

# Family Caregivers' Experiences During Transitions Out of Hospital

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**Background:** Family caregivers play a central yet under recognized role in ensuring quality and safety during a loved one's transition out of the hospital.

**Objective:** To explore facilitators and challenges family caregivers face in assuming postdischarge family caregiving roles and completing complex care tasks.

**Methods:** A qualitative study recruited 32 participants from 4 sites. Participants were unpaid family caregivers whose loved one was recently discharged from an acute care hospital. A modified Grounded Theory approach was used.

**Results:** Five central themes emerged from the analysis: (1) family caregivers' contributions to the care of their loved one unfold along on a spectrum where the readiness, willingness, and ability of both parties are often dynamic; (2) family caregivers have unique and potentially incongruent goals from those of the patient; (3) family caregivers feel unprepared for postdischarge medication management; (4) family caregivers encouragement to assert an identity; (5) family caregivers often assume the responsibility for the sequencing of posthospital care plan tasks and anticipating next steps.

**Conclusion:** Family caregivers provided valuable insights into the challenges they face facilitating their loved ones' transitions. These findings may directly inform the design and testing of an evidence-based intervention to enhance their roles.

charge, no evidence-based intervention has been explicitly developed to improve the ability of family caregivers to obtain the requisite skills to successfully function in these roles during care transitions. In keeping with the principles of person- and family-centered care, the design of such an intervention should directly incorporate the voice and perspectives of family caregivers (Institute for Healthcare Improvement and Patient- and Family-Centered Care, 2006; Institute for Patient- and Family-Centered Care, 2011). The purpose of this study was to explore the facilitators and barriers that family caregivers experience during transitions in care out of the hospital toward an eventual goal of developing an evidence-based intervention.

## Review of the Literature

There has been a much needed proliferation of evidence-based models designed to improve care transitions and reduce the need for subsequent readmission (Coleman et al., 2006; Hansen et al., 2013; Jack et al., 2009; Naylor et al., 2004). In aggregate, these models make reference to the importance of involving family caregivers. However, none of these models include explicit elements in their respective protocols that are designed to actively engage and prepare family caregivers.

Thus, there remains an increasingly recognized need to consider the readiness of family caregivers when determining a patient's care plan upon discharge from the hospital (Hesselink et al., 2012). Although the field is underexamined, existing literature suggests that family caregivers are frequently dissatisfied with the amount of information they receive during the

### Keywords

family caregiver  
care transitions  
care coordination

### Purpose

Patients are often frail and vulnerable at the time of hospital discharge and consequently may have difficulty following discharge instructions, participating in self-management, and obtaining timely follow-up care (Kripalani et al., 2007). Family caregivers, when able, willing, and engaged, play an instrumental role in patient care at the vulnerable time of transitions, and yet they often receive insufficient support for this role (Fuji et al., 2013; Hesselink et al., 2012; Wolff, 2012).

Despite the importance of the family caregiver role at the time of hospital dis-

discharge process and may feel ill-prepared to manage the complex care needs of chronically ill older adults in the home setting (Given et al., 2008; Grimmer et al., 2000). In one study, care recipients with family caregivers who felt competent in their role were half as likely to experience delayed discharge from the hospital, whereas those who reported a level of caregiver burden were twice as likely to be delayed in discharge (vom Eigen et al., 1999).

Bull and colleagues found that family caregivers who reported more involvement in discharge planning had significantly higher scores on satisfaction, feeling of preparedness, and perception of care continuity 2 weeks after an older adult's hospitalization than those who reported little or no involvement in planning (Bull et al., 2000).

Foust and colleagues explored transition-related challenges in the context of patients and families who received skilled home healthcare services. Family caregivers struggled to get answers to basic questions such as when their loved one was to be discharged. Many family caregivers found the information they received was often lacking in important details, particularly regarding medication instructions. Unless they took the initiative, family caregivers were infrequently included when discharge instructions were provided (Foust et al., 2012).

A study performed by AARP and the United Hospital Fund elucidated the significant contributions made by this invisible workforce: 46% of family caregivers perform medical/nursing tasks, 78% of family caregivers manage medications, and 53% of family caregivers serve as care coordinators (Reinhard et al., 2012). When the study authors asked family caregivers how they obtained the necessary skills to complete these tasks, the majority responded that they had not received any specific training (Reinhard et al., 2012).

## Study Design and Methods

### Study Settings

A total of four focus groups were conducted at three sites. The Northwest Regional Council Area Agency on Aging (NWAAA) in

Bellingham, Washington, hosted two focus groups. The NWAAA was selected as a partner site for this study based on the project team's plan to test a subsequently developed intervention in the Bellingham area. The second partner site, Total Longterm Care (TLTC; a Program of All-Inclusive Care for the Elderly or PACE site) hosted one focus group and was selected based on its proximity to the project team's health science campus in the Denver metro area (although this site is not affiliated with the University) and the known commitment of senior management to quality improvement. The Alzheimer's Association (AA) of Denver hosted one focus group and was selected to ensure participation of family caregivers whose loved ones have progressive cognitive decline.

### Recruitment and Screening

At all participating sites, the project team used purposive sampling to assemble focus groups of up to 10 family caregivers. The eligibility requirements for the study included the following: English speaking, family caregiver must be at least 18 years old, live within 60 miles of the patient or loved one, and the loved one must have been hospitalized within the past 90 days.

At the NWAAA, recruitment efforts included word of mouth by agency staff, publication in the monthly newsletter, and on-site distribution of a project flyer. Agency staff provided contact information from interested parties to the project team to conduct telephonic screening. At TLTC, agency staff reviewed client records to identify potentially eligible subjects and then contacted them to gauge interest in the study. Contact information for interested clients was then shared with the project team to conduct telephonic screenings. At the AA, staff approached family caregivers who participated in a range of programs and services and provided the contact information to reach the project team to those interested in participating. The focus group discussions were conducted on-site at the three respective participating organizations. Participating family caregivers received a \$50 gift card to a large national retail store in recognition of their time.

**Table 1. Sample Focus Group Questions**

Think back to your recent experience with your loved one being discharged from the hospital. What went well during this experience for your loved one? What could have gone better for your loved one? What ideas do you have to improve the discharge experience for your loved one?

Now we will shift to your experience as a family caregiver. Were you involved in the discharge process? If so, how were you involved? What went well from your perspective? What could have gone better? What ideas do you have to improve the discharge experience for family caregivers?

After the hospital discharge, how confident did you feel that you would be able to address your loved one's health needs?

***Development of Focus Group Format***

A preidentified set of questions were used to guide the focus group discussions. All questions were open-ended and related to family caregiver experiences with transitions out of the hospital setting (Table 1).

***Data Collection***

Each focus group was 1.5 h in length. Proceedings were digitally recorded and deidentified before subsequent confidential transcription and analysis.

***Data Analysis***

Grounded Theory (Corbin and Strauss, 1990) was used to analyze the study data. Transcripts of the focus groups were independently analyzed by the project team using open coding. The project team next identified a list of substantive codes to formulate the emergent themes.

***Institutional Review Board Approval***

All study activities and materials, including the consent process, were approved by the Colorado Multiple Institutional Review Board before recruitment (protocol # 11-0851) and the ethics board at each partner site.

**Results**

Participant characteristics are described in Table 2.

Five central themes related to family caregiving after discharge emerged from the analysis (Table 3). Below, we elaborate on each theme and provide illustrative verbatim family caregiver quotes.

***Theme 1: Family Caregivers' Roles and Contributions to the Care of Their Loved One Unfold Along a Spectrum Where the Readiness, Willingness, and Ability of Both Parties Are Often Dynamic and Unrecognized***

Evaluating the experiences of family caregivers highlighted the observation

**Table 2. Participant Characteristics**

	N	Hispanic	African American
Alzheimer's Association	8	1	1
Northwest Regional Council Area Agency on Aging T1	6	0	0
Northwest Regional Council Area Agency on Aging T2	10	0	0
Total Longterm Care	8	3	0

**Table 3. Identification of Themes and Illustrative Quotes**

Theme 1	Family caregivers' roles and contributions to the care of their loved one unfold along a spectrum where the readiness, willingness, and ability of both parties are often dynamic and unrecognized	“My husband was, before this, totally independent and strong as a horse, better than I was physically. He would resent it, if I were called the caregiver. That would just reinforce how dependent he is right now.”
Theme 2	Family caregivers have unique and potentially incongruent goals from that of the patient	<p>“And I was trying to understand that this is not a marathon, it is going to take quite a while to happen, and so trying to maintain my own family life and my own . . . and manage her.”</p> <p>“They shouldn't just look at the needs of the patient. They should look at the needs of the family . . . if they are going to take the time to ask what are (the) goals of the patient . . . then they should ask what do you need to have that happen at home?”</p> <p>“And you know, this is all stuff I've found through past experience. Nobody has ever asked me for my goals or anything like that.”</p> <p>“. . . but nobody has ever come out and told me that at discharge, or asked me for the goals or anything like that.”</p>
Theme 3	Family caregivers feel unprepared and at times overwhelmed by postdischarge medication reconciliation and management	<p>“The pharmacist was my lifeline . . . I mean she sat there (with me) for like 20 min on a bench. Other pharmacists are filling things and she's just sitting with me. And that just made all the difference.”</p> <p>“Then I get him home and try to put his new pills with the ones he is already on and they are different names. They are different colors. They are . . . Oh my gosh! It is so confusing. Why in the world, when you are taking this particular prescription pill, why is it if you order it from this particular outlet, why is it this color? And this shape? But then you go through his mail order and it comes in a totally different shape or color.”</p> <p>“They (the pharmacists) will tell you anything you want to know about the medication. Why they are on it. Dr. L took Joe off of a pill. I called him (Dr. L) to ask him why but I never heard from back him, so I called the pharmacist and she told me.”</p> <p>“I realized that the pharmacists are so knowledgeable about medications—I don't know what these are. And so I had a question about how we could boost some of his pain medicine and what was safe and what was not. And she gave us wonderful advice. She knew who we were and I just couldn't believe it. You just feel like . . . I mean the anonymity is just shocking.”</p>

*(Continued)*

**Table 3. (Continued)**

Theme 4	Family caregivers need encouragement to assert their role and identity	<p>“And then on where the nurses write their name of who is on shift at that time, I wrote my name and my cell phone number and that I have power of attorney. Nobody, not once, called me. Even though decisions were being made and they were asking for input. Not once did somebody call me.”</p> <p>“And usually, believe it or not, I’m an introvert and quiet and shy. But I just had to be massively assertive. So the doctor comes in (and says) you are doing so well, you know. Go home. See me in a month. And I said wait a minute. You can’t leave yet. I was hanging on his pant leg practically! You cannot leave.”</p> <p>“And I was . . . really, under the radar in terms of would I be able to participate in a discussion on the discharge process.”</p> <p>“. . . and it is very stressful taking care of your parent and being their voice.”</p> <p>“I got chosen to be the one in charge of everything. And in her case, I’m the family member that knows all of her medical history. I know that this year she had a heart attack. This year she had this and this. I know those things.”</p> <p>“I go in and I see my husband in this state—and the recovery nurse just is beside herself because she can’t get him to breathe. And I immediately know what this issue is. He is just so scared and she is missing that he is so scared. It is not that he’s unconscious. So . . . I just went in and reached deep down inside of him, to bring him up. And he got better right away—she couldn’t believe he could talk.”</p>
Theme 5	Family caregivers often assume the responsibility for the sequencing of posthospital care plan tasks and anticipating next steps	<p>“We were going to Rite Aid in Lynden, and of course they close up at 9:00 a.m. So that makes that really tough. I know Walgreen’s is open 24/7 but . . . she is on oxygen. So then you have to have a little bottle—6 L—so that bottle is going pretty fast. We were sitting at Walgreen’s trying to get her prescriptions filled but I am worried that she is running out of air.”</p> <p>“And we have seven medicines. Now, these medicines cannot be mixed. I mean some of them cannot be mixed and some of them have to be taken every 4 hours. That means I have to wake up in the middle of the night. And so what I thought . . . I couldn’t imagine a flow chart</p>

*(Continued)*

**Table 3. (Continued)**

that was too hard for me. So I put these papers down and so for a 24-hr period I had this piece of paper that said . . . I put a pill on a paper and what times I had a pill on a paper and what times.”

“Sometimes the insurance questions too . . . people say we are releasing you and you need to get this, that and the other thing and you kind of don’t know, is insurance going to cover it? Do I just go buy it? You just don’t really know.”

“And then we had to have not only that person get things in order, but we also had to arrange for an Occupational Therapist and a Physical Therapist and get all those things scheduled.”

“I’m thinking about how I’m going to orchestrate everybody that I need to come in, because I’m going to have to get to work at some point. Right?”

“And I had the same situation with the medications. Where I had to just go over there and say we are not leaving until you get these medications over to the right pharmacy (the health plan’s designated pharmacy was not open on Sunday), so instead we get them from the Afterhours Care Center. I had to explain to them, I cannot go to a regular pharmacy and get these medications because that is not the way (our health plan’s pharmacy coverage) it works.”

that family caregiver–patient relationships exist along a continuum where the respective roles are often in flux. All too often when the patient is acutely ill or otherwise, impaired health professionals will turn to a family caregiver to help execute the care plan. However, rarely do health professionals ascertain the family caregiver’s readiness for participation in the execution of the care plan or whether the family caregiver perceives the patient to be ready for transfer or discharge on a clinical level. In many cases, the family caregiver plays a dynamic role with greater involvement during the immediate discharge or transfer period and a decreasing role as the patient begins to recover and regain prior function. Helping health professionals and family caregivers appre-

ciate the spectrum of this “sliding scale” relationship, and offering support to the patient and family caregiver accordingly would represent a significant step forward in promoting the role of family caregivers.

### ***Theme 2: Family Caregivers Have Unique and Potentially Incongruent Goals from that of the Patient***

A recurring theme of the focus groups was that the health-related goals of the patients were not always aligned with the goals of the family caregivers. Family caregivers often have two related goals—a goal for their loved one’s health recovery and a goal for themselves. Instructive examples included not depleting one’s bank of personal time off hours and being able to concurrently

meet the needs of their young children. To illustrate how goals might differ in important ways, a patient's goal might be to return to a former state of mobility (in this case to resume walking the dog in a surrounding neighborhood). Although the family caregiver may understand the motivation for this goal, she or he might have a goal for the patient to be safe at home which might, in turn, discourage attempts at regaining mobility. It is noteworthy that not one family caregiver participant in our study had a health professional inquire the nature of her or his goal.

***Theme 3: Family Caregivers Feel Unprepared and at Times Overwhelmed by Postdischarge Medication Reconciliation and Management***

Family caregivers in our focus groups uniformly struggled with medication reconciliation and management. Many individual family caregivers adapted by experimenting with different approaches to ensure that their loved one benefited from and was not harmed by their medications. Perhaps, the most promising approach identified across all 4 focus groups was the opportunity to establish a trusting longitudinal relationship with an individual community pharmacy or pharmacist. Another key activity for potential collaboration between the family caregiver and pharmacist was gaining advice on how to approach the patient's physician to request (if safely possible) a reduction in the absolute number of medications taken or to simplify the dosing of the current regimen.

***Theme 4: Family Caregivers Need Encouragement to Assert Their Role and Identity***

Family caregivers reported not feeling confident in assimilating the roles that were often imposed on them without warning or preparation. In some cases, family caregivers acknowledged that the hospital staff appreciated their involvement. However, many family caregivers sensed that their presence may have triggered feelings of annoyance or additional burden on behalf of health professionals. Further complicating this tension,

family caregivers described instances when they were able to identify both the problem faced by their loved one and its solution but had no voice to bring these observations to the attention of the treating health professionals. In other experiences, family caregivers perceived that the health professionals felt threatened by the fact that the family caregiver had the solution to a problem when they did not.

Related to asserting their identity, focus group participants were asked to reflect on the term "family caregiver" and to share their opinions of how they would prefer to be addressed. Most participants were not overly concerned with what specific term that was applied to them, as long as they felt that they were a valued member of the care team, were apprised of new information, and were included in decision making. Several family caregivers suggested that family titles (i.e., daughter or spouse) seemed to garner more respect from health professionals. Others made reference to the importance of being identified in a functional role such as healthcare power of attorney. More important than the specific terminology around their roles, family caregivers wanted to be more visible to health professionals both during the hospital stay and after discharge.

***Theme 5: Family Caregivers Often Assume Responsibility for the Sequencing of Posthospital Care Plan Tasks and Anticipating Next Steps on Behalf of Their Loved One and the Healthcare Team***

In coordinating the discharge care plan, there is often an optimal order and timing for how to sequence each step. Many family caregivers expressed both challenge and frustration while sequencing the discharge care plan. However, there were cases when family caregivers noted that they had insight into the proper sequencing of the care plan when healthcare professionals did not. In these examples, the ability to both anticipate and sequence key tasks of the discharge care plan spoke to the resourcefulness of family caregivers. The participants of all four focus groups expressed a desire to have a single

trusted professional they could contact when they needed help or positive reinforcement for this sequencing role.

### Strengths and Limitations

The primary strength of this study is its contribution of novel findings in a relatively unexplored topic area. The sampling strategy led to the recruitment of family caregivers from three diverse settings in two states who offered their perspectives and experience.

However, due to the relatively small sample size and the relative homogeneity of the focus groups, the generalizability of our findings to the larger population of family caregivers in other geographic regions is unknown. Furthermore, we did not explore the motivation for why participants consented to the study. It is possible that they agreed because of a previous negative experience during care transitions that they wanted to share.

Finally, family caregiving is a broad and multifaceted topic. This qualitative study does not attempt to address the comprehensive dimensions of family caregiving. Rather the focus was on how to better address the particular needs of family caregivers during the vulnerable time of posthospital care transitions.

### Directions for Future Research

The results of this qualitative study suggest that family caregivers are often silent and unrecognized partners on the healthcare team. Yet, they play multiple critical roles in ensuring quality and safety through identifying medication errors, anticipating care needs, determining the sequence of key steps for executing the care plan, and performing complex care tasks. Many caregiving relationships are dynamic, changing with time and with circumstance. Family caregivers might step in and out of assuming certain support roles as their loved ones resume the ability to self-manage their care. Understanding these complex roles will be important for informing the design and implementation of an intervention aimed at engaging family caregivers.

### Discussion

Family caregivers provided valuable insights into the challenges they face while facilitating their loved ones' transitions out of the hospital. Perhaps, even more importantly, they also suggested strategies for how health professionals might be more supportive of their need to gain confidence and skills. These findings have the potential to directly inform the design and testing of an evidence-based intervention to further enhance their roles.

### Implications for Practice

Our focus group interactions provided a number of insights into how to develop a robust and meaningful intervention designed to better meet the diverse and complex needs family caregivers experience at times of transitions. Feedback from these discussions resulted in 3 major levels of recommendations, including format and delivery, content, and logistical and operational considerations.

Regarding format and delivery, a new intervention would benefit from a mechanism by which the readiness of family caregivers and their loved ones might be ascertained along a spectrum. On one end of the spectrum, the family caregiver might play a primary role, fully engaged in each aspect of care. On the other end of the spectrum, the family caregiver might play a modest secondary role if the patient is rapidly regaining self-care abilities. This ability to recognize that the readiness, willingness, and ability of both parties may be in flux throughout the intervention time period will ensure that the delivery of the intervention is tailored appropriately.

When considering key content, the observation that family caregivers who established a trusting relationship with a pharmacy or pharmacist seemed to have more positive experiences during the transition out of the hospital is particularly noteworthy. Developing a deeper understanding of what specific characteristics of this relationship are most important will be integral to an intervention's design. Furthermore, the content of a new intervention might place greater emphasis on

facilitating family caregivers' ability to translate the care plan into an ideal sequence for the events that follow and anticipate next steps. Borrowing from the very same concepts of simulation that we use to prepare health professionals for their respective roles, such an intervention would ideally extend beyond simply providing education through spoken word and written materials, providing an opportunity for "hands-on" learning (Coleman, 2014).

Logistical concerns must recognize that family caregiving roles change with time and are balanced against occupational roles and other family roles. Our findings suggest that an intervention that includes face-to-face or telephonic encounters should be flexible and accommodating of family caregivers' schedules and competing demands. This might translate into encounters that occur outside of typical business hours and may also require increasing the number of encounters if home visits are included.

Finally, although this qualitative exploration has provided new and potentially valuable insights into how health professionals might better support the roles of family caregivers during the vulnerable time of transitions, we would like to emphasize that as with most challenges, one size will not fit all. The qualitative analytic approach we used aims to identify the common themes but we should point out that there was noticeable heterogeneity among our family caregivers. Some of them clearly strived for mastery in their newly defined roles, whereas others desired for healthcare professionals to relieve them of much of their roles. We urge our professional colleagues to create an opportunity to have candid discussions with family caregivers to determine their readiness, willingness, and ability to function in this capacity and to build in feedback loops to modify the plan based on new learning or experiences.

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