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What Can We Learn from the Caregivers of Adults with Dementia? A Qualitative Study

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What Can We Learn from the Caregivers of Adults with Dementia? A Qualitative Study

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*With deep gratitude.....
To the selfless caregivers who shared their stories,
thank you for teaching me.*

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Abstract

Introduction: In the US today, there are approximately 6.5 million people age 65 or older living with Alzheimer’s Disease or other dementias. This number is expected to increase to 12.7 million by 2050. Dementia imposes debility and frailty upon those effected, which is progressive and often follows an unpredictable trajectory. This places significant burdens on their informal caregivers, negatively impacting financial security, emotional and physical health, and overall quality of life. Informal caregivers are a heterogeneous group of partners, spouses, adult children, family members and others.

Purpose: This qualitative study explores the experiences, worries and concerns of informal caregivers of older adults with dementia, in order to describe improved policy and service delivery models that could provide efficient and sustainable solutions to their challenges.

Methods: Semi-structured interviews were conducted with seven informal caregivers. Transcripts of these interviews were analyzed using the Grounded Theory analytic process referred to as the Constant Comparison Method, consisting of coding, memoing and theorizing.

Results: Nine sub-categories and three categories were identified from analysis and data comparison. The three categories were “Difficult day-to-day experiences and activities,” “Inner thoughts and suffering” and “Hoping to make a difference. The final theme emerged as “Informal caregiving for older adults with dementia is a condition.” Some literature has referred to this as “caregiver stress” or the Caregiver Syndrome.

Conclusion: Informal caregivers of older adults with dementia experience significant physical, and emotional stresses that result in concerns about their overall wellness. This in-turn impacts their ability to function as sustainable caregivers for their family members at home. Lack of reliable in-home personal care supports, patient companionship and respite result in excess worry, stress and loss of quality of life for the caregiver. Over a trajectory of years, inherent in the dementia diagnosis, informal caregivers are likely to encounter negative physical and mental health outcomes. Without changes in both policy and reimbursement through home health, hospice, palliative care and community-based resources, this condition of caregiver stress or “syndrome” will contribute to the ongoing challenges of caring for an ever-increasing number of vulnerable elderly individuals.

Keywords:

Dementia, informal caregiver, qualitative research, grounded theory, inductive reasoning, theoretical sampling, constant comparison method.

Introduction

There are approximately 6.5 million people in the US today, aged 65 or older living with Alzheimer's disease or other dementias. (Alzheimer's Association, 2022, p. 21). By 2050 that number is expected to increase to 12.7 million (p. 26). Alzheimer's Disease is the 6th most common cause of death in this country, and the 5th highest for those age 65 and older. Deaths from other causes, such as heart disease, strokes and HIV, have decreased from 2000-2019, but deaths due to Alzheimer's have increased by 145% (p. 32). In 2020 COVID-19 had a profound effect on death causality, and came in at number 3 in overall US mortality, only behind cancer and cardiovascular disease. This moved Alzheimer's to the seventh leading cause overall. Further demonstrating the vulnerabilities of this group of patients, COVID-19 resulted in an increase in the total number of Alzheimer's death by 10.5% between 2019 and 2020 (p.31).

It is important to clarify that while Alzheimer's Disease is the most common cause of dementia, there are other diseases that can result in a similar path of cognitive and functional decline. These include Vascular Dementia, Lewy Body Disease, Frontotemporal Lobar Degeneration, Parkinson's Disease and mixed pathologies (Alzheimer's Association, 2022, p 6-7). For the purpose of this study and discussion, there is no distinction between the various forms of dementia. Whenever "dementia" is referred to in this discussion, it is assumed to be due to one of the several etiologies. In study purpose and design, there is a focus on the effect on caregivers, rather than the particular type of dementia.

As the trajectory of all types of dementia unfold, it imposes debility and frailty that stress families, caregivers, health care providers, facilities, systems and payers, alike. The course is often slow and insidious. People age 65 older have life expectancies that average 4-8 years after time of diagnosis. Yet some may live as long as 20 years. This long and often unpredictable nature of dementia makes care planning challenging, and explains why people who die of dementia are more than 2 -3 times more likely to die in nursing homes, than those dying of cancer and other conditions (p. 35).

As the disease progresses to its later stages, those with dementia become increasingly dependent on others, and eventually care is needed 24 hours a day. (Zwaanswijk & al., 2013).

Today, more than 11 million informal caregivers are providing care to older adults with dementia, amounting to 16 billion hours, valued at \$256.7 billion (Alzheimer's Association, 2022, p.38).

Almost all Informal caregivers assist with Instrumental Activities of Daily Living (IADLs, such as managing finances, shopping, transportation, meal preparation), while 60% assist with Activities of Daily Living (ADLs, such as bathing, feeding, toileting, grooming) and 58% assist with nursing and medical needs. Over half of caregivers report a sense of purpose and fulfillment, but there are significant negative impacts on caregivers' quality of life, financial stability, emotional health and their own underlying medical conditions (AARP, 2020, p. 6; Lindeza et al., 2020) Caregivers who are married, females, and/or those providing more intensive care suffer greater decreases in mental health and physical wellness (Bom et al., 2018). Older adults with dementia impose more burdens, depression and diminished quality of life on caregivers, than those without dementia. (Karg et al., 2018).

In Maine, the average age of informal caregivers for older adults with dementia is 49 years old, with 43% between ages 45 and 64, and 30% age 65 or older. Approximately two-thirds are women, and one in 4 belongs to that "sandwich generation," providing care for those in at least 2 other generations besides their own. More than half of all caregivers have been providing care for at least 2 years (Alzheimer's Association, 2022, p 39-41), and as many as 57% have provided care for 4 years or more (Kasper et al., 2015). Although there are demographic trends, there is no typical caregiver. They are a heterogeneous group of people, partners and families caring for their own.

Spousal caregivers are a particularly vulnerable set of caregivers for older adults. They are typically older, with their own medical challenges. It is not infrequent for married caregivers to be the only caregiver for an older adult with serious illness (Ornstein et al., 2019).

Maine is the most rural state in the United States. Rural caregivers are especially vulnerable due to both physical isolations, as well as the documented disparities in both health care access and quality (Douthit et al., 2015).

Purpose

This qualitative study explores the experiences, worries and concerns of informal caregivers of older adults with dementia, in order to describe improved policy and service delivery models that could provide efficient and sustainable solutions to their challenges.

Methods

Design:

A Grounded Theory qualitative research approach was applied to this particular project. Grounded Theory (GT) is one of the most widely used methodologies in qualitative research today. GT was initially introduced by Glaser and Strauss in 1967, as a path to the construction of new theory that is grounded in data (Corbin & Strauss, 2015, pp. 3-6).

Some attributes of GT include the concept that the researcher becomes part of the discovery of new theory. He/she typically engages in the exploration using an inductive rather than a deductive reasoning process. This means that the researcher has little knowledge about the topic, and is willing to put aside the typical steps of in-depth research, or inserting his/her own information and set of experiences into the research environment. The researcher is then free to observe, reflect and arrive at new theory through an ongoing and repetitive process of sampling, data collection and analysis (Charmaz, 2014, p. 342).

Theoretical Sampling is the foundation for defining a study population in GT research. While it initially provides a framework for data collection, it is actually a dynamic and fluid process. It becomes molded by the researchers ongoing relationship with the data, while paying attention to categories that emerge during ongoing analysis. The initial sampling can be arbitrary, and loosely based on initial research questions. As the researcher learns from the data, he/she can refine the sampling process based on new questions that arise, or categories that need refinement (Charmaz, 2014, pp 192-212) .

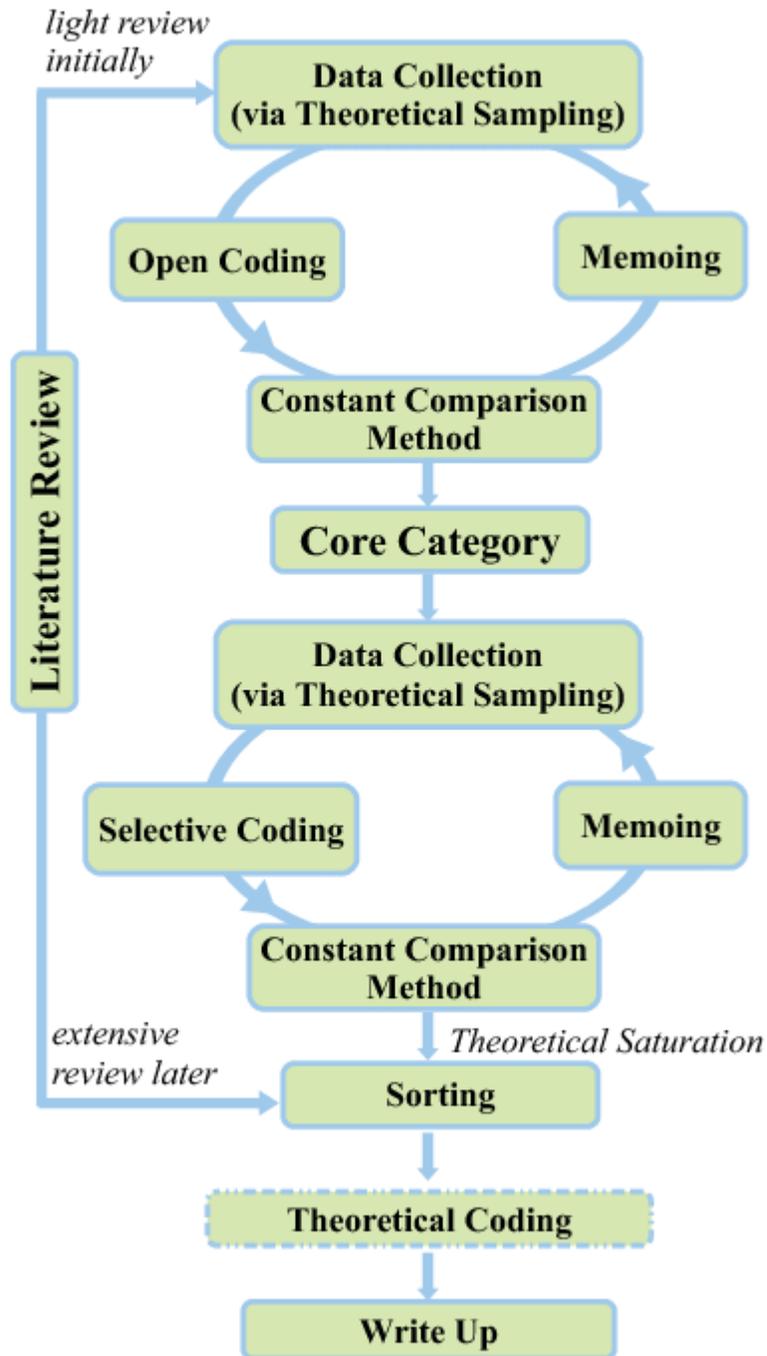
Data is gathered through typical qualitative methods, such as direct observations, focus groups, interviews, surveys or other recordings that might be made in natural settings. In the case of interviews, transcripts are typically recorded and transcribed, and then analyzed through a uniquely qualitative analytic process called the *Constant Comparison Method (CCM)* (pp. 342-343). The first critical step of CCM is *open coding*, which is the breaking down of transcripts into individual excerpts, which when grouped together based on comparison forms a *code* (pp. 116-120). Multiple iterations of theoretical sampling pull similar codes together (*axial coding*) into *categories* (pp 147-159). Multiple categories can finally be assimilated as core categories (*selective coding*), which eventually lead to a final theory (pp. 341-342).

The coding process, embedded within CCM, requires an ongoing assessment of similarities, differences, contrasts and connections between the various excerpts, codes, and then categories. It is the sorting and organization of data, on the way to new theories. As a researcher compares and contrasts the evolving codes and categories, it is critical that he/she track and record ongoing responses and thoughts. This process is called *memoing*. Memos are written records of the analysis by the researcher, as the final theory is developed. It is a way for the researchers to actually engage with the data (Corbin & Strauss, 2015, page 107). See Figure 1 for an overview of Grounded Theory Qualitative Research.

There are several other concepts in the GT approach that require mentioning. They include *Theoretical Sensitivity*, which relates to the researcher's ability to generate meaning and subtlety from the data (Charmaz, pp. 160-161). Can he/she see the difference between relevant and irrelevant factors?

Theoretical Saturation describes that point where the researcher recognizes the limits of theoretical sampling successes, and identifies the point when he/she is no longer gaining more insight or information as a new theory or theme is identified (Charmaz, 2014, pp. 344-345).

Figure 1: Overview of the Grounded Theory of Qualitative Research guided by Theoretical Sampling, followed by data collection and analysis through Constant Comparison Method, leading to the discovery of theories (Hoda et al., 2010).



Participants, Settings and Semi-Structured Interviews:

The University of Southern Maine's Institutional Review Board granted approval for this study. Participants were recruited after contacting the 5 Area Agencies on Aging in the State of Maine, and the Maine Hospice Council. See Appendix 1 for Recruiting Flyer shared with these collaborating partners. The criteria for participation in this study included:

1. Individual between the ages 45-75 acting as an informal caregiver for an adult with dementia who is age 65 or older
2. Caregiver has access to a computer, the internet, and is comfortable with Zoom videoconferencing.

Eight informal caregivers were recruited from Spectrum Generations Area Agency on Aging, the Aroostook Area on Aging, and the Eastern Area Agency on Aging, and the Maine Hospice Council. One participant needed to withdraw due to illness. The remaining 7 participants were informed as to the nature of this study, and consents were obtained.

All participants took part in semi-structured interviews with the Principal Investigator, each lasting between 45 and 70 minutes. All interviews took place and were recorded through Zoom videoconference platform. The interview guide was developed by the Principal Investigator, and included open-ended questions regarding types of caregiving activities, daily challenges, particular worries, needs and goals for future care. Figure 2 shows interview guide questions included in the semi-structured interview guide. The actual scripted Key-Informant Interview Guide is included as Appendix 2.

Figure 2. Interview Guide Questions

Interview Guide Questions

1. Can you tell me a little bit about your family member? For example, how long have you known him/her? How long has he/she had dementia? How long have you been involved in his/her care at home?
2. Can you describe for me the effect that dementia has had on your family member? For example, how has he/she coped with the disease, and how has it changed his/her life?
3. Can you describe for me the types and amounts of care needed by your family member on a daily basis? Can you estimate the number of hours per week that you spend in providing care to your family member?
4. Can you describe how this has changed in recent months or years? For example, are you needing to provide more or lesser care these days, compared to previous months and years?
 - a. Are there other family members, or individuals who assist you in providing care for your family member with dementia? Are you able to leave your family member alone? Are you able to go to your own appointments?
5. What are the most challenging parts of the care that you provide to your family member with dementia?
6. What parts of the care that you provide are most rewarding, or provide greatest satisfaction?
7. Can you describe a typical day in the life of your family member for me? (2 minutes)
8. Please consider the following words and phrases. Can you tell me if any of these are goals you have for your family member? Can you tell me why?
 - Quality of life
 - Comfort
 - Dignity
 - Home
 - Control
9. Now please consider the following words and phrases. Can you tell me if any of these are things you worry about? Can you tell me why? Are there others?
 - I want to keep my family member at home
 - I hope I have the skills needed to keep family member comfortable and safe
 - There are other family members who also need me
 - Stress, worry, sadness
 - Financial struggles
 - My own health issues
10. As you think about your experiences as a caregiver for an older person with dementia, and the things you are most concerned about, can you describe for me the most important services and aspects of care you would need from your physicians and health care system?
11. Can you describe for me how confident you are that you will be able to receive those services and aspects of care from your physicians and health care team?
12. Although it is not pleasant to think about, perhaps your physician has mentioned to you that dementia is not a curable disease. Can you share with me some of your thoughts about this?
13. Does your family member have an Advance Directive? This is also referred to as a Living Will.
 - a. Do you know who your family member's Power of Attorney for Health care is?
 - b. If it is you, have you had conversations with your family member about his/her wishes for end-of-life care?
 - c. Do you know how your family member feels about having a feeding tube, if he/she is unable to eat one day?
 - d. Do you know how your family member feels about having a breathing tube if his/her breathing gets difficult one day?
 - e. Do you know how your family member feels about having CPR, when his heart stops one day?
 - f. How confident do you feel that you will be able to honor those wishes?
14. Can you tell me what you know about hospice care? Can you tell me what you think it means?
 - a. Do you think that this is something that might be helpful to you, as you take care of your family member?
15. Can you tell me what you know about palliative care? Have you heard of this type of care before?
 - a. If yes, can you tell me, in your own words, what it means to you?
16. What do you think is the most important thing that you would like other people, and your health care team, to know about being a caregiver?
17. Lastly, is there anything else you would like to tell me today?

Analysis:

Each transcribed interview was considered to be an individual unit for analysis, and was reviewed multiple times by the Principal Investigator. The Principal Investigator coded the data line-by-line using an inductive Constant Comparison Method. Specifically, excerpts were pulled from each transcript, and placed into unique codes through open coding. Subsequent organization of codes resulted in sub-categories, then categories (axial coding). Final organization of categories resulted in creation of a theme (selective coding).

Memoing by the Principal Investigator guided the creation of codes, sub-categories, categories and final theme. The identification of the final theme was informed by a second and deeper search of the literature regarding caregiver experiences, as Grounded Theory allows and requires (Hoda & al., 2010)

This study was limited in time and scope, and therefore only one round of interviews was completed. This study does not fully satisfy all elements of Grounded Theory. This would require multiple rounds of theoretical sampling, interviews, data collection and analysis, which was not the intention of this Capstone. However, this study might provide a foundation for further research.

Results

Open coding of 7 transcripts revealed hundreds of excerpts, approximately 25-30 codes, 9 sub-categories, 3 categories, and 1 final theme:

7 transcripts → hundreds of excerpts → 25-30 codes → 9 subcategories → 3 categories → 1 final theme

Categories are: (1) the difficult day-to-day activities and experiences (2) inner thoughts and suffering and (3) hoping to make a difference, for other caregivers. The overall theme or theory that evolved was that informal caregiving for an older adult with dementia comes with a set of experiences that affect people in negative ways with regard to physical, emotional and social elements of overall health and wellness. Specifically, **informal caregiving for adults with dementia is a condition**. See Figure 1 for codes, sub-categories, and categories and theme. Figure 2 shows categories, sub-categories with examples of excerpts from interviews.

Table 1: Examples of Codes, identified sub-categories, categories and final theme

Examples of Codes	Sub-category	Category	Theme
Feeling restricted Needing to do everything Not enough patience Quality of life Caring for Spouse versus parent Satisfaction My other family members Things that can't be said out loud So much guilt The unknown Financial worries My own health How much time Advance care planning What others don't know	Tremendous Responsibility Financial Worries Neglecting health of self Quality of Life Conflicted Emotions Guilt Grief Lack of information Advocates for change by telling their story	Difficult day-to-day experiences and activities Inner thoughts and suffering Hoping to make things better for other caregivers	Informal caregiving for older adults with dementia is a condition

Table 2: Categories, sub-categories and examples of excerpts

Category	Subcategories
<p>Difficult day-to-day experiences and activities</p>	<p>Tremendous Responsibility <i>"I do everything. The work around the house, the shopping. I need to do all his cleaning and personal care. If I did nothing, he'd still be in bed right now."</i></p> <p>Financial Worries <i>"Money struggles stress me very much. He is destitute. He used up all his money years ago. Who knew he would live this long? Now, it's all on me."</i></p> <p>Health Worries <i>"I've put on weight. I'm used to being very active. So, I'm worried about the toll this is taking on me. I worry about being able to keep going."</i></p>
<p>Inner thoughts and suffering</p>	<p>Quality of Life <i>"I would say his quality of life is better than mine. I'm the one who is suffering. I don't say that to imply I don't want to be here. But my quality of life is terrible."</i></p> <p>Conflicted <i>"And this is terrible to say, but that feeling I had for him, say 20 years ago isn't there anymore. It's more of an obligation, and I feel very guilty about that. For me to have to sit with him is very difficult. I hate it. It drives me nuts. I don't have a choice. If I had a choice, I wouldn't be doing this."</i></p> <p>Guilt <i>"I can't do this for another 3 years. I think I'll die. There is so much guilt."</i></p> <p>Grief <i>"Once in a while, there's a look in his eyes, of who he was. But mostly he's just gone. It's like he's already dead."</i></p> <p>Unknown <i>"I am almost envious of people who get a doctor to say 'ok, you've got 3-6 months. I mean I would kind of like to hear that. It's harder not knowing."</i></p>
<p>Hoping to make things better, for themselves and other caregivers</p>	<p>Advocates for Change <i>"In the past few years, as a caregiver for my husband, I have learned how little support exists for caregivers, on a professional and caregiver level. I hope my story can help others."</i></p>

Discussion

The results of this study show that caring for an older adult with dementia imposes a heavy physical and emotional burden on their caregivers. The day-to-day experiences, over time, take its toll on overall sense of wellness and quality of life, such that caregivers often worry about their ability to sustain their functions. There are multiple issues that contribute to these experiences. These were described quite specifically by the participants in this study.

Sense of Responsibility:

Caregivers are guided by their commitments to their spouses, partners and family members. But sometimes it is less a choice, and more the acceptance of the right thing to do. Providing care for loved ones in-need embodies the definition of family, and people don't typically run from it, especially if there is no one else around. But it is not without a negative impact on a caregiver's quality of life.

Financial Concerns:

Caregivers spend time worrying about money issues. Without adequate resources the opportunity to hire outside help diminishes, and adds to worries about the future. Most caregivers wish to honor a family member's desire to stay at home. But there was also a worry expressed that institutional long-term care could deplete resources and leave them with significant financial stresses. They worried that the system would likely ask them to spend down, leaving very little to live on during the rest of their lives.

Health Concerns:

Caregivers recognize that their own health is often neglected while caring for their family member. There was a universal recognition that they were less active, carried more weight, and felt more fatigued. They were postponing their own medical care, if there was no backup for in-home caregiving. The concern seemed less about their own longevity, and more about their ability to continue providing care for their family member. Several mentioned the fear

and possibility of reaching a “breaking point,” when their bodies would no longer allow them to continue in their role. Several wondered if they might die before their family member.

Quality of Life:

In response to questions about the family member’s quality of life, there was almost complete agreement that quality of life was fine for the person with dementia. Family members were clean, fed, and ultimately cared for. Yet, caregivers suffered loss of things that were meaningful to them, such as jobs, attending other family gatherings and engaging in social activities. Multiple caregivers reported that their quality of life was more significantly diminished than that of their family member with dementia. There was the impression that he/she “did not know the difference.”

Conflicted Emotions:

Caregivers, as a group, appear to be somewhat conflicted in their emotions. They are committed to their family member based on love, family, tradition and an understanding that it is the right thing to do. Yet, over time this leads to fatigue, frustration, and a tension between caring for a loved one and their own sanity and survival. For example, participants worry about the future, and how much longer they can sustain their roles. They are conflicted between perceptions of the family member’s suffering and their own. By wondering how long their loved one will live, they wonder if they could be perceived to be wishing their family member gone. By asking the question, it’s like I’m wanting him to die. I feel so guilty about that. I wonder what’s best.”

They try to “stay in the moment.” At most they try to “stay in the day.” Yet the worries about future challenges makes that goal very difficult. As they are forced to stay in the moment by the repetitive nature of the care and often lonely, mundane tasks, they often think of both sides. They don’t want their family member to die, but in dark quiet moments, they know it will happen eventually. Thinking the thought makes it real, and makes some caregivers feel complicit.

Guilt:

Conflicted emotions are an expression of guilt. So much of the work is thankless, expected, grueling, repetitive and tedious. Caregivers feel guilty for speaking out loud about their own needs. Everything needs to be couched into “not wanting him to suffer,” and making sure his needs are met, even when they are pretty sure he “does not know the difference.” Caregivers don’t speak too openly about when this will “all be over.” They look forward to a time when his suffering will end. But it’s agonizing to admit “that’s when my suffering will end too.”

They feel guilty for not always identifying a sense of satisfaction for the opportunities to care for a loved one. Some were able to articulate some positive aspects about their caregiving role. For adult children caring for parents, there was a sense of gratitude and pay back for “what they did for me.” There was pride in doing it well. Others had a more difficult time articulating that sense of satisfaction. “Who knew I could learn to do so much? Who knew I was so competent?” Although this participant quickly added, “I’d rather not have to go through this to learn that I can do a good job. There are other ways.” Others admitted feeling trapped and restricted, leading to guilt, resentment and sadness.

Grief:

Dementia robs people of who they are before it ends their life. Caregivers recognize the loss of their partners, spouses and loved ones before an actual death occurs. This adds to the conflict and guilt on the part of caregivers, as the grief is often not in sync with the layers of losses. Grief is in response to loss of recognition and companionship, as well as in anticipation of the death. Caregivers struggle with how to manage this, in the context of present caregiving needs.

The Unknown:

Caregivers frequently described gaps in their understanding of the future. Almost all caregivers report that their health care providers offer little or no information regarding prognosis or what to expect. Caregivers are left to research, read, “Google,” and guess. While it’s true that the science of prognostication is fraught with uncertainty, caregivers would enjoy

more discussions with providers, even if it's simply to affirm and share that uncertainty. The void in caregivers understanding of dementia's trajectory results in additional stress and worry. When told that the prognosis might be anywhere between 4 and 8 years, and as long as 10 years, it interferes with the ability to plan, live normally and even grieve. The vague and unhelpful information overwhelms them. The only certainty they describe is that with every year the condition will only progress, the needs will only increase, and the burden will only feel heavier. Conflicting emotions, chronic smoldering loss of a partner or parent, and waning resources all lead to inner whispers of "wanting it to be over."

Advocates for Change:

Caregivers are realistic and resilient. They are problem solvers and survivors. Yet, they acknowledge their journeys have been difficult, and wish to contribute to improved experiences for the caregivers who follow them. They have participated in this study to add their voice to others, in hopes of creating new solutions to the struggles they have described here.

The Grounded Theory approach allows a second look at the literature. Caregiver stress, and more specifically "Caregiver Syndrome," have started to appear in the writings of advocates and those familiar with caregiver issues (Barron et al., 2022). While medical literature has historically identified caregiving to particular negative outcomes, conclusions have not definitively linked caregiving, itself, as the culprit. Rather it is theorized that the individual's perception of stress and strain is what leads to declines in overall health and potential early death. Yet, it has been reported that up to 18% of caregivers die before their family members with dementia, in spite of having lower mortality risks (Gaugler et al., 2018).

Caregiver Syndrome has been referred to as a debilitating condition, triggered by unrelieved constant care of someone with dementia or other chronic illness. It is characterized by physical, mental and emotional exhaustion, and may manifest as anger, rage or guilt (Piesyk, 2007). These are the characteristics demonstrated by the caregivers in this study. Physical and

emotional demands, social isolation, financial insecurity, anticipatory grief, and uncertainty about the future lay the foundation for this particular condition.

Summary of Final Theory: Caregiving is a Condition

- Caregiving is not just something these individuals do, it is what they become, it becomes them
- Caregiver Syndrome is a debilitating condition triggered by unrelieved constant care of someone with dementia or other chronic illness
- Caregiver Syndrome is characterized by physical, mental and emotional exhaustion, and may manifest as anger, rage or guilt
- Caregiving imposes a set of circumstances and conditions that lead to medical complications, bypassing the step of labeling “stress” as the culprit.
- 18% of caregivers die before their family members with dementia, in spite of having lower risks of mortality.

Limitations of this Study

This study obviously represents a small sample of caregivers of older adults with dementia, and findings might not be consistent across greater samples of caregivers. This GT approach consisted of one round of interviews, and does not allow the full model to explore possible new theory. All caregivers were recruited from organizations who were also providing supports through individual counseling and support group participation. This represents the possibility of selection bias if these caregivers differ from other caregivers, based on either their motivations or experiences gained from these supportive interventions.

A significant challenge, if not a limitation, was the experience and skill set of the principal investigator as a palliative care physician. Previous interactions with dementia patients and their caregivers in clinical encounters presented opportunities to influence multiple steps of this study, including interview questions presented, data collection and analysis.

Conclusions

Informal caregivers of older adults with dementia experience significant physical and emotional stresses that result in concerns about their overall wellness. This, in-turn, impacts their ability to function as sustainable caregivers for their family members at home. Lack of reliable and sustainable in-home personal care supports, patient companionship and respite for the caregiver result in excess worry, stress and loss of quality of life for the caregiver. Over a trajectory of years, inherent in the dementia diagnosis, informal caregivers are likely to encounter negative physical and mental health outcomes. The ongoing lack of support for caregivers ultimately leads to more challenges in meeting the overall needs of this vulnerable population, whose numbers will only increase during the upcoming years and decades.

Without recognition of the significant role played by caregivers in keeping dementia patients safe, well-cared for and supported at home, we are headed toward a non-sustainable situation, “a crisis,” as identified by one of the participants. The present system is broken, short-sighted, and fails on so many levels. A positive change can only happen with a resetting of the way we take care of these patients, as a health care system. Some suggestions for medical providers, policy makers and advocates to improve the experiences of patients with dementia and their caregivers include the following:

- Move the lens from the patient exclusively, but rather to the “dyad” of the patient and caregiver, as a singular unit. Recognizing the importance of this relationship and supporting it will result in better outcomes for the patient.
- Invest resources and research into a better understanding of caregiver stress. This includes further study of the Caregiver Syndrome, and the impact it has on the overall wellness and health outcomes of caregivers.
- Evaluate the present structural and reimbursement mechanisms for medical care of dementia patients in home care settings in existence today, which include the skilled Medicare home health benefit and the Medicare Hospice Benefit. Explore the limitations of each and consider ways to fill gaps in services and access that would support caregivers, as well as patients.

- Consider ways to expand access to caregiver supports and respite services through collaboration with community resources. Some examples are the Area Agencies on Aging, the local Alzheimer’s Association and volunteer services embedded within local hospice Programs.
- Explore enhanced models of home-based service delivery that incorporate clinical services and case management, in home personal care aides, with psychosocial supports for both patient and caregiver. One current example in process is L.D. 1064, *An Act to Advance Palliative Care Utilization in the State*, passed in 2021 (Craven, 2021). According to the World Health organization, Palliative Care “improves the quality of life of patients and their families who are facing life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual” (WHO, 2020). The cornerstones of palliative care are communication, information-sharing, goal setting and the delivery of interventions to support quality of life for patient and their caregivers, through collaboration with traditional medical providers and community-based resources. (Kelley & Morrison, 2015).

Appendix A: Recruitment Flyer



Volunteers Needed for Research Study on the Needs of Caregivers of Older Adults with Dementia

We are looking for volunteers to participate in one-on-one interviews regarding the needs, worries and concerns of caregivers of adults with dementia. We would like to learn and know more.

This Research Project is open to adults between the ages of 45-75 years old and are caregivers for an adult age 65 or older with dementia. Enroll through March 15, 2022.



*Help us
understand....*

Caregivers of Older Adults with Dementia Research Project:

- Principal Investigator: Lauren Michalakes, MD
- Location: Remote, at a familiar or comfortable location, through Zoom
- Commitment: 60-minute interview with Principal Investigator, Lauren Michalakes, asking about your experiences as a caregiver for your family member with dementia
- Participation is voluntary. There is no compensation. You will receive a \$10 gift card at a local coffee shop for your time.
- There are no direct benefits or risks to participation. Others may benefit from the results.

For more information, or to request participation, contact Lauren Michalakes at (207) 691-0343 or Lauren.Michalakes@maine.edu

Appendix B

Key-Informant Interviewer's Guide

Opening: (5 minutes)

Hello. My name is Lauren Michalakes. As part of my graduate work, I am doing a research project on caregivers of adults with dementia. When you signed up to participate in this project, you shared that you are a caregiver for someone with dementia, and would be willing to share some of your experiences. Thank you so much for your time today.

Many times, caregivers, like yourself, are husbands, wives, partners, children, other family members or companions. For the sake of today's discussion, I would like to refer to the adult with dementia, under your care, as your family member. Would that be okay with you?

(If not, how would you prefer that I refer to the person with dementia?)

The purpose of this study is to help me to learn more about what it is like to be a caregiver. It would be very helpful to me if you could think carefully about the questions I ask you, and answer them as honestly as you can. As already covered in the consent form you signed, everything you say here will be kept confidential. Our video Zoom session will be recorded, so that I do not miss any of the important information that you share. I am the only one who will have access to these recordings. As I analyze your responses to these questions, there is no way for anyone to identify anything about this conversation, or even know that you have participated. After I have completed the analysis of these recordings, I will delete and destroy them. I will never use or access these recordings again, after that part of the study is done.

I want to reassure you that I am in a very private room right now. There is no one else here with me. This is not only to make sure we are not interrupted, but to make sure that this conversation is private. I would ask that you are also in a private room, so that we are not interrupted, and you are free to speak as freely as you like. I will pause a few minutes here, to give you a chance to move to a private room, if you are not already there.

Our conversation today will take no more than 60 minutes.

Before we get started, do you have any questions?

Okay, great. My first question will help me learn more about your family member with dementia, and your relationship with him/her.

Getting to know family member (5 minutes):

1. Can you tell me a little bit about your family member? For example, how long have you known him/her? How long has he/she had dementia? How long have you been involved in his/her care at home?
2. Can you describe for me the effect that dementia has had on your family member? For example, how has he/she coped with the disease, and how has it changed his/her life?

The next set of questions will help me understand your role as caregiver for your family member with dementia.

Understanding Caregiver involvement (10 minutes)

3. Can you describe for me the types and amounts of care needed by your family member on a daily basis? Can you estimate the number of hours per week that you spend in providing care to your family member? (2 minutes)
4. Can you describe how this has changed in recent months or years? For example, are you needing to provide more or lesser care these days, compared to previous months and years? (2 minutes)
 - a. Are there other family members, or individuals who assist you in providing care for your family member with dementia? Are you able to leave your family member alone? Are you able to go to your own appointments?
5. What are the most challenging parts of the care that you provide to your family member with dementia? (2 minutes)
6. What parts of the care that you provide are most rewarding, or provide greatest satisfaction? (2 minutes)
7. Can you describe a typical day in the life of your family member for me? (2 minutes)

These next questions will help me understand what your goals and worries might be regarding the care of your family member with dementia.

Caregiver Goals and Worries (18 minutes)

8. Please consider the following words and phrases. Can you tell me if any of these are goals you have for your family member? Can you tell me why?
 - a. Quality of life
 - b. Comfort
 - c. Dignity
 - d. Home
 - e. Control

9. Now please consider the following words and phrases. Can you tell me if any of these are things you worry about? Can you tell me why? Are there others
 - a. I want to keep my family member at home
 - b. I hope I have the skills needed to keep family member comfortable and safe
 - c. There are other family members who also need me
 - d. Stress, worry, sadness
 - e. Financial struggles
 - f. My own health issues

These next questions will help me understand your plans for future health care needs of your family member with dementia.

Planning for future health care needs (18 minutes):

10. As you think about your experiences as a caregiver for an older person with dementia, and the things you are most concerned about, can you describe for me the most important services and aspects of care you would need from your physicians and health care system? (3 minutes)

11. Can you describe for me how confident you are that you will be able to receive those services and aspects of care from your physicians and health care team? Can you explain why or why not? (2 minutes)

12. Although it is not pleasant to think about, perhaps your physician has mentioned to you that dementia is not a curable disease. Can you share with me some of your thoughts about this? (2 minutes)

13. Does your family member have an Advance Directive? This is also referred to as a Living Will. (5 minutes)

- a. Do you know who your family member's Power of Attorney for Health care is?
- b. If it is you, have you had conversations with your family member about his/her wishes for end-of-life care?
- c. Do you know how your family member feels about having a feeding tube, if he/she is unable to eat one day?
- d. Do you know how your family member feels about having a breathing tube if his/her breathing gets difficult one day?
- e. Do you know how your family member feels about having CPR, when his heart stops one day?
- f. How confident do you feel that you will be able to honor those wishes?

14. Can you tell me what you know about hospice care? Can you tell me what you think it means? (3 minutes)

- a. Do you think that this is something that might be helpful to you, as you take care of your family member?

15. Can you tell me what you know about palliative care? Have you heard of this type of care before? (3 minutes)

- a. If yes, can you tell me, in your own words, what it means to you?

Wrap up (4 minutes):

So those are the last formal questions I have for you today. But before we finish up, we have a few more minutes. I have two more questions for you

16. What do you think is the most important thing that you would like other people, and your health care team, to know about being a caregiver? This is a really important question to me. (2 minutes)

17. Lastly, is there anything else you would like to tell me today? (2 minutes)

Okay. That completes our discussion today. I want to thank you so much for your time. This is an important topic that will affect so many people some day. Perhaps the discussion has given you something to think about, as you travel your own journey as a caregiver.

I want to remind you that this conversation is private. Although you have shared important details of your experience today, I want to reassure you that I will not share any details about this conversation with anybody else. Although I have recorded this conversation, I want to reassure you that I will also keep this private. I will need to carefully review the video and audio recordings, as part of my study. But I will delete and destroy these recordings as soon as I am done reviewing. And when I study the results of my study, I will continue to honor your privacy. I will not release any information that can be linked to you or your family member.

Thank you again for your time. As you think about this conversation today in the upcoming days, feel free to reach out to me, if questions arise. I think you already have my contact information. But here it is again.

Lauren Michalakes

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Appendix C

Summary for Community Partners
What Can We Learn from the Caregivers of Adults with Dementia?
A Qualitative Study

Thank you to the Area Agencies on Aging and the Maine Hospice Council for their partnerships and support in assisting me in the completion of this study. It is my hope that it adds another layer of understanding to the complexities and challenges that our caregivers face, as they work tirelessly and selflessly, to meet the needs of their loved ones and family members. Solutions will not be easy. But the next step is ours to make.



*With deep gratitude.....
To the selfless caregivers who shared their stories,
thank you for teaching me.*

What Can We Learn from the Caregivers of Adults with Dementia? A Qualitative Study

Abstract

Introduction: In the US today there are approximately 6.5 million people age 65 or older living with Alzheimer’s Disease or other dementias. This number is expected to increase to 12.7 million by 2050. Dementia imposes debility and frailty upon those effected, which is progressive and often follows an unpredictable trajectory. This places significant burdens on their informal caregivers, negatively impacting financial security, emotional and physical health, and overall quality of life. Informal caregivers are a heterogeneous group of partners, spouses, adult children, family members and others.

Purpose: This qualitative study explores the experiences, worries and concerns of informal caregivers of older adults with dementia, in order to describe improved policy and service delivery models that could provide efficient and sustainable solutions to their challenges.

Methods: Semi-structured interviews were conducted with seven informal caregivers. Transcripts of these interviews were analyzed using the Grounded Theory analytic process referred to as the Constant Comparison Method, consisting of coding, memoing and theorizing.

Results: Nine sub-categories and three categories were identified from analysis and data comparison. The three categories were “Difficult day-to-day experiences and activities,” “ Inner thoughts and suffering” and “Hoping to make a difference. The final theme emerged as “Informal caregiving for older adults with dementia is a condition.” Some literature has referred to this as “caregiver stress” or the Caregiver Syndrome.

Conclusion: Informal caregivers of older adults with dementia experience significant physical, and emotional stresses that result in concerns about their overall wellness. This in-turn impacts their ability to function as sustainable caregivers for their family members at home. Lack of reliable in-home personal care supports, patient companionship and respite result in excess worry, stress and loss of quality of life for the caregiver. Over a trajectory of years, inherent in the dementia diagnosis, informal caregivers are likely to encounter negative physical and mental health outcomes. Without changes in both policy and reimbursement through home health, hospice, palliative care and community-based resources, this condition of caregiver stress or “syndrome” will contribute to the ongoing challenges of caring for an ever-increasing number of vulnerable elderly individuals.

Purpose

This qualitative study explores the experiences, worries and concerns of informal caregivers of older adults with dementia, in order to describe improved policy and service delivery models that could provide efficient and sustainable solutions to their challenges.

Discussion

The results of this study show that caring for an older adult with dementia imposes a heavy physical and emotional burden on their caregivers. The day-to-day experiences, over time, take its toll on overall sense of wellness and quality of life, such that caregivers often worry about their ability to sustain their functions. There are multiple issues that contribute to these experiences. These were described quite specifically by the participants in this study.

Sense of Responsibility:

Caregivers are guided by their commitments to their spouses, partners and family members. But sometimes it is less a choice, and more the acceptance of the right thing to do. Providing care for loved ones in-need embodies the definition of family, and people don't typically run from it, especially if there is no one else around. But it is not without a negative impact on a caregiver's quality of life.

Financial Concerns:

Caregivers spend time worrying about money issues. Without adequate resources the opportunity to hire outside help diminishes, and adds to worries about the future. Most caregivers wish to honor a family member's desire to stay at home. But there was also a worry expressed that institutional long-term care could deplete resources and leave them with significant financial stresses. They worried that the system would likely ask them to spend down, leaving very little to live on during the rest of their lives.

Health Concerns:

Caregivers recognize that their own health is often neglected while caring for their family member. There was a universal recognition that they were less active, carried more weight, and felt more fatigued. They were postponing their own medical care, if there was no backup for in-home caregiving. The concern seemed less about their own longevity, and more about their ability to continue providing care for their family member. Several mentioned the fear and possibility of reaching a “breaking point,” when their bodies would no longer allow them to continue in their role. Several wondered if they might die before their family member.

Quality of Life:

In response to questions about the family member’s quality of life, there was almost complete agreement that quality of life was fine for the person with dementia. Family members were clean, fed, and ultimately cared for. Yet, caregivers suffered loss of things that were meaningful to them, such as jobs, attending other family gatherings and engaging in other social activities. Multiple caregivers reported that their quality of life was more significantly diminished than that of their family member with dementia. There was the impression that he/she “did not know the difference.”

Conflicted Emotions:

Caregivers, as a group, appear to be somewhat conflicted in their emotions. They are committed to their family member based on love, family, tradition and an understanding that it is the right thing to do. Yet, over time this leads to fatigue, frustration, and a tension between caring for a loved one and their own sanity and survival. For example, participants worry about the future, and how much longer they can sustain their roles. They are conflicted between perceptions of the family member’s suffering and their own. By wondering how long their loved one will live, they wonder if they could be perceived to be wishing their family member gone. By asking the question, it’s like I’m wanting him to die. I feel so guilty about that. I wonder what’s best.”

They try to “stay in the moment.” At most they try to “stay in the day.” Yet the worries about future challenges makes that goal very difficult. As they are forced to stay in the moment by the repetitive nature of the care and often lonely, mundane tasks, they often think of both sides. They don’t want their family member to die, but in dark quiet moments, they know it will happen eventually. Thinking the thought makes it real, and makes some caregivers feel complicit.

Guilt:

Conflicted emotions are an expression of guilt. So much of the work is thankless, expected, grueling, repetitive and tedious. Caregivers feel guilty for speaking out loud about their own needs. Everything needs to be couched into “not wanting him to suffer,” and making sure his needs are met, even when they are pretty sure he “does not know the difference.” Caregivers don’t speak too openly about when this will “all be over.” They look forward to a time when his suffering will end. But it’s agonizing to admit “that’s when my suffering will end too.”

They feel guilty for not always identifying a sense of satisfaction for the opportunities to care for a loved one. Some were able to articulate some positive aspects about their caregiving role. For adult children caring for parents, there was a sense of gratitude and pay back for “what they did for me.” There was pride in doing it well. Others had a more difficult time articulating that sense of satisfaction. “Who knew I could learn to do so much? Who knew I was so competent?” Although this participant quickly added, “I’d rather not have to go through this to learn that I can do a good job. There are other ways.” Others admitted feeling trapped and restricted, leading to guilt, resentment and sadness.

Grief:

Dementia robs people of who they are before it ends their life. Caregivers recognize the loss of their partners, spouses and loved ones before an actual death occurs. This adds to the conflict and guilt on the part of caregivers, as the grief is often not in sync the multitude of losses. Grief is in response to loss of recognition and companionship, as well as in anticipation

of the death. Caregivers struggle with how to manage this, in the context of present caregiving needs.

The Unknown:

Caregivers frequently described gaps in their understanding of the future. Almost all caregivers report that their health care providers offer little or no information regarding prognosis or what to expect. Caregivers are left to research, read, “Google,” and guess. While it’s true that the science of prognostication is fraught with uncertainty, caregivers would enjoy more discussions with providers, even if it’s simply to affirm and share that uncertainty. The void in caregivers understanding of dementia’s trajectory results in additional stress and worry. When told that the prognosis might be anywhere between 4 and 8 years, and as long as 10 years, it interferes with the ability to plan, live normally and even grieve. The vague and unhelpful information overwhelms them. The only certainty they describe is that with every year the condition will only progress, the needs will only increase, and the burden will only feel heavier. Conflicting emotions, chronic smoldering loss of a partner or parent, and waning resources all lead to inner whispers of “wanting it to be over.”

Advocates for Change:

Caregivers are realistic and resilient. They are problem solvers and survivors. Yet, they acknowledge their journeys have been difficult, and wish to contribute to improved experiences for the caregivers who follow them. They have participated in this study to add their voice to others, in hopes of creating new solutions to the struggles they have described here.

The Grounded Theory approach allows a second look at the literature. Caregiver stress, and more specifically “Caregiver Syndrome,” have started to appear in the writings of advocates and those familiar with caregiver issues. While medical literature has historically identified caregiving to particular negative outcomes, conclusions have not definitively linked caregiving,

itself, as the culprit. Rather it is theorized that the individual's perception of stress and strain is what leads to declines in overall health and potential early death. Yet, it has been reported that up to 18% of caregivers die before their family members with dementia, in spite of having lower mortality risks.

Caregiver Syndrome has been referred to as a debilitating condition, triggered by unrelieved constant care of someone with dementia or other chronic illness. It is characterized by physical, mental and emotional exhaustion, and may manifest as anger, rage or guilt. These are the characteristics demonstrated by the caregivers in this study. Physical and emotional demands, social isolation, financial insecurity, anticipatory grief, and uncertainty about the future lay the foundation for this particular condition.

Summary of Final Theory: Caregiving is a Condition

- Caregiving is not just something these individuals do, it is what they become, it becomes them
- Caregiver Syndrome is a debilitating condition triggered by unrelieved constant care of someone with dementia or other chronic illness
- Caregiver Syndrome is characterized by physical, mental and emotional exhaustion, and may manifest as anger, rage or guilt
- Caregiving imposes a set of circumstances and conditions that lead to medical complications, bypassing the step of labeling "stress" as the culprit.
- 18% of caregivers die before their family members with dementia, in spite of having lower risks of mortality.

Conclusions

Informal caregivers of older adults with dementia experience significant physical and emotional stresses that result in concerns about their overall wellness. This, in-turn, impacts their ability to function as sustainable caregivers for their family members at home. Lack of reliable and sustainable in-home personal care supports, patient companionship and respite for the caregiver result in excess worry, stress and loss of quality of life for the caregiver. Over a

trajectory of years, inherent in the dementia diagnosis, informal caregivers are likely to encounter negative physical and mental health outcomes. The ongoing lack of support for caregivers ultimately leads to more challenges in meeting the overall needs of this vulnerable population, whose numbers will only increase during the upcoming years and decades.

Without recognition of the significant role played by caregivers in keeping dementia patients safe, well-cared for and supported at home, we are headed toward a non-sustainable situation, “a crisis,” as identified by one of the participants. The present system is broken, short-sighted, and fails on so many levels. A positive change can only happen with a resetting of the way we take care of these patients, as a health care system. Some suggestions for medical providers, policy makers and advocates to improve the experiences of patients with dementia and their caregivers include the following:

- Move the lens from the patient exclusively, but rather to the “dyad” of the patient and caregiver, as a singular unit. Recognizing the importance of this relationship and supporting it will result in better outcomes for the patient.
- Invest resources and research into a better understanding of caregiver stress. This includes further study of the Caregiver Syndrome, and the impact it has on the overall wellness and health outcomes of caregivers.
- Evaluate the present structural and reimbursement mechanisms for medical care of dementia patients in home care settings in existence today, which include the skilled Medicare home health benefit and the Medicare Hospice Benefit. Explore the limitations of each and consider ways to fill gaps in services and access that would support caregivers, as well as patients.
- Consider ways to expand access to caregiver supports and respite services through collaboration with community resources. Some examples are the Area Agencies on Aging, the local Alzheimer’s Association and volunteer services embedded within local hospice Programs.
- Explore enhanced models of home-based service delivery that incorporate clinical services and case management, in home personal care aides, with psychosocial supports for both patient and caregiver. One current example in process is L.D. 1064,

An Act to Advance Palliative Care Utilization in the State, passed in 2021. According to the World Health organization, Palliative Care “improves the quality of life of patients and their families who are facing life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.” The cornerstones of palliative care are communication, information-sharing, goal setting and the delivery of interventions to support quality of life for patient and their caregivers, through collaboration with traditional medical providers and community-based resources.

References

- 2022 Alzheimer's disease facts and figures. (2022). Retrieved April 9, 2022, from <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>
- AARP, N. A. for C. (2020, May 14). *Caregiving in the United States 2020*. AARP. Retrieved January 4, 2022, from <https://www.aarp.org/ppi/info-2020/caregiving-in-the-united-states.html>
- Barron, Rosenberg, & Mayoras. (2022, January 24). *How to address Caregiver Syndrome: BRMM Elder Law Attorneys*. Barron, Rosenberg, Mayoras & Mayoras P.C. Retrieved April 6, 2022, from <https://www.brmmmlaw.com/blog/2022/january/is-caregiver-syndrome-a-real-medical-diagnosis/>
- Bom, J., Bakx, P., Schut, F., & van Doorslaer, E. (2018). The impact of informal caregiving for older adults on the health of various types of caregivers: A systematic review. *The Gerontologist*. <https://doi.org/10.1093/geront/gny137>
- Botek, A.-M. (2021, November 18). *The dangers of broken heart syndrome*. AgingCare.com. Retrieved April 5, 2022, from <https://www.agingcare.com/Articles/broken-heart-syndrome-156250.htm>
- Charmaz, K. (2014). *Constructing grounded theory*. SAGE Publications Ltd.
- Chun Tie, Y., Birks, M., & Francis, K. (2019). Grounded Theory Research: A design framework for novice researchers. *SAGE Open Medicine*, 7, 205031211882292. <https://doi.org/10.1177/2050312118822927>
- Cohen, L. S. (2011). The takotsubo (broken heart syndrome). *Translational Vascular Medicine*, 129–136. https://doi.org/10.1007/978-0-85729-920-8_8
- Corbin, J. M., & Strauss, A. L. (2015). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. SAGE.
- Craven, M. (2021). *An Act to Advance Palliative care utilization in the State, L.D. 1064, 130th Maine Legislature, First Session-2021*. legislature.maine.gov. Retrieved January 8, 2022, from <https://legislature.maine.gov/LawMakerWeb/summary.asp?ID=280079571>
- Douthit, N., Kiv, S., Dwolatzky, T., & Biswas, S. (2015). Exposing some important barriers to health care access in the Rural USA. *Public Health*, 129(6), 611–620. <https://doi.org/10.1016/j.puhe.2015.04.001>
- Gaugler, J. E., Jutkowitz, E., Peterson, C. M., & Zmora, R. (2018). Caregivers dying before care recipients with dementia. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, 4(1), 688–693. <https://doi.org/10.1016/j.trci.2018.08.010>
- Gibson, A., Holmes, S. D., Fields, N. L., & Richardson, V. E. (2019). Providing care for persons with dementia in rural communities: Informal caregivers' perceptions of supports and services. *Journal of Gerontological Social Work*, 62(6), 630–648. <https://doi.org/10.1080/01634372.2019.1636332>
- Hoda, R., Noble, J., & Marshall, S. (2010). Using grounded theory to study the human aspects of software engineering. *Human Aspects of Software Engineering on - HAoSE '10*. <https://doi.org/10.1145/1938595.1938605>
- Kasper, J. D., Freedman, V. A., Spillman, B. C., & Wolff, J. L. (2015). The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Affairs*, 34(10), 1642–1649. <https://doi.org/10.1377/hlthaff.2015.0536>

- Kelley, A. S., & Morrison, R. S. (2015). Palliative care for the seriously ill. *New England Journal of Medicine*, 373(8), 747–755. <https://doi.org/10.1056/nejmra1404684>
- Lindeza, P., Rodrigues, M., Costa, J., Guerreiro, M., & Rosa, M. M. (2020). Impact of dementia on informal care: A systematic review of family caregivers' perceptions. *BMJ Supportive & Palliative Care*. <https://doi.org/10.1136/bmjspcare-2020-002242>
- Ornstein, K. A., Wolff, J. L., Bollens-Lund, E., Rahman, O.-K., & Kelley, A. S. (2019). Spousal caregivers are caregiving alone in the last years of life. *Health Affairs*, 38(6), 964–972. <https://doi.org/10.1377/hlthaff.2019.00087>
- Piesyk, C. (2007, August 23). *Caregiver Syndrome: Realty for many caregivers dealing with dementia*. Clarkvilleonline.com. Retrieved April 19, 2022.
- Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. *The Gerontologist*, 55(2), 309–319. <https://doi.org/10.1093/geront/gnu177>
- Wagner, C., & Kassner, C. (2016, November 4). *Prevalence of palliative care in Maine*. Maine Hospice Council. Retrieved January 3, 2022, from https://mainehospicecouncil.org/images/Palliative_Care_Market_Research.pdf
- WHO. (2020, August 5). *Palliative care*. World Health Organization. Retrieved January 7, 2022, from <https://www.who.int/news-room/fact-sheets/detail/palliative-care>
- Zwaanswijk, M., Peeters, J. M., van Beek, A. P. A., Meerveld, J. H. C. M., & Francke, A. L. (2013). Informal caregivers of people with dementia: Problems, needs and support in the initial stage and in subsequent stages of Dementia: A Questionnaire Survey. *The Open Nursing Journal*, 7, 6–13. <https://doi.org/10.2174/1874434601307010006>