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Exploration of Informal Caregiving Following Hip Fracture

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Abstract

Hip fracture, a significant health issue for older adults, is an acute event in which older adults can recover their prefracture functional abilities. The recovery phase is often difficult for older adults, and the role of informal caregivers is particularly important. The aim of this qualitative study was to explore informal caregivers' experiences with providing care to older adults over the first 6-month trajectory of hip fracture recovery and their support needs. Participants ($N = 10$) were interviewed twice at 0–2 and 5–6 months. Analyses of the verbatim transcripts revealed multiple shared themes. Some themes were consistent across phases, such as hip fracture as a turning point toward a frailer state, feeling tired, frustration with communication issues in health care delivery, and lack of information about caregiving-related activities. Certain themes were phase-specific. For instance, in the early phase, management of hospital bills and transitions between care settings were especially burdensome. The caregiving situation, however, was viewed as an opportunity to spend more time with their loved ones. Findings from this study revealed unmet support needs expressed by caregivers of older adult hip fracture patients. Ongoing research and clinical interventions are needed to establish effective methods to empower these caregivers.

Maintenance and improvement of functional abilities are vital for quality of life among older adults^{1,2} and are a priority in current aging research.² One of the conditions prevalent among older adults is hip fracture, a significant public health problem.^{3–5} Hospital admissions for hip fractures among adults over age 65 have increased from 245,000 in 1991 to 320,000 in 2004.⁶ The mortality rate for persons who sustain a hip fracture in the United States ranges from 11% to 31% at 12 months.^{7–9} Moreover, up to 56% of older adults surviving hip fractures will have sustained functional disability^{10–12} Many hip fracture patients (10–20%) suffer subsequent fractures.^{13,14}

Unlike other debilitating conditions (e.g., Alzheimer's disease [AD]), hip fracture is an acute event, and older adults can recover their prefracture functional abilities with appropriate interventions.^{15–19} In most cases, the initial intervention following a hip fracture is to undergo a surgical repair of the fracture. The recovery process following the surgical intervention varies on the basis of the patient's comorbidities, cognitive and functional status, and psychosocial state. Generally, older adults will experience significant functional dependency for varying amounts of time and undergo extensive rehabilitation therapies.^{20–25} This recovery phase is difficult for older adults, and the role of informal caregivers (hereafter referred to as "caregivers") is particularly important.

As older adults transition through different health care settings and providers, caregivers remain engaged in the full trajectory of recovery and offer constant support.^{23,24} In particular, these caregivers can facilitate the recovery process by encouraging older adults to adhere to their therapy regimens and activities and offer positive comments about their efforts.²⁵

Hip fracture patients undergo a difficult period, and their caregivers also face enormous challenges. Many caregivers assume the caregiver role without much preparation and have to learn about many aspects of care within a short time period. Often caregivers do not know what to expect during hip fracture recovery. They face situations in which they have to manage various care-related tasks, such as arrangement of rehabilitation services and assistive devices, as well as management of hospital bills and handling Medicare and insurance coverage.^{24,26} These situations become more stressful when the caregivers have to juggle their own work and family lives. Although there seems to be a significant need for support for caregivers of hip fracture patients, few studies have been conducted in this area of caregiving.

Caregiving to Older Adult Hip Fracture Patients

The care burden related to hip fracture, an acute injury, may decrease over time; however, it is often prolonged over 12 months or beyond.^{20,22} Caregivers tend to experience the greatest stress for the first 2 months postfracture, with the stress being associated with increased care demands and care cost.²¹ Care recipients, however, may need to live with the caregiver for prolonged periods of time. Older adults at the 12-month post surgery were more dependent on caregivers for help with activities of daily living than their nonhip fracture counterparts.^{20,27,28}

Although limited, some prior findings have shown the importance of caregivers as motivators for older adults during their recovery from hip fracture.^{23,24} In a qualitative study ($N = 30$),²⁴ researchers investigated the caregivers' involvement in the care and rehabilitation of hip fracture patients. Findings showed that caregivers play an important role in both physical care, such as helping with eating and drinking, and emotional support, by providing encouragement and social interaction. In another study that explored mother–daughter dyads' experiences during recovery from hip fracture,²⁵ both mothers and daughters reported some positive experiences, including the renewal of relationships and the sense of empowerment experienced through the successful management of the hip fracture crisis.

Previously, our investigative team explored caregiving experiences posthip fracture as explained by exercise trainers from the Baltimore Hip Studies who worked with patients and their caregivers during the first 12 months after hip fracture.²⁶ A focus group meeting with 5 exercise trainers revealed several challenges and resource needs surrounding the recovery process. These include factors such as what to expect following surgery (e.g., differences in leg length, referred pain [i.e., hip fracture but back pain]), insufficient rehabilitation training concerning the use of assistive devices, or insufficient information regarding routine life activities (e.g., when to resume driving or knowing how much activity is considered too much or too little).

In this study, we explored informal caregivers' experiences providing care to older adults through the first 6 months of hip fracture recovery^{15,29} with a particular focus on the support needs of the caregivers. This time period was selected because during the early posthip fracture period, caregivers are involved in direct hands-on caregiving and have to make multiple decisions associated with the rehabilitation process.²⁰

Methods

Design

In-depth interviews were conducted twice over the first 6 months posthip fracture (at 0–2 and 5–6 months) using selected open-ended interview questions (Table 1). The Dutch phenomenological approach^{30,31} was used to guide this research. The phenomenological approach, which attempts to study specific phenomena as experienced by individuals, has evolved over time.³² Specifically the Dutch approach allows the researcher to employ both descriptive (existential) and hermeneutic phenomenological approaches to understand individuals' lived experiences.³¹

Setting and Sample

Upon approval from the university's institutional review board, a purposive sample of 10 participants was recruited from an urban community hospital participating in the Baltimore Hip Fracture Study network. The sample size was determined on the basis of the literature about the approach used in this study³³ and the available participants during the recruitment period. The sample size was decided on the basis of the literature review and available participants in the selected hospital. A caregiver was eligible if he or she was 21 years or older and a family member, friend, or significant other identified by a hip fracture patient (age ≥ 65) as the person who would provide the majority of assistance in personal care and household tasks. The caregiver also had to reside in Maryland and could not have a personal history of hip fracture.

To identify eligible hip fracture patients, a research nurse visited the hospitals daily to check the admission log and contact the registration desk in the emergency department. After a potential hip fracture patient was identified, the nurse contacted the individual, explained the study, and asked permission to contact his or her caregiver. Once the individual gave permission to contact his or her caregiver, the research nurse contacted the caregiver and screened for the eligibility criteria. If the caregiver met the inclusion criteria, the research nurse explained the study, obtained consent, and enrolled him or her into the study.

Instrument

Before the in-depth interview, participants' demographic data (e.g., age, sex, employment status, number of family members) and the caregiving situation (e.g., relationship, living arrangement, average time spent caregiving) were obtained.

The interviews were conducted using open-ended questions (Table 1). The first interview focused on the experiences surrounding acute care needs during the early phase (0–2 months) posthip fracture. The second interview, occurring 5–6 months posthip fracture, focused on the care experience from 3 to 6 months postfracture. Participants were encouraged to explain their experiences in as much detail as possible. Reflections on the participants' comments were used to encourage the participant to continue. Probing questions (e.g., "Tell me more about ...") were used to clarify the participants' statements.

Procedures

After the caregiver agreed to participate in the study and signed the consent and Health Insurance Portability and Accountability Act forms, the research nurse scheduled 2 interviews at the time and location of his/her convenience. The interviews lasted approximately 40–60 minutes, and all interviews were audiotaped and then transcribed verbatim.

Analysis

The demographic data were analyzed using descriptive statistics (e.g., frequencies, means). The transcripts were analyzed using the technique used by Dutch phenomenologists³⁴ by two doctorally prepared investigators who have conducted and published multiple qualitative studies. The investigators analyzed the data separately. They read through each participant's transcripts and extracted from each what seemed to be important "moments" ("which fly up like sparks from the descriptions")³⁴ from each participant's experience. The investigators then analyzed all moments from participants and developed shared themes.

When searching for shared themes among participants, some unique themes pertinent to only certain participants emerged. These unique themes enriched the understanding of shared themes. As the analysis progressed, there was a continual movement back and forth from text to theme statements, and there was a movement of themes into the variation category or vice versa. To enhance the rigor (the reliability and validity) of the study, the findings from the two investigators were compared. There were some minor discrepancies in extracted shared themes. After discussions, they came to a consensus in data reduction.

Results

The mean age of caregiver participants was 64.8 ± 13.1 (range, 49–86), and their care recipients' age was 85.1 ± 4.7 (range, 80–93). Nine caregivers and 8 care recipients were female. Only 8 caregivers participated in the second interview. One care recipient died in the second week after discharge from the rehabilitation hospital, and 1 caregiver did not return our phone calls for the second interview. Six caregivers (60%) were children of care recipients, and 2 were spouses. The other 2 caregivers included a niece and a nephew. The majority (70%) of caregivers had full-time jobs. Before hip fracture, half of the care recipients lived independently, 4 lived with their caregivers, and 1 was living in an assisted living setting. At the second interview, most care recipients returned to their original residence. Even though the caregivers did not all live with their care receivers, they spent a significant amount of time taking care of them as shown in Table 2.

Analyses of the verbatim transcripts revealed multiple shared themes. Some themes were consistent across phases, and others were more distinct in each phase.

Caregiving Experience Consistent across Different Phases

Theme 1. Hip fracture as a turning point toward a frailer state—When caregivers were informed of their loved one's hip fracture, they worried that this event would be a turning point for their loved one toward frailer health. At the later phase of the recovery process, they confirmed actual mental and physical changes in their loved one requiring more direct help with basic activities of daily living than was needed before the hip fracture:

"Very scared, very nervous. The thought running through my head, what's going to happen? ... Just very worried and apprehensive about the future."

"... oh, there's a big change. And, um, she was actually telling me when I stopped over yesterday, she said, you know, sometimes I have trouble remembering you're my daughter! And remembering who you married, and.... But, I mean, she always knows us, you know, but it's just...."

Theme 2. Feeling tired and having experienced a lack of sleep due to demanding caregiving-related activities—Caregivers constantly had to juggle their time between caregiving-related activities, work responsibilities, and their families, which resulted in exhaustion. They also often lost sleep worrying about caregiving-related issues:

“And I found I didn’t sleep good because of this; I lost sleep; I was tired and I went to sleep and I’d wake up and think about it; and I thought, I don’t have time to mess with this, but somebody should be aware of what the situation created.”

“Um, very stressful. Um, it was just trying to juggle everything. You know, work, making sure things were taken care of with his household, my household, visiting him every day. ...so, trying to juggle everything was probably the most difficult thing.”

Theme 3. Being frustrated with the lack of communication from health care providers and communication loopholes during transitions of care—

Communication problems were described across many levels. Insufficient or ineffective communication occurred between health care providers and caregivers or during care transition from one setting to another. For instance, during transfer from the hospital to a rehabilitation facility, important medication information was not passed on from one care setting to the next, resulting in missed medication doses. This had a negative impact on the recovery process. Communication problems also occurred in relation to the scheduling of various health care services, such as home-care nursing, physical therapy, and other necessary outpatient services:

“I don’t feel like there was follow-through from, the social workers between the hospital and rehab. There was poor communication. My husband was off antidepressants for 13 days and withdrew from antidepressants at rehab. I felt helpless that he wasn’t on the Celexa and that he worsened because of not getting it.”

“That was very frustrating. I’m a person that likes to have everything in a row. If they [the outpatient clinic staff] had called me on Friday, we could have worked out the fact that he was going to the doctor on Monday. Well, come to find out, they couldn’t see him [care recipient] on Monday because he already had 2 appointments and Medicare wouldn’t cover it because he was being seen by physicians on that day so they have no need to come out and check his vitals and blah, blah, blah. So they wouldn’t come out that day. So that put a burden on me because I couldn’t get back out there Tuesday.”

Theme 4. Lack of information about caregiving-related activities—Most caregivers face caregiving responsibilities without much preparation. Often they may be unaware of the questions they need to ask health care providers. In the acute setting, most of the information given to care recipients was provided at the time of discharge, and caregivers did not have adequate opportunities to review the information and ask questions. In rehabilitation care settings, most information associated with care was provided to the caregivers during care planning meetings or through physical therapists. Although several caregivers expressed their appreciation of certain health care staff members’ thoughtful assistance, in general, most caregivers expressed having received insufficient and nonindividualized information in a hurried manner. Furthermore, they expressed difficulties in attending health care planning team meetings at the scheduled times:

“Well, she [the nurse] could have been a little bit more helpful, and, you know.... I thought I had a right to know, I mean, because I’m a caregiver and I’m also going to be one of the ones that, when she needs help, I’m one of the ones that will be taking care of that because she’ll be living here. But, uh, that irritated me a little bit.”

“... they had handed me packs of papers when I went over for the care planning meeting at the nursing home, you know, and you’re just so busy and you don’t always sit down and look at and read through something this thick, you know.”

Theme 5. Specific resource needs—Caregivers wanted more in-depth and timely explanations from health care providers and access to resource materials available to them at their convenience. They also expressed that more practical information must be given more proactively by health care providers.

Phase-Specific Caregiving Experiences

Some themes were directly associated with a specific phase of caregiving. Table 3 summarizes those themes per each phase. In the early phase, although caregivers faced various challenges in caregiving situations, they recognized some positive aspects of caregiving. For instance, caregivers who were children of care recipients reported that they had the opportunity to spend more time with their loved ones and had gotten to know them better. Most participants expressed a great deal of concern about the care received in rehabilitation settings. Specifically, they were concerned that their loved ones were not cared for properly. Some of the cited reasons included a lack of individualized care (e.g., adjusting sleep and activity schedules to meet the patient’s requests/lifestyle) or concerns that therapies were too difficult for their loved ones.

In the later phase of recovery, difficulties with arranging health care appointments continued and became more burdensome. For example, transportation for the patient to follow-up appointments was described as a burden for caregivers, especially for those with a full-time job. When care receivers made the transition from the acute period to the steady recovery period, caregiving seemed to be a more draining experience because caregivers needed to juggle their life responsibilities for a prolonged period of time.

Discussion

The results from our study are similar to prior findings showing that the care burden related to hip fracture is greatest in the first 2 months and that although the burden may decrease over time, it is often prolonged over 12 months or more.^{20,22} Our findings expanded on this prior work and revealed more specific information about the experience of caregiving through the 6-month posthip fracture trajectory. The new caregiver role can be overwhelming requiring management of a multitude of caregiving activities, including assistance in physical care, financial transactions, and placement after discharge from the acute hospital. Furthermore, most caregivers are unfamiliar with the recovery process posthip fracture, which progresses quickly with changing care needs as the care recipients transition from emergency room, to operating room, onto a regular hospital unit, to a rehabilitation setting, and home. The associated stress and caregiving burden often result in a lack of sleep and exhaustion, which may have a significantly negative impact on the caregivers’ health and quality of life. Caregiving responsibilities may also affect other members of the caregiver’s family and society with negative consequences such as a lack of attention to household work or missed work days.^{26,35}

The goal of recovery following a hip fracture is to regain baseline functional activities.^{17,36} Prior findings, however, show a significant gap between this goal and reality. A large number of older adult adults surviving hip fracture suffer decreased functional ability (up to 50% in prior studies)^{10,11,37,38} and experience recurrent hip fracture.^{13,14} In particular, the caregivers in our study anticipated that the hip fracture event would become a turning point toward frailer health. Their anticipation was confirmed during the later recovery phase as their loved ones became frailer than they were before their hip fracture. To facilitate optimal

recovery, it may be helpful if hip fracture patients, caregivers, and health care professionals clearly articulate a realistic recovery goal for the patient and work together toward that goal. Although further studies are needed, there seems to be some mismatch in appraising care recipients' physical abilities among caregivers, health care providers, and patients. During the rehabilitation phase, most caregivers perceived the therapies given by the therapists as being too hard for their frail loved ones. A mismatch between the caregiver's appraisal of the care recipient's functional abilities and their actual abilities has been reported in other caregiving situations.^{39,40} This mismatch is a major concern because caregivers need to serve as motivators throughout the patient's hip fracture recovery period.⁴¹ Caregivers' and care recipients' increased understanding of both short and long-term rehabilitation goals and expectations throughout the recovery process is critical to optimize outcomes. Education of patients and caregivers and open communication with health care providers are the best approaches to decrease this mismatch.

The majority of caregivers in our study expressed concerns about the care provided in the rehabilitation setting, generally focusing on their care recipient not receiving the level and amount of care the caregiver assumed necessary. Caregivers, however, must understand that a major goal of the rehabilitation care is to assist patients to recover their desired functional abilities. Thus, optimal rehabilitation care incorporates a restorative care approach in which caregiving is more focused on teaching and encouraging patients to perform activities as independently as possible rather than on the health care professional's completion of tasks for the patient (e.g., wheeling a patient versus helping the patient walk).⁴²⁻⁴⁴

Mismatches in appraisal of functional abilities continue to be significant when the older hip fracture patient returns to his or her home setting. Caregivers may believe that their care recipients need more assistance in performing tasks and thus perform those tasks for their care receivers, rather than encouraging them to complete the tasks with as little assistance as possible. Thus, additional education is needed to emphasize the importance of restorative care, as well as methods to motivate their loved ones to maximize their activity levels with necessary safety measures.^{42,45,46}

Communication loopholes and a lack of information were identified as consistent problems. Poorly coordinated transitions between care sites have been shown to result in increased hospital readmissions, duplication of services, medical errors, and other problems.⁴⁷ In case of hip fracture, care transitions happen rapidly involving various health care professionals, and the problems can be worse. Increased and timely communication between the caregivers and the professional health care team and more anticipatory information will likely improve the transition process for the patient and the caregiver. Health care providers should be provided with appropriate training in their educational programs about the optimal way to work with and help these caregivers. In addition, necessary resources must be available to caregivers in a way that is convenient for them to access. Health care professionals, however, may not be readily available when caregivers need and are able to learn about the recovery process. An innovative approach to augment face-to-face communication is the use of an online resource center. This method could include didactic educational information with searchable resources, as well as interactive communication functions to allow for individualized discussions between the health care professional team and the caregivers. Caregivers could access these resources at their convenience.

For many caregivers the hip fracture event can become an important opportunity to renew bonds with care recipients, especially when caregivers are the children of care recipients. When children grow up and leave home, they do not have many opportunities to spend significant amounts of time with their parents, who are now older adults. The caregiving situation allows them to experience and learn more about each other as they spend more

time together overcoming the new life challenge, such as hip fracture. This is an important positive aspect of caregiving that has significant implications in practice. For instance, interventions maximizing this psychosocial dynamic within the dyad, such as caregiver educations to help care recipients adhere to therapy plans, could be effective approaches.

Our study employed a small convenient sample, and the majority of the caregiver participants were females and Caucasian. We recognize that male caregivers may have different caregiving experiences and resource needs. Further studies including more varied samples may yield expand our understanding of the needs of all caregivers.

Conclusion

Hip fracture is a significant health problem that affects a large number of older adults and their caregivers. Although the event must be understood according to each adult's underlying health condition, older adults can recover to their prior physical and functional level. To maximize recovery efforts, individuals involved in the provision of care must work as a cohesive team with clear rehabilitation goals and responsibilities. Caregivers of older adult hip fracture patients have assumed a critical role, providing consistent support to these individuals. Findings from this study revealed that there are unmet support needs expressed by caregivers of older adult who have experienced a hip fracture. Ongoing research and innovative clinical interventions such as the use of online resource centers are needed to optimize the recovery of hip fracture patients and limit the potential stress and health implications experienced by caregivers.

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Table 1
Interview Questions for Each Phase
Questions for the 0- to 2-Month Period

- Tell me what it was like when you heard your _____ (care recipient) had a hip fracture.
- Tell me about your experiences with providing care while (care recipient) was in the hospital.
- Tell me about your care experiences immediately after (care recipient) was discharged from the hospital.
- Tell me about resources, support, or information that have helped you to take care of (care recipient) during the first 2 months of his or her hip fracture.
- Can you think of any additional resources, support, or information that would have been helpful to you while you cared for (care recipient)? If so, tell me about them.

Questions for the 5- to 6-Month Period

Thinking back 2 months from your care recipient's hip fracture until today:

- Tell me about your care experiences.
- Can you describe the types of resources, support, or information that have helped you to take care of (care recipient)?
- Can you think of any additional resources, support, or information that would have been helpful to you while you cared for (care recipient)?
- Tell me what you think about (care recipient's recovery from the hip fracture. For example, how would you describe how (care recipient) is doing now as compared to his/her condition before the hip fracture?

Table 2

Caregivers' Care Hours per Week

Caregiver	At 0–2 months	At 5–6 months
1	Constant care	Constant care
2	Constant care	Constant care
3	38.50	10
4	24.00	*
5	21.00	1.5
6	35.00	5
7	Constant care	Constant care
8	14.00	28
9	Constant care	Constant care
10	7.00	*

*
No second interview.

Table 3
Themes Specific to Each Phase

<p>0–2 months</p> <ul style="list-style-type: none"> • Caregivers felt badly about seeing their loved ones in pain and in a frail state. They often perceived therapies as being too harsh for them. • Caregivers were satisfied with the care received from the acute hospital. (Participants were recruited from 1 recruitment setting.) However, most participants expressed concerns about some of the care received in rehabilitation settings, citing a lack of individualized attention, as well as therapies being too aggressive. • Management of hospital bills and arrangement of transfers from one setting to another were especially burdensome. • Caregivers became advocates for their loved ones. • The event was an opportunity to spend more time together with their loved ones and get to know them better than before. <p>5–6 months</p> <ul style="list-style-type: none"> • Difficulty with arrangement and coordination of health care services had continued, and some had more trouble with transportation.
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