

# Caregiver Inclusion in IDEAL Discharge Teaching

## *Implications for Transitions From Hospital to Home*

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### ABSTRACT

**Purpose:** Despite recognition that unpaid (e.g., family, friends) caregivers play an important role in successful transitions home after hospitalization, limited information is available about whether and how caregiver experiences of discharge align with current strategies for providing high-quality discharge processes, and how these experiences at discharge impact successful transitions home. The purpose of this study was to explore perceptions of caregivers regarding their discharge preparation, focusing particular attention on whether and how they believed discharge preparation impacted postdischarge patient outcomes.

**Methods:** We conducted in-depth, case interviews with four English-speaking caregivers (61–75 years of age). Content analysis was framed by the nature of caregiver involvement proposed by the Agency for Healthcare Research and Quality's (AHRQ's) IDEAL (Include, Discuss, Educate, Assess, Listen) discharge planning strategy.

**Results:** Caregivers reported receiving clear discharge instructions, or basic education, and yet felt only passively included in discharge teaching. Once home, the caregivers reported gaps in their knowledge of how to care for the patient, suggesting key gaps related to knowledge of warning signs and problems. Two of the four caregiver participants attributed a hospital readmission to postdischarge knowledge gaps.

**Conclusion:** The experiences of these caregivers demonstrate how their limited, passive involvement in discharge education may result in suboptimal patient outcomes after hospitalization. Our findings suggest that structured programs aimed at increasing caregiver involvement in discharge, particularly related to assessment of caregiver problem solving, planning, and postdischarge support, are important in efforts seeking to improve care transitions and postdischarge outcomes.

**Implications for Case Management:** This study assesses caregivers' experience with discharge planning and problems they encounter post-discharge, providing case managers with important information regarding the effectiveness of discharge processes. This study of caregiver experiences suggests that the IDEAL discharge planning strategy remains a useful and important framework for case managers to follow when providing discharge services.

**Key words:** caregiver, caregiver education, care transitions, discharge complications, discharge planning, hospital readmissions, ideal discharge, inclusion

Annually, millions of Americans are discharged from the hospital with the expectation that their treatment plan can be followed at home (Alper et al., 2020). Although medically able to recover at home, an estimated 15%–20% of patients are readmitted to the hospital within 1 month of being discharged (Zuckerman et al., 2016). Hospital readmissions are costly for the health care system, but as—or perhaps more—importantly, readmissions cause undue stress and burden on the patient due to delayed recovery, time away from work, and unnecessary distress (Luther et al., 2019).

Hospital discharge involves transitioning from a hospital setting to a home or community setting where patients are expected to be responsible for the

majority of their care including managing new medications, transportation to follow-up appointments, surgical drains, diet restrictions, and other activities

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of daily living while coping with limited functional abilities. This can be a vulnerable time for patients trying to recover from serious medical illness or surgery. Several studies have shown that family/informal (vs. formal or paid) caregivers play a crucial role in helping patients manage their needs during this vulnerable transition period (Hahn-Goldberg et al., 2018). For example, at the time of discharge, caregivers can advocate for patients, including asking additional questions, voicing needs and concerns, and remembering discharge instructions. At home, caregivers often assume the role of providing direct medical care (e.g., dressing changes, medication administration), care-plan management (e.g., remembering instructions, coordinating follow-up appointments), and assorted tasks of daily living (e.g., cleaning and errand-running). After discharge, caregivers may also take on the role of sentry, watching for worsening symptoms and ensuring that the patient is recovering (Hahn-Goldberg et al., 2018). Through each of these roles, caregivers play a large part in facilitating patients' successful recovery at home and, when well prepared through proper discharge teaching, can improve patient outcomes and prevent hospital readmissions (Dossa et al., 2012).

Large-scale care transition studies have begun identifying a host of organizational factors impacting quality and outcomes of care transitions, including implementation of strategies for clear communication and fostering trust with both patients and caregivers (Naylor et al., 2017; Sorra et al., 2021). In concert with these efforts, the Agency for Healthcare Research and Quality (AHRQ) has directly addressed the role of caregivers and offers a structured discharge planning process intended to improve discharge planning and reduce adverse events postdischarge (Agency for Healthcare Research and Quality, 2013). The IDEAL (Include, Discuss, Educate, Assess, and Listen) strategy focuses on actively engaging the patient and the caregiver in the discharge process. The importance of caregiver engagement is highlighted throughout this framework, recognizing that patients' informal networks are key to successful recovery at home. For instance, the "Include" portion of IDEAL involves early identification of a family member or a friend who will provide

competent and consistent care at home. In addition to the patient, IDEAL recognizes the caregiver as a full partner and active participant in the discharge planning process. Similarly, the "Discuss" portion encourages the care team to discuss with the patient and the caregiver five critical areas to prevent complications at home:

1. Describe what home life will be like.
2. Review medications the patient will be going home with.
3. Highlight warning signs and problems to watch out for.
4. Explain any test results.
5. Schedule follow-up appointments.

For the "Educate" portion, the care team is asked to focus on the need to educate both patients and caregivers using simple terms about the patient's condition and diagnosis, the discharge process, and next steps at every opportunity throughout the hospital stay. The "Assess" portion encourages the care team to use techniques such as teach-back to determine whether the patient and the caregiver understand the patient's condition, diagnosis, and next steps. Finally, care teams are encouraged to "Listen" to the patient and caregiver's goals, preferences, observations, and concerns, and honor them (Agency for Healthcare Research and Quality, 2013). See Table 1 for a summary of the IDEAL discharge steps.

In addition to the IDEAL discharge process, the American Association of Retired Persons (AARP) developed state legislation advocating for family caregivers called the CARE Act (AARP, 2014). The CARE Act, adopted now by 40 state legislatures, requires that hospitals record the name of the family caregiver, inform them of their family member's discharge, and also provide the family member all discharge education and instruction. Similar to the IDEAL discharge process, identification and inclusion of the patient's caregivers at home are vital to attending to the complex care responsibilities at home, improving patient and caregiver satisfaction, and avoiding unnecessary health care costs and readmissions.

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**TABLE 1**  
IDEAL Discharge Steps<sup>a</sup>

IDEAL Discharge Steps		
Step	Description of Nursing Actions	Notes to Remember
I	"Include patient and caregivers as full partners"	1. Family in the hospital may not be family providing caregiving.
D	"Discuss with patient and caregivers five key areas to prevent problems at home"	1. What life will be like at home, what to expect. 2. Medications at home. 3. What do watch for red flags, signs and symptoms of problems. 4. Any test results. 5. Follow-up appointments.
E	Educate everyone in plain language	1. Ask patients and caregivers their goals and needs for education. 2. Include addressing patient's condition, discharge process. 3. Use teach-back, show-back with all education provided.
A	Assess how well we have explained the diagnosis and conditions and care needs.	1. Teach in "small chunks." 2. Repeat key points. 3. Ask patient and caregivers to repeat back to you in their own words.
L	Listen and honor our patient and caregiver goals, preferences, and concerns.	1. Ask open-ended questions. 2. Schedule a time with patient and caregiver to discuss planning. 3. Encourage patient and caregivers to make notes of questions and concerns.

<sup>a</sup>From *IDEAL Discharge Planning, Overview, Process, and Checklist*, by Agency for Healthcare Research and Quality, 2013, June. [https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/strategy4/Strat4\\_Tool\\_1\\_IDEAL\\_chklist\\_508.pdf](https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/strategy4/Strat4_Tool_1_IDEAL_chklist_508.pdf)

process are aligned with the specific recommendations of the IDEAL discharge model and, if they are, whether the model effectively addresses caregiver postdischarge needs. As such, the purpose of this study, part of a larger parent study examining the quality of hospital discharge, was to use four case interviews of family caregivers for patients discharged from a tertiary academic health sciences center hospital to explore caregiver perceptions of their discharge preparation, and whether and how they felt discharge preparation impacted postdischarge patient outcomes (Appendix A).

## METHODS

Using a qualitative descriptive approach, this study examined in-depth experiences of four unpaid caregivers for patients discharged from surgical services of a tertiary academic medical center hospital. Qualitative description supports close evaluation of the words participants use to describe their experiences (Neergard et al., 2009). All procedures were approved by the University of Utah Institutional Review Board.

## Sample

The sample included unpaid caregivers of patients discharged from the hospital between February 2,

2020, and March 12, 2020, who had previously agreed to be contacted for follow-up after discharge. All individuals were adults (older than 18 years) who could speak and understand English and were caregivers of patients discharged directly home (vs. to a skilled nursing facility) from an ortho-trauma surgical services or surgical specialty and transplant unit. Patients were excluded if they were admitted for bariatric surgery, organ transplant, or mental health (e.g., suicidal ideation/attempt, intentional overdose, 1:1 observation room), or if they were incarcerated or discharging with hospice. No additional inclusion criteria were applied to caregivers.

## Procedure

After completing interviews with patients who had recently been discharged, the interviewer asked the patients to share the research team's contact information with the patients' postsurgical caregiver and to invite them to reach out to the research team member for a separate interview about the caregiving experience. Using this referral technique, 14 caregivers were identified and four agreed to participate. Because interviews were conducted by telephone in April 2020, additional sampling was limited and, instead, focused on the in-depth interviews with a smaller sample. Interviews lasted approximately 20 min.

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After completing the informed consent process, all interviews were audio recorded and professionally transcribed.

Data Analysis

Transcribed interviews were uploaded into Dedoose, a qualitative coding computer software program (Dedoose Version 8.3.45, 2018). Content analysis was used to analyze the transcripts (Elo & Kyngas, 2008). The first stage of analysis involved thoroughly reading and rereading the interview transcripts. Then, open codes were developed on the basis of the language used by participants (Elo & Kyngas, 2008). The primary author (E.T.) coded the first interview and then reviewed the coding with an additional team member (E.J.). Differences in coding were discussed until agreement was reached. The remaining interviews were then coded following the established process, which was then reviewed by additional team members (A.B., A.S.W). After completion of open coding, the codes were organized and interpreted into themes (Elo & Kyngas, 2008), and all team members discussed differences until agreement was reached (Creswell & Poth, 2016).

RESULTS

All caregiver participants were between 61 and 75 years of age and identified as being the spouse of the patient. Two (50%) were female, all self-identified as White, and non-Hispanic. All participants identified as being spouses of the discharged patient. Analysis

Analysis resulted in two major themes falling under two distinct points in time: (1) involvement during discharge teaching; and (2) role at home after discharge.

resulted in two major themes falling under two distinct points in time: (1) involvement during discharge teaching; and (2) role at home after discharge. Each major theme had two subthemes. See Figure 1 for the major themes and subthemes (Appendix B).

Theme 1: Caregiver Involvement During Discharge Teaching

During discharge, caregivers largely felt that they received clear instructions during discharge teaching or, according to the IDEAL model, they received basic education. However, throughout the discharge planning process, and specifically during discharge teaching, caregivers described having a passive role suggesting limited engagement in discussing and limited assessment of skill and understanding.

Instructions Clear at Discharge But May Not Always Meet Needs Once Home

Generally speaking, when asked about the quality of discharge teaching, the caregivers described receiving clear instructions that were well understood at the time of discharge. “Their advice was pretty clear and

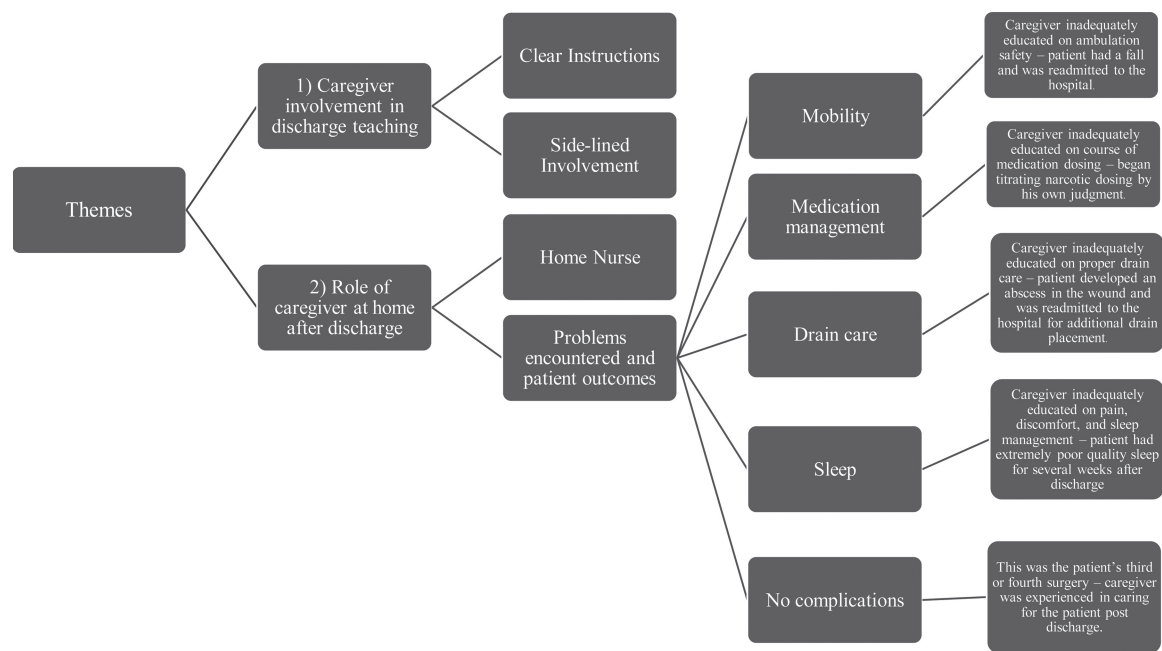


FIGURE 1  
Caregiver interview themes.



well understood, I think.” (Caregiver 3) When asked how discharge teaching went, another caregiver rated discharge instructions on a scale of 1–10, with 1 being terrible and 10 being very well. “[...] I’d say a nine out of ten, very well.” (Caregiver 1)

Two caregivers spontaneously made the connection between discharge instruction to postdischarge experiences. One caregiver described the instruction process as clear and straightforward, and afterward, feeling comfortable in their ability to care for the patient once they discharged home. “So that’s kind of what we felt, they were clear enough and pretty straightforward as to what needed to be done [...] I can’t say that they missed anything, and going home I felt comfortable with it.” (Caregiver 4) However, in contrast, one caregiver reflected on adverse patient events that happened after discharge and spontaneously described having not received the information during discharge teaching that they needed once returning home, “[...] we had a hard time getting the information that I think we really needed [...] so that could have been done the first time around and that would have really helped.” (Caregiver 2)

### **Sitting on the Sidelines During Discharge Teaching**

When asked about their role in discharge teaching, caregivers described their involvement as being a passive receiver of information and a wish to be more actively involved. One caregiver described their involvement as simply being present as a listener. “I was involved, I was there. I was listening.” (Caregiver 1) Referring to doctors and nurses as the “caregivers,” one caregiver not only described their role as a passive observer but also feeling “sidelined” during discharge teaching: “Most of the interactions were between [the patient] and the caregivers, I was kind of on the side [...] a lot of the stuff was directed straight at her, and I was like an observer.” (Caregiver 3) Another caregiver described an assumption that the care team knew best what the patient’s needs were because the care team was at the hospital more often than they were and providing most of the care:

I don’t really know [...] because when I was there, I took care of him but they were doing all that stuff too, so I wasn’t there the whole time they were [...] So I assumed that they knew what his needs were. (Caregiver 2)

Caregiver 3 expanded on what the others described as passive recipients of discharge teaching by describing his desire to be encouraged, or perhaps invited, by the care team to be more actively involved in the discharge process and recovery at home: “I really think the one thing that maybe could be addressed a little better [...] I wouldn’t say forcing, but encouraging me to think more deeply about the recovery process.”

## **Theme 2: Role of Caregiver at Home**

Once home, the caregivers described filling the role of a home nurse, completing many tasks they observed nurses and other professionals doing in the hospital. However, while describing these roles, the caregivers also identified clear, concrete gaps in their knowledge about how to care for the patient, with two caregivers attributing their patient’s hospital readmission to their own knowledge gaps.

### **Assuming the Role of Home Nurse**

Caregivers described their role at home in terms of tasks they would complete and responsibility they would shoulder in order to care for and support the patient, similarly to how nurses care for patients in the hospital. One caregiver actually described himself as a home nurse. “So, I was her nurse. So, I did everything that needed to be done to ensure that she was safe and accomplished what she needed to be accomplished upon discharge.” (Caregiver 1) Caregiver 1 went on to describe some of the ways they filled the role of a home nurse, including medication management and pain management:

When we came home, we had a list of 10 medications, including two narcotics. And I took the role of charting all the times that they were to be given, the quantities, the dosages, and I tracked her pain level. I basically acted like a nurse. (Caregiver 1)

Caregivers also described assisting with mobility, ambulation, and physical therapy (PT). “He had to be careful getting into bed at first. Because it was back surgery, I had to lift his legs to make sure he didn’t bend at the waist.” (Caregiver 4) Caregiver 1 expanded by describing their role maintaining patient safety during PT and ambulation:

I was doing the PT stuff with her as well, to help her move out of bed and to the bathroom [...] We were discharged with a safety belt that I put around her

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waist every time that she got out of bed to walk to the bathroom, or to do whatever. (Caregiver 1)

Caregiver 2 also described assisting the patient with mobility and ambulation. “I helped him get dressed, and helped him get to bed [...] just overall care, pretty much, helping him going to the bathroom, helping him walk places, helping him get up, standing up and all that.”

Finally, Caregiver 3 reported a role in offering psychological support. “I think mostly psychological support [...] It’s hard for her to see the progress sometimes. So, I try to comment on that when I think it’s appropriate.” (Caregiver 3)

### **Problems at Home**

Throughout the interviews, the caregivers highlighted different problems they encountered at home. Three of the four caregivers described knowledge gaps in how to care for the patient and associated complications postdischarge in the following areas: mobility, medication management, drain care, and sleep. The fourth caregiver reported no gaps in knowledge of how to care for the patient.

**Mobility:** In response to a question about what the hospital staff could have done to make the discharge process a “10 out of 10 experience,” Caregiver 1 described how he felt inadequately trained to think critically about how to prevent a fall or injury to his wife (the discharged patient) while helping her ambulate to the bathroom:

During the night, understand that for at least three days, you’ve got to make sure that your loved one is able to move safely and be safe [...] And I didn’t quite get that, honestly [...] How important my role was, that something bad could happen if I wasn’t on my game. (Caregiver 1)

Caregiver 1 went on to explain that because of his lack of training at discharge, his wife suffered a fall in the bathroom and was readmitted to the hospital. The caregiver shared:

I wasn’t trained [...] I wasn’t aware that I shouldn’t have left her sitting on the toilet without being there and supporting her. [...] And the first morning upon waking up, [the patient] had fall. [...] And it was because yours truly went to bathroom first, got [the patient] situated, went out of the room for a moment, and that’s when the nausea came, dizziness, blacked out. [...] And so, we went back to the hospital. (Caregiver 1)

**Medication management:** Caregiver 1 took the time to explain another complication he ran into when it came to helping his wife (the patient) taper down on her pain medication:

We didn’t receive upon discharge, a tapering schedule of when to start it, what were the symptoms or

lack thereof the symptoms we should look for and then begin [...] you know, what do we try to do? She was on five to six Tramadol’s in a 24-hour period. Do we drop that by half, during each dose, or what? We didn’t know. (Caregiver 1)

Caregiver 1 then went on to explain the tapering schedule, they eventually used, that he came up with:

Just take one 325 milligram dose out of the two, and do that once a day, and then do that twice a day, because there were three doses. Or three time, to administrate the doses. And then we just began that whole process and based on [the patient’s] pain level, we got to the point where she was down to a quarter tab of a 325-milligram tablet, three times a day. And once we got there, we just then took away one dose of the three, and then the second dose of the three, and then left the weening dose for two or three days. And it worked. (Caregiver 1)

**Drain care:** Caregiver 2 described receiving mixed and incomplete instructions about how to manage the patient’s surgical drain. “But I guess the drain care was the main thing because he got different instructions at different times and it would have been nice to have it all at first.” (Caregiver 2)

Caregiver 2 went on to describe that the patient developed an abscess due to a lack of proper drain care after discharge and was consequently readmitted to the hospital to replace the drain:

We didn’t find out about the back-flushing until the drain was replaced this time around [...] they were really surprised the last time around that I hadn’t been back-flushing and maybe that would’ve made a difference. [...] If I knew what to expect and what it meant that might help more [...]. (Caregiver 2)

**Sleep:** When asked what could have made discharge instructions more helpful, Caregiver 3 felt that there was a lack of education on how to manage pain and discomforts at night and because of this, the patient slept poorly for the first month after discharge. The caregiver shared:

I think that the sleep aspect was actually the thing that maybe could be addressed in a little more prescriptive fashion. [...] maybe a little bit of more clarity on discomforts in sleep, adaptations, things she could do to help her sleep [...] that’s really the only thing I can think of that was kind of an issue for, I don’t know, a month or so, something like that. (Caregiver 3)

Specifically, the caregiver felt that more information should have been provided, stating:

And so that would be my one take-away by you [...] I wouldn’t say forcing, but encouraging me to think more deeply about the recovery process [...]. Telling her what to expect, and maybe emphasizing which drugs will do what for her and just strategies for better sleep. (Caregiver 3)

*When exploring caregiver involvement in discharge processes and whether and how they felt their experience with discharge planning and education affected patient outcomes after hospitalization, we found that while caregivers reported that instructions appeared clear at the time of discharge, upon transitioning home, gaps emerged in their knowledge of how to care for the patient.*

**No reported complications:** Caregiver 4 reported that because this was the third or fourth surgery the patient had recently undergone, they did not feel like anything was particularly missed in the discharge instructions. Caregiver 4 did not report any adverse patient outcomes.

I didn't feel like anything was missing [...]. Maybe if it was my first time, I would be able to think of something, but this is like his third or fourth surgery so I can't say that they missed anything [...] and going home I felt comfortable. (Caregiver 4)

## DISCUSSION

When exploring caregiver involvement in discharge processes and whether and how they felt their experience with discharge planning and education affected patient outcomes after hospitalization, we found that while caregivers reported that instructions appeared clear at the time of discharge, upon transitioning home, gaps emerged in their knowledge of how to care for the patient. Caregiver participants provided clear examples of how postdischarge knowledge gaps contributed to challenges with, and even two readmissions related to, core areas of mobility, medications, drain care, and sleep. These findings echo a growing body of literature highlighting how the inclusion of family caregivers during discharge can reduce postdischarge resource use and costs (Rodakowski et al., 2017) and reinforce the AARP-sponsored CARE Act legislation requiring that caregivers are identified, informed, and educated regarding the needs of their loved ones postdischarge (AARP, 2014). However, more concretely, our findings illustrate gaps in caregiver preparedness and, potentially, how intentional, active engagement of caregivers in discharge education may improve patient outcomes, findings that align with others who report that verbal and written health education often places caregivers in an observational versus participant role (Fields et al., 2020).

Shih et al. (2020) collected data surrounding caregiver perception of the patient's readiness for

discharge and found that "Family-centered care enables patients to safely pass through the transition phase from hospital to community and reduces the post-release consumption of medical resources" (p. 1355). As patients transition to home settings, caregivers often assume new responsibilities caring for patients. For example, upon discharge from surgical units, patients can go home with surgical drains that need regular emptying and monitoring, surgical wounds requiring daily care at home, a long list of medications to manage, and an overall decreased mobility related to their surgery. Many times, an informal caregiver such as a spouse assumes a large portion of the responsibility of caring for the patient after discharge. In a sense, discharge teaching can be likened to a kind of "shift report" and, using the words of our caregiver participants, informal caregivers are like the "on-coming nurse" but often without formal training and experience.

Our case interviews offer clear guidance about what caregivers believe active inclusion in discharge teaching could look like and demonstrate how the active inclusion of the caregiver could be used to ensure successful transitions from hospital to home. Caregivers described their role in discharge teaching as a passive receiver of information rather than an active participant and, as a consequence, described a lack of knowledge once they got home. As complications in the patient arose, they described not knowing how to handle the issues yet making do as best they could. Two of the four caregiver participants attributed their own knowledge gaps as playing a role in the care recipient's readmissions. Caregivers gave specific recommendations about how involvement in discharge teaching could be improved, describing a desire to be challenged to think more critically about what responsibilities in postdischarge care would look like, giving opportunity to ask questions, be directly involved in discharge teaching, and practice troubleshooting with the nurse.

Alongside the emerging literature suggesting that clear communication and trust are key in high-quality

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care transitions programs for both patients and caregivers (Naylor et al., 2017), incorporating the IDEAL framework as the standard framework for discharge teaching, including the emphasis on active informal caregiver inclusion, may ultimately decrease the risk for postdischarge complications and overall reduce hospital readmission rates. As described previously, although it appears that caregivers were to some extent *Included* in discharge *Education* (caregivers reported receiving clear instructions), their level of involvement was only passive. Caregivers may have reported increased readiness for discharge if they had been able to actively *Discuss* discharge teaching with the nurse and other health care professionals, ask questions, clarifying teaching points, and practice various tasks they would assume responsibility for postdischarge—such as drain care, ambulation, comfort measures, and medication management. After this active discussion, the nurse and other health care professionals should have *Assessed* the caregiver’s understanding of postdischarge instructions and responsibilities, utilizing the technique of teach-back. This would allow the nurse or other health care professional to clarify misunderstandings and fill in knowledge gaps. And finally, the nurse or other health care professional should have *Listened* to the caregiver, giving them an opportunity to express their own concerns, goals, and areas where additional support may be needed. As part of this *Listen* piece, it may be worthwhile to create a Caregiver Readiness for Discharge Scale that specifically measures the caregiver’s readiness to care for the patient at home. The IDEAL discharge framework focuses on *intentionally engaging the caregiver* in the discharge process. While analyzing the different patient–caregiver scenarios explored in this study, it appears that application of the Discuss, Assess, and Listen pieces of the IDEAL discharge framework would have actively involved the caregiver in discharge teaching and may have improved patient outcomes postdischarge.

### Limitations

This study is limited in several ways. First, we acknowledge that our small sample of caregivers is from one academic health sciences center, and that

this study was conducted in the landscape of several efforts aiming to improve the quality of discharge support. In addition, the timing of the COVID-19 pandemic and the related availability of Telehealth, Home Health, or other community support programs, while not directly addressed during caregiver interviews, may have impacted caregiver perceptions: caregiver interviews took place in April 2020. Finally, all participants from whom demographic data were collected reported their race as White/Caucasian and their ethnicity as not Hispanic or Latino, so representation from other racial/ethnic groups is missing from this study. All this said, the quality of insights and perspectives shared by this sample uncovered common themes and resulted in clear next steps in efforts to improve discharge support for caregivers that may, ultimately, improve patient outcomes and readmissions.

### Implications for Case Management

Case managers need to know that caregivers often feel “sidelined” in the discharge process and want to be included as an active participant in all anticipatory planning, education, and preparation. Also important, this study identified that caregivers perceived that they are inadequately educated on a list of vital caregiving needs such as ambulation safety; medication dosing and titration; wound and drain care; and pain, discomfort, and sleep. The readily available IDEAL framework offers case managers an evidence-based process to systematically prepare patients and caregivers for their postdischarge experience. Specifically, IDEAL addresses what to expect as the normal course of healing and recovery and what to watch for as typical “red flags” prompting them to communicate with outpatient providers.

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## Appendix A

### A Qualitative Interview Guide: Caregiver

#### Caregiver Demographics

1. What gender do you identify as?  
Male  
Female  
Other  
Prefer not to answer
2. What is your racial background? Select all that apply.  
White or Caucasian  
Black or African American  
Asian  
Pacific Islander or native Hawaiian  
American Indian or Alaskan native  
Prefer not to answer
3. Are you Hispanic or Latino?  
Yes  
No  
Prefer not to answer
4. Age (years):  
18-30  
31-45  
46-60  
61-75  
76-90  
91 +
5. Relationship to patient (self-defined)

#### Questions for the caregiver

1. What role do you play in providing care for (the patient)? For example, do you share the residence or come over when needed?
2. Were you in the room when (the patient) received discharge instructions?

#### Discharge experience

1. When you were with (the patient) in the hospital, how well did you feel like the doctors, nurses, and physical therapists understood (the patient)'s needs at home?
  - a. Who on the care team (e.g., nurse, case manager, surgeon) seemed to know what the patient needed best?
2. How involved were you in the discharge planning process?
  - a. Did the hospital staff give you specific instructions about medications or how to care for (the patient) once you both returned home?
3. How well do you feel everything was communicated to you and (the patient) by their doctors and nurses?
  - a. Do you feel like the treatment team was all on the same page or was there inconsistency in information that was conveyed to you and (the patient)?

#### Experience of returning home

4. How helpful have the provided discharge instructions been since you returned home?
  - a. How well have you been able to help the patient follow through on discharge instructions?
5. What additional instructions would have made it easier for you?
  - a. Is there anything you wish the hospital staff would have addressed with you or the patient?
6. How well do you feel the discharge instructions matched your and (the patient)'s needs? Did the doctors and nurses seem to take (the patient)'s needs into account?
7. Since you have taken on a caregiver role, how are you feeling physically and emotionally?
8. Have you or (the patient) used any community resources to help with recovery? How helpful have those been?

#### Concluding questions

9. Since you have returned home, how well has the patient been able to follow through on their discharge instructions?  
5: Extremely, 4: Very, 3: Moderately, 2: Slightly, 1: Not at all
  - i. How?
    - a. Do you think the patients' ability to recover well at home has been impacted by the COVID-19 crisis?  
5: Extremely, 4: Very, 3: Moderately, 2: Slightly, 1: Not at all
    - i. How?
      - b. Do you think the patients' ability to recover well at home would have been impacted if they were discharged today?  
5: Extremely, 4: Very, 3: Moderately, 2: Slightly, 1: Not at all
10. What have been your biggest challenges/problems as a caregiver since (the patient) came home?
11. Is there anything else you would like to add?

## Appendix B

### Caregiver Responses to Qualitative Interview Guide

Theme	ID	Quote
1. Caregiver involvement in discharge teaching		
a. Passive involvement	1	<p>"I was involved, I was there, I was listening."</p> <p>"I'd ask questions if I had any questions about what we needed to think about."</p>
	3	<p>"Most of the interactions were between [the patient] and the caregivers, I was kind of on the side ... a lot of the stuff was directed straight at her, and I was like an observer."</p> <p>"I really think the one thing that maybe could be addressed a little better ... I wouldn't say forcing, but encouraging me to think more deeply about the recovery process."</p>
	2	"I don't really know ... because when I was there, I took care of him, but they were doing all that stuff too, so I wasn't there the whole time they were .... So I assumed that they knew what his needs were."
	4	"They just really explained things well to me."
	4	<p>"... they just really explained things well to me. I knew what to expect and what he shouldn't do and what he should do."</p> <p>"So that's kind of what we felt, they were clear enough and pretty straightforward as to what needed to be done."</p> <p>"The nurses made sure that I understood the instructions because he was on a lot of painkillers at the time."</p> <p>"I can't say that they missed anything, and going home I felt comfortable with it."</p>
b. Clear instructions	1	<p>"I'd say very well. I'd say a nine out of ten, very well."</p> <p>"They were very helpful ...."</p> <p>"Yes, they gave us a full list with the patient packet inserts as well, printed out, that had all the information that you'd want to know on an eight and a half by eleven sheet, sometimes multiple pages per medication. And that was really helpful, because [the patient] did have an allergic reaction."</p> <p>"Well, for sure ... and that was a combination of the nursing protocol to review the discharge, and the physical therapist to teach, train, instruct and on how to do all the basic getting around from point A to point B at home, versus being in the hospital and having support at the hospital. And so, I would see on a scale of one to ten ... I would say an eight or a nine out of ten. Meaning good."</p>
	3	<p>"Their advice was very clear and pretty well understood, I think."</p> <p>"People explained themselves well."</p> <p>"It looked like they had it pretty well laid out in terms of what we needed to do ... the actual things that she needed to do at first were very minimal, it seemed like, and nice and clear. We knew where to go with it."</p> <p>"The PT part went pretty well."</p> <p>"The instructions were consistent, and we were very pleased."</p> <p>"They were clear enough and pretty straightforward about what needed to be done."</p> <p>"Let's see, the pharmacist came in and went through the medicines and stuff that he had and he did that."</p>
	2	<p>"The last went through really good. They were more complete. So, it would've been good if we had ... I guess I was really surprised that they didn't come home the first time with it ... but they weren't given those instruction."</p> <p>"... we have a hard time getting the information that I think we really needed ... so that could have been done the first time around and that would have really helped."</p>
2. Role of the caregiver at home after discharge		
a. "Home-Nurse"	4	<p>"... I took the next day off and made sure that he was comfortable, made sure we were doing the pills on time, the painkillers ...."</p> <p>"He had to be careful going into bed at first. Because it was back surgery, I had to lift his legs to make sure he didn't bend at the waist."</p> <p>"What we did was before he went in for surgery, we made two big crockpots of soup. So, we had meals already prepared and I would make a salad or bake some bread or something for a side on it, or roast some vegetables."</p> <p>"We actually wrote down what medications to take at what time and his phone would go off with an alarm and we knew, 'Okay, so there's a medication that you need to take.'"</p> <p>"There were times when he felt bad that he couldn't do much, and I would tell him, in two weeks you'll be able to or in three weeks, whatever it was, you'll be able to do more. But even now I make sure that he doesn't lift heavy things ... sometimes he's hard on himself and I have to tell him, 'No you're doing what you can and this is good and you're fine.' He puts more pressure on himself and he feels bad. When I am home, I do remind him that, 'Yeah, you can't lift two gallons of milk at the same time even though you really want to.'"</p> <p>"... every once in a while, he would feel good and think he could back off on the painkillers and that's when it got worse, and then a couple of times I did have to remind him, 'Okay, you need to take a painkiller.' 'You know I hate taking them,' and I said, 'Yeah, but it's better that you're not in pain than being in pain.'"</p>

(continues)

## Appendix B

### Caregiver Responses to Qualitative Interview Guide (*Continued*)

Theme	ID	Quote
	3	<p>"I think mostly psychological support."</p> <p>"I would help her when she needed help with PT, encourage her to take drugs as needed, but not over-encourage her, especially on the pain meds and stuff like that. And the just kind of keep a positive air about how well she's recovering and how well she's doing with her PT, and stuff like that."</p> <p>"It's hard day to day for her to see the progress sometimes. So, I try to comment on that when I think it's appropriate."</p> <p>"Just the first couple of days, I did most of the cooking."</p> <p>"I think probably my main thing was during the pain management aspects of it, where I would try to get her to go ahead and take use of the pharmaceuticals, after all they're legal. And to stay ahead of the pain curve a little more. She had a lot of trouble sleeping, because she does have some osteoporosis, and she had had that hip surgery, and so there was a little compromising for her to have to kind of stay still at night. And yet, it was early enough after the surgery that rolling and changing position was uncomfortable."</p>
	1	<p>"So, I was her nurse. So, I did everything that needed to be done to ensure that she was safe and accomplished what she needed to be accomplished upon discharge."</p> <p>"... elevate both her legs with pillows, and ensure that she was comfortable and could rest and sleep until she needed to get up to use the washroom or get something to eat ... I was doing the PT stuff with her as well, to help her move out of bed and to the bathroom .... We were discharged with a safety belt that I put around her waist every time that she got out of bed to walk to the bathroom, or to do whatever."</p> <p>"I also, when we came home, we had a list of 10 medications, including two narcotics. And I took the role of charting all the times that they were to be given, the quantities, the dosages, and I tracked her pain level. I basically acted like a nurse ...."</p> <p>"Every day and night, I would ask at least a couple of times, 'What's your pain level?' And so, all of that was charted, so we can see her maximum pain to when it tapered off, and when it started to go down. I added ... poop and pee ... yes or no, daily."</p> <p>"... the process of discharge the methodical things you needed to do during the course of caregiving. I just built that into my schedule."</p>
	2	<p>"I helped him get dressed, and helped him get to bed .... Just overall care, pretty much, helping him going to the bathroom, helping him walk places, helping him get up, standing up and all that."</p>
b. Problems encountered at home and patient outcomes		
i. Mobility	1	<p>"And the first morning upon waking up, [the patient] had a fall. And it was a combination of nausea, pain, dizziness, blacked out. And went down ... in our half bath. And it was because your truly went to the bathroom first, got [the patient's] situated, went out of the room for a moment, and that's when the nausea came, dizziness, blacked out. Happened, and it happened in seconds .... Because I wasn't aware that I shouldn't have left her sitting on the toilet without being there and supporting her. She fell on her head, and went down. So, she had a bloody mouth, a bloody nose, a bruise above her eye. But she was okay. And so, we went back to the hospital."</p> <p>"Any opinion as to what they could have done to be a 10 out of 10?"</p> <p>"Yeah. And that would be around physical therapy, training. What you really should be thinking about, night one, day one, day two, day three at home .... In the middle of the night when you've got to get up because you've got to go to the bathroom, you want to be on your game and not half asleep."</p> <p>"So physical therapy and the importance of physical therapy, and really helping whoever is the support person, during the night, understand that for a at least three days, you've got to make sure that your loved one is able to move safely and be safe .... And I didn't quite get that, honestly .... How important my role was, that something bad could happen if I wasn't on my game."</p> <p>"I wasn't trained, and I didn't know that initially, to move from a position, laying on the bed, to a standing position, to use the walker to move from the bed to the bath, we did all that. But at first, I would leave [the patient] unattended for a little bit. And I didn't realize that I shouldn't do that, and that was not emphasized. So, something like that is emphasized during discharge, during your training in physical therapy and who's going to be the nurse during that period of time at home, I think that just needs to be emphasized."</p> <p>"And more training around that, the importance of making sure that ... upon discharge, you know what your responsibilities are."</p>
ii. Medication management	1	<p>"We didn't receive upon discharge, a tapering schedule of when to start it, what were the symptoms or lack thereof the symptoms we should look for. And then begin ... you know, what do we try to do? She was on five to six Tramadol's in a 24-hour period. Do we drop that by half, during each dose, or what? We didn't know."</p> <p>"Just take one 325 milligram dose out of the two, and do that once a day, and then do that twice a day, because there were three doses. Or three times, to administer the doses. And the we just began that whole process and based on [the patient] pain level, we got to the point where she was down to a quarter tab of a 325-milligram tablet, three times a day. And once we got there, we just then took away one dose of the three, and then the second dose of the three, and then left the weening dose for two or three days. And it worked."</p>

(continues)



## Appendix B

### Caregiver Responses to Qualitative Interview Guide (Continued)

Theme	ID	Quote
iii. Drain care	2	<p>"But I guess the drain care was the main thing because he got different instructions at different times and it would have been nice to have it all at the first."</p> <p>"We didn't find out about the back-flushing until the drain was replaced this time around, and so the first time when we were in the hospital, the nurse said that we needed to wash it just with normal flushes and clean the wound daily, and then when we went back, the nurse said, 'Oh, you don't need to clean the wound daily.' So, it was still hit and miss there."</p> <p>"Yeah, so I made sure I went back and stuff, but we were really surprised the last time around that I hadn't been back flushing, and maybe that would've made a difference."</p> <p>"... we still kind of wobbled back and forth, when the drain does weird things and it might just be because he had to go back in and have the abscess and stuff. So, we're a little more weary because even today it was a different color and different things. If I knew what to expect and what it meant that might help more ...."</p>
iv. Sleep	3	<p>"... maybe a little bit of more clarity on discomforts in sleep, adaptations, things she could do to help her sleep .... I think that the sleep aspect was actually the thing that maybe could be addressed in a little clearer and prescriptive fashion."</p> <p>"If she could have gotten a little early guidance on dealing with the discomfort and the sleep aspect, that's really the only thing I can think of that was kind of an issue for, I don't know, a month or so, something like that."</p> <p>"I really think the one thing that maybe could be addressed a little better would be the sleep issue. And so that would be my main takeaway by you .... I wouldn't say forcing, but encouraging me to think more deeply about the recovery process .... Telling her what to expect, and maybe emphasizing which drugs will do what for her and just strategies for better sleep."</p>
v. No complications	4	<p>"I didn't feel like anything was missing .... Maybe if it was my first time I would be able to think of something, but this is like his third or fourth surgery so I can't say that they missed anything ... and going home I felt comfortable."</p>

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