


# Conflicts Experienced by Caregivers of Older Adults With the Health-Care System

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## Abstract

**Background:** Family caregivers of older adults frequently navigate the health system for their loved ones. As older adults experience more medical issues, the interactions between caregivers and the health system can be fraught with conflicts. **Objective:** To characterize the conflicts that caregivers of older adults experience with the health-care system. **Methods:** A cross-sectional national online survey with open-ended questions was conducted among family caregivers ascertaining experiences with the health-care system. Qualitative thematic analysis was completed using constant comparative analysis and review by a third author. **Results:** Over a 2-month period, 97 caregivers completed the survey. Common themes where caregivers experienced conflicts were Difficulty With Accessing/Communicating With Providers, Delivery of Emergency Care, Disjointed Transitional Care, Unaddressed Clinical Concerns, and Financial. Caregivers reported needing to act as patient advocates in the conflicts with the health-care system. **Conclusion:** Understanding the conflicts that family caregivers encounter with the health system provides potential targets for future interventions to combat the challenges faced by caregivers of older adults and ultimately improve delivery of geriatric care.

## Keywords

older adults, caregivers, conflicts, health care

## Introduction

As people live longer, the prevalence of chronic disease and complex medical conditions with subsequent hospitalizations is on the rise. Not surprisingly, many older adults rely on family caregivers to function on a day-to-day basis and complete health-related task (1,2). In 2017, 22% of adults older than 85 years needed “help with personal care,” compared to 9% of adults aged 75 and 84 years and only 3% of adults aged 65 and 74 (1). Family caregivers by definition include spouses, children, parents, relatives, or loved ones, who provide assistance that is above what is typical in that relationship (3). Caregivers often experience burden from their respective roles, which is associated with decline in caregivers’ physical health, mental health, and health-related quality of life (4). Caregiver burden also has an effect on patient health care; increased burden has been shown to negatively impact patients’ emotional affect, interfere with how well caregivers assess patient pain and other symptoms, and influence long-term medical decision-making for patient

(5–7). Contributing to their burden, caregivers frequently have to interact with the health-care system. Examples of these interactions are scheduling medical appointments, talking with health-care providers, obtaining medications, handling insurance concerns, and repetitive billing. The term “health-care system” includes health-care providers (including physicians, nurses, therapists, pharmacists, other staff members), private health insurance companies, government-based insurance systems, hospitals, pharmacies, clinics, nursing facilities, and so on.

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In the health-care system, caregivers commonly play the role of “patient advocate” in conflicts as they fight for optimal care for their loved ones (8–10). The term “conflict” is defined as a struggle, serious disagreement, or argument between at least 2 people. Caregivers of older adults awaiting hospital discharge reported needing to intervene and “work the system” to ensure their loved ones were placed in an appropriate long-term care facility and that their personal care needs are met (11). A similar theme was echoed from caregivers of patients with mental illness who needed to fight for access to crisis-related services and learn how to make themselves heard by providers who tried to wave away their concerns (12). Besides these articles, very little is known about the conflicts that caregivers experience from a caregiver perspective.

Prior research has asked caregivers to discuss what, from their perspective, make up the components of quality health care (13–16). A study in 2018 analyzed the interactions of health-care professionals and caregivers from the perspective of health-care providers (9). However, this is the first study that aims to characterize how caregivers of older adults face conflict within the health-care system and delineate possible targets for improvement.

## Methods

### Design and Sample

Data were compiled from a national public survey administered in 2017 by Caregiving.com, a third party non-profit organization that provides support and resources to caregivers throughout the United States. The survey included questions about demographic information and aspects of caregivers’ specific roles such as length of time as a caregiver, time spent daily as a caregiver, how often other family members assist in caregiving, and ability to care for their own physical, emotional, and health needs. Open-ended questions were asked about experiences with the health-care system in providing care to their older adult.

### Analysis

Following survey completion, open-ended responses were qualitatively analyzed using constant comparative analysis and tiebreak (A.R., L.A.L., V.R.-Z.). Each coder reviewed the responses separately and during the coding process, each participant’s response could be assigned to more than one category. The categories were then consolidated into a set of specific themes that reflected participants’ responses accurately (17). Descriptive statistics were used to analyze the quantitative responses (18). This study was considered exempt by the institutional review board of Northwestern University.

**Table 1.** Demographics of Caregiver Respondents.

| Variable                             | N = 97     |
|--------------------------------------|------------|
| Age (years)                          |            |
| 21-34                                | 8.3% (8)   |
| 35-49                                | 21.7% (21) |
| 50-59                                | 30.9% (30) |
| 60-69                                | 27.8% (27) |
| 70 and older                         | 11.3% (11) |
| Female                               | 90.7% (88) |
| Education                            |            |
| Less than high school degree         | 1.0% (1)   |
| High school degree or equivalent     | 5.1% (5)   |
| Some college but no degree           | 28.9% (28) |
| College or higher degree             | 64.9% (63) |
| Married                              | 72.2% (70) |
| Offspring living at home             | 16.5% (16) |
| Number of care receivers             |            |
| 1                                    | 72.9% (70) |
| 2                                    | 20.8% (20) |
| 3 or more                            | 6.2% (6)   |
| First time as a caregiver            | 53.7% (51) |
| Second time as a caregiver           | 26.3% (25) |
| Third or more time as a caregiver    | 19.0% (19) |
| Length of time as a family caregiver |            |
| Less than 1 year                     | 6.0% (7)   |
| 1-2 years                            | 5.7% (5)   |
| 2-5 years                            | 38.6% (34) |
| 5-9 years                            | 23.9% (21) |
| More than 10 years                   | 23.9% (21) |

## Results

A total of 97 adult caregivers participated in the national survey, with the majority being female (90.7%) aged 50 and 69 years (58.8%). Most participants (72.2%) were married and 16.5% had children living at home. With regard to caregiving, 72.9% had 1 care receiver per caregiver, 20.8% had 2, 5.2% had 3, and 1.0% had 4 or more. Only 14.6% were reimbursed for providing care. In terms of weekly time spent caregiving, 53.4% reported providing care 24/7, 3.4% spent about 40 hours, 9.1% spent between 20 and 40 hours, 9.1% spent between 10 and 20 hours, 6.8% spent between 1 and 10 hours, and 18.2% spent less than 10 hours. Chronic illness in the caregiver was reported by 35.2% of participants.

When asked how often other family members assist with providing care, 8.6% of caregivers reported several times a week, 12.4% reported once a week, 11.1% reported several times a month, 11.1% reported once a month, 9.9% reported 3 or more times a year, and 46.9% reported that family members did not help with caregiving. Reasons for why relatives did not help with caregiving include that the relatives live out of town (45.8%), the caregiver is the only adult child or only healthy relative (19.4%) and that relatives have refused to help when asked to do so (23.6%; Table 1).

The majority (57.7%) of participants reported not taking adequate care of their own physical, emotional, dental, and emotional needs (see Table 2). Reasons reported for this lack

**Table 2.** Caregiver Experiences With Health Care.

| Theme  | Supporting Quotes   |
|--|---|
| Communication<br>With and<br>Access to<br>Physicians | “Doctor sees husband for 15 minutes every 3 months but no other contact and when I try to discuss what I see is going on with him she shuts the conversation down.”   |
| Emergency<br>Department<br>Care                      | “Twice the ER has sent [my 93-year-old mother] home and I had to turn around and take her back and fight to get her admitted.”<br>“Many trips to the ER with my 93-year-old mother and they do not treat the elderly with care, compassion, or concern.”  |
| Transitional<br>Issues                               | “I don’t understand why ailing people are discharged from hospitals before they are well; you want your loved one to be nearby but I’ve found the best skilled nursing facilities are not easily accessible.”<br>“Getting additional help at home is impossible in the rural area that we live in.”   |
| Medications<br>Diagnosis                             | “With the new laws on pain medications there is more paperwork and hassle. Dealing with medical system to get prescriptions refilled now is a nightmare that occurs on a monthly basis”<br>“I have been able to catch some [medication mistakes] before they happened (about to perform a medical procedure while still on blood thinners) and I have had to deal with them after they happened (seizures due to anti-seizure not being administered)”<br>“Our original neurologist was very frustrating and would ask me what I thought his diagnosis should be.”  |
| Finance  | “Billings for services are never quite understandable and cause stress when hospital bills us but insurance company says we don’t owe bill.”<br>“My mother doesn’t have Medicare part B and her private insurance has a high copay. She doesn’t have any savings and it was a horrible experience trying to pay off her doctors’ bills and move her into an assisted facility last year.”<br>“Sometimes I just pay out of pocket just to not have to beg someone to approve what’s already been approved.”<br>“Vultures who take advantage of her very good insurance without actually providing her with very good care” |

of self-care include not having the energy (43.6%), “something’s got to give and that is what gives” (65.5%), not having health insurance (18.2%), and not having a backup plan to care for their loved one (29.1%). This lack of time and energy could be considered a proxy for the amount of personal burden experienced as a result of caregiving and advocating for the care recipient.

Thirty-three participants provided narrative comments to the question “How would you describe your experience with

the healthcare system?,” which reflected overall experiences and the ensuing conflicts.

### *Overall Themes of Experiences With the Health-Care System*

A common overall theme identified was that caregivers discussed stress and frustration associated with their experiences with the health-care system. A few of the thematic reasons behind the frustration were lack of control in health-care decision-making, disappointment associated with poor care, paucity of high-quality nursing or assisted living facilities, and struggles as a long-distance caregiver. “It can be frustrating when I am the long distance caregiver and checking in on their situation.” “No matter how many times [my mother] gets disappointed [in the healthcare system] and I tell her it is unrealistic, it’s very difficult to see her frustration and it makes her judge the system.”

Reinforcing prior research, caregiver subjects remarked on the necessity of personally advocating for their care receivers within the health-care setting. “I take detailed notes and photo document everyone. Keeps them on their toes.” “My very active involvement has been a must. I am my mother’s ‘voice’ and her advocate.” Another overall theme was that caregivers discussed extensive interactions and conflicts with physicians, nurses, and insurance companies, including having to confirm and clarify medications, calling for new supplies, and taking notes at doctor appointments. These interactions and conflicts with the health-care system were identified as being time-consuming and time-wasting.

*Themes of conflicts between caregivers and the health-care system.* As a result of the qualitative analysis, we identified specific themes of the conflicts experienced (1) Difficulty With Accessing/Communicating With Providers, (2) Delivery of Emergency Care, (3) Disjointed Transitional Care, (4) Unaddressed Clinical Concerns, and (5) Financial Conflicts (Table 2).

#### *Theme #1: Difficulty With Accessing/Communicating With Providers*

The most commonly reported conflict was related to accessing and communicating with physicians, an issue mentioned by 12 (36.4%) participants. Issues with access included difficulty receiving timely responses from physicians and accessing physicians, particularly specialists, in nonurban areas. Finding a health-care provider who communicates empathetically with patients and families was another significant challenge noted by multiple respondents.

#### *Theme #2: Delivery of Emergency Department Care*

One of the themes that emerged from the survey responses was related to conflicts and care within the emergency department. Caregiver participants brought up this issue

specifically that treatment of the elderly in the emergency department had been substandard and nongeriatrics focused with providers who appeared to lack compassion or concern for their older adults.

### **Theme #3: Disjointed Transitional Care**

The transitions from inpatient care to a skilled nursing facility and eventually to home health care were a broad source of conflicts. For example, participants commented on hospital stays that were either too long or too short, lack of proximity to high-quality nursing facilities, and limited access to home health care.

### **Theme #4: Unmet Clinical Concerns (Medications and Diagnoses)**

Problems relating to medications for care receivers were discussed as a source of conflict. Specifically, medication issues revolved around the transition of medications from the inpatient to outpatient setting, side effects or adverse events due to medication use, obtaining medication refills in a timely fashion, and multiple comorbidities resulting in contraindications to the use of certain medications. Caregivers commented on diagnosis-related issues for their care receivers, including difficulty obtaining a clear diagnosis, lack of provider knowledge necessary to make a diagnosis, and providers lacking hope for improvement in certain medical situations or diagnoses.

### **Theme #5: Finance**

Financial conflicts associated were common among the caregiver respondents. Caregivers perceived health-care providers and insurance companies as greedy, and also commented on expensive co-pays, difficulty obtaining health insurance, and confusing/conflicting hospital bills.

## **Discussion**

In their own words, caregivers frequently experience conflicts with the health-care system that necessitate them being an active advocate for their older adult loved one. It is important to know about these conflicts as they likely contribute emotional stress, frustration, time drains, and burden to the life of the family caregiver. Given that caregivers are often the frontlines of communication with health-care providers, having a nuanced understanding of caregivers' experiences and conflicts with the health-care system is highly valuable.

With our sample, many of the conflicts could have been remedied, which would be less stressful to caregivers. The most common issue that arose in this survey was related to quality of communication and access to health-care providers. In particular, caregivers commented on physicians interacting solely with the patient during visits without inquiring about or considering the caregiver's point of view.

In most situations, the caregiver is able to provide key information about the patient's health that can influence treatment plans and decision-making. Asking caregivers directly "How are you doing?" or "What do you think?" could help engage them in the discussion and affirm the caregiver's role as a vital member of the patient's team. Also, designating a point person for the physician to call after or during the appointment may improve physician communication with the caregiver and keep the caregiver in the loop with regard to medical updates or changes. Calling during the appointment would reduce the need for the physician to call after the appointment while allowing the caregiver and patient to ask clarifying questions and ensuring everyone is on the same page, thereby addressing the needs and concerns of the patient as advocated by the caregiver.

Care specific to a location of health-care delivery (eg, in the emergency department, transitioning from hospital) reflected a number of conflicts. With emergency care, there are more health systems that are embracing a geriatric emergency department which consists of staff trained in the needs of older adults. Research has shown that emergency departments with geriatrics-trained nurses can provide higher quality care to older adults which might help remedy the caregiver conflicts (<sup>19,20</sup>).

A consistent theme was the need for caregivers to actively advocate and fight for their older adults to ensure that they received the correct medications and diagnoses. Essentially, the caregiver had to fight to protect their loved ones from being adversely affected by the health-care system. This fact is somewhat counterintuitive as most people seek health care to feel better, but with the nature of complex medical treatments, it is widely known that medical errors do occur. With older adults who may not question their health care, the caregiver is vital to catching medical errors and syncing care between multiple providers. Caregivers in our sample commented on frustration with their loved ones' chronic, incurable medical diagnoses for which medical therapy has not shown significant improvement. A more robust geriatrics education could help create more opportunities for physicians to be adequately trained and equipped to care for older adults and their caregivers. It can also enhance referral to geriatricians, thereby adding a level of specialized support for patients and their families. Even though some diseases such as Alzheimer are currently incurable, there are issues with the support system currently in place for caregivers that can be remedied and improved.

A key strength of this study is its focus on the narrative caregiver experience. The structure of the survey itself allowed for participants to express themselves fully without worries of judgment or repercussions. The survey participants were diverse in demographics such as age, education level, and socioeconomic status. One limitation of this study is that a large majority of the participants were female; it is difficult to say if our results would be different with a more

equal representation of male and female responses. Given that this survey was administered by a national nonprofit organization, our sample is not geographically skewed and represents caregivers throughout the United States. However, this means that our sample is primarily representative of caregivers with access to caregiving resources such as Caregiving.com. It is possible that caregivers unfamiliar with such resources and without access to a supportive caregiver community would have different experiences with the health-care system, experiences that are not necessarily represented by this study's findings.

## Conclusion

This qualitative research provides a larger understanding of how caregivers experience conflicts within the health-care system and has implications for improving the care of older adults. Future steps building from this research can focus on interventions targeting areas of conflict and providing caregivers with better support in handling these conflicts. Ideally, a conflict-free health system that provides the needed support for both caregivers and older adults would enable a better quality health care.

## Authors' Note

The research was considered exempt by the institutional review board at Northwestern University. Informed consent was not obtained since the information obtained was collected in such a manner that the identity of the subjects could not be ascertained, directly or indirectly.

## Declaration of Conflicting Interests

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