

Dementia Caregivers' Perceptions of Types of Long-Term Care

Hannah Hwang

St. Paul's School, USA

ABSTRACT

The purpose of this research is to investigate the financial and emotional effects the disease can pose on female caregivers living in the US aged 20-60 who also are the daughters of dementia patients and how these effects have changed their perception of types of long-term care. My question for this research was, what are the perceptions of the types of long-term care from women in their 20s-60s living in the US who are primary caregivers and daughters of dementia patients, and how does it change over time, affected by emotional and financial aspects? The study also addresses aspects these caregivers consider when choosing between types of long-term care (institutional vs. non-institutional) and why. This paper also highlights how the familial relationship—specifically, the daughter-parent relationship—between caregivers and parents with dementia affects such decision-making and how this relationship evolves. Finally, some possible solutions to combat any stated negative aspects are provided.

Introduction

Often, people fail to acknowledge the hardships caregivers face when taking care of dementia patients, leading to a lack of passive support outlets available for these caregivers. The mental, physical, emotional and even financial stress placed on these caregivers is not to be understated. Nearly half of caregivers reported struggles in mental health, especially emotional care (Black et al., 2013).

As the average life expectancy is rising as new innovations in medicine are constantly being discovered, rates of dementia among the elderly are also increasing. The realm of caregiving for dementia patients is not a new concept, but various systems surrounding caregiver support are still relatively void. From a personal approach, all three of my surviving grandparents have varying stages of dementia and I have seen my parents—as my grandparents' primary caregivers—struggle with the decision between institutional long-term care (nursing homes) and non-institutional care (stay-at-home care). Over time, their disdain for institutional care has changed to reluctant acceptance as they have realized that the symptoms of mid/late stage dementia are beyond their capabilities as caregivers with separate lives and jobs.

Literature Review

Ensuring the safety of the person with dementia and managing caregiving stress is important. As the caregivers' goals for the dementia patients differ from official healthcare policies, it may be beneficial to incorporate comments and ideas from the former because they provide a unique insight into the situation. There are five main domains identified by patients and caregivers: medical care, physical QOL, social and emotional QOL, accessibility of services and supports, and caregiver support (Jennings et al., 2017). These categories identified in the study can be combined with ideas of the caregivers I have interviewed and researched to give a clearer picture on caregivers' perceptions of types of long-term care from not only an individual perspective, but also a general trend, or societal perspective. Through my interviews, I can see why certain opinions of types of long-term care shift due to the goals mentioned in the journal.

Daughter caregivers prioritized the social and emotional quality of life of their parents the most in early/mid stage dementia, favoring non-institutional care which can provide this as well as better caregiver support (in their opinions). However, as the dementia progressed, they prioritized physical QOL over the emotional and social QOL, because they realized that non-institutional care compromised physical QOL, which in turn also threatened the other four domains. They have to switch the type of long-term care to institutionalization. Caregiver stress also links to the decision-making process of resorting to institutional long-term care, or more specifically, nursing homes. High stress among caregivers similarly results in the instability of non-institutional care solutions and forces the caregiver to resort to institutional long-term care, such as nursing homes. (Spillman & Sharon, 2009).

Methods

Online interviews were conducted with interviewees who fit the demographic (women in their 20s-60s living in the US who are primary caregivers and daughters of parents with dementia). I also collected various anecdotes from online platforms. This information has been analyzed to find commonalities/differences and links to possible reasons why caregivers believe a certain way. I recorded the interviews on Zoom and then imported them into Otter.ai to generate the transcript, going through and fixing the AI-generated mistakes. I used online forum platforms and support groups to look for my interviewees.

I chose this demographic because the majority of caregivers are women, so I want to know the emotional effect parents with dementia have on their daughters. The age 20-60 is typically the working age for these types of people. Also, I chose people from the US because I wanted policies and experiences with the system to be as consistent as possible.

Because caregiving for a parent with dementia is a sensitive topic, this situation should be addressed with the utmost care. Additionally, privacy is very important for my research, because I interviewed and interacted with people who may not want their situation and hardships to be broadcasted to the public. To ensure the confidentiality of the interviews and interviewees themselves, each interviewee was assigned a research ID/alias. Participation from the interviewees was completely voluntary on their behalf.

The following codes were used: timeline, patient's situation, emotional/personal aspect, perspective of non-institutional care, aspects for decision-making, financial aspects, and solutions. The code "timeline" details the journey of the interviewee's parent's dementia. "Patient's situation" describes the patient's care situation. "Emotional/personal aspect" addresses their mental state and how the interviewee navigated their own lives amidst dealing with their parents' dementia. "Perspective of non-institutional care" emphasizes the interviewee's opinion on non-institutional long-term care, mainly stay-at-home care. "Aspects for decision-making" highlights aspects taken into consideration for the decision between institutionalization versus non-institutional long-term care. "Financial aspects" covers how the interviewee dealt with medical bills, and others that are involved when taking care of someone long-term. Finally, "solutions" involves the interviewee's personal opinion about any solutions they would want the government/society to make.

Results

Table 1. Coding analysis of interviews and responses

Timeline	Patient's situation	Emotional/personal aspect	Perspective of non-institutional care	Aspects for decision-making	Financial aspects	Solutions

Started 10 years ago	Severe/late-stage dementia	Family shares the burden of care, so everyone in the family is having a hard time.	Pro: can directly provide a better QOL for the dementia patient.	The dementia situation affects the whole family system	Medicaid, but the government does not provide sufficient money to hire a caregiver, thus the stay-at-home care	The government should provide more money
Family struggle started 5/6 years ago	Can't do anything by herself (except eating)	Only focus is dementia patient; no family time — ingrained in her life	Pro: Family can spend some time together as caregivers	Need whatever will provide higher QOL for the dementia patient (chose non-institutional)	Three years ago, the situation was worse	Government should provide an educational program for family members
	Gets “good care” from <u>Katie</u> and the rest of the family	Stress because she doesn't know when it is gonna end	Con: Ended up doing it because they couldn't afford a professional caregiver			
	24/7 stay-at-home care from family members	Find information on how to be a caregiver through Google				

Discussion

One of my main points was the decision between institutional and non-institutional long-term care. I found that all the individuals I had interviewed and researched had chosen non-institutional long-term care initially. They considered happiness (of themselves and the parent) as the standard for considering quality of life (QOL). They, as caregivers, felt they could provide personalized, genuine care to their parents and also feel more emotionally stable when in non-institutional care, showing that they regarded happiness of the parent and themselves to be the standard for QOL. However, personal anecdotes from interviewees addressed the limitations of home care. As dementia and aging in general progresses, muscle control weakens drastically. Some reported their parents having to get surgery due to them falling down and breaking their bones. Also, surgery leads to more complications for elders, such as the possibility for infections. The daughter caregivers began to prioritize the life itself of their parents, without the luxury to care

about the QOL. They unwillingly resorted to institutional long-term care when their parent's dementia deteriorates further to the late stage.

Their choice to initially turn to non-institutional care led to a multitude of benefits and problems. On the upside, the interviewees could spend more time with their parents. Because of the familial relationship, they felt more emotionally comfortable when they could directly take care of and contribute to the QOL of their parents with dementia at their home. However, non-institutional care has limitations because it is family members taking care of the patient and not professional caregivers. Interviewees felt it difficult to maintain their own personal lives amid their caregiving duties. They felt mentally burned out and stressed because they did not know when the situation was going to end. After this frustration, they would feel guilt that they would want the situation to end, because the only way it would end would be for the parent to die—while they wanted the situation to end, they obviously did not want their parent to die.

There was a clear outline of several problems that were repeatedly mentioned by these daughter caregivers. First, they had a severe distrust of institutional long-term care—more specifically nursing homes. They heard horror stories from their acquaintances and the media of how elders placed in nursing homes were abused and neglected. They did not trust strangers to take good care of their parents. Second, interviewees wanted an official educational course/program they could access easily. Daughter caregivers sometimes resorted to looking up information online, which might contain misinformation or have unclear information prone to misinterpretation. Lastly, I deduced that they believed the government should provide more financial aid, as Medicaid and other programs often only cover nursing home costs and not other caregiving costs. One interviewee struggled to afford a professional caregiver, forcing her to take up the role herself.

Conclusion

If I had more time, I would increase my sample size and decrease the demographic range I am interviewing to narrow down my results and range of error in my conclusions. My statements will become more applicable to that smaller demographics. Even so, there is the need for further research into how to balance the financial efficiency of dementia caregiving insurance as well as satisfy the emotional satisfaction from these people benefitting from the money. I hope this research can generate actionable insights for future government policies. Also, I hope it can make others better understand the challenges that come with types of long-term care of those with dementia.

Limitations

This research project has a very small sample size of interviewees, leading to possibly skewed or inaccurate data that may not represent the overall population's opinion. This is also due to the tight time constraint within the Barnard Pre-College Program.

Acknowledgments

I would like to thank the Barnard Pre-College Program and all the professors.

References

Black, Betty S., Deirdre Johnston, Peter V. Rabins, Ann Morrison, Constantine Lyketsos, and Quincy M. Samus. "Unmet needs of community-residing persons with dementia and their informal caregivers: findings

from the maximizing independence at home study.” *J Am Geriatr Soc.* (2013 Dec); 61(12): 2087–2095. doi: 10.1111/jgs.12549. PMID: 24479141; PMCID: PMC4001885.

Jennings, Lee A., Alina Palimaru, Maria G. Corona, Xavier E. Cagigas, Karina D. Ramirez, Tracy Zhao, Ron D. Hays, Neil S. Wenger, and David B. Reuben. “Patient and Caregiver Goals for Dementia Care.” *Quality of Life Research* 26, no. 3 (2017): 685–93. <http://www.jstor.org/stable/44853251>.

Spillman, Brenda C., and Sharon K. Long. “Does High Caregiver Stress Predict Nursing Home Entry?” *Inquiry* 46, no. 2 (2009): 140–61. <http://www.jstor.org/stable/29773414>.