Online Self-Care Advice for Caregivers of People with Alzheimer’s and Dementia

ABSTRACT

Advice to caregivers of people with Alzheimer's and dementia for how best to care for themselves and others is critical for their interpersonal relationships. This study explored the ways that a variety of organizations offered advice to caregivers of how best to pursue their role. I found 332 online resources containing specific advice to nonprofessional caregivers of people with Alzheimer's and dementia in 2019. Of these online resources were 1024 pieces of individual advice that were thematically grouped into three categories: caregiver well-being, people with Alzheimer's or dementia well-being, and daily routine. In this paper, I thematically describe this advice, focusing on caregiver self-care, and point to areas of need for further development of caregiver communication study.

Keywords: *Caregivers, Dementia, Alzheimer's Disease, Self-Care, Communication*

INTRODUCTION

“What’s the matter with me?”

“You’ve got a problem with your short-term memory,” I say. Sometimes Mum asks me if dementia is the culprit. I explain that it’s Alzheimer’s disease, a type of dementia.

“Do I have a future?”

“What exactly do you mean?” I inquire. Mum knows I’m stalling, though. She tells me she needs hope. (Sarah Jane, Aging Care)

Advice to caregivers of people with Alzheimer’s and dementia for how best to care for themselves and others is critical for the interpersonal relationships of caregivers and people with Alzheimer’s and dementia. In this study, I explore the ways that a variety of organizations offered advice to caregivers of how best to pursue their caregiving role. The specific purpose of this paper is a closer thematic analysis of the caregiver self-care advice that these organizations offer. I found 332 online resources that offered specific advice to nonprofessional caregivers of people with Alzheimer’s and dementia in 2019. Of these online resources, 39 contained advice related to communication. Within those 39 online resources were 1024 pieces of individual advice that were thematically grouped into three categories: caregiver well-being, people with Alzheimer’s or dementia well-being, and daily routine. In this paper, I thematically describe this advice, focusing on caregiver self-care, and point to areas of need for further development of caregiver communication study.

Many caregivers and people with Alzheimer’s disease (AD) hope for a cure for the disease to be found as soon as possible. However, until that day comes, caregivers and people with Alzheimer’s and dementia can focus on using their agency to do what is possible to live thriving lives. Although I do not personally have experience with AD or dementia, I do have sustained caregiver experience with someone who occasionally has lapses in memory and needs assistance across daily tasks. My mom has had stage four brain cancer for slightly over two years, and as I have been a primary caregiver for her, I have recognized the need for all caregivers to be able to use communication to express their own needs, the needs of the person they are caring for, and how to best go about meeting those needs. Furthermore, I have the experienced what other caregivers have expressed across my research: moments of frustration, burnout, anxiety, combined with gratitude, interpersonal growth, and exuberance as well.

What drew me to want to research caregiver communication is my position as a caregiver for my mom with stage four brain cancer. At the time of writing this I have been a caregiver for over two years. While I recognize that my position as a caregiver for my mother with cancer is different from the position of someone who is a caregiver to a person with Alzheimer's or dementia, just as every individual situation is different, the position of being a caregiver is a unique one. My background may have caused me to subconsciously or not sway my search for information towards what would have been helpful for me, personally, however one trend was made clear early on: information on caregiver communication, particularly caregiver self-care, is sparse, especially in terms of credible resources. In my experience, I was given very little information beforehand in regard to what to expect as a caregiver and so I had hoped that ample information would be accessible online, and upon further research, I found this to be false.

Given this lack of information, I wanted to contribute to fill the gap in the dialogue on caregiver communication and, ultimately, allow others to have access to the information that I could have benefitted from two years ago. This research is one small step toward better understanding how society can use communication to better the lives of caregivers and the people with various types of memory loss that they serve.

In this project, I asked the research question, “What information is available regarding how caregivers of people with AD or dementia can best care for themselves and communicate that need for self-care while not sacrificing the care they are providing for the person with AD or dementia?” In this research report, I analyze what little information on caregiver self-care when caring for a person with AD or dementia is readily available online for nonprofessional caregivers. Caregiver self-care is crucial to fostering a productive interpersonal dialogue and co-creating relationship with the person they are caring for. Through my thematic analysis, I call for further study of areas of need so as to best support caregivers of people with Alzheimer’s and dementia both currently and in the future. In this paper, I first give a brief overview of AD and dementia and the communication challenges that can arise in that relationship. I then outline the online data collection and thematic data analysis approach used in this project, describe the results of the study, discuss main findings, and conclude with next steps.

CAREGIVING, ALZHEIMERS, AND DEMENTIA

Alzheimer’s disease is a “chronic brain disease that gradually erodes an individual’s memory, intellectual abilities and personality” (American Psychiatric Association (APA), 2019). It is a type of dementia that impacts behavior and thinking as well as memory, and symptoms gradually worsen over time until the disease interferes with daily tasks and eventually leads to death (Alzheimer’s Association, 2019). This interference with thinking, memory, and daily tasks also prompts the need to have assistance in the form of a caregiver, be that a family member, a friend, a home health care service, or hospice.

It has long been established that how to provide care to individuals is just as important as determining impacts of caregiving (Ellis and Miller, 1989).

Caregivers experience burden, stress, and negatively impacted mental health (Alpert and Womble, 2014). Even more noteworthy is how caregivers who experience strain due to their position, potentially face mortality rates 63% higher than non-caregivers (Alpert and Womble, 2014). Due to this, it is crucial that the caregiver be taken care of, just as they are taking care of the person with AD or dementia.

The availability of social resources and the perception of support will impact the caregiver's reaction to their situation of caring for someone at home (Ellis and Miller, 1989) Even having the buffer of knowing they have outside support will provide a benefit while they are in the high stress position of being a caregiver. The opposite is also true, when the caregiver does not perceive that they have a support network, they experience more negative impacts.

Being a caregiver for someone with AD or dementia can result in caregiver burnout, negative psychological, and physical outcomes for the person giving care, resulting in carer burden (Lloyd, Muers, Patterson, Marczak, 2018). While it has been proven that higher levels of self-compassion is related to carer burden (Lloyd, Muers, Patterson, Marczak, 2018), exactly how caregivers can care for themselves is not widely discussed, which prompts a need for further research. Negative impact on relationships, employment, community, spirituality, and more can also arise as a result of being a caregiver as the caregiver's physical and emotional health decline. When anticipatory grief is added to this tumultuous combination, the caregiver's space and time to process can be negatively impacted, as well (Jones, 2007). All of this can quickly overwhelm a caregiver, and motivate a need for caregiver self-care and means through which to promote caregiver well-being.

There is a cycle of caregiving that results in negative outcomes for both the caregiver and the person they are caring for. The caregiver provides ample care which takes up much of their time and energy, therefore eliminating most opportunities to take part of outside activities. Occasionally they, as a caregiver, can have responsibilities given to them by other family members. This limits the caregiver's ability to meet their own outside relational needs, resulting in social isolation and scheduling burden, which in turn causes health problems, decrease positive well0being, and sometimes depression. This cycle can, however, be broken by communication and social support, as these are interwoven (Ellis and Miller, 1989), but without communication, these negative outcomes can be felt by the caregiver, which will not only negatively impact their own well-being, but the well-being of the person they are caring for. The existence of communication and social support can only come after the means through which to achieve these things is understood and known by the public. Just how much information about caregiver self-care is in existence is further analyzed in the next section.

METHODS AND RESULTS

For this study, I used multiple online search engines (Google, Yahoo, and Bing) between February 18, 2019 and March 25, 2019 to find information about the online communication advice given to nonprofessional caregivers of people with Alzheimer's and dementia about self-care. I used search terms such as "alzheimer's," "dementia," "memory loss," "caregiving," "caregiver," "care," "long term," "memory loss resources," and "communication" (among others) to find any and all instances of caregiving communication advice for nonprofessional caregivers. For the scope of the research, I focused on English text-based resources while audio or video resources (e.g., podcasts and/or videos) were not included. A total of 332 on-topic sources were located through the online search (on-topic being defined as resulting from one of my various above search terms, and related to caregiving, Alzheimer's, or dementia), but of those, only 89 sources were related to verbal or nonverbal communication. This number was reduced to 79 sources after omission of videos, organization's home and navigational pages that did not include any relevant information relevant to the research question and scope of this study. In total, upon reaching salience with these search terms related to advice given to caregivers about how to pursue self-care, a total of 79 online sources (with each source being a different webpage) were found through this online search.

Once these 79 sources were identified, they were printed out, read through, and reduced a second time. All sources had to be related to Alzheimer's, Dementia, or long-term memory loss, they had to be aimed at the nonprofessional caregiver (family, friends, or other individuals who had no formal caregiver training), and had to discuss verbal or nonverbal communication directly or indirectly. The omission of any one of these categories resulted in the resource being removed. The updated online resource list was then reduced to 39 sources. Twenty-two organizations that offered online advice to caregivers included organizations such as the Family Caregiver Alliance, Aging Care, and the National Institute for Health (among others). See Figure 1 below for a complete list:

Figure 1: Organizations Offering Caregiver Advice

Family Caregiver Alliance	19
Aging Care	16
National Institute for Health	12
Today's Caregiver	8
Caregiver Library	5
Alzheimer's Association	2

Elizz	2
American Association of Retired Persons	1
Alzheimer’s and Dementia Resource Center	1
Alzheimes.net	1
Amen Clinics	1
Assisting Hands	1
Crisis Prevention Institute	1
Daily Caring	1
American Heart Association	1
Leisure Care	1
Matrix Care	1
Medicare	1
Schwartz Center	1
Take My Hand At Home	1
This Caring Home	1
Veteran Affairs	1

These 39 texts were then read through a third time, and each piece of advice aimed at the nonprofessional caregiver, either directly framing it as advice (e.g., “I recommend you…”) or indirectly by giving directives of things that should be done, but not directed specifically at the caregiver and/or reader of the text (ex. “Don’t give up when communication is difficult”). Data was also categorized into “emphasized” or “unemphasized” – with emphasized text being bullet pointed, bolded, or both, and unemphasized text being plain text with no extra markings. This data collection ultimately resulted in the 1024 pieces of specific caregiver communication and well-being advice that acts as the central discourse of this analysis.

These 1024 pieces of advice were uploaded into the textual analysis software QDA Miner Lite and thematically coded based on a deep reading. There were three primary thematic categories that this advice was categorized into, including “Daily Routine,” “Caregiver Self-Care,” and “People with Alzheimer’s or Dementia Well-Being.” Daily Routine consisted of day-to-day pieces of advice that must be done as a fundamental aspect of life such as meal routines, morning and night routines, dressing, travel, etc. Caregiver Self-Care was defined as anything having to do with the caregiver improving their own personal mental, physical, or relational wellbeing. People with Alzheimer’s or Dementia Well-Being was any piece of advice that contributed to bettering the quality of life of the person with AD or dementia. Pieces of information could be in multiple categories because often times something that would improve the quality of life of the person with AD or dementia can also be a task that can be incorporated into their day to day life. Under each of these primary themes, data was further analyzed into micro-themes, but for the purpose of this paper I will focus solely on Caregiver self-care. The initial 1024 pieces of advice were thematically analyzed into three codes; “Daily Routine,” “Caregiver Self-Care,” and “People with Alzheimer’s and Dementia Well-Being.” Of the 1024 total pieces of advice, they were roughly broken down as follows:

- Daily Routine: 63%
- Caregiver Self-Care: 11%
- People With Alzheimer’s and Dementia Well-Being: 26%

After further narrowing down my findings related to the self-care of caregivers caring for people with Alzheimer's and dementia, I was left with 118 pieces of individual advice. These were further separated into three sub-themes: "Physiological/Physical," "Emotional," and "Relational." These codes were chosen because they were the common themes I saw in the caregiver self-care advice data. All of these were deemed as crucial to one's self-care both in general in order to have happy and healthy intrapersonal and interpersonal relationships, dialogue, and existence, as well as in order to best care for a person with Alzheimer's or dementia.

The absence of information readily available on Caregiver Self-Care Communication proves that there is a piece of the caregiver conversation missing, which limits our understanding of the importance of caregiver self-care as well as limits the awareness of means through which a caregiver could maximize their self-care. The vast majority of the advice covers the daily routine that a caregiver can implement when caring for a person with Alzheimer's or dementia in order to make their day-to-day activities run more smoothly. Slightly over one quarter of the advice was specifically on how to improve the quality of life of the person with Alzheimer's or dementia. This leaves the remaining 11% of the information on caregiver self-care, which is lacking, and proves that future research is needed.

As the Caregiver Self-Care is the focus of this paper, the Caregiver Self-Care advice was then thematically analyzed into sub-codes. The three sub-codes for Caregiver Self-Care were: Physiological/Physical, Emotionally, and Relationally. The pieces of advice and how they were sub-coded within the Caregiver Self-Care category are broken down as follows:

- Physiological/Physical: 15%
- Emotionally: 42%

- Relationally: 43%

The following is a more detailed breakdown of the sub-codes of Caregiver Self-Care:

- Physiologically/Physically: 29 pieces of advice out of 1024
- Emotionally: 81 pieces of advice out of 1024
- Relationally: 83 pieces of advice out of 1024

Of the 1024 pieces of advice I originally found, only 8.1% were about caregiver relational self-care, 7.9% were about caregiver emotional self-care, and 2.8% were about caregiver physical self-care.

A majority of the advice was implicit rather than explicit, so not only is it difficult to find information regarding communication of caregivers of people with Alzheimer's or dementia, but extra labor must be done for the reader to determine what that information even is.

In summary, for this research project I reached salience of online searching for any and all online advice to nonprofessional caregivers of people with Alzheimer's and dementia about their own self-care at 39 total texts, representing 22 organizations, and yielding 1024 pieces of advice with themes related to daily routine, caregiver self-care, and people with Alzheimer's or dementia well-being," and only 193 pieces of advice related to caregiver self-care and of that advice a vast majority was implicit. In the next section, I will more closely examine the importance of caregiver self-care from the perspective of what is necessary to produce dialogue, as well as point out a few further barriers that could prevent caregivers from accessing what little advice on caregiver self-care exists.

DISCUSSION

In order to have a proper communication between a caregiver and a person with AD or dementia, both parties within the dialogue are needed. However, when it comes to advice across the online channel, there is little about the caregiver. In order for the caregiver to best contribute, they need a groundwork on which to build, and yet there is little information out there about how the caregiver can best care for themselves. This leads to a few questions. How can a caregiver best care for the person with Alzheimer's or dementia if they do not know how to best take care of themselves? How can a caregiver best implement the common advice of day-to-day routines to improve their care situation if they do not know how to best take care of themselves? How can a caregiver improve the quality of life of the person with Alzheimer's or dementia to the best of their ability if they do not know how to properly take care of themselves first? This seems like the obvious first step in the caregiving dialogue—for the caregiver to be able to initiate that conversation, to enter a space knowing that they are taken care of and can therefore participate as much as physically possible and show up for the person they are caring for. However, this is not possible if the caregiver is experiencing severe burnout with no way of helping themselves, this is not possible if the caregiver is not getting enough sleep or support from others because it will impair their ability to partake in the dialogue and daily care activities that their position requires of them.

That is what I am arguing: if a caregiver does not know how to best take care of themselves, how can they be expected to care for a person with Alzheimer's and dementia to the best of their ability, in a way that will maximize the quality of life for the person they are caring for? They cannot, and that is a problem.

I knew I was close to reaching salience in my initial research when I noticed that many of the resources I was coming across all began linking to the same sources of information. In particular, I noticed copies of pages from The National Institute on Aging (NIA) were very common, as were resources from the Family Caregiver Alliance (FCA) and Medline. However, despite the fact that these resources were frequently externally linked across other resources, it was rare for me to come across anything from NIA, FCA, or Medline in my direct searches on Google, Yahoo, and Bing. Rather, I had to click on a link I found through those search engines, and comb through the website for their external links taking me to NIA, FCA, or Medline pages. This necessity of resource rabbit holes makes the information even less accessible, as most people may not take the time to follow multiple links within a resource to locate the information they are looking for.

The vast majority of the resources that I found were all in English due to this being a United States based study. The resources assumed their readers were English speaking, however if the intention was for anyone to share this information with someone who did not have English as their first language, there was a shortage of resources which had the option of viewing the same advice in various languages, making accessibility even more slim. The exception was Family Caregiver Alliance which also had resources in Spanish, Chinese, Korean, and Vietnamese.

Due to how a majority of the information was unemphasized and implicit, it causes extra work for the reader if they want to view these online resources for specific advice related to caregivers of people with Alzheimer's and dementia. These online resources were aimed at nonprofessional caregivers, and most readers have a short attention span. Requiring for readers to sludge through paragraphs of text and information in order to find the advice is impractical and likely to reduce readership, causing a slim field of information to become even slimmer due to lack of time and patience.

CONCLUSION

This study was spurred by the question, “What information is available regarding how caregivers of people with AD or dementia can best care for themselves and communicate that need for self-care while not sacrificing the care they are providing for the person with AD or dementia?” Utilizing a thematic analysis, I learned that not only is there little information related to the caring for people with AD or dementia from the perspective of caregivers in general, but caregiver self-care was even less likely to be discussed online. Given the lack of information on caregiver self-care physically, relationally, and emotionally, the dialogue that caregivers can have with the people with AD or dementia who they are caring for is negatively impacted. Due to this, more research is needed.

It should be taken into account that this research was done within the United States and are therefore most relevant to that location as well as to English speakers, due to all of my searches being in English. The intersectionality of being a caregiver across race, ethnicity, sexual orientation, gender, age, socioeconomic status, and more were not taken into account when thematically analyzing caregiver advice. Furthermore, the searches were solely done with Google, Yahoo, and Bing, and so could not include other search engines that one might utilize to research. Furthermore, a limitation of this study could be my own perspective as the researcher; because I am a caregiver, I may have subconsciously been more inclined to search for information that would have been the best help to me and my own situation, and may have thematically framed information in ways that made the most sense given my own experiences. There is ample opportunity for future studies, including but not limited to: a closer analysis of the caregiver self-care advice in terms of effectiveness, what impact does implicit versus explicit framing of advice have on the reader? What impact does emphasized versus unemphasized advice have on the reader? How does caregiver self-care advice differ across the people who they are caring for?

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