ORIGINAL RESEARCH

"It's Really Overwhelming": Patient Perspectives on Care Coordination

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Purpose: **Failures of care coordination among health care providers are known to lead to poorer health outcomes for patients with complex medical needs. However, there has been limited research into the perspectives of patients who receive care from a variety of health care providers. This qualitative study sought to characterize the factors leading to emergency department (ED) patient satisfaction and dissatisfaction with their care coordination.**

Methods: **Semistructured telephone interviews were conducted with 25 adult patients following ED visits about their experiences with their care coordination. All patients interviewed had 2 or more ED visits and hospitalizations in the past year and/or health providers in more than one health system. Interview transcripts were coded and analyzed following a modified grounded theory approach.**

Results: **Four broad categories of themes emerged from the patient interviews covering the following: (1) perceptions of care coordination between their providers, (2) the role of electronic health records, (3) challenges with information exchange between health systems, and (4) sources of support for care coordination activities, emphasizing the important role of the primary care provider.**

Conclusions: **Patients with multiple health care providers identified significant barriers to communication among providers and inadequate support with care coordination activities. Expansion of team-based models of primary care and prioritizing interoperable technology for sharing patient health information between providers will be critical to improving the patient experience and the safety of transitions of care. (J Am Board Fam Med 2018;31:682–690.)**

Keywords: **Electronic Health Records, Emergency Departments, Grounded Theory, Hospitalization, Patient Satisfaction, Primary Health Care**

Delivery of high quality health care to patients with chronic illness requires effective care coordination. Coordinated care can only be accomplished through deliberate activities that engage the various members of a care team, patient, family, and providers to realize the timely and appropriate delivery of care.[1,2] Care patterns in which patients see multiple physicians across different practices reflect not only a significant need for but also a major challenge to coordinated delivery of care.[3,4] Failures of coordination remain commonplace particularly at the primary-specialty care interface and at hospital discharge, leading to medication conflicts, duplicate testing, hospital readmissions, and gaps in delivery of preventive care.[5,6] With the number of Americans living with chronic conditions expected to grow to 157 million by 2020, care coordination represents a compelling area for health care quality improvement, with significant implications for cost savings.[7]

Primary care providers (PCPs) play an important role in the coordination of their patients' care. PCPs can arrange for appropriate referrals and re-

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solve conflicting clinical recommendations, responsibilities that could otherwise prove daunting to patients and their caregivers.[8] PCPs are challenged, however, to coordinate care when patients move between care settings, for example between outpatient and emergency department (ED). Hospital admissions often result from failures of outpatient care coordination and have been associated with increased dispersion of care across multiple providers.[9,10]

While current interventions have largely focused on improving coordination processes at the provider level, understanding of care coordination from the perspective of US patients with chronic medical conditions has been limited by a lack of qualitative research.[11] This qualitative study aims to fill this gap in patient-centered research by capturing a broad set of experiences and attitudes from a diverse set of patients presenting to the ED, a setting that accounts for the majority of unscheduled hospital admissions and is thus uniquely suited to identifying problems related to fragmentation of care.[12] The goal of the current study was to capture patient perspectives on factors influencing the effectiveness of care coordination.

Methods

Study Design

The authors conducted semistructured open-ended qualitative interviews with a purposive sample of patients, identified during their ED visit as having 2 or more ED visits and hospital admissions in the past year and health care providers in different health systems. These criteria were intended to select for patients with high need for care coordination and the potential for rich descriptions of a range of experiences. The patients who participated in the interviews were a subset of subjects drawn from a larger study surveying ED patients for their opinions regarding health information exchanges (HIEs).[13] The study protocol was approved by the Institutional Review Board of the University of Pennsylvania with verbal informed consent for the ED survey and audiotaped follow-up phone interviews, which generally occurred within 7 to 10 days of the ED visit.

Study Setting and Population

Patient recruitment into the larger ED survey occurred between April 28, 2015, and August 11, 2015, in an east coast, urban, tertiary care hospital with an annual ED visit volume of 65,000. Trained assistants conducted verbal surveys of awake and alert nonemergent patients presenting to the ED during data collection periods (weekdays between 7 AM and 10 PM). Patients were considered ineligible if they were under the age of 18, unable to provide informed consent, non-English speaking, or not medically or cognitively able to participate in a verbal survey. Patients were also not approached if they were pregnant, sleeping, in too much pain or too ill, receiving medical care, under influence of drugs or alcohol, or cognitively impaired. Eligible consenting ED patients completed a brief verbal survey pertaining to their demographics, experiences with health care providers and medical records, and interest in a follow-up interview on their care coordination. Most (59%) of the surveyed patients expressed an interest in being contacted for a follow-up phone interview.

"Super-utilizers" of the ED, determined solely by the treating ED provider, were not included in the qualitative study, as they were anticipated to have higher needs for behavioral health interventions.[14] A purposive sample of enrolled patients who gave permission for follow-up interviews were contacted by phone for follow-up semistructured interviews if their survey responses suggested that they had at least 2 ED visits and 2 hospital admissions in the previous year and/or health care providers in more than one health system. Interviews were conducted with ongoing qualitative analysis until theme saturation was reached.

Data Collection

A semistructured interview guide with open-ended questions was developed by the authors to uncover a broad range of patient experiences and perspectives on care coordination (Table 1). The content for the guide was vetted by a group of emergency medicine clinicians and health services researchers. Questions inquired into patients' overall experiences with and attitudes toward their health care, including coordination between their providers and use of their medical records. Four qualitatively trained research assistants conducted the interviews, which were audiotaped, professionally transcribed, and entered into NVivo (version 10.0; QSR International, Doncaster, Australia) for qualitative data management and analysis. Stata (ver-

Table 1. Sample of Questions in Interview Guide

Can you tell me about your overall experience with healthcare?
How do you organize your healthcare?
What, if anything, is challenging about organizing your healthcare?
When you have questions about your healthcare, who do you ask?
What advice would you give someone who was coordinating their care with multiple providers?
What has your experience been with your various health care providers having access to your records?
If you could give advice to providers about what would make your visits be better coordinated, what would you say to them?

sion 11.2; StataCorp, College Station, TX) was used for quantitative analyses.

Data Analysis

Analysis was conducted using a modified grounded theory approach, which included the use of an a priori set of themes that addressed the research questions, as well as a set of themes that emerged from the data de novo through iterative line-by-line reading of the interviews. Four trained research assistants reviewed all audiotapes and transcripts during the data collection period and, in consultation with the senior author, created a tentative thematic framework informed by the research aims and patterns of responses identified during the initial overview of early interviews. Each theme was applied to all transcripts by trained research assistants who independently coded the transcripts line-by-line. Interrater reliability was measured for each theme within NVivo, with agreement surpassing 90% noted. Consensus meetings to discuss any themes with an interrater reliability of less than 90% resolved discrepancies in coding. Themes and the relationships among them were used to develop a conceptual model for understanding patient perspectives on care coordination.

Results

Characteristics of Study Subjects

From 1,017 participants in the initial ED survey, a purposive sample of 25 patients was recruited for semistructured qualitative interviews that lasted approximately 30 to 45 minutes. Table 2 shows the characteristics of the larger population and those selected for interviews.

Qualitative analyses of the interviews identified both positive and negative experience with care coordination. Table 3 identifies 4 broad themes that emerged during the interviews with representative patient quotes. The 4 themes were the following: (1) patient experiences and perceptions of care coordination between their providers, (2) the role of electronic health records (EHRs) in provider-to-provider information exchange, (3) challenges with information exchange between health systems, and (4) sources of support for care coordination activities, emphasizing the important role of PCPs.

Perceptions of Communication between Providers

Participants who expressed satisfaction with care coordination between their providers often assumed that the clinicians caring for them were communicating with each other even when there was no clear evidence that this happening: “I really did not have any knowledge of the old [provider] giving [my health information] to the new, but I was glad that that happened” (patient 1). For those who experienced problems, on the other hand, poor provider-to-provider communication was often thought to be the culprit.

A common complaint was that that providers lacked knowledge of each other’s recommendations and produced conflicting care plans. Some participants reported that they had to convey their medical information multiple times to different providers. This led to concern that their providers lacked complete knowledge of their medical history and treatment plan: “they do not really have a full picture of what is going on with me other than what I am taking, giving, bringing to the table. And I may miss stuff” (patient 2). One participant suggested that record sharing would go more smoothly if all providers sent copies of their letters to all the patient’s other providers.

The Role of EHRs in Information Exchange

Many participants attributed effective sharing of their health information to the use of EHRs. One participant was dissatisfied with her primary care

Table 2. Characteristics of Survey Participants

Characteristic*	Survey Participants (N = 1017)	Interview Participants (N = 25)
Age (yr), mean (range)	51 (18–99)	52 (27–73)
Sex, n (%)		
Male	433 (43)	11 (44)
Female	580 (57)	14 (56)
Race, n (%)[†]		
African American	546 (55)	11 (48)
White	373 (38)	12 (52)
Hispanic/Latino	21 (2)	0 (0)
Asian	21 (2)	0 (0)
Other	32 (3)	0 (0)
Education, n (%)		
Some high school	113 (11)	1 (4)
High school graduate/GED	325 (33)	6 (24)
Vocational training/trade school	68 (7)	1 (4)
Some college	208 (21)	6 (24)
College graduate	286 (29)	11 (44)
Living situation, n (%)		
At home, by self	182 (18)	4 (16)
At home, with someone else	797 (80)	20 (80)
Nursing home/assisted living	9 (1)	0 (0)
Other	8 (1)	1 (4)
Has a regular doctor, i.e. primary care physician, n (%)		
Yes	842 (85)	22 (88)
No	154 (15)	3 (12)
Usual source of care uses electronic health records, n (%)		
Yes	739 (78)	20 (83)
No	42 (4)	2 (8)
Unsure	169 (18)	2 (8)
All medical care in same system as ED, n (%)		
Yes	441 (45)	10 (40)
No	493 (60)	15 (60)
Unsure	54 (5)	
Has seen doctors outside of same system as ED, n (%)		
Yes	778 (79)	21 (84)
No	212 (21)	4 (16)
Primary care physician helps with care coordination, n (%)[‡]		
Checked	259 (27)	9 (36)
Unchecked	705 (73)	16 (64)

* Figures for each question reported for only those survey participants for whom a response was recorded.

[†] Survey question asked to "check all that apply"; sum of percentages >100 as a result of multiracial participants.

[‡] Survey question read "Who helps you coordinate your healthcare?" and asked to "check all that apply"; figures reported for selection of "My primary care physician" option.

ED, emergency department.

physician's use of paper records, which she felt was a "haphazard" (patient 3) record-keeping system compared with the EHR at the health system her husband visited. Participants often expressed relief at not having to retell their history or bring medication lists when their providers could just pull up their health information in an EHR. One element of an EHR that some patients particularly appreciated was the online patient portal, which provided access to portions of their health records and facilitated prompt communication with their providers.

Table 3. Representative Quotes

Theme	Satisfaction with Care Coordination	Dissatisfaction with Care Coordination
Perceptions of communication between providers	And that the doctors all talk to one another. Like when I had problems with my kidneys, and I saw a nephrologist at [Hospital Name 1], so he was able to tap in with my—my cardiologist spoke with him. So those two spoke and then said, okay, you know what? Yeah, this is not looking good; so let's change some of her medication that she's taking for her heart.	I think that what they should do is get together—before they talk to the patient, get together and converse about it. And then tell the patient. Because what it looks like is that they don't communicate with each other. One's saying one thing and another saying another thing, and that's what makes it seem like they don't know what they're doing.
	Communication between [my doctors] is fine. Communication between all three of them, I have no idea.	I have to keep telling people over and over again what my history is. No matter where I go, and I always say can't you just call up my doctor? [. . .] They say no. No, we can't.
		I actually do more communicating with the different doctors—which I shouldn't have to do—than my doctors do.
Role of EHRs in information exchange	Well, actually everything as far as technology-wise, is things go easier. They had the patient portal and stuff like that. So everything is actually getting to them. Everything actually improved, especially with the technology.	I felt like that should be something that you're able to pull up on your computer and see the results of my two tests that you just asked me about right at your fingertips. So that's what I'm saying when I mean disconnect. And he's kind of looking at me like—I said, you didn't get that? [. . .] he still uses the paper files and taking out a piece of scrap paper to jot things down.
Information exchange across health systems	If it's a [Hospital 1] doctor, they have everything right there right on the computer. And it doesn't have to be in [Location 1]. It could be in [Location 2] or it could be in [Location 3]. Wherever he is, they're all networked. And that's a really wonderful thing. I think everybody should be on that page.	I wish sometimes the different hospitals can communicate a little bit—the medical records could be more effective in letting the—for example, I wish that [Hospital 1] could've gave them the information when they requested it, instead of have them do it two and three and four times.
	I guess [. . .] it's been good because I was all a part of the network, so all my doctors could see, when I had discussed that test, the results and everything. It was in the computer. So that worked out well for me.	And then getting the stuff from [Hospital 1], my medical records from [Hospital 1], so they could update it at [Hospital 2] was a nightmare. So finally [. . .] we got my records from [Hospital 1], and we got home to send them to [Hospital 2]. Well, they were password protected and the password was nowhere to be found.
Support for care coordination from primary care providers	When I have to go to my different appointments [my primary care provider] do help with that. She gets me [. . .] whatever referral I need it for. She do do that.	When I call the primary doctor to order [referrals], they're like, well you're the one that's supposed to be coordinating this. I said, you're coordinating my medical. I'm not coordinating it. And then they say, well maybe the specialist should be coordinating it. [. . .] So, it costs me even more money because I'm not using all of my insurance because no one's coordinating it.
	My primary care physician at [Hospital 1] sends me a message in the [Hospital 1] system and says, I got your blood results, everything was good. He sends it to me every week. My primary care physician, he's awesome. He's so busy, but he does it.	

EHR, electronic health records.

However, even with systems in place to enable information transfer, some participants reported issues with how they were used by providers. One participant got the impression that medical professionals "do not look at any of [the records]. What they do is they continue to ask you to go over stuff, and they miss stuff" (patient 4); this was based on an experience being misdiagnosed by emergency physicians who apparently did not read her records or contact her regular physician who was at the hospital at that very time. Another complained that her doctors at one hospital rarely made use of its patient portal and wished that they would "just send [her] a frickin' message" (patient 5). Omissions of appointments and imaging results were also mentioned as sources of frustration.

Challenges with Information Exchange across Health Systems

A consistent challenge for information exchange was the dispersion of care among different hospitals and practices. Participants who received most of their care from a single health system felt that coordinating their care was easier with all their records in a single EHR. On the other hand, one participant expressed concern about a possible "disconnect" (patient 3) between her primary care provider and cardiologist who were not in the same system.

While some patients who visited multiple health systems had no problems with communication between their providers, others faced major barriers with transferring information from one institution to another. One participant recounted a "nightmare" experience in the ED of one hospital that lacked access to her health records being kept in the hospital for an abnormal finding previously deemed benign: "[…] they were gonna take my blood draw, just to check because it is easier to do a blood draw than it is to get blood results from another hospital into the system, which is kind of ridiculous" (patient 6). Accordingly, multiple participants expressed frustration with the lack of a unified repository for their medical records for all their providers to access. One remarked, "[…] it baffles me that there is not an electronic health record that is just tied to your Social Security number" (patient 7).

Sources of Support for Care Coordination and the Role of PCPs

Patients often noted confusion about roles in coordination of their care among multiple providers, and the majority expressed a desire for someone to be primarily responsible for helping coordinate their care. Patients with involved PCPs had very positive experiences and specifically appreciated efforts by their PCPs to communicate pertinent information to outside doctors and keep patients informed about the status of information transfer among their providers. However, some participants specifically mentioned wanting their PCPs to play a more active role instead of shifting the responsibility onto them.

Many participants reported that they personally handled their own care coordination. In situations where patients needed additional help, family and friends often took on a major role with scheduling their visits and searching for providers. Not all patients who coordinated their care on their own did so by choice, with some feeling forced to bear the burden due to a lack of outside support. Many patients spoke to the importance of "[being] your own advocate" (patient 8) to obtaining care that met their needs. Another participant commented, "You literally should not show up—if you have multiple doctors, whatever—never show up to a place without a pencil and a piece of article. […] They might have 8 minutes to give you, at best, and so it is really overwhelming" (patient 9).

Discussion

This study adds to the primary care literature by qualitatively examining the perspectives on care coordination of adult patients with high care coordination needs. Preventable ED visits have been identified as a marker of poor care management and inadequate access to primary care.[15] Patients identified during their ED visits as having high coordination needs revealed that factors affecting their experiences with care coordination were the effectiveness of information exchange between providers and the adequacy of support patients received from the health care system. One notable finding across the spectrum of interviews was the increased salience of care coordination as a topic of conversation among participants who expressed the highest dissatisfaction with their health care experiences. Those who were satisfied generally had fewer observations to offer, often professing lack of familiarity with how their providers coordinated their care. This finding reinforces studies that find patient perception is most sensitive to poor care coordination, resulting in unmet expectations and adverse health events.[11,16] It seems that successful care coordination is often taken care of behind the scenes by providers and, from the patient perspective, may be reflected less by active appreciation than by how invisible and unobtrusive it remains to them.

Although the study purposively sampled for patients with multiple health care providers, patients consistently identified their PCPs as their preferred source of support and information regarding their care coordination. Primary care has long been identified as an ideal setting for care coordination, serving as a hub for the storage of patient health information and management of referrals.[5,8,17] Consistent with prior qualitative work, the results of this study suggest that patients are more satisfied with PCPs who play an active role in coordinating their care and experience significant dissatisfaction and distress when those expectations are not met.[18–20] This was especially true of patients lacking social support, a group at particular risk for poor health self-management and more frequent visits to the hospital.[4,21] These results highlight the value of screening patients in the primary care setting for their level of social support and providing additional needed resources for their care coordination.

The qualitative findings of this study are broadly supportive of the potential of Medicare's Advanced Primary Care (APC) initiative to improve the patient experience with their care coordination. This program endeavors to build on the many-year experience with the patient-centered medical home (PCMH) model and seeks to study and provide funding for new models to improve the delivery of care for patients with chronic illness and complex care needs.[22] Patient expectations regarding provider communication and support with care coordination activities strongly aligned with the goals of the PCMH model, involving interdisciplinary teams of physicians and nonphysician staff to help patients navigate the complexities of the health care system. One prior qualitative study found that patients at PCMH-adopting practices encountered far fewer problems with their care coordination between their providers.[23] In light of this study's findings, the invisibility of care coordination processes to these patients could be viewed as a measure of success for current medical homes. Further research into this topic is needed for a more definitive evaluation of the APC initiative as PCMH models become more widely adopted in primary care.

Barriers to sharing health records plagued the care coordination of many of the interviewed patients, highlighting the critical need for improved health information flow and interoperability. These patient perspectives parallel those of physicians using EHRs, who often lack access to patient records at other sites and referral tracking capabilities and still rely on article-based methods to communicate with outside providers.[24] A central expectation for all APC models is the use of health information technology, although a recent study revealed that many have yet to incorporate it into their care coordination processes.[25,26] Significant progress in care coordination across separate health systems could be achieved with improved interoperability among various EHR systems.[27,28] Mirroring calls for the establishment of a national standardized health information system, multiple participants verbalized a desire for a unified health record that would be accessible to any doctor they see.[28] Indeed, many states and regions have invested heavily in HIEs to enable information flow among local health organizations. Survey and qualitative research has indicated very strong support among patients who recognize the potential of HIE to improve health care quality.[13,29–32] Less is known about the actual impact of existing HIE communities on the care coordination of patients in the areas they serve, which represents an important avenue for future research.

This study has the typical limitations of a qualitative study, including that it is primarily hypothesis-generating. Because participants were recruited from a single ED at an urban academic medical center, their experiences may not be generalizable to other populations in other areas of the country. Furthermore, participants interviewed constituted only a small fraction of those who came through the ED, as the purposive sampling selected for patients who had multiple providers and medical problems that had resulted in ED visits and admissions. Therefore, the themes that emerged from this sample would not necessarily be representative of the greater population; it is possible that patients with chronic illness who have not required emergency care may have had their care coordination needs more adequately addressed by their outpatient providers than the subjects of this study. Indeed, high-need patients have been characterized as an extremely diverse group that defy easy categorization.[33] Further research is needed to explore the unique needs of certain populations excluded in this study, including non-English-speaking patients whose experiences may be affected by language barriers, as well as "super-utilizers" who may require higher levels of social support and have more complicated coordination needs with providers for behavioral health issues. From this study, the insights gained can help inform next steps in the development of interventions to improve transitions across care settings.

In summary, this study qualitatively reports on the perspectives of a sample of adult patients identified in the emergency setting with high care coordination needs. The patients interviewed in this study strongly endorsed the need for better communication, interoperable health records, and improved transitions of care between providers and health systems. They also strongly expressed the desire to have their primary care physician play a central role in coordinating their care. Consideration of these perspectives is critical to the development of policies and practices to improve overall care coordination in an effective, safe, and patient-centered manner.

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