

Potential caregivers for homebound elderly: More numerous than supposed?

This study suggests that caregivers may be drawn from a broader pool than first-degree female relatives.

Abstract

Background This qualitative study examined the experiences and perspectives of caregivers of homebound elderly patients.

Methods We performed in-depth, semistructured interviews with 22 caregivers (average age 59 years) of homebound elderly patients and analyzed them to determine major themes. The homebound patients were part of a house call program of a US academic medical center in Baltimore, Maryland.

Results Caregiver relationships in our study were diverse: 41% were spouses or children, and 41% were unrelated to the homebound patient; 36% were male. We identified 3 themes: (1) caregiving has both positive and negative aspects, (2) caregiver motivation is heterogeneous, and (3) caregivers sometimes undergo transformation as a result of their caregiving experience.

Conclusion Caregiver experience is varied. Interviewees reported a variety of motivations for becoming caregivers and both positive and negative aspects of the experience. Caregivers in this study

were diverse with respect to sex and relationship to the patient, suggesting the pool of potential caregivers may be larger than previously thought.

When thinking about long-term home care for the chronically ill elderly, many people automatically imagine a spouse or child as the primary caregiver. In our study, however, 41% of the caregivers interviewed were unrelated to the person receiving the care. In addition to this diversity, we found that motivations for providing care varied among participants; that their different experiences ranged from positive to negative, or a little of both; and that a few caregivers felt their attitudes changed for the better over the course of giving assistance.

We must plan for an aging population

In 2000, 35 million people, or 8% of the US population, were 65 years of age or older. In 2040, there will be 80 million seniors, or 20.4% of the US population.¹ The National Long Term Care Survey found that in 1999, 3.9 million Medicare enrollees with a chronic disability were receiving care in their homes. A sig-

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■ **Common caregiver themes**

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TABLE 1

Characteristics of the caregivers we interviewed

Sex	Female 14/22 (63.6%)
Average age	59.3 years
Ethnicity	Caucasian 19/22 (86.4%) African American 3/22 (13.6%)
Average length of relationship with patient	37.4 years
Relationship to patient	<p>Related 13/22 (59.1%)</p> <p>1 wife 4 sons 4 daughters 2 grandchildren 1 daughter-in-law 1 grandson-in-law</p> <p>Unrelated 9/22 (40.9%)</p> <p>4 friends (1 paid) 3 paid professional caregivers 1 paid nonprofessional caregiver 1 distant nonblood relative</p>

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It may be helpful to describe for caregivers the potentially transformative nature of caregiving.

nificant portion of caregiving burden is borne by patients' relatives and friends; more than 90% of homebound patients were receiving some degree of informal, unpaid assistance.² As the population ages, more caregivers will be needed to tend chronically ill elders, and most will be informal caregivers.

The reason for our study

Research over the past few decades has found that the burden is significant for those caring for older adults.³⁻⁶ Daily challenges and stressors increase the burden caregivers feel in their role.^{7,8} More recent work has also examined interventions to alleviate caregiver burden.⁹ Studies of caregivers—published predominately in the social science and nursing literature—have seldom reported on the positive aspects of the role.¹⁰⁻¹² Only 1 study in the US medical literature, a national survey, noted positive aspects of the caregiving role.¹³

Through in-depth interviews, we

sought to learn more fully about the experiences of caregivers of chronically ill homebound elderly people.

Methods

Design, setting, study population

This qualitative study of caregivers, a focused ethnography,¹⁴ was part of a larger project that interviewed the patients and their doctors. We conducted the study through the Johns Hopkins Geriatrics Center Elder Housecall Program (EHP) from 1997 to 2001. Since 1979, EHP has provided medical and nursing care to generally frail, homebound elderly (mean age 77), predominantly white (82%) and female (69%) patients in a largely blue-collar community in east Baltimore. Annual mortality for patients is 25%.¹⁵ We selected a qualitative approach because we wanted to learn more about the experiences and perspectives of the caregivers.

Sampling

The parent study used a purposive and probabilistic sampling strategy to select patients, as described elsewhere.^{16,17} We found subjects for our caregiver study through the patients, who identified the individuals who assist them. The range of caregiver responsibilities included, but was not limited to, coordinating services, managing medical and financial affairs, and directing such activities as bathing, dressing, and meal preparation. All caregivers we invited to participate did so.

Measurements

We conducted in-depth, semistructured interviews lasting approximately 1 hour. We also collected demographic information. As a starting point for each interview, we used the following brief guide:

- What has your experience as a caregiver for the patient been like?
- Do you recall any particular examples of rewarding aspects of the role?
- Do you recall any particular ex-

TABLE 2

Common caregiver themes that emerged during interviews

<p>Positive aspects of caregiving</p> <ul style="list-style-type: none"> • Feeling needed • Seeing patient improve • Younger generations learning from patient • Patient advocacy • Friendship and companionship • Financial payment 	<p>Negative aspects of caregiving</p> <ul style="list-style-type: none"> • Confining • Limitation of activity and travel • Stress • Financial cost • Emotional burden • Balancing needs of family and patient • Extensive planning
<p>Caregiver motivations</p> <ul style="list-style-type: none"> • Duty • Love and friendship • Divine purpose • Reciprocity 	<p>Caregiver transformation</p> <ul style="list-style-type: none"> • Ability to better cope with dying • View of caregiving role improved • Life planning changed – “day-by-day” approach adopted

amples of difficult aspects of the role?

- Are there any particular challenges or important issues in your relationship with the patient that you wish to share?

An investigator trained in qualitative research (JC) asked additional questions, as needed, to further explore caregiver responses. We gave interviewees considerable latitude in commenting on points or topics they considered relevant.

Analysis

Two of this study's authors (JC, JM) audiotaped, transcribed, and independently coded the interviews, and compared them for agreement. We used an editing style analysis.¹⁸ Thematic categories and subcategories became apparent during coding, and we modified them as the interviewing proceeded. We examined and conceptually organized the categories, using the qualitative research software program NUD*IST 4 (Qualitative Solutions and Research Pty Ltd, Victoria, Australia) to facilitate data management and analysis.

A consensus approach

At least 2 investigators participated in each step of the analysis (eg, reading and coding of transcripts; identification, modification, conceptual organization of categories; and selection of themes for

presentation). The team made all decisions by consensus.

Human subjects research approval

A Johns Hopkins University School of Medicine Institutional Review Board approved this study, and we obtained written informed consent from all study participants.

Results

We interviewed 22 caregivers (TABLE 1). The number of caregivers per patient ranged from 0 to 3 (20 patients altogether). Most patients had 1 caregiver, but several had 2 or 3. Sixteen interviews involved 1 caregiver, and 3 involved caregiver teams. The average age of the caregivers was 59.3 years, and they had known the patients for an average of 37.4 years. Fourteen of the 22 caregivers (63.6%) were female (a finding similar to results from a Kaiser Family Foundation study in 1998 of 1002 caregivers, in which 64% of the 511 primary caregivers were female).¹⁹ Nine of the 22 (40.9%) participants were unrelated to the patient. Caregivers were primarily unpaid relatives or friends (77.3%), but compensated individuals were also included.

Three major themes emerged from analysis of the interview transcripts: (1) positive and negative experiences of caregiving, (2) caregiver motivation, and

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Consider explaining to patients and families that the pool of potential caregivers may be larger than they realize.

(3) caregiver transformation. Representative quotes are used to illustrate the themes presented. Specific examples of these themes are shown in **TABLE 2**.

Positive and negative aspects of caregiving

Caregivers described very different experiences of their roles—some only negative, some only positive, and others both positive and negative. Accounts of 6 of the 22 interviewees were essentially value-neutral.

Negative aspects of caregiving. Seven of 22 caregivers reported only negative feelings toward their role, including feeling burdened.

A 62-year-old retired son described how caring for his mother adversely affected his life:

Yeah, I sleep here. I don't even go to my bed. I haven't been to bed in over 3 years, because... if I don't go down as soon as she rings the bell, she can't hold her water. ...I used to go out to Pennsylvania and go up in the battlefield there. I used to go down Skyline Drive, places like that. I can't do that anymore.

Positive aspects of caregiving. Four caregivers addressed only positive aspects of caregiving.

A 71-year-old retired secretary who was asked if she had encountered any difficulties in caring for her friend said:

I haven't had any. We've become very close friends and her friendship means a lot... I don't think there's any problems with going up there...Because I call her before I go to the grocery store to make sure she's got everything on the list and then I go and just take it up to her and do from there.

Mixed experiences with caregiving. Five of our participants discussed both positive and negative aspects of caregiving; 4 of these 5 lived with the patient.

A 47-year-old machine technician who cared for his grandmother described

the benefits his 16-year-old son was receiving from the caregiving arrangement:

It's been a plus for him to have his great-grandmother living here. I think he enjoys her company, the little stories that go along and plus they always had a good relationship when he was a small child... I would hope he would realize the importance of family and I feel we're losing that in our society, we're losing our family. Seems like everybody is moving away and not being associated as close as probably we once were, and you know you realize that sometimes people need a little bit of help and not to be as selfish as you would want to be and maybe learn from that that we all kind of need one another at one time and not to be so independent, like it seems like our society has gone.

He also identified negative aspects of caregiving, including the burdens associated with selling his grandmother's home and helping her settle into his family's home:

For the last year it has been kind of hectic with trying to make things easier, doing what needs to be done, taking care of her house. Now that that's out of the way, that's a big burden out of the way.

Caregiver motivations

Eight caregivers shared their motivations for deciding to care for a homebound relative or friend. These comments were unsolicited and unexpected. Four caregivers believed they were repaying the patient for help received earlier in life.

A 69-year-old daughter-in-law said the following:

I say to her the same thing I said to my mother: "You took care of me when I was little and I am taking care of you. Now it is my turn." ...I mean we are put on this earth for a purpose and I figure this is our purpose. God put us down here to take care of someone or to help someone.

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"I figure this is our purpose ... to take care of someone or help someone," one caregiver said.

Potential for caregiver transformation

Another unexpected finding from our study was that 3 interviewees reported that they or their family members were changed by the caregiving experience. Transformations included changing one's outlook on life, changing one's views of the caregiving role, and being able to better cope with the death of others.

A 59-year-old homemaker related how her feelings about caregiving changed over time, and she felt she was repaying her mother for help she herself had received:

My major thing in the beginning was I really felt dumped on, like you have to do this whether you want to or not to prevent her from going in a place she didn't want to go to. But then, after a while, I didn't feel that way no more because she helped me when I needed help, when my kids were little. She was always there for me.

Discussion

While the medical literature to date has focused on the burdens and difficulties of caregiving, our study shows that caregivers have positive as well as negative experiences in their roles, and that, for some, the experience is a complex mixture of burdens and benefits. Interestingly, 4 of the 5 caregivers who experienced that mixture lived with the patient, suggesting that proximity and increased exposure may result in a more complex experience. In addition to these findings, some caregivers have different motivations for providing care. A small number even describe the experience as transformative.

These findings are consistent with a few studies from the nursing and social science literature that address the positive aspects of caregiving.^{11,20} For example, 2 studies found that caregivers of patients with dementia experienced both positive and negative aspects of their role.^{10,12} A recent analysis of a national survey of caregivers noted that two-thirds had feel-

ings of personal reward.¹³

How can you support caregivers? A deeper understanding of caregivers' diverse motivations and experiences can help physicians prepare others for this important role, and support and encourage those who are already caring for someone.

You can offer support by discussing with current and prospective caregivers the possibility that the role may bring both positive and negative experiences.

It may also be helpful to describe the potentially transformative nature of caregiving—to point out that some people report that their negative feelings have become more positive in time. In the end, care of dependent elderly patients may improve with such awareness.

Pool of potential caregivers larger than expected. Another finding of our study is the diversity of caregivers. Only 9 of the 22 caregivers interviewed were spouses or children, and only 5 of these 9 were wives or daughters. Among the children, there were just as many sons as daughters. Grandchildren were also represented, and 41% of the caregivers were unrelated to the patient.

Traditionally, many health professionals and the public have looked to female adult children or spouses to care for patients, and the literature on the caregiver experience often represents their views. However, some studies have noted that friends and others are also involved.²¹ Our finding adds to an evolving understanding that potential caregivers for the homebound elderly can be drawn from a broader pool than first-degree, female relatives.

Limitations of this study. The study sample was small—22 caregivers who live in a particular section of the greater Baltimore metropolitan area. In addition, most of the caregivers were Caucasian and thus do not reflect the ethnic diversity of the United States. As such, we must be cautious in extrapolating these findings to other caregivers in other settings. Nevertheless, we believe that aspects of the care-

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Among those we interviewed, sons and daughters were equally likely to be caregivers.

giver experience reported here will ring true to caregivers who live elsewhere.

Americans are living longer, and many of them have chronic medical problems. An increasing percentage of these elderly will require some level of caregiving to stay in their homes. Future studies might explore in more depth caregiver motivations and caregiver transformation to gain better insight into these important issues. ■

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Disclosure

The authors reported no potential conflicts of interest relevant to this article.

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