### ORIGINAL RESEARCH

# Patient and Caregiver Understanding of Prognosis After Hip Fracture



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#### **ABSTRACT**

#### **Background**

Hip fracture (HF) is common and requires communication between patient, family, surgeons, and hospitalists. Patient and family understanding of the seriousness of HF is unclear.

#### Methods

We interviewed older patients (age > 65 years) hospitalized with HF at two Canadian academic hospitals, or their surrogate decision-makers (SDMs). We used qualitative methods to explore understanding of HF treatment options and prognosis. Participants estimated probability of mortality and living independently 30 days after surgery. Results were compared with estimates from the National Surgery Quality Improvement Program (NSQIP) surgical risk calculator.

#### Results

9 patients and 3 SDMs were interviewed. Mean age of 12 patients was 82.5 years (75% female). Participants were uncertain about recovery timeline and degree of functional recovery, as well as content and duration of rehabilitation. Participants' mean estimated 30-day mortality of 6.7% did not differ significantly from estimated mortality predicted by NSQIP (7.5%; p = .88). Participants' mean estimated probability of living independently 30 days after surgery was 90.8% (range 65–100%).

#### **Conclusions**

Older patients and SDMs lack understanding about prognosis and functional recovery even after providing informed consent for HF surgery. Clinical teams should improve communication of prognosis and recovery information to patients and surrogates.

**Key words:** hip fracture, shared decision-making, prognosis, informed consent

#### INTRODUCTION

Approximately 340,000 Americans and 30,000 Canadians experience hip fracture annually. (1) Hip fracture in the elderly is a marker of frailty and results in significant morbidity and mortality. One-year mortality after hip fracture exceeds 30%; (2) mortality among frail subgroups (for example, nursing home residents) is much higher. (3) Half of formerly independent older adults never live independently after hip fracture. (4,5)

Hip fracture management involves urgent decision-making about type of surgery, type of anaesthesia, and management of medical comorbidities.<sup>(6,7)</sup> Care is typically provided by orthopaedic surgeons, geriatricians, and hospitalists.<sup>(8,9)</sup> Ideally, decision-making is shared between medical team and patient, or surrogate if patient is incapacitated.<sup>(10,11)</sup> However, pressures to expedite hip fracture surgery to reduce risk of patient complications can make it logistically challenging to implement an optimal shared decision-making model.<sup>(12,13)</sup>

Even in the absence of shared decision-making, the informed consent process stipulates that patients (or surrogates) should understand the risks and benefits of hip fracture treatment, as well as the anticipated outcomes. However, the literature on patient and surrogate understanding of hip fracture is limited. (2) While it is known that the public significantly underestimates morbidity and mortality following hip fracture, patient understanding at time of hip fracture has not been studied. Given the gaps in the existing literature, we examined patient and surrogate understanding of hip fracture treatment, recovery, and prognosis within 72 hours of hospital admission. In addition, we explored their experience of communication with their health-care team. We hypothesized that patients and surrogates would have a poor understanding of hip fracture treatment and prognosis, even after providing informed consent for surgery. We anticipated that participants would underestimate morbidity and mortality, and overestimate chances for full recovery.

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#### **METHODS**

#### **Setting**

We used qualitative methods to conduct semi-structured interviews to gain a deep understanding of participants' experiences and perspectives. (14) We conducted our study at two academic hospitals in Toronto, Canada. Annually each hospital admits approximately 150 hip fracture patients, most over 65 years old. Orthopaedic surgery residents explain hip fracture treatment options and obtain informed consent for surgery. Internal Medicine and Geriatrics specialists co-manage at one hospital and are consulted on an as-needed basis at another. Surgery is performed within 48 hours of admission when possible. (13) Average hospital length of stay is approximately 6 days before transfer to rehabilitation. (15)

We approached patients over 65 years old admitted for isolated hip fracture between August 2015 and July 2016. We identified eligible patients by daily review of orthopaedic admissions lists, excluding those with pathologic or multiple fractures, and those who could not speak English.

We screened eligible patients for cognitive impairment using the Mini-Cog. A cut-off of less than 3 points on the Mini-Cog has been validated for dementia screening. (16) Patients who scored above the cut-off were invited to participate. For patients who scored less than 3 points, we invited their surrogate decision-makers to participate. We excluded patients with cognitive impairment who lacked a surrogate decision-maker (see Figure 1).

All interviews were conducted by the lead author (RE) within 72 hours of hospital admission, either pre- or post-operatively. In all cases, participants had provided informed consent for hip fracture surgery prior to the interview.

#### Data Collection

We developed a semi-structured interview guide informed by the literature on shared decision-making and the clinical experience of our research team. The interview questions (Appendix A) explored three topics:

- 1. Understanding of hip fracture and treatment options;
- 2. Understanding of recovery and prognosis; and
- 3. Reflections on communication and decision-making role.

We conducted two pilot interviews to optimize wording and clarity.

We collected basic information (age, sex, type of hip fracture, type of surgery) for all hip fracture patients admitted during the study period. For study participants, we reviewed their medical charts to collect additional information required for calculation of surgical outcomes using the American College of Surgeons National Surgical Quality Improvement Program (ACS-NSQIP) risk calculator including height, weight, smoking history, functional status, American Society of Anaesthesia (ASA) class, and past medical history.<sup>(17)</sup>

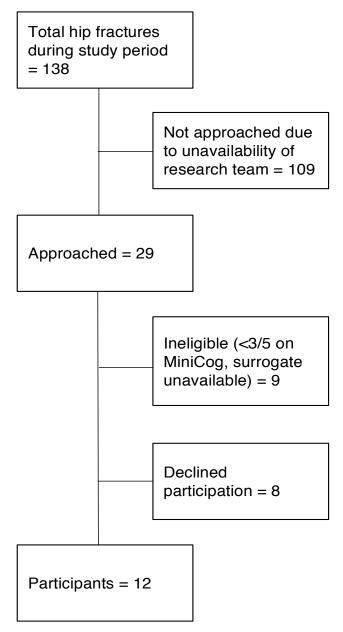


FIGURE 1. Inclusion/exclusion flow chart

We asked respondents to estimate morbidity and mortality risk with the following questions (designed to approximate information from the ACS-NSQIP risk calculator):

- 1. If you had to pick a number between 0 and 100, how likely do you think it is that you will be alive 30 days from today?
- 2. If you had to pick a number between 0 and 100, how likely do you think it is that in 30 days from today you will be able to live where you were living before you broke your hip?

Wording was modified to accommodate surrogate decision-makers.

We anticipated reaching thematic saturation after 10–15 interviews. (18) We deemed saturation to have been reached when no new themes emerged in two consecutive interviews, leading to a sample size of 12. Interviews were audio-recorded and transcribed verbatim.

#### **Data Analysis**

We compared demographics of participants and non-participants using bivariate methods (*t*-test, Chi-square statistic). We summarized categorical information (sex, type of hip fracture) with percentages and continuous measures (age) with mean and standard deviation.

We used the NSQIP risk calculator (publicly available at: http://riskcalculator.facs.org/RiskCalculator/) to calculate 30-day mortality risk for each patient, as well as probability of being discharged to a nursing home or post-acute care. (17) We compared participants' mortality estimates with NSQIP estimates. Statistical analyses were conducted using Microsoft Excel with *p*-values < .05 deemed statistically significant.

Using a phenomenographic approach, we conducted thematic content analysis of interview transcripts. (19) To establish intercoder reliability, three study team members (RE, PC, and AG) conducted independent line-by-line coding of the first four transcripts, resolving disagreements by consensus. Subsequent interviews were coded by RE. Interviews were analyzed immediately following transcription, facilitating iterative revision of the interview guide. Using constant comparative analysis, themes were continually refined and all transcripts recoded as new themes emerged. The final coding scheme was applied to the entire data set systematically.

Our study was approved by the Research Ethics Boards of University Health Network and Mount Sinai Hospital. All participants provided written informed consent prior to being interviewed. This study had no industry funding, and none of the authors have any commercial interest related to the current research.

#### **RESULTS**

We approached a convenience sample of 29 of 138 potential participants, of whom 20 (69.0%) met eligibility criteria (Figure 1). Twelve of the eligible participants (60.0%) agreed to participate (nine patients, three surrogates); age and sex of patients who agreed and declined to participate was similar. Mean age of patients was 82.5 years and nine of 12 were women (Table 1). Eleven lived at home prior to hip fracture, although seven required assistance with walking and four required assistance with other activities of daily living. Additional descriptors are provided in Appendix B.

Only six of 12 participants (50%) could estimate risk of mortality within 30 days of surgery. The mean estimated mortality was 6.7% (range 0–20%), compared to the NSQIP predicted mortality of 7.5% (range 0.1–27.8%, p=.88). Participants estimated a 90.8% probability of living independently 30 days after surgery (range 65–100%), while NSQIP

predicted a 33% probability (range 23.4–64.4%) that patients would be discharged home.

We identified four main themes and several subthemes from our qualitative analysis (Table 2).

## 1. Nature of Injury Event and Experience

Every participant (P# = participating patient; S# - surrogate participant) described falling, followed by pain and inability to walk. Some recalled little else:

"I can go back over a few seconds clearly in my mind of what happened, but other than that all I can

TABLE 1. Study population demographics

	Patients (n=12)
Age of patient, years, mean (sd)	82.5 (±10.1)
Sex of patient, female, number (%)	9 (75.0)
Type of hip fracture Femoral neck, number (%) Intertrochanteric, number (%) Subtrochanteric, number (%)	6 (50.0) 5 (41.7) 1 (8.3)
Type of surgery Internal fixation, number (%) Hemiarthroplasty, number (%) Total hip arthroplasty, number (%)	5 (41.7) 5 (41.7) 2 (16.7)
Highest education level Did not complete high school, number (%) High school, number (%) Post-secondary, number (%)	2 (16.7) 1 (8.3) 9 (75.0)
First language English, number (%) Other, number (%)	8 (66.7) 4 (33.3)
Interview conducted with surrogate, number (%)	3 (25.0s)

TABLE 2. Themes and subthemes

Theme	Subthemes	
Nature of injury	Event and experience	
	Seriousness	
Treatment	Details	
	Options	
	Health team	
Recovery	Details	
•	Trajectory	
	Prognosis	
Patient experience	Satisfaction	
1	Values and roles	

remember is a flood of pain for days. So that's it, that's what I know" (P5).

Others described arriving at the emergency department, undergoing medical imaging, being admitted to hospital, signing informed consent, and going to the operating room.

Some participants perceived hip fracture as "just one of those unfortunate accidents that can happen to everyone" (S10), while others understood that chronic illness, impaired balance, and osteoporosis predisposed them to fracture. Participants also varied in their understanding of their injury. While some simply knew that their hip was broken, others had an elegant understanding of hip anatomy and the location of their fracture (Table 3, Q1).

#### Seriousness

Participants who understood the anatomy of their hip fracture could explain whether it was a "good" or "bad" fracture:

"They told me that there's a ball in your hip that makes your hip move around to go. That's where I broke it, the ball. Of all places that's the worst place you can break it" (P3).

Regardless of whether they understood the anatomy of their fracture, however, participants believed that hip fracture was a serious injury (Table 3, Q2). Reasons for this belief included both their experience of hip fracture (pain, inability to walk) and their underlying health (age, frailty and illness).

#### 2. Treatment

#### **Details**

Participants understood their treatment plans to varying degrees. Some used their understanding of hip anatomy in describing their surgery:

"So my understanding of the surgery was that the head of the femur was tilted back into position, and then the pins were what was required...to hold the break so that it could heal" (P1).

Other participants were completely unaware of their surgery details:

"Healed it, nailed it, put it together. I don't know" (P4).

Interviewer (I): "Do you know why they need to operate?" P5: "Yeah. Because my hip's broken." I: "And what are they going to do in the operation?" P5: "Fix it. And don't ask me how."

#### **Options**

Some participants believed that there was only one treatment option for hip fracture:

"There didn't seem to be a decision, right. Because usually when you have a decision there are options. This or this or this or this. There wasn't a this or this or this or this" (P11).

Others understood that there are multiple types of hip fracture surgery, but none expected to be involved in decision-making about type of surgery, as this was perceived to be a decision based on surgical expertise. Three of 12 participants were aware that non-surgical management was a treatment option; none were enthusiastic about it (Table 3, Q3).

#### **Health Team**

Participants frequently referred to the large size of their health-care team, which for some reflected high-quality health care (Table 3, Q4). Others were frustrated with perceived inconsistencies in information received from different health-care providers.

#### 3. Recovery Expectations

Participants were more uncertain about recovery than the injury and its treatment. Uncertainty was evident within three domains: recovery details, recovery trajectory, and completeness of recovery.

#### **Details**

One participant imagined a passive recovery process:

"Just be patient and get better. Walk if you can. I mean, it's all I can do... Just behave myself and not stress it, and just take care of it as best you can and take the pills that you need constantly for pain killing" (P4).

All other participants understood that recovery involved rehabilitation and exercise. Not all participants knew why they required rehabilitation, but the most commonly cited reasons were strength and mobility. The two youngest participants (P1 and P11) were particularly motivated to begin recovery even prior to transfer to rehabilitation (Table 3, Q5). However, even these motivated participants could not remember all of the exercises they were instructed to practice.

#### **Trajectory**

Participants gave a wide range of timelines for recovery, ranging from 10 days to eight weeks, but averaging two to three weeks (Table 3, Q6). Three participants could not estimate their recovery timeline:

"Well, no one knows and it all depends. Everyone goes differently depending on their condition. They can't give you any time limit because that's the future, they don't know" (P3).

#### **Prognosis**

Of all aspects of their hip fracture, participants were most uncertain about their prognosis. Most participants did not know how well they would recover, or whether they would be able to walk again (Table 3, Q7-8). One participant was determined to return to regular activities, demonstrating an expectation that hip fracture would not limit that patient's functionality permanently:

"I still intend to go out to lunch and dinner with my friends and go to church and walk my dog and do my housework. You know yah, do my laundry. Maybe a little more slowly for a while but I intend to do it" (P8).

### 4. Patient Experience Satisfaction

Some participants were satisfied with their health-care team's communication, and felt adequately informed and that their questions had been answered. These participants also believed they had received high-quality health care.

However, many participants felt uninformed about their injury. One participant was upset because he did not know where his hip was broken or what his operation entailed. Another was distraught because she did not know whether her operation was successful or how well she would recover (Table 3, Q9).

#### Values and Roles

In describing their hip fracture experiences, participants reflected on their values. These values affected how they perceived the respective decision-making roles of patients and health-care professionals. Some participants were content to accept their surgeons' recommendations:

"I know I need to listen to the experts. So when the doctor says you need surgery and this is what we're recommending, that is—that's the kind of information and communication I want to hear so that I can say "go ahead" very clearly" (P1).

Others were emphatic about making their own healthcare decisions:

"I am very glad that I was able to make a decision because decisions are so hard to make when you are old. And of course also that I very much still think that I would do the right decision" (P2).

For some, the desire to make their own decisions about their health care stemmed from misgivings about doctors, since "just because somebody has a degree doesn't mean a damn thing" (S6). They perceived doctors as serving "a technician role, a very well-trained technician role, but it's not caring, involved, or anything like that" (P11).

#### **Mortality**

Finally, for a subset of participants, hip fracture was a stimulus to reflect on mortality. These participants had limited understanding of hip fracture, and were uncertain about both trajectory and completeness of recovery. They reflected on their age, and were resigned to the consequences of their injury (Table 2, Q10).

#### **DISCUSSION**

We found that patients and surrogates understand the mechanism of hip fracture, but are generally unaware of prognosis. Our findings are noteworthy since we conducted our interviews perioperatively, shortly after patients and surrogates provided informed consent for surgery.

A number of our findings warrant elaboration. First, participants' recall of the mechanical aspects of their fracture, including fall, anatomy, and surgical repair, was generally good. Nonetheless, the lack of understanding exhibited by several participants suggests continued opportunities for improved communication, perhaps through implementation of decision aids, which are known to be effective in improving patient knowledge. (20)

Secondly, participants' limited understanding of hip fracture recovery is concerning. Prognosis for elderly patients after hip fracture is generally poor, with high mortality and impaired mobility for many who survive. (2,5) Yet we found that 50% of participants were unable to entertain mortality as a potential short-term outcome, and expectations for return to prior physical functioning were overly optimistic when compared to available data.

It is important to consider why participants had difficulty estimating prognosis. We conducted our interviews after informed consent for surgery had been obtained, so participants should have discussed prognosis with their care team. Moreover, our study hospitals are major academic teaching hospitals within a regionalized hip fracture trauma system with well-developed hip fracture care.<sup>(8)</sup> Thus, if anything, we would expect that our findings represent a "best case" compared to hospitals with less developed hip fracture care.<sup>(21)</sup>

Given that we did not observe informed consent discussions, it is possible either that prognosis was not discussed in detail, or that information was not retained. It has been previously demonstrated that informed consent discussions are poorly understood by patients. (22) Decision aids are known to improve patient knowledge of medical conditions and to increase the accuracy of their risk perceptions. (23,20) Future research could investigate the implementation of patient-centered decision aids in informed consent discussions for hip fracture treatment.

Timing is another possible reason for subjects' poor understanding of prognosis. We conducted our interviews within 72 hours of admission, and it is possible that the health-care team had not yet addressed functional recovery. Given that length of hospital stay after hip fracture is around six

# TABLE 3. Questions with selected quotations from patients

Quotation Number	Theme/Subtheme	Quotation		
Q1	Nature of Injury: event and experience	He did explain – and I don't know if I have it right or not – but he showed me that my femur, which is long leg bone, has a head on it. And he made a fist. And then I put my I put my other hand over the and that's the hip socket. And if I understand correctly, the femur snapped back. So two things happed it came out of place from the socket joint and it broke at the base of the head (P1).		
Q2	Nature of Injury: seriousness	I think it's very serious because of his age and because he's got one kidney, an artificial bladder, to stents in his heart. And he also has a blocked artery on the right side of his neck, and a tiny spot of blo in his skull. So and because of his age and fragility, and because he's had so many operations before this is really the the fifth operation that he's had, and due to his age, I think it's – yes it's serious (S10).		
Q3	Treatment: options	The nurse told me the x-ray showing the broken hip and broken leg. So it needed surgery. Or keep it months or something like thatlay down on the bed, is bedridden. So what is your suggestion? What you want me to do with your wife? I said, I said, better for the patient, best for the patient, that is what choose. And she saidthe operation will work out, she may be able to walk. She may be able to walk within 2 days' time. I said, that's the best option, I accept (S7).		
Q4-5 Treatment: health team		We've had a constant stream of doctors coming in to check on him. Um, they examined him, and they also discussed his medical history with him at length. It's very obvious that they're monitoring him, all of them, every inch of his body I think, they are monitoring. They're all very very well aware. Every doctor that came in examined him and either went through his case history (S10).		
		There's such a wide spectrum because so many people, like doctors and nurses, have told me different things. The surgeon said that they could have me out of here in a couple of days. And I said, what does that mean, does that mean going home or going to rehab, and he said it all depends on what the physios think (P1).		
Q6-7 Recovery: details	They're going to work with me, they're going to give me exercises, they may basically kill me in the process but they're going to show me exercises that I can do to get mobility back in the hip to strengthen the muscles in the leg (P8).			
		Well, the sooner I get moving the sooner I'll heal. But I need to get moving in the right way. Like, they were showing me how to use the walker. I had no idea. And it's the same thing with a cane. You might think it's simple and you know what to do. I don't. I learnt today with the walker that I move the bad leg first, then I put the weight on the walker with my hands so I'm not standing on the bad leg, and then I can move my other leg forward (P1).		
Q8	Recovery: trajectory	Well, I was told that normally there's a 3-day period where you remain here at the hospital, where the staff do get the patient up the next day immediately, to start walking, because it's necessary to protect the organs and the muscles and the function of the body, to get the body functioning again. The very next day they get the patients up and walking I was told that he probably will be [in rehab] for 2 to 3 weeks.		
Q9-12	Recovery: prognosis	Am I going to be lame? Is it going to be essentially okay? (P2)		
	I don't know. If I recover. I don't know, I had in mind that this was my last days on earth. I had that feeling because I'm very superstitious, you know. I never felt like that before. This is the first time I felt this is it, this is the end (P3).			
		I don't know when I'm going to recover from this hip surgery, or how well. I don't know (S5).		
		Only thing, you know, what is going to happen in the future, she normally walk again? It's only I want to know. You know just a normal life again? She will get back again normal life? (S7)		
Q13-14 Patient experience: satisfaction		They know what they're doing around here. A moment didn't go by when someone wasn't talking to me from the hospital about thewhat's happening and they kept me informed. And everyone seems to know what they're talking about (P9).		
		I know they are very busy. I know they are really concerned. But how about my concern? How about me? I didn't even remember the name of the doctor! And after the operation, he came to the, my room and he said, can you, can you, uh, push your fingers and toes? And I said yes, I'm done, and then he said okay, yeah. I didn't know about my surgery. He didn't take the time to talk to me about my recovery I am in limbo. Right now I am going to tell the nurse I want to see my doctor. And I want to have some questions, maybe some for them it's stupid question, but for me it's very important to know that (P12).		
Q15	Patient experience, mortality	It's just that what's the use. You have no medical knowledge and you live alone and, you know, I guess that's life and you're not young, you're not getting younger every day, you have to go sometime. A lot of young people don't think they're every gonna get old, but they will, you know, because that's life. People don't stay young forever (P3).		

days, (15,24) we argue that early discussion of recovery is important. Poor patient and surrogate understanding is surprising given that our hospitals have well-developed multidisciplinary geriatric fracture care; (8) results of the current study are a reminder that, even when medical care is excellent, communication of prognosis and risk may require distinct attention. That said, it is important to recognize that discussion of prognosis and recovery could be left until the time of hospital discharge or for discussion in the post-acute-care setting.

Thirdly, it is important to think about the downstream implications of poor patient and surrogate understanding of prognosis and recovery. A wealth of literature has described health-care expenditures during the last six months of life. (25) There is also evidence that improved goals-of-care planning or enrollment in hospice can reduce use of costly treatments in patients with incurable illness. (26,27) Hospitalist and geriatric co-management services are now ubiquitous, and data suggest that such models are beneficial. (28,29) Our findings make it reasonable to ask whether co-management models should redouble efforts to communicate prognosis to patients and surrogates.

Our study has limitations that warrant mention. Our sample size was modest, but it was consistent with many qualitative studies. (18) Our study was conducted in two academic teaching hospitals in Toronto and our results should be generalized to other settings with care; it is possible that patients and surrogates elsewhere may have better understanding of hip fracture prognosis and recovery. Finally, we did not observe informed consent discussions between patients, surrogates, and the health-care team. Future research could consider direct observation of the informed consent process.

#### CONCLUSIONS

We found that hip fracture patients and their surrogates have poor understanding of prognosis even after providing informed consent for surgery. We suggest that hip fracture clinical care pathways should be explicit about when prognosis and recovery are discussed with patients and who (geriatricians, physiatrists, hospitalists) leads the discussions.

#### CONFLICT OF INTEREST DISCLOSURES

The authors declare that no conflicts of interest exist.

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#### **APPENDICES**

#### **APPENDIX A: Interview Guide**

PATIENT AND CAREGIVER UNDERSTANDING OF PROGNOSIS AFTER HIP FRACTURE In-Depth Interview Guide

#### **Treatment: understanding and role**

- 1. Can you tell me in your own words what happened to your hip?
- 2. When you came to the emergency department, what treatment options were you told about for your hip?
  - What treatment did you receive?
  - What is surgery going to do for you?
  - What are the risks of surgery?
- 3. What was your role when it came to making decisions about your hip treatment?
  - Who made the final decision?
  - Is that the person who you would ideally like to make the final decision?
  - Do you feel like the decision that was made was the best one for you?
  - Are you satisfied with the role you played in making decisions about your hip?

#### Recovery and prognosis

Let's switch gears and talk about what your recovery is going to look like.

- 4. What have you been told about your recovery?
  - · How long will it take?
  - What will you have to do to recover?
- 5. What concerns do you have about your recovery?
- 6. Based on what the doctor told you, how serious do you think your hip injury is?
  - What impact do you think it will have on your daily activities?
  - How will your daily life be different compared to before you broke your hip?
- 7. Given what you know about your health, if you had to pick a number between 0-100, what would you say are the chances that you will still be alive in 30 days?
- 8. Given what you know about your health, if you had to pick a number between 0-100, what would you say are the chances that when you leave hospital you will go back to where you were living before you hurt your hip?

#### Satisfaction

- 9. How satisfied are you with the way that the doctor communicated about your hip?
  - · What did you like?
  - What didn't you like?
  - Do you feel like you know enough?
    - ° Is there anything you would like to know more about?
    - ° Is there anything you would have preferred that the doctors hadn't told you?
  - Were you able to ask all the questions you had?
- 10. If there were one thing that you wish your doctor would explain better to the next patient, what would that be?

#### Conclusion

11. That's all the questions I have today. Is there anything else you would like to tell me?

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### **APPENDIX b: Participant descriptors**

Identifier	Patient or Surrogate Decision-Maker	Sex of Patient $(F=female, M=male)$	Age of Patient	
P1	Patient	F	67	
P2	Patient	F	85	
P3	Patient	F	92	
P4	Patient	F	87	
P5	Patient	M	73	
S6	Surrogate	F	98	
S7	Surrogate	F	79	
P8	Patient	F	77	
P9	Patient	M	95	
S10	Surrogate	M	89	
P11	Patient	F	69	
P12	Patient	F	79	