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Authors

Thai, Julie N
Barnhart, Caroline E
Cagle, John
[et al.](#)

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“It just consumes your life”: Quality of Life for Informal Caregivers of Diverse Older Adults with Late-Life Disability

Julie N. Thai, MPH¹, Caroline E. Barnhart, BA^{1,2}, John Cagle, MSW, PhD³, and Alexander K. Smith, MD, MS, MPH^{1,2}

¹University of California, San Francisco

²San Francisco VA Medical Center

³University of Maryland, Baltimore

Abstract

Objective for the study—Our objective was to generate hypotheses about factors affecting QoL assessments for informal caregivers of diverse older adults 65+ with late-life disability.

Results—Overall, 52% of caregivers experienced a decline in QoL. Factors affecting caregivers' QoL were grouped into 4 domains: social, emotional, physical and financial. Factors associated with decreased QoL were less time for self, competing financial demands, and the physical and emotional impact of the patient's illness. Factors associated with no change in QoL were minimal caregiving responsibilities, a sense of filial duty, and QoL being consistently poor over time. Factors associated with improved QoL were perceived rewards in caregiving, receiving institutional help, and increased experience. Chinese caregivers were more likely to cite filial duty as their motivator for continued caregiving than were Caucasian caregivers.

Conclusion—Informal caregivers take on a huge burden in enabling older adults to age in the community. These caregivers need more support in maintaining their QoL.

Keywords

caregiving; geriatrics; quality of life; disability; palliative care; informal caregivers

INTRODUCTION

Older adults with late-life disability make up a large and growing segment of the American population and will need increasing assistance with activities of daily living to remain independent. Our present health care system is not equipped to support the needs of these older adults, resulting in a large dependence on informal caregivers, most of whom are untrained and unpaid family members. In 2009, about 42 million people served as unpaid family caregivers at any given point in time, providing an average of 18 hours of care per week, or an estimated economic value of approximately \$450 billion, up from an estimated \$375 billion in 2007.

The social circumstances of patients affect their health outcomes, including morbidity, mortality, and quality of life. Informal caregivers are an integral component of these social circumstances, particularly as patients approach the end of their lives and require increased levels of caregiving. Since the palliative model of care is designed to support both the patient and their informal caregivers, evidence about the factors affecting informal caregivers' QoL has direct implications for palliative care practice, research and policy. The current literature on informal caregivers is dominated by studies of individuals who care specifically for persons with cancer and dementia, yet caregivers provide care such as direct care or social support, especially in late life, for care recipients of all types. However, surprisingly little is known about the informal caregivers who provide unpaid care to older adults experiencing disability in late life due to a multitude of causes, particularly as it pertains to caregiver QoL. Moreover, little is known about the caregiving experience of culturally diverse elders living with late-life disability. This qualitative study was done as a first step to generate hypotheses about the QoL for caregivers of diverse older adults with late-life disability.

METHODS

Study Design and Sample

For this qualitative interview study, semi-structured interviews were conducted with informal caregivers caring for disabled older adult relatives 65+. A broad cross-section of caregivers were recruited from multiple sites, including a Program of All-inclusive Care for the Elderly (PACE), caregiver support groups, multi-purpose senior facilities, geriatrics clinics – all in Northern California - and an advertisement through a national caregiver advocacy group website (Family Caregiver Alliance; <https://www.caregiver.org/>).

Calls and e-mails from interested caregivers were screened over the phone by our research team to determine eligibility. Caregivers who spoke English or Cantonese and who provided assistance to a disabled older adult relative 65+ were eligible for participation in the study. Late-life disability was defined as needing assistance with at least one activity of daily living (ADL) – bathing, toileting, transferring, eating and dressing. Caregivers could be bereaved (within the last 5 years) or currently providing care and could be co-residing, proximal, meaning living within 1 hours travel time, long-distance (>1 hour travel time), or mixed, meaning sometimes co-residing with the patient, sometimes apart. We included informal caregivers of older adults residing at home as well as in nursing homes, as the literature suggests that informal caregivers of nursing home residents experience substantial caregiver stress.

Data Collection

After obtaining informed consent, willing and eligible caregivers were interviewed by telephone (~45 minutes) using a common interview guide. Interviews were conducted in English and Cantonese. After translation from English into Cantonese, the interview guide was reverse-translated to ensure accuracy. Where words or concepts did not translate well from English to Cantonese, we located a word or concept that worked well in Cantonese and translated back to English. Participants were asked open-ended questions that explored their

caregiving experience, including how they rated their QoL over time. Participants were also asked to complete a short demographic survey after the interview.

To assess QoL changes over time, caregivers were asked to respond to the question, “How would you rate your overall quality of life?” with one of five answers: “excellent,” “very good,” “good,” “fair,” or “poor.” Caregivers were asked to reflect back on their time at two different time points: (1) when they first started caregiving; and (2) for caregivers of living patients, QoL during the past month before enrollment in the study or, for caregivers of deceased patients, QoL during the last month of the care recipient’s life. Participants were also probed to appraise their caregiving experience by explaining why they assigned their QoL a certain rating. Probes included inquiries about: the types of care provided, expectations about patient’s disease progression, coping strategies/personal resources, and QoL for the patient.

Data Analysis

Interviews were audio-recorded, transcribed, and then analyzed using NVivo 8 (). Data were analyzed using a constant comparative analysis; and reiteratively reviewed to identify new themes (-). A random subset of transcripts (N=10) were jointly coded by the authors (JNT, JGC, AKS) and an initial common codebook was developed. QoL was assessed in two different ways: by using the QoL ratings to determine the trajectory of QoL over time and by using descriptions of how caregiver QoL changed to look for common themes. Codes were added as new themes emerged throughout the coding process. When no new themes emerged, saturation was reached and no further interviews were conducted. Themes were examined for potential differences by cultural group. The Committee on Human Research of the University of California at San Francisco and the San Francisco Veterans Affairs Research and Development Committee reviewed the informed consent forms and approved this study.

RESULTS

Characteristics of Caregivers and Care Recipients

The mean caregiver age was 54 years, ranging from 28 to 85 years; 76% (n=32) of caregivers were female. Caregivers represented all 4 U.S. Census regions, with predominance from the West (see Table 1). Fifty-two percent of caregivers specifically mentioned providing help with at least 1 ADL, 69% with at least 1 IADL, and 40% with both ADLs and IADLs (note: 26% of care recipients were nursing home residents, and received full ADL support from nursing home staff). The majority (79%) of care recipients were 75+ years, 60% were female and 74% were community-dwelling. The top three diagnoses reported for the care recipients were dementia (38%), frailty/non-specified decline in function (17%), and heart disease/stroke (17%).

Overall Quality of Life

Overall, 52% of caregivers reported a decline in their QoL over time, 26% recalled no change, and 21% recalled an improvement. The reasons behind their QoL trajectories were

due to modifying factors that we grouped into 4 domains: social, physical, emotional and financial.

Quality of Life Declined

The caregivers who experienced a decline in their QoL identified the following reasons: they had less time for self (social and financial domains), their health declined (physical domain), and the emotional impact of the patient's illness took a toll on them (emotional domain) (see Table 2).

One caregiver, a 58-year-old wife of an older man with Huntington's disease, likened her caregiving to incarceration. She said,

“It drains everything and ruins your social life. There's a prison in our community and when I would drive by, I would be so jealous because the prisoners were given an hour outside to play basketball and have fun and I was working every single minute seven days a week.”

Another caregiver described her own health problems as a reason for her own decline in QoL, saying,

“I also have my own health issues that have arisen in the last few years where I deal with a lot of pain. As things get worse for him I know my stress level goes up and therefore I have a lot more pain. My quality of life is a lot worse than it was a few years ago.”

Other caregivers talked about how the emotional impact of their loved one's illness caused them distress, thus lowering their QoL. The daughter of a 94-year-old man with a stroke said,

“My quality of life declined substantially because I loved – still do – my father so much and seeing him decline and the thought of losing him was extremely upsetting. Dealing with mortality is a very depressing thing.”

Quality of Life Stayed the Same

The reasons for caregivers' QoL remaining the same depended on caregivers' individual circumstances and included feeling a filial duty to care for loved ones (emotional), viewing their caregiving duties as unobtrusive or minimal (social/financial), and perceiving their QoL as being consistently poor over time (physical). For example, a 28-year-old man caring for his grandmother discussed having to fulfill a filial duty:

“I know my priorities. I know what's right and what's wrong. I know what needs to get done and be done. So I do it because I know that's the right thing to do. She's family.”

The sub-theme of filial duty was more prominent among Chinese caregivers. A 50-year-old man caring for his diabetic father described how his caregiving duties rarely intruded into his life saying,

“Everything was relatively easy. All I had to do was drive my father around – it was just like visiting my father pretty much...and I’d be able to do whatever I needed to do.”

A quote from a woman caring for her spouse exemplifies how her QoL continued to be poor:

“It was very difficult to process. I wondered how I going to continue on with life. It’s just as hard as before. How can it be better? It is just as difficult.”

Quality of Life Improved

The caregivers who gave a positive assessment of their experiences described their experiences as “rewarding” (emotional), or had their QoL improved due to the help of professional care providers (financial and social), or increased experience (physical and emotional). As one 31-year-old caregiver said,

“After I dealt with the initial questions I came to find it a very rewarding experience to take care of my grandma – she raised me.”

Others stated that their QoL improved only after the care recipient became institutionalized and the caregiver burden was mitigated. A man caring for his 94-year-old mother with dementia explained,

“In the beginning, it was more difficult. Ever since she went to institutionalized care it has been easier. It’s been better with institutionalized care’s help. It’s not as problematic.”

Caregivers felt that they had more time to enjoy time with their care recipients once the primary care taking duties had been passed on to professionals. Moreover, these caregivers felt that they were able to resume normal activities, such as working, and thus, their financial situations also improved. Overall, for these given reasons, institutionalized care immensely boosted quality of life for a selected number of caregivers.

Gaining experience and mastery over care-related tasks over time was also reported to contribute to improvements in QoL over time. In one case, after caring for his 83-year-old grandfather, one caregiver became so inspired that he sought training as a nurse’s aide. He shared,

“I learned to help people and I began to like helping people.”

The experience gained either made caregiving easier or it motivated caregivers to pursue further education in a related field.

Findings by Cultural Group

Compared to the non-Chinese group, Chinese caregivers more frequently cited filial piety as a primary motivator for providing care. One Chinese woman caring for her mother-in-law with Alzheimer’s disease said,

“I should care for her. I’m her daughter in law. I’m a pretty traditional person.”

This theme was most prominently expressed in Chinese participants’ explanations for providing care in home settings rather than nursing home care. For example, a 28 year old

Chinese male caring for his grandmother with vascular disease discusses the traditional structure of the Asian family and how it lends itself to caring for an aging relative at home:

“What I see is that Asian families stick together. They care for their own. Just like my grandma, she lives with us. She doesn’t live in a caregiver’s home or retirement home or whatever you want to call it. She lives with us.”

While traditional values was a recurring justification for why Chinese caregivers provide care for their relatives, the importance of filial piety was less evident in the non-Chinese cohort, who cited financial reasons for avoiding nursing home care. One Caucasian live-in caregiver caring for her mother with dementia said,

“Some people friends seem to push putting her in a facility and to me it’s not an option because you’re talking about substantial money.”

A proximal caregiver caring for her father with frailty proposed,

“When the time comes, our goal is keep him at home for as long as financially possible.”

DISCUSSION

Our study found that the majority of caregivers for diverse older adults with late-life disability perceived their overall QoL to have declined, though a substantial minority felt that their QoL had either improved or remained the same. Although these findings are not surprising, what is most interesting about the results are the reasons caregivers gave for their respective quality of life appraisals. Specifically, the factors that caregivers described as influencing their QoLs fell within a range of four domains: social, physical, emotional and financial. Caregivers whose QoL declined described lack of personal time, dwindling financial resources, severely constricted social lives, and the toll of caregiving on their physical and emotional health. In the cases in which QoL stayed the same or improved, caregiving was perceived to have either little or a positive effect on the four domains. Caregivers whose QoL remained the same over time generally felt that it was their filial obligation to provide care. Moreover, the caregivers whose QoL showed improvement felt emotionally rewarded in serving as their loved ones’ primary caregiver.

Other studies of QoL for informal caregivers of older adults with other specific conditions suggest similar findings. Glozman and Duggleby et al. found that most caregivers had experienced some degree of QoL decline due to competing employment or familial responsibilities, loss of social life, and lack of personal time. As in our study, Duggleby observed that receiving help with caregiving helped to improve caregiver QoL. Our study builds on these findings by demonstrating that these domains of caregiver QoL also apply broadly in late-life disability. Our study is also unique in that it examined how caregivers perceive their QoL changing over time, which adds another layer of perspective to factors affecting caregiver QoL. Additionally, in our diverse cohort we found that a sense of obligation or filial duty was particularly important for Chinese caregivers, suggesting that factors related to caregiver QoL are highly contextualized within the cultural backgrounds of caregivers. Moreover, our study found that cultural differences had a significant influence on

the motivation for providing care. Specifically, Chinese caregivers were more likely to state tradition as the reason for not placing an elderly relative in a nursing home whereas their non-Chinese counterparts were more likely to cite financial reasons for avoiding institutionalized care.

We recognize that as a primarily qualitative study, these findings cannot be used to make generalizations about the informal caregiving experience and that due to the small sample size, correlations between caregiving circumstances and how they affect QoL cannot be made. However, the perspectives of our caregiver participants and the identified themes can be used to inform descriptive models of the caregiver experience or guide the development of supportive interventions for caregivers. Furthermore, this was not a longitudinal study and cannot serve to delineate changes in QoL for caregivers over an extended period of time. This study was also retrospective, and therefore subject to recall bias. For example, the recalled perceptions of the start of the caregiving process may differ from reports of caregivers assessed prospectively. It is unclear, however, if this bias would favor a more negative or positive direction with regard to QoL. Perspectives of bereaved caregivers may have been influenced by recollections of the death experience in ways that current caregiver experiences were not. Nevertheless, this study serves to inform larger studies whose data would allow for developing associations to better understand the effects of various aspects of caregiving on QoL in late life disability.

Findings from our semi-structured interviews reveal that QoL for informal caregivers is affected by physical health, social circumstances, financial status, and emotional well-being. Because caregivers largely shape their care recipients' social circumstances, which affect patient health outcomes, more attention should be paid to the QoL of family caregivers. Unfortunately, the present system often does not do enough to support caregivers who provide care in the home. The National Family Caregiver Support Program, though specifically created in 2000 to provide support for family caregivers, varies widely from state to state in its effectiveness and often leaves service gaps in important areas such as transportation, financial assistance, and respite services, all areas that would affect a caregiver's physical health, social circumstances, financial status, and emotional well-being and therefore their QoL.

Another problem is access; even when sufficient support services are available, many caregivers either do not know the services are available or do not know where to get the services. Since caregivers consider healthcare providers one of their primary sources of support, increasing access could begin with the patients' care team, which can act as a point of reference, informing caregivers of the resources available to them. Though the care team may feel that caregivers are outside their scope of responsibility, given the burden that family caregivers often assume, physicians and nurses should see them as both part of the care team and as potential patients who may need attention of their own.

To alleviate the burden caregivers assume, we should push for health policies that support improved caregiver QoL. Specifically, more funding should go towards implementing formal education programs that would train caregivers to more effectively care for their loved ones or towards expanding palliative care teams, which often provide much needed emotional and

educational counseling to informal caregivers. Furthermore, we should push for the nationwide expansion of programs like the Family Caregiver Alliance (FCA), which supports caregivers through education, services, research, and advocacy. By working to improve caregiver QoL, we will enable informal caregivers to more easily allow disabled older patients to age in place, which has large implications for both improved patient health outcomes and health care savings.

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The four listed authors were the sole contributors to this manuscript. All authors who meet the criteria for authorship stated in the Uniform Requirements for Manuscripts Submitted to Biomedical Journals have been listed. AKS designed and supervised the study. JNT recruited study participants, carried out data collection and analysis, and led the drafting of the manuscript. CEB helped with the drafting and revision of the manuscript. JGC assisted with data analysis. All authors contributed to critical revisions of the manuscript. As corresponding author, AKS had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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Table 1

Sample Characteristics of Caregiver Respondents (N =42) and Patients

Characteristics	N (%)
<i>Caregiver Characteristics</i>	
Age <i>M (SD)</i>	54.4 (12)
Gender	
Female	32 (76%)
Race/Ethnicity	
African American	2 (5%)
Chinese	11 (26%)
Caucasian	25 (60%)
Latino/Hispanic	2 (5%)
Other	2 (5%)
Years of Education	
<12	2 (5%)
12–16	26 (62%)
16+	13 (31%)
Caregiver status	
Active caregiver	33 (79%)
Bereaved caregiver	9 (21%)
US Census Region	
West	21 (50%)
Midwest	4 (10%)
Northeast	4 (10%)
South	5 (12%)
Relationship to Patient	
Spouse/Partner	7 (17%)
Child	28 (67%)
Other Relative *	6 (14)
Friend	1 (2%)
Caregiver Proximity	
Co-residing	17 (41%)
Proximal	15 (36%)
Long-distance	5 (12%)
Mixed †	4 (10%)
<i>Patient Characteristics</i>	
Age	
60–69	4 (10%)
70–79	8 (19%)

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Characteristics	N (%)
80–89	13 (31%)
90+	16 (38%)
Female	25 (60%)
Nursing Home Resident	11 (26%)
Primary Diagnosis [‡]	
Dementia/Memory-related	21 (50%)
Heart Disease/Stroke	13 (31%)
Frailty/Non-specific decline	12 (29%)
Hip Fracture	4 (10%)
Diabetes	3 (7%)
Lung Disease/COPD	2 (5%)

* Other relative included granddaughters, a grandson and daughter-in-law

[‡] Mixed are caregivers who described themselves as sometimes co-residing with the patient, sometimes living apart

[‡] Patient's primary diagnosis and co-morbid conditions were based on caregiver report

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Table 2

Summary of Domains and Themes

Quality of Life Trajectory	Domain	Quote
Declined	Emotional (subtheme: <i>emotional impact of patient's illness on caregiver was negative</i>)	<p>"The responsibility is wearing. It's a feeling that I'm responsible for this other human being in terms of all of these decisions. Are my decisions right? Who knows? Who knows?"</p> <p>"It was good up until the time that she was hospitalized and was in the – having the crises that basically led to her death. I was depressed, I was scared, I was overwhelmed. I didn't want to deal with it. I had this feeling of kind of black hole-ness. It's like I went to go and deal with her and if she was not completely compos mentis I was scared and felt like I wanted to run away. So it was hard, very hard."</p>
	Social (subtheme: <i>less time for self</i>)	<p>"You don't have time for your friends. You feel frustrated; you don't feel like you ever get any rest and you never get a vacation from it. I don't know, it just consumes your life basically. I get depressed because, you know, I have nothing to look forward to. I mean I can't go to movie. I can't sneak out occasionally. I think in eight years I think I saw about two movies."</p>
	Financial	<p>"I'm single and my mother has no money so this is all my savings, right. I'm juggling. My life is not easy."</p> <p>"I tried for years to try and get respite care. I called every agency I could think of. It was impossible; I could not get it. I could not afford it and I couldn't get financial help with it."</p>
	Physical (subtheme: <i>caregiver's health declined</i>)	<p>"I tried to give him the best quality of life that I thought he should have, which was a superior quality of life, but in exchange I gave up a lot of my own health."</p> <p>"I think it's been a bad thing in that – physically it's been a bad thing. It's hard to tell exactly whether ten years going from 57 to 67 I would have deteriorated physically as much as I have and I think that the confinement and the repetitive lifting, moving, pushing her wheelchair, things like that are hard on the body. So I think there's been definitely a decline in my physical health."</p>
No Change	Subtheme: <i>feeling a filial duty to care for a loved one</i>	<p>"I think it's my responsibility to care for them. You only have one mom and dad in your whole lifetime. So I want to do the best of my ability."</p> <p>"I mean I know my priorities. I know what's right and what's wrong. I know what needs to get done and be done. So I go and do it cause I know that's the right thing to do. She's family."</p>
	Subtheme: <i>Minimal responsibilities as a caregiver; having help</i>	<p>"I've been taking care of him at home with the help of the VA. They send in caregivers in the morning and caregivers at night."</p>
	Physical: (subtheme: <i>QOL was consistently poor over time (i.e. never improved)</i>)	<p>"It's very hard to explain unless you've walked that road. It's relentless. It is incredibly stressful and especially when you're one person and you're a sole caregiver."</p> <p>"That's really wearing because to get her up, get her dressed, get her fed, help her take a shower, get the wheelchair in the car, drive six miles to the doctor's office in Los Angeles traffic, go up into a waiting room in a doctor's office and no matter how much they love her have to wait because it's termed a "nurse visit" so that she can have a finger stick and have them say, "Great, you can go home," is really super wearing and then you have to do the whole process in reverse. It's real wearing and it eats your whole day."</p>
Improved	Emotional (subtheme: <i>caregiving was rewarding</i>)	<p>"When I give my mom a bath or rub her back I just am joyful to do it and it's a blessing to me that I can do that for her. I think to be a receiver of a gift you have to be a giver and that's probably improved my life a lot, made me a better person."</p> <p>"I felt fortunate that I had the time and the independence to care for my dad and considered that a gift to be able to give to him because I chose to, not out of obligation but as he had always given to me and to our family. And so my quality of life was even better than it was before because of having the gift to give him such a gift."</p>
	Subtheme: <i>caregiver became easier with time and experience</i>	<p>"Along the way when I learned more and just got used to it and got into a routine. I learned more about what worked and I learned more about myself and I learned more about how to – just basically to relax more myself and not be so tense. Just to go with it, go with the flow."</p> <p>"And we had – we got along extremely well and we had our layout of things that, as I was explaining earlier, that we would do and the longer – the longer I provided care for him for me it became a lot easier in order to do it. And it became better as he became more adjusted to it and more accepting."</p>
	Subtheme: <i>having institutionalized care/ financial resources helped</i>	<p>"She's safer with the support from living at the assisted facility whereas before when she was living on her own, I think she fell. I would worry about her eating properly, taking her medications because I wasn't going to be there 24 hours around the clock with her. I never knew what was going on when I went over there. Now there are people that are kind of looking out for her. In terms of her safety and security, I think it's safer where she is now. However, at the same time, she has to share her room with her roommate so she doesn't have her own place and her own privacy"</p> <p>"Financially I can't say that right now it's been a problem. I mean my father does have good health insurance through his retiree pension so that has not been a major problem. As I said, I'm able to support him. It does not create a financial problem for me if I do need to help him out."</p>