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Pain Points Along the Journey from Skilled Nursing Facility to Home: Patient and Caregiver Perspectives

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Transitions of care are a precarious time for patients and their caregivers, and especially so for frail elders living with chronic diseases and complex medical issues. Care transitions have received increased attention over the past decade; efforts to improve transitions have originated, for the most part, in hospitals and focused on patients being discharged to either a skilled nursing facility (SNF) or home. However, there has been less focus on the needs of patients who are being discharged home following a short-term stay in a SNF.

Building on a longstanding commitment to improving care transitions for patients and family caregivers, and an interest in advancing solutions to common and persistent problems, UHF engaged eight SNFs in a two-year learning collaborative, supported by the Mother Cabrini Health Foundation. With a market research firm, UHF designed a survey of patients and family caregivers who had recently experienced a discharge to home from the participating SNFs. This report presents the responses and the surveys themselves, evaluating four domains related to the SNF stay: transition planning and patient preparation, patient education about medication, experience after discharge, and response and information about COVID-19.

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Introduction

Transitions of care are a precarious time for patients and their caregivers, and especially so for frail elders living with chronic diseases and complex medical issues. Health risks that patients and caregivers may experience during transitions include avoidable use of acute care and emergency services, high levels of stress and anxiety, social isolation, and dissatisfaction with care.[1] Poor outcomes are even more likely for Medicare beneficiaries with multiple chronic conditions, lower socioeconomic status, dual enrollment in Medicare and Medicaid, cognitive impairment, or limited English proficiency.[2]

Care transitions have received increased attention over the past decade due largely to the initiation of payment penalties in 2013 by the Centers for Medicare & Medicaid Services (CMS). These penalties were designed to reduce the approximately 2.6 million seniors who are readmitted to hospitals within 30 days, at a cost of over $26 billion every year.[3] Efforts to improve transitions have originated, for the most part, in hospitals and focused on patients being discharged to either a skilled nursing facility (SNF) or home. Although CMS also began penalizing SNFs in 2018 for higher-than-average rates of hospital readmission, those penalties have not yet led to much-needed improvement in preparing patients and family caregivers for the return home from a short stay. According to CMS, only 50% of patients with Medicare Part A coverage successfully returned to home or their community following a short stay in a SNF, highlighting a sizeable gap for targeting quality improvement efforts.[4]

Building on a longstanding commitment to improving care transitions for family caregivers and an interest in advancing solutions to common and persistent problems, UHF engaged eight SNFs in a two-year **learning collaborative,** supported by the Mother Cabrini Health Foundation. The SNFs were very interested in addressing these well-documented challenges related to transitions of care and helped UHF capture the perspectives of their own patients and caregivers, even amid the first surge of the COVID-19 pandemic in New York. In the spring of 2020, UHF worked with a market research firm, Market Decisions Research (MDR), to design a survey of patients and family caregivers who had recently experienced a discharge to home from the participating SNFs. The survey's purpose was to help each SNF identify pain points in the process from the perspectives of patients and family caregivers. This report presents the main findings from the survey. These results were shared with the SNFs and used to inform their quality improvement projects, which will be profiled in a subsequent report.

1 Naylor, Mary, and Stacen A. Keating. "Transitional Care: Moving Patients from One Care Setting to Another." *The American Journal of Nursing* 108, no. 9 Suppl (September 2008): 58–63. https://doi.org/10.1097/01.NAJ.0000336420.34946.3a.

2 Toles, Mark, Cathleen Colón-Emeric, Mary D. Naylor, Julie Barroso, and Ruth A. Anderson. "Transitional Care in Skilled Nursing Facilities: A Multiple Case Study." *BMC Health Services Research* 16 (May 17, 2016). https://doi.org/10.1186/s12913-016-1427-1.

3 https://innovation.cms.gov/innovation-models/cctp

4 Centers for Medicare & Medicaid Services, Rate of Successful Return to Home and Community from a SNF, https://www.medicare.gov/care-compare/

Background

During a four-month period from August to December 2020, MDR contacted by phone, mail, and email patients who had been discharged within the past six months and family caregivers. The patients surveyed were not necessarily related to the family caregivers who were surveyed. Therefore, the responses from an individual patient and their caregiver could not be matched and then compared.

The survey instruments evaluated four domains related to the SNF stay: transition planning and patient preparation, patient education about medication, experience after discharge, and response and information about COVID-19. Some domains included sub-categories which are explained later in the report, and the caregiver survey included an additional domain with questions about experiences caring for the patient.

Response rates and responses to the survey were clearly affected by the pandemic in numerous ways. For example, the suspension of elective surgery at hospitals in the New York metropolitan region resulted in large drops in short-stay patient volume at the SNFs, staffing shortages affected care delivery and the experiences of patients and family caregivers, and visitation restrictions precluded in-person training of caregivers. Still, we were able to obtain 263 responses to the survey from patients and 249 from caregivers (an average of 32 patient responses per facility and 31 caregiver responses).

It should also be noted that while the report reflects the important perspectives of patients and caregivers, some of the survey questions relate to actions taken by SNF staff during their stay. Even in the best of times, patients and caregivers are not always aware of the efforts being made by SNF staff to ensure a smooth transition to home or may not remember the many steps that were taken on their behalf. It is possible, and even likely, that pandemic-related stress may have widened gaps in awareness or recall or both.

Additional details on survey methods and limitations appear in Appendix A, including response rates, sampling error, and self-reported demographic characteristics.

Demographic Characteristics

Although the data collected on gender, race/ethnicity, and education level of respondents was incomplete, we did find some differences between patients and caregivers. Table 1 shows the background characteristics of the sample.

TABLE 1.
BACKGROUND CHARACTERISTICS OF THE SAMPLE

	Patient	Caregiver
Gender		
Male	37%	27%
Female	48%	62%
Unknown	16%	12%
Age		
64 or younger (50-64)	20%	38%
65 to 74 years	17%	18%
75 to 84 years (75 or older)	19%	12%
Unknown	27%	10%
Race		
Black or African-American	16%	13%
White	48%	56%
Multi-racial	2%	16%
Unknown	35%	15%
Ethnicity		
Hispanic or Latino	8%	10%
Non-Hispanic or Latino	71%	73%
Unknown	22%	17%
Educational Attainment		
High School/GED/Did Not Finish High School	37%	19%
Associate's/2-Year Degree/Some College	5%	23%
Bachelor's/4-Year Degree	11%	21%
Graduate School/Professional	10%	25%
Unknown	21%	12%

Overall Findings

The key findings from the patient and caregiver surveys, which are discussed in more detail later in this report, identified areas where patients and caregivers felt that their needs were being met appropriately, as well as some concerning gaps that make the transition home more challenging.

On the positive side:

- Over 80% of patients reported that they received and understood **discharge instructions**.
- Over 70% of patients and caregivers reported that they obtained **needed services after discharge**, including medications, equipment, and additional help.
- More than 75% of patients surveyed reported that **home care services** were delivered on time.

These findings revealed that the SNFs are carrying out essential components of discharge planning effectively.

Yet performance fell short in several areas:

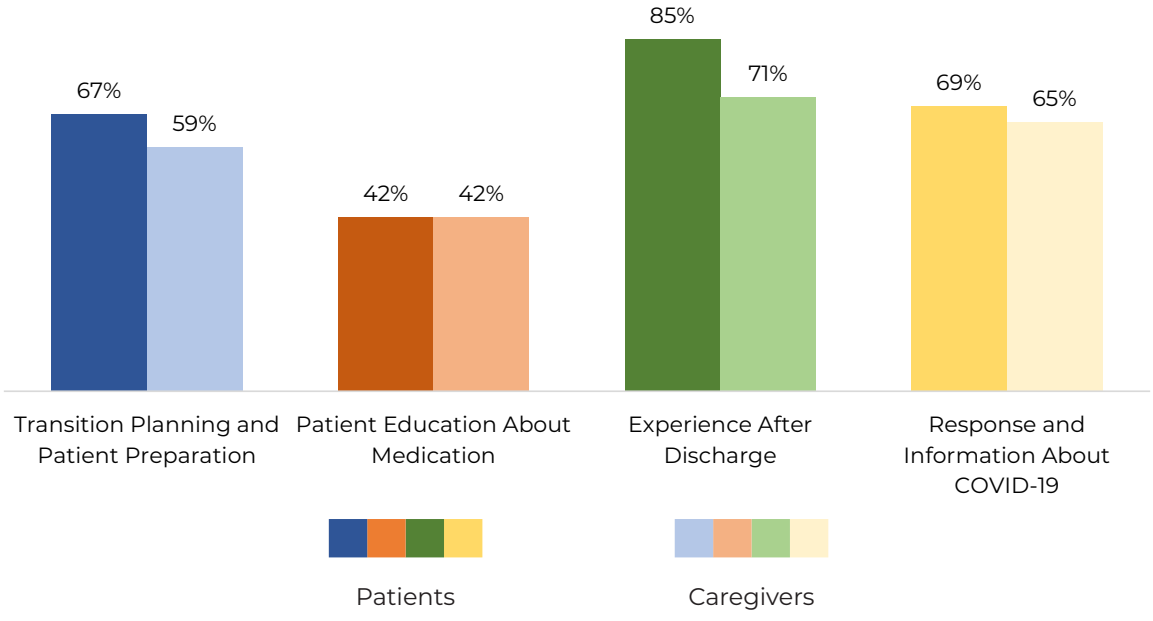
- At least two-thirds of both patients and caregivers needed more help **understanding medications** and seeking assistance with side effects.
- Almost half of patients and caregivers also needed more help **understanding signs and symptoms** of their conditions post discharge.
- Patients reported they were not frequently asked about **concerns related to social needs** (e.g., food, housing, transportation, affording care) and even when asked, close to half were not referred to services to help mitigate those concerns.
- Patients and caregivers reported that **follow-up appointments with primary care providers or specialists** were arranged less than half the time—a finding warranting closer examination to reduce any avoidable gaps in care coordination.
- More than 40% of patients and caregivers reported that they did not receive a **follow-up call from the SNF** after they were discharged. This requires examination, as post-discharge follow-up calls are considered a best practice that can help identify and address problems early and possibly avoid more serious complications, acute care utilization, and patient and caregiver stress.

Domain Findings

The following section explores the four main domains and the results of selected survey questions in more detail and is ordered as follows: transition planning and patient preparation, patient education about medication, experience after discharge, and response and information about COVID-19. The figures included below correspond to the domains accordingly: Figure 1 describes responses in all four domains; Figures 2 to 5 examine responses related to transition planning and patient preparation; Figure 6 highlights responses on education about medication; and Figure 7 looks at responses related to experience after discharge.

Patient and caregiver experiences assessed by the survey were relatively consistent.[5] In order of positive responses, the domains that received higher ratings include the following: experience after discharge, facility response and provision of information about COVID-19, transition planning and patient preparation, and patient education about medication. Caregivers rated two of the domains lower than patients: experience after discharge and transition planning and preparation. This is not surprising given that the burden of care responsibility often falls on the caregiver and is a well-documented issue.

FIGURE 1. PERCENTAGE OF PATIENTS AND CAREGIVERS WHO PROVIDED A POSITIVE RESPONSE TO HALF OR MORE QUESTIONS IN THAT DOMAIN



5 A rating for each domain was calculated based on selection by patients or caregivers of the most positive response options (e.g., strongly agree/agree), which were then counted as a positive rating. The domain rating is the percentage of respondents who provided a positive rating to half or more of the questions included in the domain.

Transition Planning and Preparation

Transition planning and preparation covered questions related to the patient's discharge home, including discharge instructions, insurance coverage for services at home, concerns related to social needs, and referrals to meet those needs.

Discharge Instructions and Insurance Coverage

Although 90% of patients felt prepared to go home, only 66% of caregivers felt prepared to care for the patient after the return home, which represents a sizeable and concerning difference. This finding suggested the need for further focus on the engagement and preparation of caregivers in the discharge planning process. Lack of clarity about what home services would be covered by insurance was also common among both patients and caregivers. (Figure 2.)

Social Needs Screening and Referrals

Survey responses indicated that SNF staff did not routinely ask patients and caregivers about their social needs. While less than half of patients reported being asked about access to transportation, fewer patients were asked about stable housing or their ability to afford care or food. When SNF staff did ask about social needs, they tried to address concerns by referring patients and caregivers to an appropriate program or organization. Affording food was the best-addressed social need, followed by financial assistance, reliable transportation, and stable housing. These findings show that standardizing the routine assessment and referral for social needs could yield significant opportunities for improvement. (Figure 3.)

FIGURE 2. PERCENTAGE OF PATIENTS AND CAREGIVERS WHO PROVIDED A POSITIVE RESPONSE TO QUESTIONS ABOUT TRANSITION PLANNING AND PREPARATION

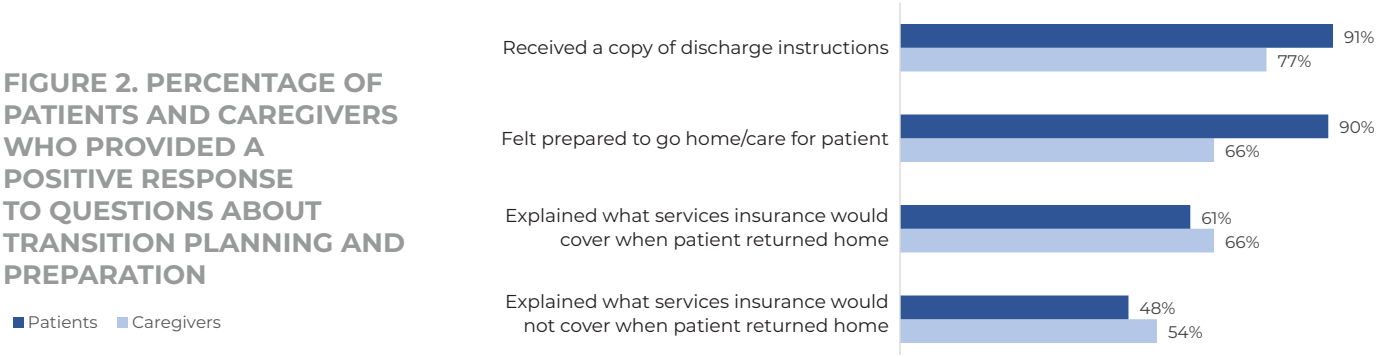
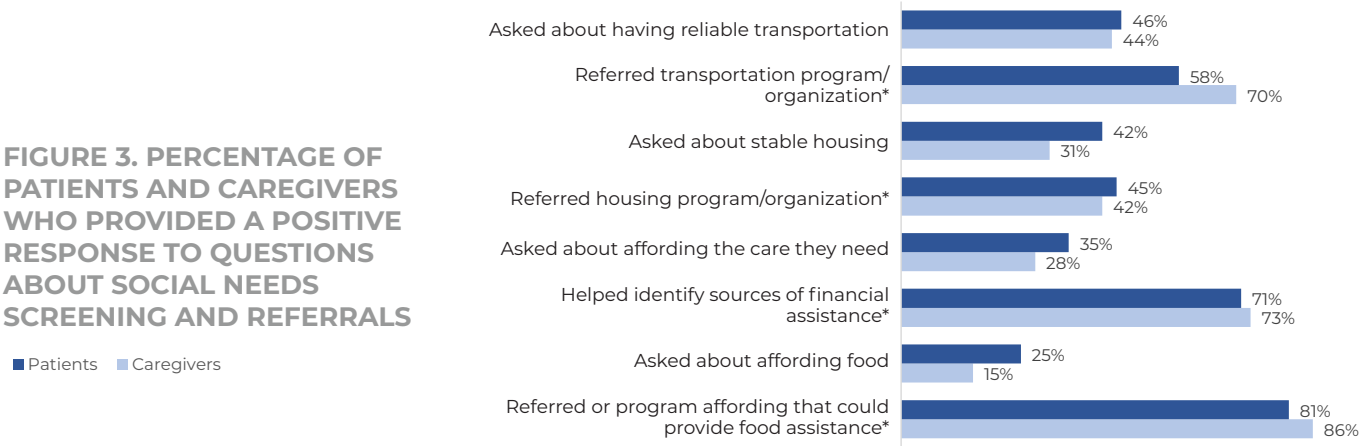


FIGURE 3. PERCENTAGE OF PATIENTS AND CAREGIVERS WHO PROVIDED A POSITIVE RESPONSE TO QUESTIONS ABOUT SOCIAL NEEDS SCREENING AND REFERRALS



Self-Care Needs and Managing Symptoms

Overall, patients felt slightly more prepared to take care of their medical and personal needs compared with caregivers. However, at least half the patients and caregivers felt they did not receive information about the kinds of symptoms and problems they may experience upon their return home. Patients were a little more informed than caregivers about how to handle these issues if they emerged, but neither group felt fully informed. (Figure 4.)

Arrangements for Home Care Services and Medical Equipment

Services ordered for the patients were reported to be provided largely on time, including medical equipment (over 85% of patients and caregivers) and home care (over 65% of patients and caregivers). More than nine in ten patients and caregivers were able to use the medical equipment once it arrived at home, and close to seven in ten patients and caregivers were able to understand the information they were given about home care services that had been arranged. (Figure 5.)

Arrangements for Primary Care Provider Follow-Up Appointment

Only four in ten patients reported that the SNF arranged a primary care follow-up appointment for them, and even fewer caregivers, almost one in three, reported that an appointment was arranged for their family members. Although the pandemic likely posed barriers to scheduling follow-up appointments, this gap demands further attention to ensure effective care coordination and continuity.

FIGURE 4. PERCENTAGE OF PATIENTS AND CAREGIVERS WHO PROVIDED A POSITIVE RESPONSE TO QUESTIONS ABOUT RECEIVING INFORMATION ABOUT SELF-CARE NEEDS AND SYMPTOM MANAGEMENT

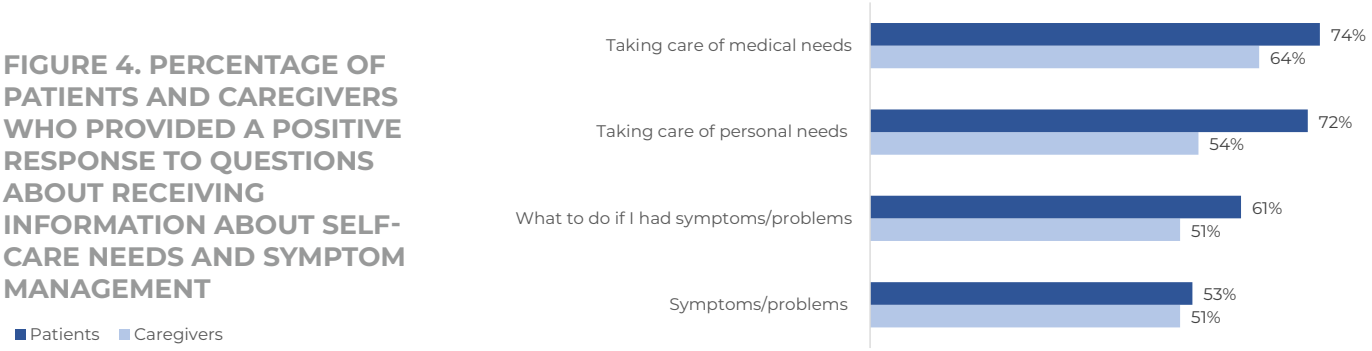
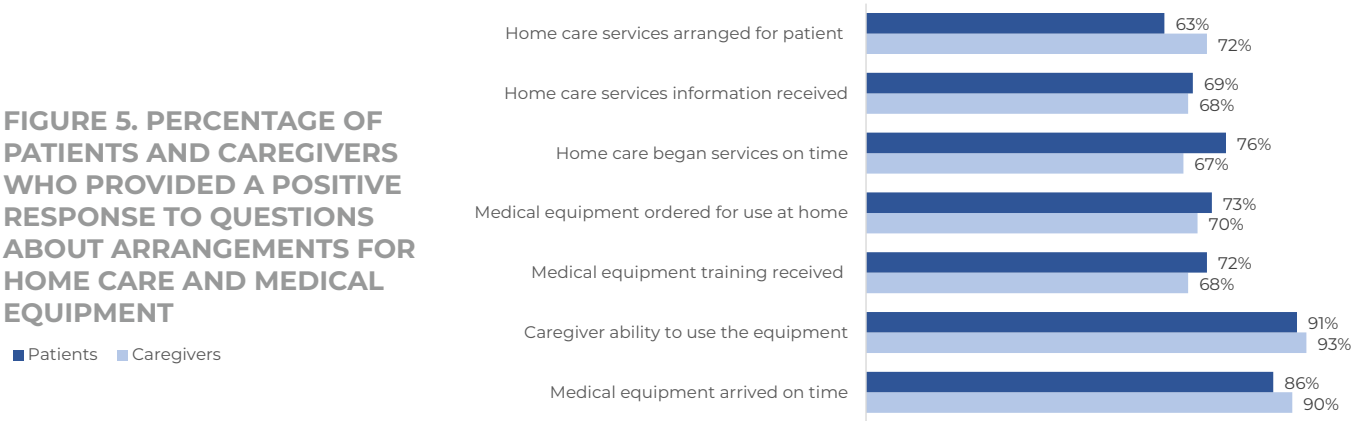


FIGURE 5. PERCENTAGE OF PATIENTS AND CAREGIVERS WHO PROVIDED A POSITIVE RESPONSE TO QUESTIONS ABOUT ARRANGEMENTS FOR HOME CARE AND MEDICAL EQUIPMENT



Medication Education

Overall, both patients and caregivers did not feel well educated about the patient's medications, one of the more alarming survey results. A little over half of patients (57%) and caregivers (56%) reported receiving written information about the purpose of each medication. Just over half of patients and caregivers were told how to take the medications. (Figure 6.)

Only three in ten patients (30%) and just over a quarter (28%) of caregivers were informed by facility staff about medication side effects. Similarly, only a third of patients (32%) and caregivers (29%) were told how to handle medication side effects. Considering the common occurrence of polypharmacy in older adults as well as the complexity of side effect profiles and interactions of prescription and over-the-counter drugs, more attention must be paid to educating both patients and caregivers about medications.

Experience After Discharge

After discharge, about three quarters of patients and caregivers reported that the patient was receiving all the help needed at home. However, nearly 60% of caregivers responded that the patient experienced problems after returning home. Improving performance on post-discharge follow-up calls could help ensure that patients who experience problems are identified and receive helpful instructions on how to address them. (Figure 7.)

Response and Information About COVID-19

Since the survey was conducted during the first year of the pandemic and SNFs in New York were severely affected, we included a few questions to assess the response and information about COVID-19 that facilities relayed to patients and caregivers.

Just over six in ten patients (62%) and caregivers (63%) stated that they received timely information about the SNF's efforts to control the spread of COVID-19.

FIGURE 6. PERCENTAGE OF PATIENTS AND CAREGIVERS WHO PROVIDED A POSITIVE RESPONSE TO QUESTIONS ABOUT EDUCATION ON MEDICATIONS

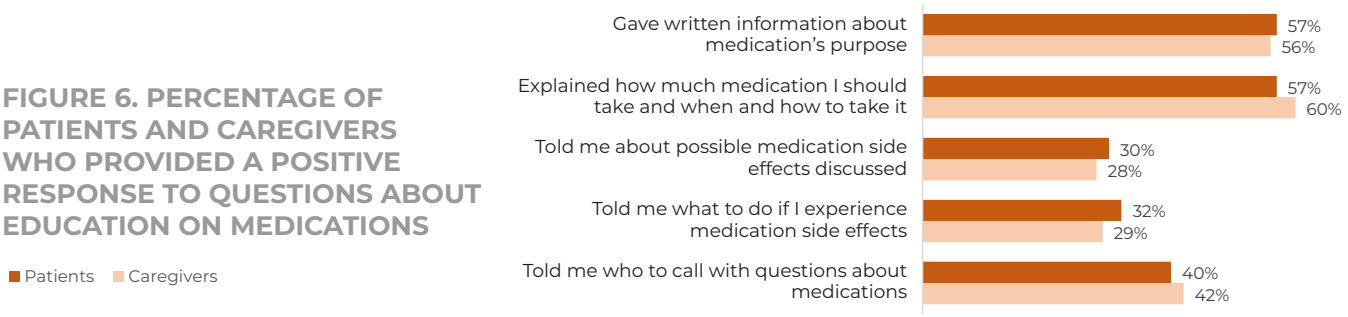


FIGURE 7. PERCENTAGE OF PATIENTS AND CAREGIVERS WHO PROVIDED A POSITIVE RESPONSE TO QUESTIONS ABOUT THEIR EXPERIENCE AFTER DISCHARGE TO HOME

Discussion and Opportunities for Improvement

The survey findings summarized in this report align with other published research on the challenges patients and families experience during their transitions specifically from SNFs to home.[6,7,8,9] Facility-specific results have helped identify where each SNF is succeeding and where pain points make it difficult for patients and family caregivers to transition smoothly and more effectively manage their care at home. Such detailed feedback was invaluable to the SNFs as they examined their discharge planning processes and designed interventions to improve the experience of transitions for patients and family caregivers. The survey highlighted gaps in patient and family caregiver preparation, education, care coordination, and post-discharge follow-up. But the good news is that there is no shortage of opportunities to help ensure smoother transitions, greater continuity of care, and early identification of problems.

We found differences between the patients' and caregivers' perspectives about their level of preparedness to manage at home. The importance of caregiver involvement from the time of admission through post-discharge cannot be overstated—it is often the caregiver who manages their loved one's chronic conditions or continued recovery at home by administering medications, arranging and attending appointments, performing complicated nursing tasks, and supporting activities of daily living and other patient needs. Caregiver stress is well documented, and SNFs have an important role to play in ensuring caregivers are prepared and have their questions answered throughout the patients' stay, not just in the rush of activity right before discharge.

Some specific areas of opportunity to make the transition to home more effective for patients and caregivers:

Patient and caregiver education with a focus on understanding their condition, including signs and symptoms to look out for at home; who to call with questions; and information on the use, dosage, and administration of medications and their side effects.

Social needs screening and referrals can improve the health outcomes of older, vulnerable patients. Screening for needs such as ability to afford care and medications, stable housing, and transportation for follow-up appointments should be routinely

6 Okrainec, Karen, et al. "Patients' and Caregivers' Perspectives on Factors That Influence Understanding of and Adherence to Hospital Discharge Instructions: A Qualitative Study." CMAJ (September 2019): E478–83

7 Mitchell, Suzanne E et al. "Care Transitions from Patient and Caregiver Perspectives." The Annals of Family Medicine 16, no. 3 (May 1, 2018): 225–31.

8 Scott, Allison et al. "Understanding Facilitators and Barriers to Care Transitions: Insights from Project ACHIEVE Site Visits." The Joint Commission Journal on Quality and Patient Safety 43, no. 9 (September 1, 2017): 433–47.

9 Strategy 4: Care Transitions from Hospital to Home: IDEAL Discharge Planning. Content last reviewed December 2017. Agency for Healthcare Research and Quality, Rockville, MD. https://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/strategy4/index.html

conducted in tandem with referral to appropriate services in the community.

Post-discharge follow-up phone calls can identify early issues with the transition and address any problems that emerge after the patient's return home.

Appointments with primary care providers arranged by SNF staff to facilitate continuity of care in the patient's community and potentially address health issues the patient may face following discharge.

Arrival of home care services on time to ensure that the patients and caregivers are not left to manage on their own without appropriate support.

For these strategies to succeed, SNFs must first assess patient and caregiver needs and then tailor services and resources to help them manage their recovery and maintain their health and well-being. Patient and caregiver needs related to preferred language, health literacy, and cultural beliefs and practices are also key considerations and should be incorporated into transition planning.

Conclusion

Our survey results add to the evidence that transitions of care continue to demand far greater attention. Smoother transitions can help mitigate poor outcomes and make a meaningful difference in preparing short-stay patients and caregivers, so that they are more confident and equipped with the appropriate resources and support to make the journey home a success. Caregivers must be integrated from the outset and their needs and capabilities considered for quality improvement efforts to take root and spread.

Patient and caregiver voices are essential to the quality improvement cycle, and it is extremely important to engage them in such initiatives. The survey has helped the SNFs in our collaborative learn from their own patients and caregivers as they dedicate themselves to making improvements in their transition of care processes. We hope that other SNFs will use the survey instruments in Appendices B and C to better understand the perspectives of the patients and families they serve and work toward reducing the pain points in transitions of care and ensuring that more journeys home succeed.

Acknowledgments

We would like to acknowledge the hard work of the eight SNFs that participated in our learning collaborative and the survey. We appreciate their commitment to this project, especially during this very challenging time of the COVID-19 pandemic.

From UHF, Adam Fifield and Miles P. Finley provided editing and design support, and Catherine Arnst assisted with report dissemination. We would also like to thank Anne-Marie Audet for her contributions to this work.

Appendix A: Methods and Sample

Existing survey instruments and relevant literature related to transitions and patient experience were reviewed to identify potential topics and questions for inclusion. We then worked with MDR to develop survey questionnaires for the patients and their caregivers. Each of the eight SNFs provided their sample of eligible patients and caregivers to MDR for distribution. Surveys were collected in four phases using a multi-modal approach of mail, email, and phone calls.

Limitations

A major limitation is that the survey was administered during the pandemic, which affected the volume of patients discharged from SNFs, the experience of both patients and caregivers, and the transition to home process. Some patients went directly home from the hospital to avoid a stay in a SNF, rehabilitation services were modified to avoid exposure, and visitation restrictions affected the ability of SNFs to educate caregivers in person. Additionally, potentially sicker patients may have been discharged home more quickly to avoid infection, staffing shortages, and other resource constraints. Survey sample sizes were limited by the decreased volume of short-stay discharges. Patient and caregiver responses were not paired, and thus we were unable to match or compare the experience of an individual patient and their associated caregiver.

PATIENT AND CAREGIVER SAMPLE DATA SUMMARY

	Patient	Caregiver
Overall Sample Size	263	249
Average Sample Size per SNF	32	31
Range of Sample Size across 8 SNFs	(8-74)	(5-95)
Overall Response Rate	29%	37%
Overall Sampling Error	6.0%	6.2%

BACKGROUND CHARACTERISTICS OF THE SAMPLE (REPRINTED FROM PAGE 3)

	Patient	Caregiver
Gender		
Male	37%	27%
Female	48%	62%
Unknown	16%	12%
Age		
64 or younger (50-64)	20%	38%
65 to 74 years	17%	18%
75 to 84 years (75 or older)	19%	12%
Unknown	27%	10%
Race		
Black or African-American	16%	13%
White	48%	56%
Multi-racial	2%	16%
Unknown	35%	15%
Ethnicity		
Hispanic or Latino	8%	10%
Non-Hispanic or Latino	71%	73%
Unknown	22%	17%
Educational Attainment		
High School/GED/Did Not Finish High School	37%	19%
Associate's/2-Year Degree/Some College	5%	23%
Bachelor's/4-Year Degree	11%	21%
Graduate School/Professional	10%	25%
Unknown	21%	12%

Appendix B: Patient Survey

United Hospital Fund

Skilled Nursing Facility (SNF) Short Stay Patient Survey

Introduction

For this survey, "caregiver" refers to the family member or friend who most often helps you with your medical needs.

For any question, if you feel you do not have enough experience or information to answer a question, please mark "Does Not Apply." Answering the questions should take about 10 minutes of your time.

If you feel you do not have enough experience or information to answer a question, please mark Does Not Apply.

COVID-19 Questions

COVID-19 (the coronavirus) is impacting everyone's lives. We have included the following questions about how the COVID-19 outbreak may have affected your experience with this SNF.

COVID1

Did you receive training from the facility about how to avoid getting COVID-19?

- Yes
- No

COVID2

Did you receive timely information about the facility's efforts to control the spread of COVID-19?

- Yes
- No

Care Conference

FAC01

A care conference is a formal meeting between you (the patient), your care team, and your family or friends about your progress and care plan. Were you invited to participate in a care conference during your short stay in the nursing facility?

- Yes
- No

Discharge Planning

[INSTRUCTIONS]

The following questions concern your discharge planning. This is the process of transitioning from the nursing facility to your home. Your care team, and if applicable your family or friends, participate in these planning activities.

Please indicate how strongly you agree or disagree with the following statements.

[RESPONSE SCALE] Strongly agree, Agree, Disagree, Strongly disagree

During discharge planning…

TP01

When I was told I would be discharged soon, I felt prepared to go home.

TP02

Staff took my preferences into account in deciding what care I would need after discharge.

TP03

Staff explained what services **would** be covered by insurance once I returned home.

TP04

Staff explained what services **would not** be covered by insurance once I returned home.

[INSTRUCTIONS] Please answer 'Yes' or 'No' the following statements.

During discharge planning…

TP05

I received a copy of my discharge instructions.

ASK IF YES TO TP05

TP06

Staff explained my discharge instructions to me in a way that I could understand.

TP07

The discharge instructions were in my preferred language.

TP08

Staff asked if I had concerns about returning to home.

ASK IF YES TO TP07

TP09

Staff helped address my concerns about returning home.

TP10

Staff asked if I had any concerns about affording the care that I need.

ASK IF YES TO TP10

TP11

Staff helped me identify sources of financial assistance.

TP12

Staff asked if I had concerns about affording food.

ASK IF YES TO TP12

TP13

Staff referred me to a program or organization that could provide food assistance.

TP14

Staff asked if I had concerns about stable housing (own, rent, or stay in).

ASK IF YES TO TP14

TP15

Staff referred me to a housing program or organization that could help me.

TP16

Staff asked if I had concerns about having reliable transportation.

ASK IF YES TO TP16

TP17

Staff referred me to a transportation program or organization that could help me.

[INSTRUCTIONS] Please indicate how strongly you agree or disagree with the following statements.

RESPONSE SCALE: Strongly agree, Agree, Disagree, Strongly disagree

During discharge planning, I received information I could understand about…

TP18

How to take care of my medical needs when I got home.

TP19

How to take care of my personal needs (hygiene, bathing, toileting, eating).

TP20

Symptoms or problems I may experience.

TP21

What to do if I had symptoms or problems.

TP22

Food I should avoid.

TP23

Activities I should avoid.

TP23

How to obtain my medications.

TP24

Did staff from the SNF help arrange appointments with your primary care physician (or another care provider)?

- Yes
- No
- I don't have a PCP or other care provider

Services

[INSTRUCTIONS]

The following questions concern medical services provided to you while at home.

Please answer 'Yes' or 'No' to the following questions.

During discharge planning…

SER01

Was medical equipment ordered for you to use at home (For example, wheelchair, walker, oxygen, shower seat, hospital bed)?

ASK IF YES TO SER01

SER02

Did you or your caregiver receive training about how to use the medical equipment?

ASK IF YES TO SER01

SER03

After discharge, did the medical equipment arrive at your home on time?

ASK IF YES TO SER01

SER04

Were you or your caregiver able to use the equipment?

[RESPONSE OPTIONS] Yes, No, I haven't received the equipment yet

SER05

Were any of the following home care services arranged for you? Please select all that apply:

- Home infusion therapy
- Home health aide
- Homemaker (laundry, meals, housekeeping)
- Nursing
- Dialysis
- Occupational therapy
- Physical therapy
- Speech therapy
- Respiratory therapy
- Personal care attendant
- Other, please specify: _____.
- I did not need any home care services.
- I did not want any home care services.

ASK IF ANY OPTION SELECTED IN SER05 OTHER THAN "I DID NOT NEED/WANT ANY HOME CARE SERVICES".

SER06

Did you receive information you could understand about home care services (for example, what services would be provided, for how long, and by whom?)

ASK IF ANY OPTION SELECTED IN SER05 OTHER THAN "I DID NOT NEED/WANT ANY HOME CARE SERVICES".

SER07

After discharge, did home care services begin on time?

[RESPONSE OPTIONS] Yes, No, Some did and some didn't

SER08

Were you referred to any of the following community services?

Please select all that apply:

- Meal delivery
- Food bank

- Pharmacy
- Transportation
- Senior center
- Case management
- Housing assistance
- Patient support group
- Other, please specify: _____.
- I was not referred to any community services

Wellbeing

The following questions ask about your physical and mental health.

WB01

Once you were at home, how much difficulty did you have doing your daily physical activities because of your health?

- No difficulty at all
- A little bit of difficulty
- Some difficulty
- A lot of difficulty

WB02

During discharge planning, how would you rate your level of stress or anxiety?

- None
- Mild
- Moderate
- Extreme

ASK IF MODERATE OR EXTREME TO WB02

WB03

What else could [FILL NURSING FACILITY NAME] have done to reduce your stress or improve your mental wellbeing?

- Please specify: _____.
- Nothing else

Medication

[INSTRUCTIONS]

The following questions ask about medication.

Please answer 'Yes' , 'No', 'Not applicable' to the following statements.

MED01

Staff gave me written information about the purpose of each medication.

MED02

Staff told me about possible medication side effects.

MED03

Staff told me what to do if I experience medication side effects.

MED04

Staff explained how much medication I should take and when and how to take it.

MED05

Staff told me who to call with questions about medications.

MED06

Staff asked about any over the counter medications I take at home.

After Discharge

[INSTRUCTIONS]

The following questions ask about what happened once you returned home from the nursing facility.

Please answer 'Yes' or 'No' to the following questions.

After discharge…

AFTER01
Did a staff member from the SNF follow up with you by phone?

AFTER02
Did you experience any problems getting your medication?

[Response options: Yes, No, Not applicable]

AFTER03
Were you or your caregiver instructed on how to prepare your home for your return (For example, installing assistive devices like handrails, getting equipment such as a hospital bed, removing trip or fall hazards)?

AFTER04
Are you receiving all the help you need at home?

AFTER05
Did you experience any other problems once you returned home?

IF YES TO AFTER05
AFTER06
Please specify the type of problems you experienced: _____.

Facility Rating

[INSTRUCTIONS]

The following questions ask for your opinions about the nursing facility.

RATE01
Using any number from 1 to 10, where 10 is the best care possible and 1 is the worst care possible, what number would you use to rate the care at this nursing facility?

Best Care - 10, 9, 8, 7, 6, 5, 4, 3, 2, 1 - Worst Care

RATE02

During your stay at [FILL NURSING FACILITY NAME], how often did you feel that the staff really cared about you?

- Always
- Usually
- Sometimes
- Rarely
- Never

RATE03

What could [FILL NURSING FACILITY NAME] have done better to help you prepare for your return to home? Please specify: ____.

About You

[INSTRUCTIONS]

The following questions are about some of your demographic characteristics.

What is your gender?

- Male
- Female
- Other
- Prefer not to answer

What is your age?

- 18-34
- 35-49
- 50-64
- 65-74
- 75-84
- 85+
- Prefer not to answer

Are you of Hispanic or Latino descent?

- Yes
- No
- Prefer not to answer

Do you consider yourself….(Select all that apply)

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or other Pacific Islander
- White
- Other
- Prefer not to answer

What is the highest year or grade of school that you have completed?

- Did not complete high school
- High school graduate or GED
- Attended some college
- Received and Associate's or 2 year degree
- Received a Bachelor's or 4 year degree
- Received a graduate or professional degree (MA, MS, PhD, MD, JD)
- Prefer not to answer

Appendix C: Caregiver Survey

United Hospital Fund

Skilled Nursing Facility (SNF) Survey of Caregivers

Introduction

For this survey, "patient" refers to: [PATIENT NAME]

Please answer the questions in this survey about the patient's stay in the nursing facility named on the cover. Do not include any other skilled nursing facility stays in your answers.

To complete this survey, please fill in the circle for your answer or write in the space provided. Please use only blue or black ink.

Answering the questions should take about 10 minutes of your time.

INTRO01

First, what is YOUR relationship to the patient?

- Spouse/Partner
- Child
- Friend
- Sister/Brother
- Cousin
- Parent
- Mother-in-Law/Father-in-Law
- Grandparent
- Aunt/Uncle
- Other, please specify _____

For the remaining questions, if you feel you do not have enough experience or information to answer a question, please mark "Does Not Apply."

COVID-19 Questions

COVID-19 (the coronavirus) is impacting everyone's lives. We have included the following questions about how the COVID-19 outbreak may have affected your experience with this SNF.

COVID1

Did you receive training from the facility about how to avoid getting COVID-19?

- Yes
- No

COVID2

Did you receive timely information about the facility's efforts to control the spread of COVID-19?

- Yes
- No

Care Conference

FAC01

A care conference is a formal meeting between a patient, their care team and their friends or family about the patient's progress and care plan. Were you invited to participate in a care conference during the patient's stay in the nursing facility?

- Yes
- No

Discharge Planning

[INSTRUCTIONS]

The following questions concern the patient's discharge planning. This is the process of transitioning from the nursing facility to the patient's home. The patient, their care team and the patient's friends or family participate in these planning activities.

Please indicate how strongly you agree or disagree with the following statements.

[RESPONSE SCALE] Strongly agree, Agree, Disagree, Strongly disagree

During discharge planning…

TP01

When I was told the patient would be discharged soon, I felt prepared to care for them at home.

TP02

Staff took my preferences into account in deciding what care the patient would need after discharge.

TP03

Staff explained what services **would** be covered by insurance once the patient returned home.

TP04

Staff explained what services **would not** be covered by insurance once the patient returned home.

[INSTRUCTIONS] Please answer 'Yes' or 'No' to the following statements.

During discharge planning…

TP05

I received a copy of the patient's discharge instructions.

ASK IF YES TO TP05

TP06

Staff explained the patient's discharge instructions to me in a way that I could understand.

TP07

The patient's discharge instructions were in my preferred language.

TP08

Staff asked if I had concerns about the patient's return home.

ASK IF YES TO TP08

TP09

Staff helped address my concerns about the patient's return home.

TP10

Staff asked if I had any concerns about affording the care that the patient needed.

ASK IF YES TO TP10

TP11

Staff helped me identify sources of financial assistance for the patient.

TP12

Staff asked if I had concerns about affording food for the patient.

ASK IF YES TO TP12

TP13

Staff referred me to a program or organization that could provide food assistance for the patient.

TP14

Staff asked if I had concerns about stable housing (own, rent, or stay in) for the patient.

ASK IF YES TO TP14

TP15

Staff referred me to a housing program or organization that could help the patient.

TP16

Staff asked if I had concerns about having reliable transportation for the patient.

ASK IF YES TO TP16

TP17

Staff referred me to a transportation program or organization that could help the patient

[INSTRUCTIONS] Please indicate how strongly you agree or disagree with the following statements.

RESPONSE SCALE: Strongly agree, Agree, Disagree, Strongly disagree

During discharge planning, I received information I could understand about…

TP17

How to take care of the patient's medical needs when they got home.

TP18

How to take care of the patient's personal needs (hygiene, bathing, toileting, eating).

TP19

Symptoms or problems the patient may experience.

TP20

What to do if the patient had symptoms or problems.

TP21

Food the patient should avoid.

TP22

Activities the patient should avoid.

TP23

How to obtain the patient's medications.

TP24

Did a staff member from the SNF help arrange appointments with the patient's primary care physician (or another care provider)?

- Yes
- No
- The patient doesn't have a PCP or other care provider

Services

[INSTRUCTIONS]

The following questions concern medical services provided to the patient while at home.

Please answer 'Yes' or 'No' to the following questions.

During discharge planning…

SER01

Was medical equipment ordered for the patient to use at home (For example, wheelchair, walker, oxygen, shower seat, hospital bed)?

ASK IF YES TO SER01

SER02

Did you or the patient receive training about how to use the medical equipment?

ASK IF YES TO SER01

SER03

After discharge, did the medical equipment arrive at the patient's home on time?

ASK IF YES TO SER01

SER04

Were you or the patient able to use the equipment?

[RESPONSE OPTIONS] Yes, No, the patient hasn't received the equipment yet

SER05

Were any of the following home care services arranged for the patient? Please select all that apply:

- Home infusion therapy
- Home health aide
- Homemaker (laundry, meals, housekeeping)
- Nursing
- Dialysis
- Occupational therapy
- Physical therapy
- Speech therapy
- Respiratory therapy
- Personal care attendant
- Other, please specify: _____.
- Patient did not need any home care services.
- Patient did not want any home care services.

ASK IF ANY OPTION SELECTED IN SER06 OTHER THAN "PATIENT DID NOT NEED/ WANT ANY HOME CARE SERVICES.

SER06

Did you receive information you could understand about home care services for the patient (for example, what services would be provided, for how long, and by whom?)

ASK IF ANY OPTION SELECTED IN SER06 OTHER THAN "PATIENT DID NOT NEED/ WANT ANY HOME CARE SERVICES.

SER07

After discharge, did home care services begin on time for the patient?

[RESPONSE OPTIONS] Yes, No, Some did and some didn't

SER08

Was the patient referred to any of the following community services? Please select all that apply:

- Meal delivery
- Food bank
- Pharmacy
- Transportation
- Senior center
- Case management
- Housing assistance
- Patient support group
- Other, please specify: _____.
- Was not referred to any community services

Wellbeing

The following questions ask about <u>your</u> mental wellbeing.

WB01

During discharge planning, how would you rate your level of stress or anxiety?

- None
- Mild
- Moderate
- Extreme

ASK IF MODERATE OR EXTREME TO WB04

WB05

What else could [FILL NURSING FACILITY NAME] have done to reduce your stress or improve your mental wellbeing?

- Please specify: _____.
- Nothing else

Medication

[INSTRUCTIONS]

The following questions ask about the patient's medication.

Please answer 'Yes', 'No' or 'Not Applicable' to the following statements.

MED01
Staff gave me written information about the purpose of each medication.

MED02
Staff told me about possible medication side effects.

MED03
Staff told me what to do if the patient experiences medication side effects.

MED04
Staff explained how much medication the patient should take and when and how to take it.

MED05
Staff told me who to call with questions about medications.

MED06
Staff asked about any over the counter medications the patient takes at home.

After Discharge

[INSTRUCTIONS]

The following questions ask about what happened once the patient returned home from the nursing facility.

Please answer 'Yes' or 'No' to the following questions.

After discharge…

AFTER01
Did a staff member from the SNF follow up with you by phone?

AFTER02
Did you experience any problems getting the patient's medication?

[Response options: Yes, No, Does not Apply]

AFTER04

Were you or the patient instructed on how to prepare the home for the patient's return (e.g. installing assistive devices like handrails, getting equipment such as a hospital bed, removing trip or fall hazards)?

AFTER05

Is the patient receiving all the help they need at home?

AFTER06

Did the patient experience any other problems once they returned home?

IF YES TO AFTER06

AFTER07

Please specify the type of problems experienced: _____.

Caring for the Patient

[INSTRUCTIONS]

The following questions are about caring for the patient at their home.

CARE01

Do you live in the same residence as the patient?

- Yes
- No

CARE02

Currently, what sorts of care are you providing for the patient?

Please select all that apply.

- Visting/socializing with the patient
- Talking on the phone, texting, sending emails, or communicating through social media
- Helping with toileting (Includes getting on an off the toilet, changing disposable briefs or pads, etc.)
- Doing his or her laundry
- Cleaning the home
- Cooking his or her meals
- Helping with eating or drinking
- Helping with daily physical activities
- Helping with medications
- Helping with other health care needs (For example, wound care, administer IV fluids, operate medical equipment)
- Providing transportation
- Other types of care. Please specify: ____.

Facility Rating

[INSTRUCTIONS]

The following questions ask for your opinions about the nursing facility.

RATE01

Using any number from 1 to 10, where 10 is the best care possible and 1 is the worst care possible, what number would you use to rate the care at this nursing facility?

Best Care- 10, 9, 8, 7, 6, 5, 4, 3, 2, 1 -Worst Care

RATE02

During the patient's stay at the facility, how often did you feel that the staff really cared about your family member or friend?

- Always
- Usually
- Sometimes
- Rarely
- Never

RATE03

What could the facility have done better to help you prepare for the patient's return to home? Please specify: ____.

About You

[INSTRUCTIONS] Please answer these questions about the person completing this survey.

What is your gender?

- Male
- Female
- Other
- Prefer not to answer

What is your age?

- 18-34
- 35-49
- 50-64
- 65-74
- 75-84
- 85+
- Prefer not to answer

Are you of Hispanic or Latino descent?

- Yes
- No
- Prefer not to answer

Do you consider yourself….

(Select all that apply)

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or other Pacific Islander
- White
- Other
- Prefer not to answer

What is the highest year or grade of school that you have completed?

- Did not complete high school
- High school graduate or GED
- Attended some college
- Received and Associate's or 2 year degree
- Received a Bachelor's or 4 year degree
- Received a graduate or professional degree (MA, MS, PhD, MD, JD)
- Prefer not to answer