

Health Care Transitions: Perceptions from Older Patients in Rhode Island

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ABSTRACT

Health care transitions are often dangerous for older patients. Interviews with older adults about their health care moves in Rhode Island (RI) were conducted to develop an Internal Medicine (IM) curriculum designed to provide IM interns with insights about the impact of transitions on patients. This paper describes some ways patients talk about their transitional experiences. Following pilot interviews, 10 nursing home residents were interviewed about their care transitions, conversations with physicians, and advice to doctors beginning their careers. The interviews were analyzed to identify themes. Patients described multiple moves, often did not know what to expect, appreciated help from a family member and desired effective communications with physicians. Learning about patient experiences may help new physicians appreciate the experiences of transitions on patients.

KEYWORDS: transitions of care, patient experiences, nursing homes

INTRODUCTION

Problematic transitions plague the experience of older adults in health care. Our rapidly aging population is at risk from a fragmented system of care in which transitions among sites of care are poorly conducted, and experiences of older adults can be of secondary consideration.¹ Transitions among sites of care, even when appropriate, are linked to increased incidence of delirium, hospital-acquired infections and falls, and the exacerbation of pre-existing chronic conditions.²⁻⁴ Recent literature indicates that more research is needed about these transfers, and that improved communication and education among and by providers is key.^{5,6}

There is increased interest in measuring patient satisfaction with hospital care during hospitalizations;⁷⁻⁹ however, since little is known about the patient perspective regarding transitions in sites of care, experiences of older adults must be better understood. Interviews can be effective in revealing aspects of health care that are otherwise difficult to quantify.^{7,10} During medical school, students may be exposed to principles of patient-centered care, the importance of communication, and in some cases, the dangers inherent in care

transitions; however, these priorities are challenged after medical school by the exigencies of hospital routines and requirements.¹¹⁻¹³ The purpose of the research was to use the patient perceptions of their transition experiences to develop a 3-hour curriculum with Internal Medicine (IM) interns on the impact of these transitions.

This paper describes these recollections, focuses on how patients perceived what happened to them and includes some ways patients would like physicians to speak with them. A separate paper, forthcoming, describes the development of the IM curriculum.

METHODS

Three nursing homes (NH) in RI agreed to participate in this project. The administrator, director of social work (SW) and director of nurses (DoN) of each facility helped identify NH residents who might be willing to participate. Six pilot interviews were conducted with recently hospitalized NH residents who the SW or DoN of the NH determined to be cognitively intact; these were followed by interviews with 10 community-dwelling older adults undergoing rehabilitation in a skilled nursing facility (SNF) following a hospitalization. The project was explained to all respondents through an informed consent process. The respondents were asked to recall the reason for hospitalization and to relate events regarding transfers to and care in the emergency room (ER), hospital, skilled nursing facility (SNF) and any conversations they remembered having with physicians. Interviews were audio-recorded and transcribed, then analyzed for themes. The research was reviewed by the Brown University Research Protections Office and determined to be exempt.

RESULTS

After the pilot interviews were completed, we decided to conduct subsequent interviews with community-dwelling individuals who had recently been hospitalized and were now undergoing rehabilitation in a SNF. Of these, one respondent was 61 years old, three were in their 70s, and 6 were in their 80s. All but two respondents were female. A few prominent themes from the interviews are discussed below with illustrative quotes from the respondents.

Respondents describe multiple moves

Multiple moves were common occurrences related in interviews. Some respondents had transfers beyond those from home to the ER, admission to the hospital, and eventual transition to the SNF. For example, one went to a local urgent care facility, then a hospital ER before admission to the hospital and transfer to the SNF. Three went to two hospitals after the ER. One was admitted to the hospital, then went to the intensive care unit and then back to a hospital floor before entering the SNF. After admission to the SNF, a few then experienced moves within the SNF. The following excerpts are examples of recollections of ER and hospital experiences. This respondent had positive memories:

"[All I] remember is the fast ride, sirens going and feeling this blood coming out of my legs you know. It just seemed like one big drama, personal drama anyway. And I don't know, I wasn't worried about it...They were so friendly... and they weren't the least bit afraid [of] this bleeding patient...I realized this is not a big thing to those who are taking care of me...because they were so relaxed...I began to relax."

An 87-year-old participant described caring ambulance drivers: "Their personality and the way they treated you, you know. Like you wasn't just a nothing and they treated you with compassion and very nice." In the ER,

"The team of people just...started hooking you up to IVs ...And there was a lady doctor, very very nice... they had to take all these tests and x-rays. [The doctors] didn't have too much to say. They were just asking the same questions like, 'What happened?'"

However, another who recalled being in a great deal of pain said she was given a call bell to use in the ER. "They kept saying, 'It'll just be a minute.' This was obviously a lie; it wasn't just a minute. But nobody would pay attention to the fact that I was uncomfortable." She noted that despite the staff's "Ooey gooey speech" designed to be reassuring, [they] "really didn't care and I was just part of the problem... I called, but nobody answered the call bell."

Two respondents moved from one hospital to another. One's daughter was instrumental in this decision. The 78-year-old respondent said, "I went to the doctor, they bring me to the hospital over here, they bring me to the other hospital. Then they bring me back to here. And they bring me back and forth, I guess."

Moves within SNFs can be a common part of the patient's experience, too. Roommate problems sometimes resulted in room changes. A 72-year-old respondent described his frustration in being admitted to the second floor of a NH for hours before his third-floor room was ready:

"I get in here [at 5 PM]...they move me up to the third floor...[the] patient's still in [his] room...So I have to go back down to my original room...it's like 6:30... I am hungry, I am tired and the nurse...said, 'I called up to the third

floor...[to]...get my food tray...It's busy...they still have to clean the bed, wash, wipe the bed down, change the linens'...so it wasn't until about 7 o'clock when I came up here."

Respondents often did not know what to expect

Confusion and/or not knowing what to expect was another refrain heard in these interviews. One respondent said, "I really didn't know. I was just in 'blah', and I was kept thinking, where am I gonna go?" Another similarly recalled what may have been delirium:

"I had a really scary experience of not knowing what I was, who I was, or what was going on. It was scary frightening...I kind of went into la la land...It was really weird, and then they assured me that this ...happens because of the pain medication...it was this terrible experience I had of being somewhere else, me being someone else. Just disoriented...I felt very much alone..."

Some wanted more information than they remembered was given. One respondent said, "They didn't explain hardly anything...I did have questions but they never asked me about questions."

Another recalled, "What really irritated the hell out of me" was that his wife knew about his upcoming hospital discharge shortly before he did.

[The case manager] said, "Mr. [patient name], you know you're going to a rehab center?" I said, "Yeah I know. My wife told me. You didn't have the decency to come down and tell me first! You went around my back!" "Well," she said, "we were very busy...there was so much paperwork."

Family members could be very helpful

The assistance of a family member figured in these interviews. A few respondents said they did not involve themselves in decisions about the moves or the care because a daughter was performing this role. For example, one daughter asked the respondent about the choice of SNF, and the respondent said, "Just do it." The daughter retrieved the respondent's belongings from the hospital and made sure the medications were correct. "My daughter took care of everything." Another recalled crying much of the time and relying on her daughter for decisions because she became confused. When asked whether doctors or other providers explained the care, this 87-year-old respondent answered:

"Yes, they did explain. But...you're not really listening for them. My daughter...really listened to them all...She said, 'Mom, this is the best place for you because how else can you manage?...until we get to the bottom of [this]...you have to be at the hospital.'" "

A 78-year-old respondent asked her daughter, "You understand that?"... She said, 'Yeah, okay Ma.' And so I just forget about it because I get confused if you get more [information]."

Communication with physicians was described as uneven

Communication with physicians was reported to range in quality and was connected to the advice respondents offered. One enjoyed being the object of concern by her providers:

"I loved it. I like to talk about myself. And they were interested. A couple of them even had good suggestions. And I felt as if we were moving forward, that something was being done."

Another said:

"The doctors...were very nice talking to me...they were just proper...I liked them...they made you feel at home... They made me sit down, and then they sat down."

On the other hand, one was frightened by what she recalled was a too-forceful manner in one physician's recommendation:

"'If you don't do this, you will die.' That really got me...scared the hebegeebes right out of me. It didn't help matters. It really shook me up."

Advice for physicians

This respondent wanted the physician to "Put it a different way, you know. Sit my family down and say 'Look, the blood work is this, this and that.' But he didn't do that." Her advice was to, "Give [patients] the opportunity to talk. Be patient... they're not hearing everybody, you know?" An 86-year-old woman said simply, "Treat them like they were their father. You know, be gentle." A 77-year-old respondent said, "They need to be reassuring and not be the master of everything... people have their own way of thinking and organizing themselves. And it's up to the doctor to pick up on that." An 83-year-old respondent had this specific advice for physicians:

"Slow down. Just remember we have some physical difficulty...I think I am more with it than most of the patients here. And even I am exhausted by them. The people stand over me too close; if they move too fast, I get out of breath. And I am just physically wiped out. And I am perfectly capable of having a party with a team of doctors, but they've got to do it at my pace a little bit...It would be nice if they talked a little bit about our particular backgrounds. ...Many doctors make us feel that we're cute and precious and gee just doing well. But, they don't think of us as real human beings."

CONCLUSION

This small sample of interviews reveals how some older patients in RI experienced their care transfers among hospitals and SNFs. Their stories reflect patient vulnerability after a hospitalization with disruptions in sleep and other routines and when pain is common.¹⁴ The quotes remind us that patient and provider perceptions of medical events

can be markedly different.⁷ Individuals in these accounts described the variety of transfers they endured and their feelings of disorientation and confusion. Respondents had different needs for information and seemed reassured by a family member's assistance in decisions and advocacy. Their advice to physicians about how they would like to be talked with is a vivid reminder that their perception of communication is a vital element in competent and compassionate care in difficult transitions. Attention to their stories can help improve their care at these vulnerable times.

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