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Primary Care Physician Involvement During Hospitalization: a Qualitative Analysis of Perspectives from Frequently Hospitalized Patients

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ABSTRACT

Objective: To explore frequently hospitalized patients' experiences and preferences related to primary care physician (PCP) involvement during hospitalization across two care models.

Design: Qualitative study embedded within a randomized controlled trial. Semi-structured interviews were conducted with patients. Transcripts were analyzed using qualitative template analysis.

Setting: In the Comprehensive Care Program (CCP) Study, in Illinois, USA, Medicare patients at increased risk of hospitalization are randomly assigned to: 1) care by a comprehensive care program physician who serves as a primary care physician (PCP) across both inpatient and outpatient settings; or 2) care by a PCP as outpatient and by hospitalists as inpatients (standard care).

Participants: Twelve standard care and 12 CCP patients were interviewed.

Results: Themes included: 1. Positive attitude towards PCP; 2. Longitudinal continuity with PCP valued; 3. Patient preference for PCP involvement in hospital care; 4. Patient experience of interaction with PCP during hospitalization (rare in standard care; in CCP, frequent interaction with PCP fostered patient involvement in decision making); 5. Patient experience of PCP interaction with hospital-based providers (no interaction for standard care patients; CCP patients emphasizing PCP's role in interdisciplinary coordination).

Conclusion: Frequently hospitalized patients value PCP involvement in the hospital setting. CCP patients highlighted how an established relationship with their PCP improved inter-disciplinary coordination and engagement with decision-making. Inpatient-outpatient relational continuity may be an important component of programs for frequently hospitalized patients. Opportunities for enhancing PCP involvement during hospitalization should be considered.

Article summary

Strengths and limitations of this study

- This study provided a unique context within a RCT with one group of patients cared for by hospitalists and one group cared for by their PCP during hospitalization
- This study's qualitative approach allowed for a rich exploration of patients' experiences and preferences related to PCP involvement in hospitalization
- Self-selection bias is a possible limitation - patients recruited for the embedded qualitative study may have been a healthier and more engaged group than the overall study population
- This study was conducted at an academic medical center; experiences of the standard care group reflect the context of receiving care from trainees

INTRODUCTION

Before the mid-1990s, primary care physicians (PCPs) in the United States (U.S.) typically oversaw care for their own patients when they were hospitalized. Since that time, the number of hospitalists has significantly increased within the U.S.[1] This shift in care delivery model was motivated by perceptions about increased hospitalist efficiency, availability, specialized expertise, and possible cost and mortality reductions.[1, 2] Despite such advantages, the hospitalist model may increase fragmentation between inpatient and outpatient care, particularly for patients who are frequently hospitalized.[1] Previous studies found that hospitalized patients frequently had limited knowledge about their diagnosis, care plan, or post-discharge instructions.[3–5] Other studies identified discrepancies between hospitalized patients and their inpatient physicians in perceived goals of care,[6] and limited opportunities for shared decision-making.[3, 7, 8] A possible contributing factor to these communication barriers is lack of an established relationship between hospitalized patients and their inpatient physicians. In comparison, PCPs with whom patients have ongoing relationships often have intimate knowledge of patients' preferred communication style, values, family context, and care preferences, but infrequently communicate directly with patients during hospitalization.[9–11] Communication between PCPs and inpatient providers during hospitalization may also be limited in frequency and scope.[12, 13]

Particularly for patients with complex needs, PCP involvement during hospitalization may greatly impact patient experience due to their familiarity with their patients' complex health history and established relationship with patients. However, few studies directly

compare the hospitalization experiences of patients cared for by their PCP versus by hospitalists. These are limited to quantitative comparisons related to satisfaction.[14, 15] There is a need for qualitative patient perspectives on the role of a PCP in the hospital setting.

We conducted a qualitative study of frequently hospitalized patients' experiences and preferences related to PCP involvement during hospitalization. This qualitative study was embedded within a larger randomized controlled trial, the Comprehensive Care Program (CCP) Study. Patients at increased risk of hospitalization are randomly assigned to one of 2 care models: 1) a CCP physician who serves as both the outpatient PCP and hospital attending (intervention arm) or 2) outpatient care from a PCP and hospital care from hospitalists (standard care).[16] This study context provides a unique opportunity to explore and compare the experiences and preferences surrounding PCP involvement during hospitalization between patients cared for by hospitalists as compared with a patient's own PCP.

METHODS

Setting

The CCP study at the University of Chicago Medicine (UCM) is a randomized controlled trial assessing the effect of an interdisciplinary care team for patients at high risk of hospitalization. The overall CCP study recruited Medicare Part A and B enrollees with at least one hospitalization at UCM within the previous twelve months. Patients randomized to the intervention group were cared for by PCPs with limited panels of approximately 200

patients to enable them to care for their patients as the primary attending in both inpatient and outpatient settings. As outpatients, the patients also receive care from a social worker, two nurses, and a clinic coordinator. Patients randomized to the control group received "standard of care," which included following with their prior PCP (or were offered assistance in obtaining one if they did not have one) and being treated by hospitalist physicians if admitted to UCM.[16]

The broader CCP study compares clinical outcomes, health care costs, and experiences of patients in CCP versus standard care.[16] This embedded study used qualitative interviews with a subset of both CCP and standard care patients to better understand and compare patients' experiences and preferences surrounding the role of their PCP during hospitalization.

Participant selection

The participants for the embedded qualitative study were drawn from the broader CCP study. Additional inclusion criteria included, participation in the CCP study for at least one year, and having at least three hospitalizations within the previous twelve months (based on self-report during quarterly phone surveys), with the most recent hospitalization occurring at UCM. For intervention group patients, medical records were screened to confirm that their assigned CCP physician served as their primary attending during the most recent hospitalization. Patients were recruited by a research assistant or medical student in-person or by phone between July 2017 and August 2018. Recruitment continued until data saturation was reached.

Development of interview guide

The semi-structured interview guide was developed by an interdisciplinary team including a CCP physician (JT), a medical student without ties to CCP (JK), a CCP social worker (NG), and a research assistant without ties to CCP (JH). Two members of the team (JT, JH) had prior experience in qualitative research methods. The interview guide was further modified after review by three patients in the intervention arm of the CCP study. The final interview guide (Appendix A) focused on patients' care experiences during and after their most recent hospitalization at UCM, with an emphasis on: 1) communication with physicians and nurses in the hospital setting, particularly surrounding goals of the hospitalization and decision-making; 2) post-discharge care; and 3) relationship with their PCP and their PCP's role during hospitalization.

Data collection

Semi-structured interviews, approximately 30 minutes in length, were conducted in-person at UCM by a medical student and a research assistant, neither with ties to CCP (JK or AK). Patients provided verbal consent for the interview and received a $30 gift card for participation. Patient characteristics including sex, age, and healthcare utilization were collected from the medical record. This study received approval from the University of Chicago Institutional Review Board (IRB12-1440).

Data analysis

The interviews were digitally recorded and transcribed by the research team; identifiable personal data were redacted. The interview transcripts were analyzed using template

analysis, a methodology developed by Crabtree & Miller.[17] Template analysis was selected as a systematic yet flexible methodology that lends itself to analysis across the two groups of subjects. The qualitative analysis team (JT, ER, JK) was composed of one CCP physician and two medical students. The three team members separately reviewed five interview transcripts (3 control group; 2 CCP group) and engaged in discussions to develop a preliminary "template" (coding guide), a hierarchical organization of the identified themes.[18] Through an iterative process, additional codes were added to the template as they arose from the five sample transcripts. The three team members then applied the initial template to code the transcripts using NVivo 11 (QRS International) software. Two coders reviewed each of the twenty-four transcripts. During analysis, the team met weekly to resolve discrepancies in coding through discussion, and to revise the template. After the template was finalized, themes were developed through repeated review of codes and discussion. These themes were described, and representative quotes were selected and agreed upon by the entire research team. The qualitative analysis team practiced reflexivity through open communication about their preconceptions and how their roles in patient care relate to their perspective.[19]

Patient and public involvement

Three CCP patients provided feedback on the interview guide during development. As a check on the validity of the analysis, results were reviewed and discussed with the CCP study patient and community advisory board and with CCP physicians, team members, and administrators.

RESULTS

Patient sample

Twenty-four interviews were conducted, 12 with CCP patients and 12 with standard care patients. Patient characteristics are shown in Table 1.

Table 1. Participant characteristics.

Characteristics	All patients (n=24)	Standard care patients (n=12)	Comprehensive Care Program patients (n=12)
Age in years[a] [mean (standard deviation)]	53 (14)	57 (15)	49 (11)
Female [n (%)]	12 (50)	6 (50)	6 (50)
Years since CCP study enrollment[a] [mean (standard deviation)]	2.7 (1.2)	2.7 (1.3)	2.7 (1.1)
Chronic medical conditions [n (%)]			
Heart failure	11 (46)	7 (58)	4 (33)
Coronary artery disease	6 (25)	4 (33)	2 (17)
Diabetes	11 (46)	7 (58)	4 (33)
End-stage renal disease	10 (42)	5 (42)	5 (42)
Chronic lung disease[b]	8 (33)	7 (58)	1 (8)
Cancer	2 (8)	1 (8)	1 (8)
Rheumatologic disease[c]	2 (8)	0	2 (17)
Other[d]	2 (8)	1 (8)	1 (8)

[a] At time of interview.

[b] Chronic obstructive pulmonary disease, Asthma, Interstitial lung disease, Pulmonary arterial hypertension, Cystic fibrosis.

[c] Scleroderma, Crohn's disease.

[d] Sickle cell disease, Spina bifida.

For CCP and standard care groups combined, 50% were female and the average age was 53 years. Patients had been enrolled in the CCP study for an average of 2.7 years at the time of interview. All patients had two or more chronic medical conditions. Of the standard care patients, 67% received primary care from internal medicine resident physicians; all CCP patients were cared for by attending physicians.

Table 2. Themes across standard care and Comprehensive Care Program groups.

Theme	Standard care patients (n=12)	Comprehensive Care Program patients (n=12)
1. Positive attitude towards PCP	Valued comfort communicating with PCP, and PCP compassion. CCP patients additionally reported shared trust.	
2. Longitudinal continuity with PCP valued	Experienced frequent turnover of PCP	Described longitudinal relationships with their PCP which improved over time
3. Patient preference for PCP involvement in hospital care	Majority preferred some contact with PCP during hospitalization	Preferred inpatient treatment by PCP due to shared trust and their prior knowledge of the patient
4. Patient experience of interaction with PCP during hospitalization	Most did not interact with their PCP during hospitalization	Described active involvement of their PCP in decision-making
5. Patient experience of PCP interaction with hospital-based providers	Most were not aware of interaction between PCP and hospital providers	Emphasized PCP's role aligning the knowledge and goals of various providers

PCP, primary care physician.

Theme 1: Positive attitude towards PCP

Themes from interviews are summarized in Table 2.

Patient is comfortable talking with their PCP

A majority of CCP patients and a few standard care patients described feeling comfortable conversing with their PCP. Patients in both groups valued that their PCP listened to what they said. Several CCP patients, but only a few of the standard care patients, thought discussions were better with their PCP than with hospital providers. A common perception was that the patient could speak more openly with their PCP.

> It's good because I can openly talk to him and not be afraid to tell him if something is not going right. (Female, standard care)

Several CCP patients also described engaging with their PCP about topics outside of medicine, including challenging social issues.

> You want to be straight up with your primary about things. You want to tell him everything, what's giving you problems. Well my wounds are giving me problems, do you have any other issues? And you tell him: well depression issues, housing issues. (Male, CCP)

PCP is caring towards patient

Across CCP and standard care, several patients expressed that they felt cared for by their PCP. Patients appreciated that the PCP was concerned about their health and that the physician offered their time and attention.

> She sits and talks to me, she [...] connects with me, you know. Not just like business type thing, but a family type thing. (Male, CCP)

Shared trust between patient and PCP

Half of CCP patients, but none of the standard care patients, mentioned shared trust with their PCP. In several instances, CCP patients stated that their PCP trusted them to make their own decisions about care. Participants also described an increased level of trust in their CCP's judgment over time.

> See we have this really good relationship, and she knows that I am an informed patient. I know my body and I can pretty much tell her more than she can tell me about my body, and so she trusts me the same way I trust her. (Female, CCP)

Theme 2: Longitudinal continuity with PCP valued

Many standard care and CCP patients emphasized that it takes time to build a relationship with a PCP. A majority of standard care participants described discontinuity with their PCPs. A few patients attributed the frequent changes to receiving primary care from residents who graduated and transitioned their patients to new trainees.

> [...] this'll be my 4th primary care doctor in 10 years. But, you know, you guys do your 2 or 3 year residency, then you're off [...] But at some point you've got to learn, like what you're doing with me. (Male, standard care)

In comparison, CCP patients experienced greater relational continuity with their physician. A majority of CCP patients mentioned that the relationship with their CCP physician improved over time as they got to know each other. Two participants described a difficult start that morphed into a positive relationship.

> Once you get to know a person it gets better because you know the first couple of times it's not going to be smooth sailing. (Male, CCP)

Theme 3: Patient preference for PCP involvement in hospital care

A majority of standard care patients and nearly all CCP patients stated that their PCP should be involved during hospitalization. However, there was variation in the preferred form of involvement. A majority of standard care patients thought that ideally a PCP would remain in communication with their patient during hospitalization.

> It shows they care, they're concerned about my being, my health. And that's a good thing. (Female, standard care)

Patients commonly preferred that this interaction be in person, with a few specifically stating that they would prefer to be treated by their PCP while in the hospital. A few standard care patients noted that their PCP could have been able to offer emotional support during hospitalization.

> [...] he probably could have informed me and let me know more about what was going on, and I would have had less anxiety. I would have felt more relieved. (Male, standard care)

Further, a few standard care patients thought that a PCP should remain in communication with the patient's care team during hospitalization. PCP involvement was considered beneficial due to their prior knowledge of the patient's health conditions.

> I don't think he should just be in the office all the time. I think he should know about me being in the hospital and why and help me to maintain my health. I mean, these other doctors, they don't really see me that much. They don't know much about me. They just know what I come in and I complain about, and then they fix that and then they send me on my way? What if I have another issue that they're not aware of that my primary care doctor is aware of? (Female, standard care)

On the other hand, some standard care patients stated that they chose not to reach out to their PCP during hospitalization due to lack of a relationship with their PCP. Others shared that they had no expectation of PCP involvement during hospitalization. These patients thought it was sufficient for the PCP to view records following discharge or answer questions if contacted by the hospital team.

> I just concentrate on the doctors at hand, and I know that they're making notes so he see it on the chart. I don't have it where I can text him and let him know each time I'm in the hospital. I don't do that [...] like I see him every two months. So, by the time I see him, I'm quite sure there's a flag somewhere to let him know I've been in

> the hospital, and he can read the chart and see that I've been in the hospital so. (Female, standard care)

Among CCP patients, all described a preference to be treated by their PCP in the hospital setting. For several, a PCP's knowledge about their health and personal preferences was thought to expedite care and improve adherence to previously developed plans.

> Besides my opinion, she should be able to make the decision. She should be the one running stuff. Should no other doctor be running nothing or make no decisions because you don't know me. (Female, CCP)

A few CCP patients also pointed to the shared trust with their PCP. Due to previous hospitalizations or office visits patients perceived that the PCP had greater understanding of the patient's preferences, and the patient felt comfortable with the PCP's plan.

> [...] I feel like with any other doctor, it would be like: 'You were just ready to go home, now all of a sudden I say this and you're not feeling well.' I think she knows that it's not just necessary that I'm not saying I'm not feeling well, I think she knows what I've told her already, why I like the blood transfusions, so she don't look at it like a ploy. (Female, CCP)

Theme 4: Patient experience of interaction with PCP during hospitalization

There was considerable variation between the two groups in interaction between the patient and PCP during hospitalization. Most standard care patients did not interact with their PCP during hospitalization.

> He usually gets the report after I'm out [...] I just go through whatever doctor sees me in the emergency room, and then they send to the floor (Female, standard care)

For the few patients who described interaction, some initiated, and some were contacted by their PCP. The form of PCP-patient interaction also varied. A few patients received in person-visits from their PCP and one talked with their PCP over the phone. Patients expressed positive feelings towards their PCP visiting them in the hospital. However, there was little elaboration about how and to what extent the PCP actively participated in their care during hospitalization.

For CCP patients, nearly all described frequent in-person interaction with their PCP during hospitalization. Most patients discussed their plan of care with the PCP. Half described making decisions with their PCP about treatment options or the timing of discharge.

> Mainly I talked to my Comprehensive doctor. She's like the main authority over all of that. They have to talk to her first, you know to see if I'm okay with leaving. She'll come ask me: 'How do you feel about leaving today?' If I say 'I don't feel like leaving,' she'll be like: 'You can stay an extra day,' and stuff like that, you know? (Male, CCP)

Theme 5: Patient experience of PCP interaction with hospital-based providers

There was also significant variation between the two groups in experience of interaction between the PCP and hospital providers. Only two standard care patients described being aware of interaction between their PCP and hospital providers, such as providing guidance to the inpatient care team. A few standard care patients openly expressed uncertainty and concern about whether their PCP was contacted during their hospitalization.

> I don't know for sure that they're calling him and letting him know or if he's getting the reports or any of that. I need to know that he's getting this information to know I'm there. (Female, standard care)

Among CCP patients, a majority described their PCP being in communication with other hospital providers. Several of these patients referred to the PCP as leader of their healthcare team in the hospital. Patients described their PCPs keeping specialists informed and interfacing with the other providers when the patient had a concern or conflict.

> She's my main doctor, so she makes sure everybody gets the email when I'm in the hospital. They'll know that: 'OK I gotta go see how he's doing, and see if I can give him any help for his pain or anything.' So that's the best thing I can ask for. That's probably why I switched from another hospital. Since I can just ask my Comprehensive Care anything wrong with me, she'll make sure that all my other doctors know too, so I ain't gotta be worrying about it, like my pain, or if I miss an appointment they'll all be informed that I'm in the hospital [...] (Male, CCP)

DISCUSSION

The main aim of this study was to explore frequently hospitalized patients' experiences and preferences related to PCP involvement during hospitalization. A unique contribution of this study was the qualitative comparison of perspectives of standard care patients who were cared for by hospitalists or housestaff teams to those of CCP patients being treated by their own PCP during hospitalization.

Both standard care and CCP patients expressed a preference for repeated interactions with their PCP over time to build a relationship and shared knowledge. While CCP patients described consistent relationships with their PCPs that benefited from shared experiences across inpatient and outpatient settings, many standard care patients described relational discontinuity with PCPs, which sometimes weakened these relationships. These results were consistent with prior research that patients prefer, and may benefit from, relational continuity of care with physicians,[20–23] and that patients' trust in their PCP was associated with the duration of their relationship.[24]

It is concerning that in this study of patients with frequent hospitalization and multiple chronic conditions, many in standard care may not experience the benefits of long-term relational continuity. Most of the patients experiencing discontinuity received care in a resident clinic characterized by frequent turnover. It is possible that the purposive sampling of this embedded qualitative study disproportionately selected for standard care patients with resident PCPs. Unfortunately, these patients' experiences with PCP discontinuity are not unique. Previous studies found that, as compared to patients with attending PCPs, patients with resident PCPs were more likely to have multiple health conditions, and be non-white, of low socioeconomic status, and on Medicare or Medicaid insurance.[25–29] Patients who transition care to a new resident reported challenges including missed tests and difficulty building a relationship with a new provider.[30] Patients may also experience PCP discontinuity due to the resident clinic schedule.[31]

A vast majority of patients in this study wanted their PCP to be involved during hospitalization, a preference consistent with previous findings.[9, 32] Despite the overall

preference for PCP involvement during hospitalization, few standard care patients described actual involvement of their PCP during hospitalization; when involved, the PCP role was usually limited to single visits or brief conversations with the patient or hospital providers. The finding that a majority of the standard care patients did not have interaction with their PCPs during hospitalization echoes previous research.[9, 10]

In contrast, consistent with the structure of the program, CCP patients described substantial involvement of their PCPs during hospitalization. A major contribution of this study was in highlighting the value of PCP involvement in the hospital setting through the lens of patients in CCP. Specifically, patients in CCP emphasized the PCP's role as a leader of their care team. Patients found it reassuring to have their PCP working to align the knowledge and goals of the various hospital providers. CCP patients expressed that shared trust with their PCP allowed for more patient involvement in care decisions due to greater patient comfort to voice disagreement, and PCP respect for the patient's input. As the CCP model is further developed and disseminated to other care settings, longitudinal relationships and direct patient engagement in the inpatient setting will be important components to uphold.

Inpatient-outpatient relational continuity is a component of other interdisciplinary programs for frequently hospitalized patients. The nature of team involvement in the inpatient setting varies. For instance, the University of Colorado intensive outpatient clinic team collaborates with hospital providers to develop care plans.[33] In the CareMore Health System, hospitalists treat high-risk patients for a limited duration across the transition from inpatient to rehabilitation or community settings.[34] Social workers in the

Northwestern University Complex High Admission Management Program provide continuity by rounding on their admitted patients.[35] It is unknown if and to what extent findings from this CCP study may translate to programs with inpatient-outpatient continuity involving a non-PCP provider, or inpatient involvement that is not direct care. Incorporating patient perceptions into evaluation plans for these interdisciplinary programs could refine our understanding of the nature of involvement needed.

In practice, it is uncommon for patients in the United States to be treated by their PCP while hospitalized. In a sample of 2013 Medicare data, PCPs cared for their own patient in only 14.2% of hospital admissions.[36] However, for frequently hospitalized patients, increasing PCP engagement in the inpatient setting may improve patient experiences, even if the PCP is not providing direct care. PCPs can use their relationship with the patient to help assess preferences and identify needs. This may benefit the patient by encouraging patient engagement in decision-making, strengthening the patient-PCP relationship, and improving interdisciplinary coordination across settings. To achieve this, a first challenge is ensuring that PCPs receive information when their patient is hospitalized.[37] Health care systems may also consider how to provide PCPs with time and compensation for communicating with their hospitalized patients and their inpatient care teams by phone or in-person visit.[38]

There are several limitations of the patient sample and analysis. First, patients recruited for the embedded qualitative study may have been a healthier and more engaged group than the overall study population. In the case of CCP patients, those with positive feelings towards the program may have been most likely to participate. Second, while all CCP

patients had attending physicians as PCPs, 67% of the standard care patients had resident physicians as PCPs. Although a limitation, it also reflects the reality that complex, vulnerable, patients who experience frequent hospitalizations often receive primary care from residents. Third, the exclusive focus on PCPs in the analysis is a limitation. CCP PCPs may share similar roles or characteristics with specialists or other providers who see patients across care settings.

CONCLUSION

In summary, this study was a valuable contribution to the existing literature on PCP involvement during hospitalization due to the qualitative comparison of perspectives of standard care and CCP patients. Specifically, the results suggested that for frequently hospitalized patients, active inpatient involvement by a consistent PCP with knowledge of the patient's health and personal preferences could improve patient experience with interdisciplinary coordination and engagement in care during hospitalization. For frequently hospitalized patients not being treated in the hospital by their PCP, future research is needed to clarify which forms of PCP engagement may be most likely to confer these benefits.

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Appendix A: Interview Guide

"We're going to talk for about 30 minutes about your last hospitalization at U Chicago, the people who worked with you then, and your primary care doctor. I'm particularly interested in your thoughts on how you talk with these people, how they talk with you, and how these conversations and relationships affect how you feel. I'm going to record this so I can remember accurately what you said. However, nothing you say will impact your care or your relationship with doctors here; I will be the only one who can connect you to the written record of the interview. You can choose not to answer any questions that make you uncomfortable. Shall we get started?"

Think back to your last hospitalization here at University of Chicago.

1) Why did you come to the hospital?

2) How did you feel about the care you received while you were in the hospital?

3) Can you describe your mood while you were in the hospital?

    a) What made you feel that way?

4) In general, how did you feel the conversations went with your medical team during your hospital stay?

    a) What kinds of things did your doctors and nurses talk with you about?

    b) Who talked with you most about your medical care, such as any treatments or tests that you would receive?

c) How well did you understand the doctor's plan for your care while you were in the hospital?

d) What did you want to happen as a result of your stay in the hospital?

i) How well did the medical team understand what you wanted?

5) I'd like to ask you some questions about how you and your medical team made decisions about your care while you were in the hospital. Think about one important decision that had to be made while you were in the hospital (for example, related to getting a test or procedure or starting a new medication).

a) Can you describe that situation to me?

b) Did your doctor present you with different options for your care? Can you tell me about them?

c) What was your understanding of the options?

d) How did you feel about the options?

e) How well do you think your doctors understood your opinion on these options?

f) Tell me about your involvement in making the decision.

g) How do you feel about this decision?

6) How was this visit similar to other times you may have been in the hospital before you joined the CCP study?

7) How was this visit different than other times you may have been in the hospital before you joined the CCP study?

8) When you were discharged from the hospital, what kind of instructions were you given on caring for yourself?

   a) How well did these instructions fit with your daily life?

   b) Who helped take care of you after your hospital stay? How well prepared was your family/caregiver to care for you after your hospital stay?

   c) Who was responsible for your follow-up care or for monitoring you or checking in with you to make sure that you were doing well after your hospital stay?

   d) How did you feel about the follow-up care you received?

   e) Tell me about how prepared [insert name of clinic doctor or staff] was to care for you after your hospital stay.

9) Do you have a primary care doctor?

   a) Can you describe your relationship with him or her?

   b) How do you feel overall about your primary care doctor?

      i) What do you appreciate most about your primary care doctor?

ii) If there was one thing you would change about your primary care doctor, what would it be?

c) How do you feel about your conversations with him or her? Are there differences in the way you talk with your primary care doctor, compared with your discussions with your doctors in the hospital?

d) When you are in the hospital, do you typically stay in touch with your primary care doctor? Tell me more about that.

e) What role, if any, do you think your primary care doctor should have in your care while you are in the hospital?

PROTOCOL – JANUARY 2019

Background

Before the mid-1990s, primary care providers (PCPs) generally were responsible for coordinating care of their hospitalized patients. Since that time, hospitalists—specialists in inpatient care—have significantly increased within the US healthcare system (1). The shift in care model was motivated by factors including increased hospitalist efficiency, availability, and specialization (1). For instance, a randomized controlled trial (conducted 1997-1999) found that patients of hospitalists had reduced healthcare costs and lower thirty and sixty-day mortalities (2). The study suggested that this was largely mediated by the hospitalists' expertise in managing common inpatient conditions (2).

Despite such advantages, critics of the hospitalist model are concerned that patient care suffers due to fragmentation of care (1). A previous study identified significant discrepancies between the knowledge patients had of their own medical conditions and the knowledge patients' hospital physicians perceived that patients had (3). On the day of discharge, only 57% of patients correctly named their diagnosis (3). Additionally, only 10% of patients recalled being told of medication side effects (3). The lack of an established rapport between patients and physicians may also contribute to communication barriers. A PCP, based on their prior discussions with a patient, likely has greater knowledge of family context, values, communication style, and care preferences (4). Particularly for patients with complex needs, such dimensions of care can greatly impact medical decision making.

The Comprehensive Care Program (CCP) at University of Chicago Medicine (UCM) is a randomized controlled trial assessing the benefit of an interdisciplinary care team for patients with high risk of hospitalization. The teams are led by physicians who care for their panel of patients across both inpatient and ambulatory settings (5). Broadly, the CCP aims to compare the healthcare costs, outcomes, and experiences of patients in CCP versus usual care. A sub-study of this project uses qualitative interviews to better understand patient experiences with communication and decision-making during hospitalization.

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Specific Aims:

1. Explore patient experiences with communication and decision-making during hospitalization specifically surrounding trust, understanding, and alliance of goals between physician and patient.
2. Describe patient experiences and preferences on the role of their primary care provider during hospitalization.
3. Compare patient experiences in the CCP and standard care across these themes.

Hypothesis

We hypothesize that frequently hospitalized patients will describe limited involvement of their Primary Care Provider (PCP) during hospitalization as well as barriers to communication with their inpatient care team. Themes may include concerns about inpatient provider knowledge of values, context, and care preferences. In comparison, we hypothesize that patients seen by a Comprehensive Care Physician while hospitalized will describe trust, a valued interpersonal relationship, and established communication style with their physician. This is a qualitative, exploratory project, and we will be open to additional themes in the data as they emerge.

Methods

Participant Selection

The CCP study recruited from the population of Medicare Part A and B enrollees with at least one hospitalization at UCM within the previous twelve months. Patients randomized to the control group receive standard of care: as inpatients they are treated by hospitalists and as outpatients are treated by a separate primary care physician. Patients randomized to the experimental group are cared for by a team made up of a CCP internal medicine physician, social workers, and nurses. The CCP physicians have smaller patient panels and, accordingly, are able to allocate more time to each individual and coordinate care in both inpatient and outpatient settings.

The participants for the qualitative sub-study were drawn from the broader CCP study. Eligible patients had at least three hospitalizations within the previous twelve months (based on self-report during quarterly phone surveys), with their most recent hospitalization occurring at UCM. For experimental group patients, medical records were also screened to confirm that they were seen by their assigned CCP physician during the most recent hospitalization. Patients in the experimental and control groups were invited to participate by phone or in-person visit.

Data Collection

Semi-structured interviews, approximately a half hour in length, were conducted in-person at UCM. The semi-structured interview guide was developed collaboratively by the

interdisciplinary research team and incorporated feedback of three CCP program patients. Ten interviews were conducted with control group patients and ten with experimental group patients. Patients were asked for verbal consent for the interview and the audio recording of the interview (IRB12-1440). At the conclusion of the interview, patients received a $30 gift card. The interviews were transcribed and, in order to maintain confidentiality, the interview audio was deleted. Identifiable personal data in the transcripts was redacted. Patient characteristics including sex, age, and healthcare utilization were collected and summarized.

Data Analysis

The interview transcripts will be analyzed using template analysis, a methodology coined by Crabtree & Miller (1992) (1). Two researchers will separately review three interview transcripts in order to identify possible themes. The researchers will then discuss in order to reach consensus on the preliminary "template," a hierarchical organization of the identified themes (2). The initial template will be used to code the remaining seven transcripts on the NVivo software. Through an iterative process, additional themes may be added to the template as they arise from the transcripts. After the template is finalized, salient themes will be identified based on review and discussion of codes. These themes will be described, and representative quotes will be selected.

In order to identify similarities and differences in the experiences of the experimental and control group patients, matrix analysis will be performed using the NVivo software. Matrix analysis involves the generation of tables to compare the two groups. As a check on the validity of the analysis, several participants in the CCP study will be asked to provide feedback on the results.

Overall, this qualitative approach will allow for exploration of patient experiences and attitudes. The openness of this method can lead to identification of new theories and hypotheses.

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Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

	Page/line no(s).
Title and abstract	
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	pg. 1, line 1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	pg. 2, line 1
Introduction	
Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	pg. 5, line 19
Purpose or research question - Purpose of the study and specific objectives or questions	pg. 6, line 3
Methods	
Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	pg. 8, line 15
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	pg. 7, line 17 pg. 8, line 8 pg. 8, line 18 pg. 9, line 7
Context - Setting/site and salient contextual factors; rationale**	pg. 6, line 5 pg. 6, line 14
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	pg. 7, line 8
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	pg. 8, line 9 pg. 8, line 13
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	pg. 8, line 7 pg. 9, line 10

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	pg. 7, line 17 pg. 8, line 14
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	pg. 9, line 15
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	pg. 8, line 14
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	pg. 8, line 15
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	pg. 9, line 11

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	pgs. 9-18
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	pgs. 9-18

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	pgs. 18-21
Limitations - Trustworthiness and limitations of findings	pg. 20, line 1

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	pg. 22, line 9
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	pg. 22, line 1

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
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Primary Care Physician Involvement During Hospitalization: a Qualitative Analysis of Perspectives from Frequently Hospitalized Patients

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ABSTRACT

Objective: To explore frequently hospitalized patients' experiences and preferences related to primary care physician (PCP) involvement during hospitalization across two care models.

Design: Qualitative study embedded within a randomized controlled trial. Semi-structured interviews were conducted with patients. Transcripts were analyzed using qualitative template analysis.

Setting: In the Comprehensive Care Program (CCP) Study, in Illinois, USA, Medicare patients at increased risk of hospitalization are randomly assigned to: 1) care by a comprehensive care program physician who serves as a primary care physician (PCP) across both inpatient and outpatient settings; or 2) care by a PCP as outpatient and by hospitalists as inpatients (standard care).

Participants: Twelve standard care and 12 CCP patients were interviewed.

Results: Themes included: 1. Positive attitude towards PCP; 2. Longitudinal continuity with PCP valued; 3. Patient preference for PCP involvement in hospital care; 4. Potential for in-depth involvement of PCP during hospitalization often unrealized (involvement rare in standard care;

in CCP, frequent interaction with PCP fostered patient involvement in decision making); 5. PCP collaboration with hospital-based providers frequently absent (no interaction for standard care patients; CCP patients emphasizing PCP's role in interdisciplinary coordination).

Conclusion: Frequently hospitalized patients value PCP involvement in the hospital setting. CCP patients highlighted how an established relationship with their PCP improved inter-disciplinary coordination and engagement with decision-making. Inpatient-outpatient relational continuity may be an important component of programs for frequently hospitalized patients. Opportunities for enhancing PCP involvement during hospitalization should be considered.

Article summary

Strengths and limitations of this study

- This study provided a unique context within a RCT with one group of patients cared for by hospitalists and one group cared for by their PCP during hospitalization
- This study's qualitative approach allowed for a rich exploration of patients' experiences and preferences related to PCP involvement in hospitalization
- Self-selection bias is a possible limitation - patients recruited for the embedded qualitative study may have been a healthier and more engaged group than the overall study population
- This study was conducted at an academic medical center; experiences of the standard care group reflect the context of receiving care from trainees

INTRODUCTION

Before the mid-1990s, primary care physicians (PCPs) in the United States (U.S.) typically oversaw care for their own patients when they were hospitalized. Since that time, the number of hospitalists has significantly increased within the U.S.[1] This shift in care delivery model was motivated by perceptions about increased hospitalist efficiency, availability, specialized expertise, and possible cost and mortality reductions.[1, 2] Despite such advantages, the hospitalist model may increase fragmentation between inpatient and outpatient care, particularly for patients who are frequently hospitalized.[1] Previous studies found that hospitalized patients frequently had limited knowledge about their diagnosis, care plan, or post-discharge instructions.[3–5] Other studies identified discrepancies between hospitalized patients and their inpatient physicians in perceived goals of care,[6] and limited opportunities for shared decision-making.[3, 7, 8] A possible contributing factor to these communication barriers is lack of an established relationship between hospitalized patients and their inpatient physicians. In comparison, PCPs with whom patients have ongoing relationships often have intimate knowledge of patients' preferred communication style, values, family context, and care preferences, but infrequently communicate directly with patients during hospitalization.[9–11]

Communication between PCPs and inpatient providers during hospitalization may also be limited in frequency and scope.[12, 13]

Particularly for patients with complex needs, PCP involvement during hospitalization may greatly impact patient experience due to their familiarity with their patients' complex health history and established relationship with patients. However, few studies directly compare the hospitalization experiences of patients cared for by their PCP versus by hospitalists. These are limited to quantitative comparisons related to satisfaction.[14, 15] There is a need for qualitative patient perspectives on the role of a PCP in the hospital setting.

We conducted a qualitative study of frequently hospitalized patients' experiences and preferences related to PCP involvement during hospitalization. This qualitative study was embedded within a larger randomized controlled trial, the Comprehensive Care Program (CCP) Study. Patients at increased risk of hospitalization are randomly assigned to one of 2 care models: 1) a CCP physician who serves as both the outpatient PCP and hospital attending (intervention arm) or 2) outpatient care from a PCP and hospital care from hospitalists (standard care).[16] This study context provides a unique opportunity to explore and compare the

experiences and preferences surrounding PCP involvement during hospitalization between patients cared for by hospitalists as compared with a patient's own PCP.

METHODS

Setting

The CCP study at the University of Chicago Medicine (UCM) is a randomized controlled trial assessing the effect of an interdisciplinary care team for patients at high risk of hospitalization. The overall CCP study recruited Medicare Part A and B enrollees with at least one hospitalization at UCM within the previous twelve months. Patients randomized to the intervention group were cared for by PCPs with limited panels of approximately 200 patients to enable them to care for their patients as the primary attending in both inpatient and outpatient settings. As outpatients, the patients also receive care from a social worker, two nurses, and a clinic coordinator. Patients randomized to the control group received "standard of care," which included following with their prior PCP (or were offered assistance in obtaining one if they did not have one) and being treated by hospitalist physicians if admitted to UCM.[16]

The broader CCP study compares clinical outcomes, health care costs, and experiences of patients in CCP versus standard care.[16] This embedded study used qualitative interviews with a subset of both CCP and standard care patients to better understand and compare patients' experiences and preferences surrounding the role of their PCP during hospitalization.

Participant selection

The participants for the embedded qualitative study were drawn from the broader CCP study. Additional inclusion criteria included, participation in the CCP study for at least one year, and having at least three hospitalizations within the previous twelve months (based on self-report during quarterly phone surveys), with the most recent hospitalization occurring at UCM. For intervention group patients, medical records were screened to confirm that their assigned CCP physician served as their primary attending during the most recent hospitalization. Patients were recruited by a research assistant or medical student in-person or by phone between July 2017 and August 2018. Recruitment continued until data saturation was reached.

Development of interview guide

The semi-structured interview guide was developed by an interdisciplinary team including a CCP physician (JT), a medical student without ties to CCP (JK), a CCP social worker (NG), and a research assistant without ties to CCP (JH). Two members of the team (JT, JH) had prior experience in qualitative research methods. The interview guide was further modified after review by three patients in the intervention arm of the CCP study. The final interview guide (Appendix A) focused on patients' care experiences during and after their most recent hospitalization at UCM, with an emphasis on: 1) communication with physicians and nurses in the hospital setting, particularly surrounding goals of the hospitalization and decision-making; 2) post-discharge care; and 3) relationship with their PCP and their PCP's role during hospitalization.

Data collection

Semi-structured interviews, approximately 30 minutes in length, were conducted in-person at UCM by a medical student and a research assistant, neither with ties to CCP (JK or AK). Patients provided verbal consent for the interview and received a $30 gift card for participation. All patients had previously provided written consent for the broader CCP study. Patient characteristics including sex, age, and healthcare utilization were collected from the medical

record. This study received approval from the University of Chicago Institutional Review Board (IRB12-1440).

Data analysis

The interviews were digitally recorded and transcribed by the research team; identifiable personal data were redacted. The interview transcripts were analyzed using template analysis, a methodology developed by Crabtree & Miller.[17] Template analysis was selected as a systematic yet flexible methodology that lends itself to analysis across the two groups of subjects. The qualitative analysis team (JT, ER, JK) was composed of one CCP physician and two medical students. The three team members separately reviewed five interview transcripts (3 control group; 2 CCP group) and engaged in discussions to develop a preliminary "template" (coding guide), a hierarchical organization of the identified themes.[18] Some codes were identified inductively and others were rooted in the interview guide questions. Through an iterative process, additional codes were added to the template as they arose from the five sample transcripts. The three team members then applied the initial template to code the transcripts using NVivo 11 (QRS International) software. Two coders reviewed each of the twenty-four transcripts. During analysis, the team met weekly to resolve discrepancies in coding through

discussion, and to revise the template. After the template was finalized, themes were developed through repeated review of codes and discussion. These themes were described, and representative quotes were selected and agreed upon by the entire research team. The qualitative analysis team practiced reflexivity through open communication about their preconceptions and how their roles in patient care relate to their perspective.[19]

Patient and public involvement

Three CCP patients provided feedback on the interview guide during development. As a check on the validity of the analysis, results were reviewed and discussed with the CCP study patient and community advisory board and with CCP physicians, team members, and administrators.

RESULTS

Patient sample

Twenty-four interviews were conducted, 12 with CCP patients and 12 with standard care patients. Patient characteristics are shown in Table 1.

Table 1. Participant characteristics.

Characteristics	All patients (n=24)	Standard care patients (n=12)	Comprehensive Care Program patients (n=12)
Age in years[a] [mean (standard deviation)]	53 (14)	57 (15)	49 (11)
Female [n (%)]	12 (50)	6 (50)	6 (50)
Years since CCP study enrollment[a] [mean (standard deviation)]	2.7 (1.2)	2.7 (1.3)	2.7 (1.1)
Chronic medical conditions [n (%)]			
Heart failure	11 (46)	7 (58)	4 (33)
Coronary artery disease	6 (25)	4 (33)	2 (17)
Diabetes	11 (46)	7 (58)	4 (33)
End-stage renal disease	10 (42)	5 (42)	5 (42)
Chronic lung disease[b]	8 (33)	7 (58)	1 (8)
Cancer	2 (8)	1 (8)	1 (8)
Rheumatologic disease[c]	2 (8)	0	2 (17)
Other[d]	2 (8)	1 (8)	1 (8)

[a] At time of interview.

[b] Chronic obstructive pulmonary disease, Asthma, Interstitial lung disease, Pulmonary arterial hypertension, Cystic fibrosis.

[c] Scleroderma, Crohn's disease.

[d] Sickle cell disease, Spina bifida.

For CCP and standard care groups combined, 50% were female and the average age was 53 years. Patients had been enrolled in the CCP study for an average of 2.7 years at the time of interview. All patients had two or more chronic medical conditions. Of the standard care patients, 67% received primary care from internal medicine resident physicians; all CCP patients were cared for by attending physicians.

Theme 1: Positive attitude towards PCP

Themes and additional quotes from interviews are summarized in Table 2.

Patient is comfortable talking with their PCP

A majority of CCP patients and a few standard care patients described feeling comfortable conversing with their PCP. Patients in both groups valued that their PCP listened to what they said. Several CCP patients, but only a few of the standard care patients, thought discussions were better with their PCP than with hospital providers. A common perception was that the patient could speak more openly with their PCP.

> It's good because I can openly talk to him and not be afraid to tell him if something is not going right. (Female, standard care)

Several CCP patients also described engaging with their PCP about topics outside of medicine, including challenging social issues.

> You want to be straight up with your primary about things. You want to tell him everything, what's giving you problems. Well my wounds are giving me problems, do you have any other issues? And you tell him: well depression issues, housing issues. (Male, CCP)

PCP is caring towards patient

Across CCP and standard care, several patients expressed that they felt cared for by their PCP. Patients appreciated that the PCP was concerned about their health and that the physician offered their time and attention.

> She sits and talks to me, she [...] connects with me, you know. Not just like business type thing, but a family type thing. (Male, CCP)

Shared trust between patient and PCP

Half of CCP patients, but none of the standard care patients, mentioned shared trust with their PCP. In several instances, CCP patients stated that their PCP trusted them to make their own decisions about care. Participants also described an increased level of trust in their CCP's judgment over time.

> See we have this really good relationship, and she knows that I am an informed patient. I know my body and I can pretty much tell her more than she can tell me about my body, and so she trusts me the same way I trust her. (Female, CCP)

Table 2. Themes and exemplary quotes across standard care and Comprehensive Care Program groups.

Theme	Standard care patients (n=12)	Comprehensive Care Program patients (n=12)
1. Positive attitude towards PCP	Valued comfort communicating with PCP, and PCP compassion. CCP patients additionally reported shared trust.	*I was able to talk with [PCP], he was able to talk with me, and we were comfortable speaking with each other…I'm going through this, and he's like: 'I understand what you're going through, we're going to do this, this, and this.' (Male, standard care)*
		…[PCP] lets me know that 'everything's going to be okay, I've got you. If there's anything you need, if you feel like you have any problems, just let me know.'…you need that on your team sometimes. (Male, CCP)

2. Longitudinal continuity with PCP valued	Experienced frequent turnover of PCP *I usually prefer not to see the residents…I've got a long life-history as far as medical stuff, and if I have to go through it every two years it's not worth it to me. (Female, standard care)*	Described longitudinal relationships with their PCP which improved over time *We've known each other a little while now, because I was going through doctors: some come some go. But I've been with Dr. PCP here for a minute now, so I try to assess everything I can do. Let her know everything about me, so I won't be uncomfortable with her and she won't be uncomfortable with me. So when I do get in a situation like I'm hurting, I'm in pain, my anxiety, she'll know straight up what's going on. She can assess it right then and there the best way she can. (Male, CCP)*
3. Patient preference for PCP involvement in hospital care	Majority preferred some contact with PCP during hospitalization *I think the team should go back to the primary care and say: 'This is what we're doing. Do you have any suggestions for*	Preferred inpatient treatment by PCP due to shared trust and their prior knowledge of the patient *…it's just a comfortable feeling…When I'm admitted into the hospital I feel like they're my*

	us?' Because they know your health better than the new people. (Male, standard care)	*security. You get what I'm saying? Like they have my back. If something goes wrong, even if they're not there in the moment, it's only a matter of time before they get there and whatever's the issue, I know I'm going to be treated fairly. (Female, CCP)*
4. Potential for in-depth involvement of PCP during hospitalization often unrealized	Most did not interact with their PCP during hospitalization *Check on me, talk to me, say something. But they don't. (Male, standard care)*	Described active involvement of their PCP in decision-making *I took [the PCP's] advice and took the option that she give first as opposed to plan B, plan C, whatever, because she informed me and worked with me and knows my health and how the medication will affect me and what I need to do. (Male, CCP)*
5. PCP collaboration with hospital-based providers frequently absent	Most were not aware of interaction between PCP and hospital providers *No particular role…while I'm in the hospital, [the PCP] can communicate with doctors if*	Emphasized PCP's role aligning the knowledge and goals of various providers *The people when you come into the hospital: they don't know you…It*

	they needed to communicate with him. (Female, standard care)	*takes Dr. PCP and the doctors to get together and communicate with each other. Because he knows me and he knows what I went through– and he went through all that with me –he can communicate with the doctors and tell the doctors about me. With what he knows and what we've been dealing with with my medications…they can give me the better care. (Female, CCP)*

PCP, primary care physician.

Theme 2: Longitudinal continuity with PCP valued

Many standard care and CCP patients emphasized that it takes time to build a relationship with a PCP. A majority of standard care participants described discontinuity with their PCPs. A few patients attributed the frequent changes to receiving primary care from residents who graduated and transitioned their patients to new trainees.

> [...] this'll be my 4th primary care doctor in 10 years. But, you know, you guys do your 2 or 3 year residency, then you're off [...] But at some point you've got to learn, like what you're doing with me. (Male, standard care)

In comparison, CCP patients experienced greater relational continuity with their physician. A majority of CCP patients mentioned that the relationship with their CCP physician improved over time as they got to know each other. Two participants described a difficult start that morphed into a positive relationship.

> Once you get to know a person it gets better because you know the first couple of times it's not going to be smooth sailing. (Male, CCP)

Theme 3: Patient preference for PCP involvement in hospital care

A majority of standard care patients and nearly all CCP patients stated that their PCP should be involved during hospitalization. However, there was variation in the preferred form of involvement. A majority of standard care patients thought that ideally a PCP would remain in communication with their patient during hospitalization.

It shows they care, they're concerned about my being, my health. And that's a good thing. (Female, standard care)

Patients commonly preferred that this interaction be in person, with a few specifically stating that they would prefer to be treated by their PCP while in the hospital. A few standard care patients noted that their PCP could have been able to offer emotional support during hospitalization.

[…] he probably could have informed me and let me know more about what was going on, and I would have had less anxiety. I would have felt more relieved. (Male, standard care)

Further, a few standard care patients thought that a PCP should remain in communication with the patient's care team during hospitalization. PCP involvement was considered beneficial due to their prior knowledge of the patient's health conditions.

I don't think he should just be in the office all the time. I think he should know about me being in the hospital and why and help me to maintain my health. I mean, these other doctors, they don't really see me that much. They don't know much about me. They just know what I come in and I complain about, and then they fix that and then they send me

> on my way? What if I have another issue that they're not aware of that my primary care doctor is aware of? (Female, standard care)

On the other hand, some standard care patients stated that they chose not to reach out to their PCP during hospitalization due to lack of a relationship with their PCP. Others shared that they had no expectation of PCP involvement during hospitalization. These patients thought it was sufficient for the PCP to view records following discharge or answer questions if contacted by the hospital team.

> I just concentrate on the doctors at hand, and I know that they're making notes so he see it on the chart. I don't have it where I can text him and let him know each time I'm in the hospital […] So, by the time I see him, I'm quite sure there's a flag somewhere to let him know I've been in the hospital, and he can read the chart and see that I've been in the hospital so. (Female, standard care)

Among CCP patients, all described a preference to be treated by their PCP in the hospital setting. For several, a PCP's knowledge about their health and personal preferences was thought to expedite care and improve adherence to previously developed plans.

> Besides my opinion, she should be able to make the decision. She should be the one running stuff. Should no other doctor be running nothing or make no decisions because you don't know me. (Female, CCP)

A few CCP patients also pointed to the shared trust with their PCP. Due to previous hospitalizations or office visits patients perceived that the PCP had greater understanding of the patient's preferences, and the patient felt comfortable with the PCP's plan.

> […] I feel like with any other doctor, it would be like: 'You were just ready to go home, now all of a sudden I say this and you're not feeling well.' I think she knows that it's not just necessary that I'm not saying I'm not feeling well, I think she knows what I've told her already, why I like the blood transfusions, so she don't look at it like a ploy. (Female, CCP)

Theme 4: Potential for in-depth involvement of PCP during hospitalization often unrealized

There was considerable variation between the two groups in interaction between the patient and PCP during hospitalization. Most standard care patients did not interact with their PCP during hospitalization.

He usually gets the report after I'm out [...] I just go through whatever doctor sees me in the emergency room, and then they send to the floor. (Female, standard care)

For the few patients who described interaction, some initiated, and some were contacted by their PCP. The form of PCP-patient interaction also varied. A few patients received in person-visits from their PCP and one talked with their PCP over the phone. Patients expressed positive feelings towards their PCP visiting them in the hospital. However, there was little elaboration about how and to what extent the PCP actively participated in their care during hospitalization.

For CCP patients, nearly all described frequent in-person interaction with their PCP during hospitalization. Most patients discussed their plan of care with the PCP. Half described making decisions with their PCP about treatment options or the timing of discharge.

Mainly I talked to my Comprehensive doctor. She's like the main authority over all of that. They have to talk to her first, you know to see if I'm okay with leaving. She'll come ask me: 'How do you feel about leaving today?' If I say 'I don't feel like leaving,' she'll be like: 'You can stay an extra day,' […] (Male, CCP)

Theme 5: PCP collaboration with hospital-based providers frequently absent

There was also significant variation between the two groups in experience of interaction between the PCP and hospital providers. Only two standard care patients described being aware of interaction between their PCP and hospital providers, such as providing guidance to the inpatient care team. A few standard care patients openly expressed uncertainty and concern about whether their PCP was contacted during their hospitalization.

> I don't know for sure that they're calling him and letting him know or if he's getting the reports or any of that. I need to know that he's getting this information to know I'm there. (Female, standard care)

Among CCP patients, a majority described their PCP being in communication with other hospital providers. Several of these patients referred to the PCP as leader of their healthcare team in the hospital. Patients described their PCPs keeping specialists informed and interfacing with the other providers when the patient had a concern or conflict.

> She's my main doctor, so she makes sure everybody gets the email when I'm in the hospital. They'll know that: 'OK I gotta go see how he's doing, and see if I can give him any help for his pain or anything.' So that's the best thing I can ask for. That's probably

> why I switched from another hospital. Since I can just ask my Comprehensive Care anything wrong with me, she'll make sure that all my other doctors know too, so I ain't gotta be worrying about it, like my pain, or if I miss an appointment they'll all be informed that I'm in the hospital […] (Male, CCP)

DISCUSSION

The main aim of this study was to explore frequently hospitalized patients' experiences and preferences related to PCP involvement during hospitalization. A unique contribution of this study was the qualitative comparison of perspectives of standard care patients who were cared for by hospitalists or housestaff teams to those of CCP patients being treated by their own PCP during hospitalization.

Both standard care and CCP patients expressed a preference for repeated interactions with their PCP over time to build a relationship and shared knowledge. While CCP patients described consistent relationships with their PCPs that benefited from shared experiences across inpatient and outpatient settings, many standard care patients described relational discontinuity with PCPs, which sometimes weakened these relationships. These results were consistent with prior research

that patients prefer, and may benefit from, relational continuity of care with physicians,[20–23] and that patients' trust in their PCP was associated with the duration of their relationship.[24]

It is concerning that in this study of patients with frequent hospitalization and multiple chronic conditions, many in standard care may not experience the benefits of long-term relational continuity. Most of the patients experiencing discontinuity received care in a resident clinic characterized by frequent turnover. It is possible that the purposive sampling of this embedded qualitative study disproportionately selected for standard care patients with resident PCPs. Unfortunately, these patients' experiences with PCP discontinuity are not unique. Previous studies found that, as compared to patients with attending PCPs, patients with resident PCPs were more likely to have multiple health conditions, and be non-white, of low socioeconomic status, and on Medicare or Medicaid insurance.[25–29] Patients who transition care to a new resident reported challenges including missed tests and difficulty building a relationship with a new provider.[30] Patients may also experience PCP discontinuity due to the resident clinic schedule.[31]

A vast majority of patients in this study wanted their PCP to be involved during hospitalization, a preference consistent with previous findings.[9, 32] Despite the overall preference for PCP

involvement during hospitalization, few standard care patients described actual involvement of their PCP during hospitalization; when involved, the PCP role was usually limited to single visits or brief conversations with the patient or hospital providers. The finding that a majority of the standard care patients did not have interaction with their PCPs during hospitalization echoes previous research.[9, 10]

In contrast, consistent with the structure of the program, CCP patients described substantial involvement of their PCPs during hospitalization. A major contribution of this study was in highlighting the value of PCP involvement in the hospital setting through the lens of patients in CCP. Specifically, patients in CCP emphasized the PCP's role as a leader of their care team. Patients found it reassuring to have their PCP working to align the knowledge and goals of the various hospital providers. CCP patients expressed that shared trust with their PCP allowed for more patient involvement in care decisions due to greater patient comfort to voice disagreement, and PCP respect for the patient's input. As the CCP model is further developed and disseminated to other care settings, longitudinal relationships and direct patient engagement in the inpatient setting will be important components to uphold.

Inpatient-outpatient relational continuity is a component of other interdisciplinary programs for frequently hospitalized patients. The nature of team involvement in the inpatient setting varies. For instance, the University of Colorado intensive outpatient clinic team collaborates with hospital providers to develop care plans.[33] In the CareMore Health System, hospitalists treat high-risk patients for a limited duration across the transition from inpatient to rehabilitation or community settings.[34] Social workers in the Northwestern University Complex High Admission Management Program provide continuity by rounding on their admitted patients.[35] It is unknown if and to what extent findings from this CCP study may translate to programs with inpatient-outpatient continuity involving a non-PCP provider, or inpatient involvement that is not direct care. Incorporating patient perceptions into evaluation plans for these interdisciplinary programs could refine our understanding of the nature of involvement needed.

In practice, it is uncommon for patients in the United States to be treated by their PCP while hospitalized. In a sample of 2013 Medicare data, PCPs cared for their own patient in only 14.2% of hospital admissions.[36] However, for frequently hospitalized patients, increasing PCP engagement in the inpatient setting may improve patient experiences, even if the PCP is not providing direct care. PCPs can use their relationship with the patient to help assess preferences

and identify needs. This may benefit the patient by encouraging patient engagement in decision-making, strengthening the patient-PCP relationship, and improving interdisciplinary coordination across settings. To achieve this, a first challenge is ensuring that PCPs receive information when their patient is hospitalized.[37] Health care systems may also consider how to provide PCPs with time and compensation for communicating with their hospitalized patients and their inpatient care teams by phone or in-person visit.[38]

There are several limitations of the patient sample and analysis. First, patients recruited for the embedded qualitative study may have been a healthier and more engaged group than the overall study population. In the case of CCP patients, those with positive feelings towards the program may have been most likely to participate. Second, while all CCP patients had attending physicians as PCPs, 67% of the standard care patients had resident physicians as PCPs. Although a limitation, it also reflects the reality that complex, vulnerable, patients who experience frequent hospitalizations often receive primary care from residents. Third, the exclusive focus on PCPs in the analysis is a limitation. CCP PCPs may share similar roles or characteristics with specialists or other providers who see patients across care settings.

CONCLUSION

In summary, this study was a valuable contribution to the existing literature on PCP involvement during hospitalization due to the qualitative comparison of perspectives of standard care and CCP patients. Specifically, the results suggested that for frequently hospitalized patients, active inpatient involvement by a consistent PCP with knowledge of the patient's health and personal preferences could improve patient experience with interdisciplinary coordination and engagement in care during hospitalization. For frequently hospitalized patients not being treated in the hospital by their PCP, future research is needed to clarify which forms of PCP engagement may be most likely to confer these benefits.

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Appendix A: Interview Guide

"We're going to talk for about 30 minutes about your last hospitalization at U Chicago, the people who worked with you then, and your primary care doctor. I'm particularly interested in your thoughts on how you talk with these people, how they talk with you, and how these conversations and relationships affect how you feel. I'm going to record this so I can remember accurately what you said. However, nothing you say will impact your care or your relationship with doctors here; I will be the only one who can connect you to the written record of the interview. You can choose not to answer any questions that make you uncomfortable. Shall we get started?"

Think back to your last hospitalization here at University of Chicago.

1) Why did you come to the hospital?

2) How did you feel about the care you received while you were in the hospital?

3) Can you describe your mood while you were in the hospital?

a) What made you feel that way?

4) In general, how did you feel the conversations went with your medical team during your hospital stay?

a) What kinds of things did your doctors and nurses talk with you about?

b) Who talked with you most about your medical care, such as any treatments or tests that you would receive?

c) How well did you understand the doctor's plan for your care while you were in the hospital?

d) What did you want to happen as a result of your stay in the hospital?

i) How well did the medical team understand what you wanted?

5) I'd like to ask you some questions about how you and your medical team made decisions about your care while you were in the hospital. Think about one important decision that had to be made while you were in the hospital (for example, related to getting a test or procedure or starting a new medication).

a) Can you describe that situation to me?

b) Did your doctor present you with different options for your care? Can you tell me about them?

c) What was your understanding of the options?

d) How did you feel about the options?

e) How well do you think your doctors understood your opinion on these options?

f) Tell me about your involvement in making the decision.

g) How do you feel about this decision?

6) How was this visit similar to other times you may have been in the hospital before you joined the CCP study?

7) How was this visit different than other times you may have been in the hospital before you joined the CCP study?

8) When you were discharged from the hospital, what kind of instructions were you given on caring for yourself?

a) How well did these instructions fit with your daily life?

b) Who helped take care of you after your hospital stay? How well prepared was your family/caregiver to care for you after your hospital stay?

c) Who was responsible for your follow-up care or for monitoring you or checking in with you to make sure that you were doing well after your hospital stay?

d) How did you feel about the follow-up care you received?

e) Tell me about how prepared [insert name of clinic doctor or staff] was to care for you after your hospital stay.

9) Do you have a primary care doctor?

a) Can you describe your relationship with him or her?

b) How do you feel overall about your primary care doctor?

i) What do you appreciate most about your primary care doctor?

ii) If there was one thing you would change about your primary care doctor, what would it be?

c) How do you feel about your conversations with him or her? Are there differences in the way you talk with your primary care doctor, compared with your discussions with your doctors in the hospital?

d) When you are in the hospital, do you typically stay in touch with your primary care doctor? Tell me more about that.

e) What role, if any, do you think your primary care doctor should have in your care while you are in the hospital?

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

	Page/line no(s).
Title and abstract	
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	pg. 1, line 1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	pg. 2, line 1
Introduction	
Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	pg. 5, line 19
Purpose or research question - Purpose of the study and specific objectives or questions	pg. 6, line 3
Methods	
Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	pg. 8, line 15
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	pg. 7, line 17 pg. 8, line 8 pg. 8, line 18 pg. 9, line 7
Context - Setting/site and salient contextual factors; rationale**	pg. 6, line 5 pg. 6, line 14
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	pg. 7, line 8
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	pg. 8, line 9 pg. 8, line 13
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	pg. 8, line 7 pg. 9, line 10

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	pg. 7, line 17 pg. 8, line 14
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	pg. 9, line 15
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	pg. 8, line 14
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	pg. 8, line 15
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	pg. 9, line 11

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	pgs. 9-18
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	pgs. 9-18

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	pgs. 18-21
Limitations - Trustworthiness and limitations of findings	pg. 20, line 1

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	pg. 22, line 9
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	pg. 22, line 1

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
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