

**Factors which impact understanding and adherence to hospital discharge instructions:  
A multicenter qualitative study of patient and family experiences**

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## ABSTRACT

**Background:** Greater attention to patient-centered care has led to the development of interventions to improve self-care and reduce avoidable health-care utilization following hospital discharge. We assessed patient and family caregiver perspectives on factors which impact understanding and adherence to discharge instructions.

**Methods:** We conducted semi-structured interviews of participants  $\geq 18$  years enrolled in a multicenter mixed methods study who were discharged from three acute-care hospitals across Ontario with a diagnosis of congestive heart failure, chronic obstructive pulmonary disease or pneumonia. Qualitative content analysis was used to derive themes and subthemes.

**Results:** Twenty-seven participants (16 patients and 11 family members) described four overarching themes which impact understanding and adherence to discharge instructions: relationships with inpatient and outpatient health-care providers, previous hospitalization, barriers to accessing post-discharge care and discharge process. Subthemes highlighted the importance participants attribute to the individual providing instructions, the development of resilience and advocacy through previous admissions, the benefits to addressing language and physical disability barriers and reviewing instructions in a non-hurried manner, while ensuring written instructions are meaningful and actionable.

**Interpretation:** Transitional care interventions targeting greater self-care are unlikely to improve understanding and adherence to discharge instructions on their own. When taken together, the **R**elationship, **E**xperience, **A**ccessibility and **D**ischarge (**READ**) process can serve as an important patient-centered framework which may optimize understanding and adherence once home.

## Introduction

Adverse events and unscheduled visits following discharge from hospital are common, avoidable and costly (1, 2). These high rates of poor health outcomes and health-care utilization have been attributed to poor discharge processes centered around communication and a target of funding incentives and quality metrics across health-care systems in Canada and the US (3, 4). Many transitional care interventions have therefore focused on optimizing communication at discharge through various patient-centered self-management tools (5-7). The use of “teach-back” or post-discharge telephone calls, for example, aim to engage patients and reinforce or clarify important instructions and are commonly used elements of bundled-care interventions in the US (8, 9).

Studies continue to demonstrate that despite an improvement in patient communication, many patients have difficulty understanding and following discharge instructions (9). This is of significant concern particularly for those with complex chronic diseases such as congestive heart failure (CHF) or chronic obstructive pulmonary disease (COPD), as these patients account for a large proportion of potentially preventable hospital readmissions for which adherence to medications, lifestyle modifications and follow-up post-discharge is paramount and a target of funding incentives in Canada (10-12). To address this knowledge gap, we evaluate patient-reported factors which help patients’ and their families’ understand and adhere to their discharge instructions.

## Methods

### *Study design*

This qualitative study was part of a larger ongoing multicenter mixed-methods study conducted at six acute-care and rehabilitation hospitals in Ontario centered around patient

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3 discharge instructions and post-discharge outcomes (13). Participants randomized to the  
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5 intervention arm received an additional patient-oriented discharge summary (PODS), a discharge  
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7 instruction template, along with usual discharge instructions whereas participants randomized to  
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9 the control arm received usual discharge instructions (14).

### 11 12 *Participants*

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15 Participants were individuals with an admission diagnosis of CHF, COPD or pneumonia  
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17 or their family members. Patients with cognitive impairment or language barriers could  
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19 participate through the use of a professional interpreter or family member. Patients with a  
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21 prognosis of less than three months or discharged to long-term care or another hospital were not  
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23 eligible. All consecutive patients enrolled were asked to participate with enrollment stopping  
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25 once distinct recurring patterns (themes) were identified and no new themes emerged. As such,  
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27 only participants discharged from three acute-care hospitals in Ontario between March and  
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29 November 2016 are included here. Participants from both the intervention and control arm were  
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31 included and both patients and research team remain blinded to the treatment arm (13).

### 32 33 34 35 *Data collection*

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38 Baseline demographics collected at time of in-patient recruitment included: admission  
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40 diagnosis, sex, age, presence of language barrier, limited health literacy (15), self-identified  
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42 disabilities, and reliance on caregivers (formal and family) for care. Participants were then  
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44 interviewed by telephone within one week of discharge on six patient experience measures using  
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46 a standardized survey of self-reported understanding of discharge instructions (16).

### 47 48 49 *Qualitative data analysis*

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52 Two sets of standardized semi-structured interview guides were developed to collect  
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54 data; one for patients and one for caregivers based on a literature review and previous responses  
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3 from a pilot study (17). Questions aimed to explore what factors affect the understanding and use  
4 of instructions (Figure 1). The three research assistants (RA) who conducted and transcribed the  
5 audiotaped interviews were trained by a senior co-investigator (LJ) with experience in qualitative  
6 methods. Transcripts were analyzed using direct content analysis (18). The RA's and principal  
7 investigator (KO) reviewed transcripts line-by-line independently for initial codes and to reach  
8 consensus on a coding scheme. All RA's and co-investigators then independently coded the  
9 transcripts according to this initial coding schema using manual coding and NVivo Pro software  
10 to identify core themes (18, 19). Lastly, emergent themes were compared among all team  
11 members to ensure inter-rater reliability using investigator triangulation by cross comparison of  
12 the emergent themes for all team members at each iteration. Five themes emerged as critical  
13 themes throughout all the transcripts, for which the team used selective coding within each  
14 theme to determine areas of focus and derive insights. The theme on the role of the caregiver was  
15 deemed to be a large enough theme to explore further subthemes on its own and is therefore not  
16 included in the results of this paper (20).  
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### 35 *Ethics approval*

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37 This study was approved by the Institutional Review Board at each of the three  
38 participating sites.  
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### 42 **Results**

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44 A total of 27 interviews were conducted with patients (n=16) and caregivers (n=11).  
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46 Many participants were female, elderly, admitted for CHF, reported limited health literacy and  
47 physical or sensory disabilities, and were highly dependent on family for care (Table 1). Overall  
48 patient receipt and understanding of discharge instructions within a week following discharge  
49 was moderate to low (Table 1).  
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3 Our qualitative analysis identified four key themes which highlight important factors  
4 influencing understanding and adherence to discharge instructions (Table 2). The first three  
5 themes were individual-level factors: 1) relationships with health-care providers, 2) previous  
6 experience with hospitalization, and 3) accessibility barriers due to physical disability or  
7 language barriers. The last theme focused around system-level processes such as the benefits of  
8 having written instructions, a chosen time to review discharge instructions, presence of family  
9 and post-discharge follow-up.  
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### 19 **Individual-level Themes**

#### 20 ***Relationship with health-care providers***

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24 Participants highlighted relationships with hospital and community providers, such as the  
25 pharmacist or primary care provider (PCP) as an important factor influencing adherence to  
26 follow-up care. Participants remembered the health-care staff they engaged with while in  
27 hospital. Involving family members when reviewing discharge instructions often changed the  
28 dynamic such that participants felt connected to health-care staff, more engaged when reviewing  
29 discharge instructions and interested in post-discharge follow-up. The relationship with hospital  
30 physicians was often contrasted to the existing relationship with the PCP. Some participants had  
31 been with the same PCP for years and described a “family-like” bond. Others described a void in  
32 their post-discharge care and support and expected the care provided by the inpatient physician  
33 to extend into the post-discharge period. Lastly some commented on the complexity of having  
34 multiple relationships with hospital physicians and how disjointed care can feel following  
35 discharge. Despite most participants having a PCP, some expected the inpatient physician to  
36 quarterback post-discharge care, particularly when multiple specialists were involved.  
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#### 53 ***Lived experience***

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3 Almost all participants identified a change after being in hospital with “adaptation” being  
4 a necessary piece of the transition home. One participant, when reflecting on a negative  
5 transition home, described how “*Self-care is really important because our health-care system is*  
6 *not what it should be.*” A participant with previous hospital experience was more likely to reflect  
7 on subthemes of resiliency and self-sufficiency with all aspects of the discharge instructions  
8 when compared to participants who had never been admitted to hospital before. When asked  
9 whether a patient with CHF was given any instructions on diet restrictions, the patient answered  
10 “No. I think they already know that I know... *I’m telling them I can’t have a banana.*”  
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### 22 ***Accessibility and communication barriers***

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24 The theme of accessibility, particularly with respect to physical disability and language  
25 barriers, were disparities commonly described by respondents as impacting their ability to follow  
26 through with instructions. Participants found it difficult to attend follow-up appointments  
27 because of physical limitations, lack of proximity to the appointment or resources to get there.  
28 While participating hospitals had access to professional interpreters, they were rarely used when  
29 reviewing discharge instructions. Families described being there consistently to provide  
30 interpretation. Many families did not think it was necessary to have an interpreter if they were  
31 present. All participants with language barriers stressed the role their families play in their  
32 understanding and following of discharge instructions. Families who acted as informal  
33 interpreters were often the ones to emphasize the importance of taking new medications,  
34 following diet recommendations or attending follow-up appointments. For participants who were  
35 discharged without scheduled appointments, this was often the responsibility of the English-  
36 speaking family member.  
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### 53 ***System-level opportunities***

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3 The opportunity to improve the delivery of discharge instructions was a common theme  
4 raised by patients and families when describing the transition home from hospital. Subthemes  
5 included feeling rushed at discharge, preferring meaningful and actionable written instructions,  
6 benefits of including family when reviewing discharge instructions and stressing the importance  
7 of post-discharge follow-up.  
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14 Many patients and their families expressed feeling pressured to give up their hospital bed  
15 prior to having reviewed instructions. Participants stressed the importance of having verbal  
16 instructions in writing to refer to after discharge. Content highlighted as most important centered  
17 around 1) medications, 2) signs and symptoms to watch out for, and 3) home-care support.  
18 Participants shared not feeling “ready” for what was to come and highlighted the need for  
19 actionable content such as knowing what to expect and what level of support would be needed  
20 once home. Patients who reported understanding their instructions also reported adhering to their  
21 instructions and these concepts were often interconnected in phrases such as, “*I read them and*  
22 *follow them to the letter. And I make sure I understand.*” Engagement was described as “going  
23 over instructions”, often highlighted as “going the extra mile” and was often synonymous with  
24 education, such as one patient stating “They treat you but they don’t teach you.” Family reported  
25 frustration when not present at discharge even if verbal instructions were written. Involving  
26 family was highlighted as being “necessary” by those who self-identified as caregivers. This  
27 distinction is important as care from family extended across the spectrum of care and included  
28 relevant tasks linked to adherence such as picking up medication refills or equipment. The last  
29 subtheme relating to follow-up care post-discharge was described as pivotal for reviewing  
30 instructions not understood at time of discharge or for asking questions that surfaced after  
31 discharge.  
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## Interpretation

We identified four core-themes from patients and caregivers that highlight opportunities for improving understanding and adherence to discharge instructions. Participants first described themselves as being centered among a larger network of relationships; from the in-hospital staff whom provided instructions and quarterbacked care to the primary care physician or community pharmacist who reviewed instructions post-discharge. Participants then characterized the lens in which a prior lived experience with hospital discharge can provide adaptation tools to facilitate follow-through with instructions when needed. The third theme reflected persistent yet unaddressed barriers due to language or physical disability. The last theme reflected process factors related to the delivery of patient instructions. Together these four themes, **Relationships, Experience, Accessibility and Discharge process or READ**, highlight factors which when addressed at discharge may optimize understanding and adherence to instructions once home.

Our study lends insight for any health-care institution or provider who provides discharge instructions on patient-level factors that enable a successful transition home. First, the importance that perceived relationships with health-care providers may play in the patient's level of engagement and adherence to instructions is a factor which has previously been described as important for adherence to medications (21, 22). This factor is of timely importance given recent work that has found both inpatient and outpatient physicians rarely feel responsible for patient care and adherence post-discharge along with authors who have questioned whom should ultimately bear responsibility for post-discharge care (23-25). Providers who do not feel a sense of responsibility may be unlikely to spend the necessary time and effort at discharge to optimize transitions. Our study highlights a missed opportunity to improve adherence to instructions by addressing a patients' existing relationship with inpatient and outpatient providers and suggests

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3 the best health-care provider to follow-up on discharge instructions may be the one the patient  
4 has the closest perceived relationship with. The second theme identified was that of “lived  
5 experience” and the development of resilience among those with previous hospitalizations. These  
6 were participants who already understood signs and symptoms to watch out for, diet/activity  
7 restrictions, were most compliant with medications and follow-up care and who reported having  
8 the processes in place to ensure continuity of care. Our study suggests that communication needs  
9 surrounding discharge with patients and families who have prior experience may differ from  
10 those who have not yet developed resilience or adapted to a new diagnosis, medications or  
11 follow-up plan. This theme is in line with previous authors who have coined the term post-  
12 hospitalization syndrome and suggests potential areas of improvement for care transition  
13 interventions (26, 27). Next, our study highlights an opportunity for health-care providers to ask  
14 patients about any difficulties in adhering to the discharge plan due to accessibility and language  
15 barriers. Indeed, a providers’ inquiry on sociodemographic circumstances can identify the need  
16 for clarity around instructions and help identify barriers to adherence (28, 29). Our study echoed  
17 results from other studies that when professional interpreters are available, they are rarely used at  
18 time of discharge and families often aid with communication and post-discharge adherence (30).

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40 While patient communication is often a key factor in high quality transitions, time spent  
41 on communicating discharge instructions has been found to be low relative to other discharge-  
42 relevant tasks (31). Administrative hospital-level data have noted that patient engagement at time  
43 of discharge is associated with high rates of medication adherence and decreased readmissions at  
44 30 days following discharge (31, 32). The necessary system-level elements for optimal patient  
45 engagement at time of discharge are however rarely highlighted in transitional-care initiatives  
46 making it difficult to reproduce or study (5). Factors we identified lend insight to those that may  
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3 have the greatest impact on understanding and adherence to discharge instructions. First,  
4 reviewing instructions with patients prior to discharge allows patients to feel less rushed and  
5 motivated to ask questions and engage in conversation with their health-care provider regarding  
6 difficulties in following the care plan (32). Second, ensuring instructions are also included in  
7 written actionable format helps patients retain information. Content which is often missed in  
8 discharge instructions and leads to anxiety for patients include signs and symptoms to watch for.  
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10 Studies have documented the complex but indispensable role informal caregivers play in care  
11 coordination and highlight how family presence when reviewing discharge instructions and  
12 discussing follow-up can help reinforce, clarify and with adherence (20, 33, 34).  
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24 Our study contributes to the growing literature on quality of care transitions by  
25 identifying which factors improve a patient's understanding and adherence to hospital discharge  
26 instructions. Participants in our study were older, dependent on others for care and representative  
27 of populations often excluded from transitional care studies due to language barriers, limited  
28 health literacy or cognitive impairment. Our participants reported lower levels of understanding  
29 of the discharge plan than other studies and it is possible that responses might have differed  
30 among participants with higher levels of health literacy (30). Also, participants were part of a  
31 larger randomized trial and some may have received a patient instruction tool that may have  
32 influenced measures of understanding and adherence. However, our qualitative study is primarily  
33 exploratory and hypothesis-generating. Additional quantitative analysis should confirm how  
34 factors identified in the READ framework impact post-discharge adherence and outcomes.  
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49 We identified four core individual and system-level factors that highlight opportunities  
50 for improving patient understanding and adherence following discharge from hospital. When  
51 taken together, READ provides a framework when reviewing discharge instructions that may  
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promote patient engagement and patient-centered communication. Our study underlines factors that should be further studied when implementing and evaluating interventions meant to improve understanding and adherence to hospital discharge instruction.

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**Table 1.** Demographics and Patient Experience (N=27)

	N	%
<b>Demographics</b>		
Admission Diagnosis		
CHF	13	48
COPD	5	19
Pneumonia	9	33
Male Sex	10	37
Female Sex	17	63
Age (years) (Mean $\pm$ SD)	72 $\pm$ 15	
Length of Stay (days) (Mean $\pm$ SD)	10 $\pm$ 5	
Presence of Language Barrier	6	22
Limited Health Literacy	13	48
Physical Disability impacting mobility	13	48
Sensory Disability	12	44
Relationship to Caregivers		
Living with Caregiver	15	56
Reliance on Family for:		
Self-Care	10	37
Food Preparation	11	41
Medication Administration	6	22
Transportation	12	44
Appointments with doctors	11	41
Receive home support services	17	63
<b>Patient Experience Within 1 Week of Discharge</b>		
During this hospital stay, did doctors, nurses or other hospital staff talk with you about whether you would have the help you needed when you left the hospital?		
<i>Yes</i>	16	59
<i>No</i>	11	41
During this hospital stay, did you get information in writing about what symptoms or health problems to look out for after you left the hospital?		
<i>Yes</i>	12	44
<i>No</i>	11	42
Before you left the hospital, did you have a clear understanding about all of your prescribed medications, including those you were taking before your hospital stay?		
<i>Not at All</i>	3	11
<i>Partly</i>	5	18
<i>Quite a Bit</i>	7	26
<i>Completely</i>	12	44
Did you receive enough information from hospital staff about what to do if you were worried about your condition or treatment		

1  
2  
3 after you left the hospital?

4 <i>Not at All</i>	8	30
5 <i>Partly</i>	6	22
6 <i>Quite a Bit</i>	2	7
7 <i>Completely</i>	11	41

8  
9 When you left the hospital, did you have a better understanding  
10 of your condition than when you entered?

11 <i>Not at All</i>	6	22
12 <i>Partly</i>	4	15
13 <i>Quite a Bit</i>	4	15
14 <i>Completely</i>	13	48

15  
16 When you left the hospital, did you have a clear understanding  
17 about your follow-up appointments and investigations?

18 <i>Strongly Disagree</i>	2	8
19 <i>Disagree</i>	3	12
20 <i>Agree</i>	8	32
21 <i>Strongly Agree</i>	12	48

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**Table 2.** Representative Quotes from All Themes Which Form the READ Criteria (N=27)

Theme	Quote
Relationship with Health-Care Provider	<p><i>I can't say enough great things about him (inpatient physician). He listens and he really saw mom as a person. And I'm relieved that we're going to be seeing him next Tuesday. He told me to get all my questions ready and write them down so I will be able to ask them again. (family member)</i></p> <p><i>I have to go see three more specialists just to follow up. But doctor x (in-hospital physician) is going to coordinate those specialists so nothing falls through the cracks, like one prescribing one drug and then another, so he's going to be the central person there. So it makes me feel safer. (patient)</i></p>
Lived Experience	<i>I think they realize that this isn't our first rodeo so to speak. I think they realize that we were both pretty up on it. And you know didn't have to go into it (discharge instructions) too much. (caregiver)</i>
Accessibility	<p><i>Oh hunny, I can't walk. I'm tied to an oxygen tank. And I'm not able to use my stairs. I have no one to help me. And I need to take an oxygen tank with me, a wheelchair or a walker. But I need to have somebody take the wheelchair down in order for me to go anywhere. So I don't go out of my apartment. (patient)</i></p> <p><i>My mom speaks a little bit of English, like she'll understand a little bit. But if somebody talked in Portuguese to her, it would have been a different story... they'd probably feel more comfortable. I was there most of the time, and then my brother was there most of the time. We're just taking part of everything you know. I went through all her tests, I kind of explain what is going on. (family member)</i></p>
<b>Discharge process</b>	
Utility of Written Instructions	<i>That would have been nice if they could do that and just have any last minute instruction on a separate piece of paper and a summary and the main discharge papers the day before. Because then I could read it all over and asked questions right while I was there. (patient)</i>
Feeling Rushed	<i>They just let you go. Goodbye. You're gone. (patient)</i>
Meaningful and Actionable Content	<i>I sort of panicked there for a bit because I wasn't sure what I should do if he went into atrial fibrillation. So no, I think maybe we could have been told a little more ok, if it happened, here's what you do. (family member)</i>
Role of Follow-up	<i>We've got a lot of stuff to look over here and process. And this is the first time actually that we've come out and had a second chance to go back and see the doctors and talk it over with them and ask again what questions we have. You need a bit of time like this and this is great. This follow-up appointment is a big plus. I don't know if we would be able to get an appointment with my family doctor to get in and get mom checked. (patient)</i>

1  
2  
3 **Figure 1. Interview Guide**  
4

5 **1. Understanding Discharge Instructions**

6 Can you tell me about your understanding of the discharge instructions you received in hospital?  
7

8  
9 **2. Use of Discharge Instructions**

10 How did you use your discharge instructions?

11 Did receiving the instructions make you more likely to take your medications? Follow any diet  
12 or activity limitations? Visit your family doctor?

13 Was there anything you particularly liked about your instructions? Was there anything you didn't  
14 like about your instructions?  
15

16  
17 **3. Factors affecting the ability to use the instructions (determinants of health)**

18 How would you describe the effect your [insert relevant factor such as gender, language,  
19 race/ethnicity, socioeconomic status, disability] had on your ability to use and adhere to your  
20 discharge instructions?  
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## Standards for Reporting Qualitative Research (SRQR) Reporting Guideline Checklist

*\*The page and line numbers reflect the PDF Proof from Step 7 in the submission process\**

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<b>Other</b>	<b>Page/line no(s)</b>
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Funding	Page: 2 of 22 Lines: 31-33

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