

Caring for Patients with Cognitive Diseases: Grief and Loss Examined

by Stephen Milburn

As of 2020, approximately 5.8 million Americans are estimated to be suffering from Alzheimer's disease; with current trends, the figure is likely to double every 20 years.¹ Their age range, while generally skewing towards the elderly, also includes roughly 250,000 younger individuals under the age of 65 dealing with the effects of early-onset Alzheimer's disease.² Additionally, these statistics do not take into account those enduring a host of other cognitive diseases with effects similar to Alzheimer's. Terms such as Alzheimer's and dementia are now part of our common medical vocabulary, and many people have personally witnessed these diseases at work in their loved ones and communities.

Yet, there is relatively little conversation about the effects that caring for these individuals can have on the caretaker. The forms of loss and grief experienced by the caretaker are not at the forefront of our collective consciousness because they are not broadly associated with the culturally normative circumstances under which loss is considered to occur (i.e. death). For the purposes of this paper, I will examine the ways in which the caretakers of those suffering from cognitive decline experience loss, how our broader culture impacts that experience, and what we can do to support individuals in these arduous positions.

Like many forms of loss, the kind related to the degeneration of cognitive faculties is not a singular loss, but rather a series of ongoing losses that are not "concrete" in nature. There is a long period of many years where there is no physical death involved to delineate the point in time when the caretaker is now done with their

¹ Alzheimer's Association, "Facts and Figures," <https://www.alz.org/alzheimers-dementia/facts-figures>, accessed May 2020.

² Ibid.

care of the loved one, and may now occupy their time and energy with mourning, self-reflection, and the constructive incorporation of the loss into their psyche. The losses faced by caregivers are dynamic and ever changing throughout the arc of their loved one's illness.

Which other memories will be forgotten with each new day? What changes in their personalities might manifest? Will they be relatively pleasant to care for today, or will some unknown factor(s) propel them into a state of irritability and a refusal to cooperate with their care routines? Disruptions in the patient's sleep cycle due to the phenomenon of sundowning may even lead to regular losses in sleep for the caregiver themselves. On a holistic level, this can have major impacts on their overall wellbeing and further contributes towards the likelihood of burnout. It is for this reason (among others) that caregivers are often called "the invisible second patient" in the medical field.

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The nature of cognitive decline can even force caregivers to confront ontological dilemmas: What is the nature of the self? Is my loved one still themselves even though their personalities and memories are no longer the same? Are their cruel words indicative of something deeper within their psyche that they were masking before the onset of the illness, or is this just an effect the illness has upon the brain that has no relationship to their fundamental selves? Furthermore, given the ways these diseases can ravage the patient's personality, is there even a fundamental self to begin with?

³ Brodaty, Henry, "Family Caregivers of People with Dementia," *Dialogues in Clinical Neuroscience*, 2009.

Spiritual concerns may arise as a result of these lines of questioning that may require some direction from local clergy and lay leaders if the caregiver belongs to a religious community. This reveals the ways in which illness can culminate in existential anxieties that extend beyond the concerns of physical health. Given the impact serious illness can have upon our lives, it should come as no surprise that it frequently strikes at the heart of what it means to be human.

The losses here are multitudinous and complex. In this sense, there may be an overlap of chronic sorrow and ambiguous loss at the same time. They may be physically present, but the progressive decay of their cognitive abilities makes it seem like loss in the traditional sense (i.e. death) has already occurred. Alzheimer's and dementia are considered terminal diseases, and while the average patient survives around 4-8 years after their diagnosis, there have been a number of cases in which people have lived for as long as 20 years with these diseases depending on the circumstances; hence the prospect for a clinical diagnosis of chronic sorrow for caregivers.⁴

Since the duty of caregiving requires a great deal of self-sacrifice, the caregiver's own needs are in danger of being neglected. This is one of the pitfalls of such incredible displays of self-sacrifice, and the caregiver's risk of developing mental health concerns of their own greatly increases the longer their needs are left unattended to. The evidence surrounding burnout indicates that self-care is a necessity in other-care.⁵ A study conducted in 2018 found that training caregivers in mindfulness based practices

⁴ "Alzheimer's: Facts and Figures," <https://www.alz.org/alzheimers-dementia/facts-figures>, accessed May 2020.

⁵ Alves, Ludmyla et al., "Burnout Syndrome in Informal Caregivers of Older Adults with Dementia: A Systematic Review," *Dementia and Neuropsychologia*, 2019.

and emotional awareness significantly increased positive outcomes with regard to caregiver stress, and by proxy, reduced the possibility of burnout.⁶ While additional evidence is needed on the benefits of such practices in order to make more conclusive assessments, the need to equip caregivers with the tools for providing sustainable care remains obvious.

Yet, even though we can equip caregivers with tools at the individual level, larger systemic issues create significant barriers for caregivers. The state of the United States healthcare system provides a striking example. At present, costs related to medical expenses are one of the leading causes of bankruptcy within the United States.⁷ Many people cannot afford to provide full-time, professional care for their loved ones struggling with cognitive decline. Indeed, in many of the more advanced cases near 24 hour care is needed. An economic loss can accompany this - if one cannot afford full-time care in the form of nursing facilities or home visits from qualified professionals, one may be forced to forego employment to take care of their loved one. With the advent of the radical changes to the social fabric of society that occurred throughout the 20th and into the 21st century, dual incomes became a necessity for many households.⁸ The financial risk posed to individual households on account of these conditions is staggering.

⁶ Berk, Lotte et al., "Mindfulness Training for People With Dementia and Their Caregivers: Rationale, Current Research, and Future Directions," *Frontiers in Psychology*, 2018.

⁷ David U. Himmelstein MD et al., "Medical Bankruptcy: Still Common Despite the Affordable Care Act," *American Journal of Public Health*, February 2019.

⁸ Leonce, Tesa E, "The Inevitable Rise in Dual-Income Households and the Intertemporal Effects on Labor Markets," *Compensation and Benefits Review*, January 2020.

Arguably, wage stagnation, which frequently necessitates relocating for another job in order to gain a significant pay raise, has left many people unable to rely on the nearby support of extended family for child care or elderly care purposes. This has been shifted onto costly preschools, daycare centers, and nursing homes. Indeed, caring for other members of the family unit does not cease in these circumstances, and the costs add up at incredible rates. As of 2003, the global cost of dementia hovered around \$156 billion USD, or around \$5,000 USD per patient.⁹ Full-time care in an assisted living facility averages around \$4,000 a month within the U.S. - a staggering amount that relatively few families can afford.

Of course, this number has only increased since then as healthcare costs and inflation continue to rise. In a society which frequently demands dual incomes, the loss of one job in a household can have devastating effects for the family unit. A survey conducted in 2007 found that a quarter of caregivers for patients experiencing cognitive decline spent upwards of 40 hours of care or more a week - on par with a full-time job.¹⁰

Furthermore, these examples do not take into consideration that these burdens might multiply in single parent households or families which belong to communities already dealing with larger systemic issues (e.g. poverty, racism, limited healthcare access). In this sense, losses do not occur in a vacuum or in a linear fashion - multiple losses may be experienced at once within a complex web of social and material conditions.

⁹ Brodaty, 2009.

¹⁰ Ibid.

A study conducted by the NORC Center for Public Affairs Research found that 33% of caregivers experience mental health struggles and have foregone doctor visits for their own health concerns on account of their caregiving duties.¹¹ This is especially significant given that around 34% of caregivers are 65 years or older and part of a vulnerable population that is more at risk for developing health problems due to their own experiences with the aging process.¹² All of these examples illuminate the ways in which this form of loss is both multivalent and multifaceted - there is not only the possibility of mental, physical, and emotional devastation, but economic burden as well.

I believe the statistics surrounding caregivers also highlight additional factors that must be taken into consideration. For instance, the “typical profile of a dementia caregiver is a middle-aged or older female, and in the US, at least 60% of unpaid caregivers are wives, daughters, daughters-in-law, granddaughters, and other female relatives.”¹³ This perhaps points towards the patriarchal attitudes that still operate within our cultural matrix. While the number of male caregivers is increasing each year, women still seem to be expected to provide the bulk of the caregiving and emotional labor. In a society that champions individualism over collectivism and larger kinship networks, one wonders how much support these women are receiving in their caregiving efforts, or if they are relatively unsupported compared to other cultures which may provide access to better social resources for this kind of care.

¹¹NORC Center for Public Affairs Research, “Adult caregivers Overwhelmed and Undertrained,” <http://www.apnorc.org/news-media/Pages/AP-NORC-Poll-Adult-caregivers-overwhelmed-and-undertrained.aspx>, accessed May 2020.

¹² Ibid.

¹³ Brodaty, 2009.

This is not to say that developing countries are experiencing ideal conditions for providing care of this type, however. Healthcare costs, already a burden in the U.S., continue to be a greater burden in developing countries where even less government support or financial means for such care may be available. For example, in Nigeria, 84% of caregivers have cut back on work to care for family members with dementia while receiving little to no governmental support.¹⁴

The question remains: what can we do to advocate for caregivers? First and foremost, I think the cultivation of an awareness of these issues must be the starting point. I do not think the problem is that most people are not aware of the fact that it is incredibly difficult to care for someone enduring cognitive decline; quite the opposite, I think that is commonly understood. However, it is all of the compounded issues which I have listed throughout this paper that people might not be aware of in addition to the fact that many of them may be occurring all at once for particular demographics. Advocacy begins with awareness. Through the development of a richer vocabulary for understanding and discussing their experiences, the more we can respond empathically, authentically, and with competency.

I think undoing some of the stigma surrounding caregiving can help as well. While it is no doubt difficult and exhausting work, the work of caregiving may not entirely be a position occupied by constant sorrow. Many caregivers also report positive feelings and associations with their work, such as “the experience of enjoying togetherness, sharing activities, feeling a reciprocal bond, spiritual and personal growth, and feelings

¹⁴ Ibid.

of accomplishment or mastery.”¹⁵ The ways in which a caregiver views their role are determined by a variety of personal, cultural, and societal factors. One person may feel trapped in their role and burdened by a sense of guilt-laden duty, while another may feel deep satisfaction in fulfilling their duties through the honor and care of another family member. The ways which various cultures may experience and respond to caring for individuals must also be closely examined.

The organization of activist efforts in one’s own community is also a powerful way to support caregivers. Even if it’s just training your volunteers how to provide a non-anxious presence, the practice of deep and intentional listening can go a long way in helping someone feel supported. This is a kind of disenfranchised grief since it is not directly addressed by the culture at large. It may be in our collective sphere of awareness to some degree, but there is a dearth of rites, rituals, and institutions that effectively communicate the realities of the caregiver’s experience or address their fundamental needs. Even just beginning to have these discussions constitutes the first stepping stone in honoring their struggles and lived experiences.

Encouraging your volunteers to be on the lookout for people within their own communities who might be a caregiver for someone with Alzheimer’s or dementia, and offering to equip them with supportive resources is a great start. We can research resources that might be available to equip people with the skills necessary to provide care while lowering the risk for burnout (for example, the National Alzheimer’s and Related Dementias Education and Referral Center). We can also continue to be

¹⁵ Ibid.

advocates for healthcare reform at local, state, and national levels. Building a strong support system is essential for the wellbeing of caregivers, and local community institutions provide fertile grounds for the construction of these systems in light of a society which is becoming increasingly more atomized. There is a strong incentive for us to continually ask ourselves who the “invisible second patients” of our culture might be as we go forward in our lives.

Bibliography

1. Alves et al., "Burnout Syndrome in Informal Caregivers of Older Adults with Dementia: A Systematic Review," *Dementia and Neuropsychologia*, 2019.
2. Alzheimer's Association, "Facts and Figures," <https://www.alz.org/alzheimers-dementia/facts-figures>, accessed May 2020.
3. Berk, Lotte et al., "Mindfulness Training for People With Dementia and Their Caregivers: Rationale, Current Research, and Future Directions," *Frontiers in Psychology*, 2018.
4. Brodaty, Henry, "Family Caregivers of People with Dementia," *Dialogues in Clinical Neuroscience*, 2009.
5. David U. Himmelstein MD et al., "Medical Bankruptcy: Still Common Despite the Affordable Care Act," *American Journal of Public Health*, February 2019.
6. Leonce, Tesa E, "The Inevitable Rise in Dual-Income Households and the Intertemporal Effects on Labor Markets," *Compensation and Benefits Review*, January 2020.
7. NORC Center for Public Affairs Research, "Adult caregivers Overwhelmed and Undertrained," <http://www.apnorc.org/news-media/Pages/AP-NORC-Poll-Adult-caregivers-overwhelmed-and-undertrained.aspx>, accessed May 2017.