, usually older, caring for a spouse or parent that lives with them in their home. What are more common in developing countries than the U.S. however are three-generation households. Some studies show that large extended families living together may decrease caregiver strain because of the decreased workload on one person. Of course if the youngest generation is still young enough to require care, it may mean a double burden on the caregiver. The important take away is that in all cultures unmet caregiving needs lead to many consequences that impact all family members and people involved. Therefore it is important to determine how to meet the needs of caregivers and care recipients (10/66 Group, 2003).

(IX) Looking Forward

After researching this topic I have picked out several areas of dementia care that need some extra attention and improvement. The first is educating the public on early signs of dementia, as well as healthy habits to prevent or delay the onset. Being aware of early symptoms will help patients get diagnosed earlier before the dementia has progressed. During this time the individual will be able to think ahead and make requests for their future known. There will also be more time to intervene and slow the disease progression if possible. Another factor to think about with early diagnosis is informing patients about support groups and encouraging membership. Talking with other people going through the same thing can be very helpful and healthy for people with dementia.

Next, changes need to be made to keep individuals with dementia in their homes for as long as possible. Long-term care is not only extremely expensive, but as the aging population grows it also means there will be limited room in facilities. Research has shown that housing and even public buildings can be designed in certain ways that may reduce the symptoms of dementia (Langbaum, 2013). Keeping dementia patients in their home of course means they will need caregivers. Accordingly work needs to be done to give these caregivers more support. Caregivers should be given ample information at the moment their family member is diagnosed with dementia, including what to expect, plan for, and what resources are available to them. Also for caregivers, interventions should focus on maintaining their mental health and well-being in addition to their physical health. They should be encouraged to partake in support groups and be given information on how to deal with behavioral problems, coping strategies, and various effective approaches to dementia care (Ming Liew, 2010).

Finally, advanced care planning should be considered as early as possible in individuals with dementia. This process allows patients to live and progress how they choose to, and relieves stress from family members at the end of life. It is especially important to consider these decisions early while dementia patients still have the mental capacity to take part in the decision-making process.

- *Personalized Dementia Care*

Personalized care is tremendously important in dementia care because each patient expresses unique symptoms and behaviors, and respond to care differently. What makes this even more difficult is that caregivers must pay extra close attention, as people with dementia do not just come out and say what it is they want or need or what is bothering them (Van der Roest, 2007). They also will not spontaneously tell caregivers about their preferences with regard to care delivery, what they like to talk about, what makes them angry, or other important characteristics about their personality. Therefore, a major next step in dementia care is figuring out how to determine this information and deliver tailored care in the most efficient way possible.

One method that seems to be effective today is making a “one-page profile” for each resident that nurses can reference before providing care. These can contain anything, but are usually a concentrated history including likes, dislikes, tendencies, and other pieces of information about the individual. These can help nurses start or approach conversations and care-tasks, can help redirect a resident during behavior disturbances, and can even help make a resident comfortable at the end of life (Bailey, 2014).

-Local Facility Visits-

I decided that in addition to doing online research about dementia care, it may be helpful to get an actual feel for some local dementia facilities by visiting a few and speaking with staff and administrators. I mostly wanted to experience the atmosphere of each facility, see what they have to offer, and hopefully get a sense of how happy the residents were at each place. I asked a variety of questions, but will mainly focus on four aspects of each facility: floor plan and set up of unit, any unique services offered to dementia patients, staff training if any, and how quality of life is measured and how content they feel residents are

Facilities are identified by number and location, no personal information about the interviewees was obtained. The goal was not to find out which facilities are better than others, only to get a sense of where dementia care is at in our local society at this time.

- *Facility (1) - Grand Haven, MI*

This facility has two locked-down dementia units at opposite ends of the building, each consisting of 12 apartment-style rooms. Couples are welcome to live together in the units if one or both of them have dementia. There are two dining rooms with kitchenettes, and a living room area where residents can participate in activities or watch television. All doors are protected with a passcode and alarms go off if a resident attempts to elope. Finally, there is an enclosed outdoor courtyard area where residents can sit outside or garden in the company of a staff member.

Two resident aides are on staff at all times available to help residents with activities of daily living as well as a medication technician to assist with these tasks, pass medications, chart on each resident and communicate with their family and physicians. Laundry, cooking, and

household chores are all done by staff, and a life enrichment leader leads activities and events during the day throughout the building.

Staff members are taught basic caregiving techniques, safety information, and given a few tips on how to approach individuals with dementia. Most training though occurs on the job as certain situations arise. Resident aides learn how to redirect residents when they may be in distress or upset. A major influence is how well the staff members know each residents, as it makes care more personal and go more smoothly. This factor makes high staff turnover a frustration.

Quality of life for each resident is monitored periodically by staff and proxies. Staff observe and chart residents' behaviors, and mood overall on a daily basis and alert supervisors if there are any changes or declines. They then brainstorm and speak with proxies or even physicians about what to do to help make residents more content and comfortable.

- *Facility (2) - Grand Rapids, MI*

This facility has two dementia units, one in their assisted-living wing and one in their nursing care wing, each consisting of 10 rooms. Two staff members are present full-time in each. Each unit has its own dining room where they eat separate from the rest of the facility, as eating with a crowd can be overwhelming for individuals with dementia. The nursing care dementia unit has open doors, as residents are non-ambulatory so there is no risk for wandering. The assisted-living dementia unit however has secured doors with alarms. A special feature in this facility is a hallway that surrounds the entire unit. This is convenient for residents who tend to wander, and gives them a way to do so without running into barriers.

Staff at this facility receive special dementia care training in addition to their basic care skills. This training includes information on what to expect when caring for individuals with dementia, and how to approach conversations and care tasks. Their care philosophy is that each resident should be treated with dignity and respect regardless of their level of dementia. They advocate personalized approaches to care, and cater to each resident's unique needs.

Quality of life is measured via a satisfaction survey at this facility. This survey is filled out by the resident's proxy, as administrators feel that people closest to the resident can provide accurate information about their level of happiness.

- *Facility (3) - Jenison, MI*

This facility has an entire building dedicated to dementia care. Each resident gets their own room, and some residents who are more independent have the option of living in apartment style rooms. All doors are secure, and there is an enclosed outdoor area for residents to sit, walk, or do whatever they please on their own. Their approach to dementia care focuses on the individual, and tending to personal needs of each resident is their main goal.

Staff members are given training on how to provide care for physically dependent individuals, and then go through further training for dementia care. Staff are taught how to approach care and are given tips on "what to say and how to say it". Once working at this facility, staff are also given on-the-job advice and training, must complete periodic online training modules, and are required to attend in-services on new caregiving or safety information.

Administrators at this facility state that the key to content residents with high quality of life is meeting basic emotional and physical needs. They focus on monitoring anxiety, pain control,

and any triggers that may appear to make a resident unhappy or distressed. One staff member stated that “quality of life for any individual can be achieved by being in good health, eating good meals, and participating in activities that they are proud of and make them feel at home”.

- *Facility (4) - Spring Lake, MI*

This facility is located in a renovated house, and offers care on a daily basis in a relaxed home-like environment. They provide respite for caregivers allowing time for sleep, recharging, work, or seeing friends and family. They are not an elopement free program, so unlike the other facilities listed they do not have secured doors. This means that individuals with a high risk of elopement or tendency to wander may not want this option. In addition to providing basic care and safety during the day, this facility gives individuals important social interaction and activities that make them feel empowered. Activities and games focus on the strengths of each individual and help build self-esteem. These activities are also cognitively stimulating which can help slow memory loss, delaying or preventing the need for medication. An important advantage to adult day care is that it prevents premature placement in a long-term care facility, allowing individuals to “age in place” as long as possible.

The staff to participant ratio in this facility is one staff member to about four or five participants, much higher than many dementia facilities. This allows staff to not be rushed during care tasks, and can lower anxiety in the participants. Staff members are trained in basic physical and dementia care, and attend at least 16 hours of in-service training per year. The facility also brings in local resources for trainings on safety and other dementia care tips.

Administrators at this facility measure quality of life via surveys given to participants and use input from family members. They feel that you can measure quality of life in a person by

monitoring their energy, engagement, and changes in personality. A unique aspect of this facility is the attention that they pay to caregivers and the resources they provide in addition to respite day care. They encourage good health and social interaction in both caregivers and care recipients, and are aware of signs of depression in both parties. They also offer support groups for caregivers that offer education and instruction for care tasks as well as hope, encouragement, and relationships with other caregivers.

-Conclusion-

After completing this project and having personal experiences being a caregiver, there are several aspects of dementia care that I have found to be especially important. I feel that all of the needs mentioned in the literature are extremely necessary for a successful future in dementia care. As our population continues to age, I feel that more and more attention will be paid to these needs, but it is important to start preparing now. What I feel most strongly about though, ^{and} is the emotional needs of each dementia patient and how they are being met.

Most importantly, it is impossible to care for a resident that you know nothing about. You cannot make any progress caring for someone with dementia unless you know how to approach them. This gets easier if you know the person's tendencies and history. Knowing their history can also help during times when dementia patients are unaware of their current surroundings, and are living in an earlier time. Telling this person that they are confused or that they are not making sense will only lead to agitation. It is important to live in the moment in these situations, even if that moment may not be real. This can be upsetting for family members, because their loved one is not acting as they normally do, but family members should be reminded that relationships should change, not end because someone has dementia.

As Lisa Genova reminds us in Still Alice, individuals with dementia deserve attention, love, and respect.

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