

Identifying sources of patient dissatisfaction when seeking care for a chronic and complex disease

Katharine J. Head, *IUPUI*, headkj@iupui.edu

Anna K. Forster, *Indiana University*, akforste@iu.edu

Amanda Harsin, *Ivy Tech Community College*, aharsin1@ivytech.edu

Rebecca J. Bartlett Ellis, *Indiana University*, rjbartle@iu.edu

Abstract

Patients' evaluations of healthcare often rely on patient satisfaction and encounter-specific approaches. Instead, valuable information can be gained by focusing on patient *dissatisfaction* with healthcare over time. This study examined patients' sources of care dissatisfaction when seeking healthcare for a long-term chronic and complex disease (CCD). Participants with a CCD called polycystic kidney disease ($N=387$) completed an online questionnaire with an open-ended question about dissatisfying experiences. Content analysis was used to analyze responses. The coded data resulted in conceptual codes related to dissatisfaction with information, support, and care management. Analysis revealed the type of healthcare provider is often mentioned, and that more than one type of dissatisfaction can occur at the same time. Patients with CCDs are experiencing a variety of types of dissatisfaction when seeking healthcare, which may point to ongoing communication gaps between patients and the healthcare providers they see over time for their disease. Providers who see patients with CCDs should remember these patients may see multiple providers over time and have unique support needs. Providers can potentially improve care experiences by helping patients manage their care across both providers and experiences, as well as encourage patients to ask questions and express their concerns.

Keywords

Patient dissatisfaction, patient-provider communication, chronic disease management, content analysis.

Introduction

Patient satisfaction is an important and often studied area of the patient healthcare experience. Patient satisfaction is defined as a patient's affective response to received healthcare and is often used as a proxy for measuring the quality of healthcare; furthermore, it has been linked with better adherence to provider recommendations and in some cases, actual health outcome.^{1,2} Attributes of patient satisfaction can include provider attitude, technical competence, accessibility, and efficacy.³ The field of health communication has made significant contributions to the literature on patient satisfaction, identifying links between patient satisfaction and patient communication with healthcare providers.⁴⁻¹¹ These links include assessing the similarity of communication styles between patient and provider, which shows that patients are more satisfied when their communication styles match.¹² Yet, two gaps exist in the literature that require further study.

First, most work on patient satisfaction has used encounter-specific measures; for example, a physician-specific measure or a general/system-level measure (i.e., an inpatient hospital stay).^{13,14} However, some patients may think about satisfaction more generally in terms of the

healthcare they have received for a particular disease, especially for those who deal with chronic and complex diseases (CCDs) such as diabetes, cardiovascular disease, arthritis, cancer, or kidney disease.^{15,16} This suggests that the locus of patient satisfaction may best be centered in the patients' experiences with their healthcare in more general terms and over time, rather than with a particular physician or hospital stay. As Nolte and McKee noted, patients with CCDs "require complex models of care...Patients may receive care from many different providers, often in different settings or institutions, even when they have only a single disease" (p. 64).¹⁷ They went on to argue for more research that "bridges the boundaries between professions, providers and institutions through the development of more integrated or coordinated approaches..." (p. 64). In fact, in an already fragmented healthcare system, continuing to measure encounter-specific patient satisfaction only further contributes to fragmentation of patients' healthcare system experiences.¹⁸ In this vein, studying patient satisfaction from a more integrated approach that privileges the disease a patient is managing may be a necessary step in better addressing patients' dissatisfying experiences with healthcare.

Second, some scholars have argued a conceptual difference exists between patient satisfaction and dissatisfaction, rather than the two concepts being on opposite ends of the same continuum.^{19, 20} Sitzia and Wood noted, “a concentration upon areas of expressed dissatisfaction is more valuable than obtaining consistency of expressed satisfaction” (p. 1834).²⁰ Others have argued that identifying areas of patient dissatisfaction may be more appropriate, since “patients’ reports of dissatisfying events...highlight areas in which small changes in practice might greatly improve the patient experience” (p. 7).¹⁹ With this in mind, capturing a better understanding of patients’ dissatisfaction with healthcare may be particularly informative in improving patient experiences.

In sum, more work on patient dissatisfaction is needed. Much of the past work focused on patient satisfaction and has only examined it from encounter-specific perspectives. Researchers need to better understand patient dissatisfaction using an integrated approach, especially for patients dealing with a CCD who may have many different healthcare experiences under the umbrella of their disease. To address this, the current paper explores sources of dissatisfaction among patients suffering from a CCD called polycystic kidney disease.

Chronic and Complex Diseases

While somewhat amorphous, the term *chronic and complex disease* (CCD) is increasingly used in the literature to describe patients who require long-term and multifaceted healthcare. Sevick and colleagues defined it as “a condition involving multiple morbidities that requires the attention of multiple healthcare providers or facilities and possibly community (home)-based care” (p.438).²¹ CCDs can include both inherited and acquired diseases; some examples include Alzheimer’s disease, cystic fibrosis, diabetes, rheumatoid arthritis, and chronic kidney disease, among others. Patients with CCDs interact with healthcare systems designed more for episodic and acute care, rather than systems which are attuned to the long-term needs of someone with a chronic, and perhaps more uncommon, illness.²² In fact, one report showed that patients with CCDs in the United States are at particularly high risk for problems related to healthcare access, inefficiency, unnecessary readmissions, medical errors, and overall poorly organized care.²³ Researchers must work to better understand unique experiences of patients with CCDs to ensure that dissatisfying experiences are avoided in the care they are receiving.

One CCD that is understudied is a type of chronic kidney disease called polycystic kidney disease (PKD). PKD is the most common inherited kidney disease and the fourth leading cause of kidney failure, affecting about 500,000 people in the United States.^{24, 25} The disease causes non-cancerous, fluid filled cysts to grow on the kidneys over time. PKD patients most often come to clinical attention

after age 30, but age of onset, severity of symptoms, and progression of disease through kidney failure stages (Stage 1/normal to Stage 5/kidney failure) vary widely, suggesting the need for close monitoring by healthcare providers.²⁶ Like other chronic kidney diseases, PKD patients see a range of specialists during the course of their disease, including urologists, nephrologists, radiologists, transplant surgeons, and other specialists, which adds to the complexity of managing this disease. In fact, in a recent study of clinical encounter data, we found that people with chronic kidney disease (all stages) experienced a median of 22 healthcare encounters over a 1-year period and even in early stages of kidney disease (Stages 1-3), patients experienced a median of 14 to 17 encounters.²⁷ These healthcare encounters include working with clinical pharmacists, which has shown to significantly improve parathyroid hormone, blood pressure, hemoglobin, and creatinine clearance among patients with chronic kidney disease.²⁸

PKD patients face the inevitability of kidney failure, but this is coupled with the ability to make significant lifestyle changes, such as diet, that could slow the progression of the disease.²⁹ PKD is not always well understood among the general public or among some healthcare providers. Anecdotally, many PKD patients say that they know more about their disease than their doctor(s) and often do not feel they are receiving the best care possible. Patients who experience this situation understandably may experience a high degree of dissatisfaction in their healthcare. Better understanding their experiences may help to shed light on how to best address dissatisfying experiences for these patients.

Hence, the current study will identify the sources of dissatisfaction that patients with CCDs face across their illness experience; specifically, this study will focus on PKD patients. The results from this study will also provide a useful framework for others doing research on patients’ healthcare experiences with CCDs.

Methods

The study reported here is part of a larger online study (N=786) exploring the unique struggles and communication challenges faced by PKD patients conducted in Fall 2015. Patients were recruited to an online study through an email listserv devoted to PKD patients. In one section of the survey, participants were asked to indicate if they had ever been dissatisfied with the healthcare they received. Fifty-two percent of participants (n = 387) indicated that they had been dissatisfied at some point and were asked the follow-up question: “Describe what happened when you were dissatisfied with healthcare you received for your PKD.” Participants could write as much as they wanted, thus providing a very rich dataset for analysis. This study was approved by IRB with an

Table 1. Demographic Information (N=387)

Characteristic	N (%)
Sex	
Male	86 (22.2)
Female	301 (77.8)
Age (M ± SD)	52.24 ± 12.61
Race ^a	
White/Caucasian	348 (89.9)
African American	9 (2.3)
Hispanic	25 (6.5)
Asian	4 (1.0)
Native American	5 (1.3)
Pacific Islander	2 (0.5)
Other	8 (2.1)
Disease Stage	
Living with PKD, does not disrupt my daily life	87 (22.5)
Living with PKD, somewhat disrupts my life	156 (40.3)
End stage renal failure	53 (13.7)
Post-transplant	90 (23.3)
Location	
Lives in United States	358 (92.5)
Lives outside United States	29 (7.5)
Education	
Less than High School	1 (0.3)
High School / GED	27 (7.0)
Some College	74 (19.1)
2-year College Degree	55 (14.2)
4-year College Degree	107 (27.6)
Master's Degree	86 (22.2)
Doctoral Degree	18 (4.7)
Prof. Degree (JD, MD)	16 (4.1)
Prefer not to say	2 (0.5)

^a Participants could select more than one race.

exempt status. No compensation was given for participation. Prior to analysis, the first author removed any identifying information from the participant responses and used Google Translate to translate three entries from non-English to English language for analysis. Demographic data is presented in Table 1.

Procedure

This study utilized content analysis to examine PKD patient reports of dissatisfying experiences with healthcare. According to Krippendorff, content analysis is “a research technique for making replicable and valid inferences from texts...to the contexts of their use”³⁰ (p. 19). In this study, the texts analyzed are comprised of PKD patient expressions of dissatisfaction and the context is receiving healthcare for their disease. The responses from the 367 participants in the current study generated 452 unique units for analysis; units were defined as a meaningful unit of text that consisted of a complete idea.³¹ The dataset was

uploaded into Dedoose, a secure online coding software. Based on previous related research^{1, 2, 6, 32, 33} and a careful read through of the first 15 units, the first and third author generated initial conceptual categories. Then, they returned to the data to apply the initial coding scheme to an additional 30 units to identify any additional categories and to ensure the conceptual categories were both exhaustive and mutually exclusive. They met one more time to discuss the coding scheme, to clarify each category and definition, and to ensure both coders were adequately trained to use the coding scheme. Next, the first and third author took the final coding scheme and independently and concurrently coded 10% of the data to ensure coding consistency, which resulted in an acceptable inter-coder reliability (Krippendorffs' $\alpha = 0.85$).³⁰ Following this, the first and third author split the remaining dataset in half and performed the coding. The final coding scheme can be found in Table 2.

Table 2. Overview of categories and sub-categories for patient reports of dissatisfaction (N=452)

Types of Dissatisfaction	Code Counts (%)
Information	
Lack of Information	117 (25.9)
Misinformed	53 (11.7)
Support	
Lack of Compassion	39 (8.6)
Lack of Seriousness	58 (12.8)
Care Management	
Poor Communication	67 (14.8)
Misalignment of Priorities	
<i>Not Responsive to Symptoms</i> <i>(Specific symptoms mentioned)</i>	45 (10.0)
<i>Proactive vs. Reactive Approach</i>	70 (15.5)
Care Coordination	85 (18.8)
Care Delivery/Therapy	56 (12.4)
Provider Type ^a	
Nephrologist	101
Primary Care Doctor	36
ER Doctor	14
Nurse	7
Transplant Doctor	3

^aProvider type code percentages not provided because not all participants mentioned a provider; the counts presented above only represent the times a provider was mentioned spontaneously by a participant.

Results

There were nine conceptual codes (i.e., types of dissatisfaction) and five provider codes (i.e., if the participant mentioned the type of healthcare provider in their response). It was possible that codes could “co-occur” within the same unit of analysis, so the total number of applied conceptual codes (c=590) exceeds the total number of units for analysis (n=452). In addition, in the cases in which a participant mentioned the type of provider, a code was assigned, resulting in 161 coded instances of providers. Participants were not specifically instructed to list the provider. Provider type was coded on the basis of the participant describing that a particular provider was the source of the dissatisfaction; in other words, the participant had to clearly indicate that the provider mentioned was the one who caused their dissatisfying experience. There was an average of 2.06 codes applied per unit of analysis, including provider codes.

Information

The first category of dissatisfaction concerned patient reports about the level and type of information healthcare providers had about PKD. The first type, *lack of information* (n=117), was the most common type of dissatisfaction reported in the study. Participants described many instances where healthcare providers knew very little about PKD in terms of diagnosis, symptoms, progression, or treatment:

“I’ve met numerous doctors who knew less about PKD than I did.” (Participant 190)

The second type was *misinformed* (n=53). This category emerged as conceptually different from lack of information because participants reported instances where healthcare providers provided incorrect information to patients about diagnosis, symptoms, progression, or treatment.

“My second doctor, a nephrologist, when told by me that my father died of this disease, stated that, “no one dies from this, they just suffer.” (Participant 310)

Support

The second category of dissatisfaction was about the type of support patients perceived they were given from healthcare providers when dealing with their PKD. The first type was *lack of compassion* (n=39) described as the lack of emotional concern or empathy from some healthcare providers.

“Discussing PKD can be extremely difficult as well as emotionally painful. PKD families have often lost family members and have watched family members suffer the effects of this disease. You can feel helpless, angry, and misunderstood. When a provider is completel[y] insensitive to the

significant impact, you feel as though you do not want to talk about PKD.” (Participant 19)

The second type was *lack of seriousness* (n=58). Separate from the emotional aspects of managing PKD, participants also perceived many healthcare providers did not devote enough serious attention to their condition.

“Felt as though I was boring the doctor and that my questions were silly!” (Participant 176)

Care Management

The third category of dissatisfaction concerned reports about how patients’ care was managed. The first type was *poor communication* (n=67). Participants described instances where healthcare providers did not communicate about important aspects of their care, such as test results or the progression of the disease.

“A previous nephrologist would order lab tests and examine me. However, he shared very little about what was happening. ... When I switched [doctors], I learned that my kidneys had failed to approximately 30 percent function. She let me know that I probably had about a year left before total kidney failure. The previous doctor never mentioned it.” (Participant 12)

The second type was *misalignment of priorities*. Two sub-categories emerged from this type of dissatisfaction. First, *not responsive to reported symptoms* (n=45) occurred when participants would describe healthcare providers who did not act, or act sufficiently, when they reported specific PKD-related symptoms.

“I saw a nephrologist that completely dismissed my concerns about pain I was experiencing. He also did not offer any suggestions regarding pain management. He ignored my concerns about anemia.” (Participant 123)

Second, *proactive versus reactive approach* (n=70) occurred when participants described healthcare providers who they felt were not helping them take control of their PKD, but rather were waiting to respond until the patient’s disease progressed. It should be noted that for PKD, there are many diet and lifestyle changes that can be made to prolong the health of the kidneys and several ongoing clinical trials for therapies that slow the growth of the cysts.³⁴ Examples of this sub-category ranged from those who wanted to be proactive in the early stages of their disease, to those who were near end-stage renal failure and wanted to be proactive about transplant.

“I felt that I wasn't getting many answers about being proactive about the disease. That I could not do anything about having PKD except drink water

and basically wait until kidney failure. I was looking for more in depth...but was told... that nothing was effective. I sought a new nephrologist after this, one that had much more experience with PKD, and was able to get better answers. It was a huge difference. I felt more in control of my disease and my future instead of it controlling me.” (Participant 88)

“One of my nephrologists was not proactive enough for me. My GFR [glomerular filtration rate, a test to measure kidney function] was declining to the point that I knew that I could and should apply for the transplant waiting list and he indicated that there was no hurry.” (Participant 267)

The third type was *care coordination* (n=85) which focused on communication required between multiple providers and ancillary services required for healthcare. Within the care coordination category, participants described instances where coordination of their care was done improperly and included examples such as the process of care, the role of individual healthcare providers and whether they were performing their duties appropriately, and the issue of health insurance approval in order to receive care. Two examples are provided below.

“I have been extremely dissatisfied with approval and coverage for medical procedures and tests for my PKD. Having to jump through hoops for basic imaging of kidneys and for blood pressure medication has been exasperating at times!!” (Participant 296)

“I told my nephrologist that both my father and aunt had brain aneurysms [a common side effect of PKD] and asked if I should get screened and she said, “um, I think that's something you should try to clear through your PCP.” (Participant 97)

The fourth type was *patient perceptions of poor care delivery/therapy* (n=56). In these instances, participants detailed their perceptions of actual mistakes in the delivery of their PKD care, which could include misdiagnosis, providers not following guidelines for PKD care, medical mistakes such as being given incorrect medicine, or treatment prescribed that was not evidence-based.

“First I was told I had pancreatitis, then crohns, then ovarian cysts, then if I was a drug user. They stumbled upon the PKD by accident after many years.” (Participant 42)

“My regular Dr was out, so I had to see another Dr in the practice for headaches and dizziness.

This Dr immediately assumed I was dehydrated (no tests done at ALL) and took me off of my diuretic and didn't replace it with another BP med. Of course, I started swelling like a balloon and a month later I called my Dr and asked to be put back on it. No one ever said anything about how she could have caused kidney damage by taking me off the bp meds.” (Participant 238)

“I feel like my nephrologist is nonchalant about a disease that will drastically change my life. I'm not confident he is up-to-date on the latest PKD research.” (Participant 81 – *lack of seriousness* and *lack of information*; *nephrologist provider*)

“I was taken off diuretics, told to drink lots of fluids, my calls were not answered, not returned for several days, my BP climbed, my Creatinine climbed, it turned into an emergency.” (Participant 153 – *poor communication* and *care delivery/therapy*)

Code Co-Occurrence

In this study, there were also instances where a unit of analysis represented more than one code (see Table 3). Code co-occurrence happened in two ways. In 35.6% of excerpts (i.e., units of analysis), the type of healthcare provider (e.g., nephrologist) who caused the dissatisfaction (e.g., lack of sympathy) was mentioned, resulting in more than one code being used. Participants were not asked to list the type of doctor when describing their dissatisfying healthcare experiences. The most common type of healthcare provider mentioned in this study was nephrologist (n=101), followed by primary care doctor (n=36), emergency room doctor (n=14), nurse (n=7), and transplant doctor (n=3).

In some instances, more than one conceptual code (i.e., type of dissatisfaction) was present in the same unit of analysis. This occurred in 40.9% (n=185) of excerpts. The most common co-occurrence was *poor communication* and *care coordination* (n=15), followed by the co-occurrence of *lack of seriousness* and *lack of information* (n=12), and *lack of information* and *care coordination* (n=10). Two examples are provided.

Discussion

This study revealed that patients with a CCD experience various sources of dissatisfaction when seeking healthcare, including perceptions of how informed their healthcare providers are about their disease, lack of support, and poor care management. Unlike healthcare for acute conditions, care for CCD is complex, requires ongoing self-management, and recognition of the condition and treatment when seen by multiple providers over time.

Findings from this study reveal that focusing on patient expressions of dissatisfaction rather than satisfaction may lead to different types of information. For example, the widely used patient experience measure CAHPS® Clinician and Group Survey (Consumer Assessment of Healthcare Providers and Systems) specifically assesses patients’ perceptions of communication with clinicians in a clinical encounter.³⁵ Updates to the CAHPS® survey questions, that at the time of this paper are in beta testing (4.0), have moved from measures of satisfaction to directly

Table 3. Code Co-Occurrence

Categories	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Lack of Information	-	-	-	-	-	-	-	-	-	-	-	-	-	-
2. Misinformed	8	-	-	-	-	-	-	-	-	-	-	-	-	-
3. Lack of Compassion	2	2	-	-	-	-	-	-	-	-	-	-	-	-
4. Lack of Seriousness	12	2	4	-	-	-	-	-	-	-	-	-	-	-
5. Poor Communication	8	2	5	7	-	-	-	-	-	-	-	-	-	-
6. Not Responsive to reported Symptoms	4	3	3	6	5	-	-	-	-	-	-	-	-	-
7. Proactive Patient vs. Reactive Doctor	9	2	5	5	6	0	-	-	-	-	-	-	-	-
8. Care Coordination	10	5	4	5	15	4	5	-	-	-	-	-	-	-
9. Care Delivery/Therapy	2	4	2	2	6	5	1	15	-	-	-	-	-	-
10. Nephrologist	21	9	12	12	25	10	24	23	13	-	-	-	-	-
11. Primary Care Doctor	15	1	0	6	5	2	2	7	3	2	-	-	-	-
12. ER Doctor	5	1	0	3	6	3	0	11	7	5	1	-	-	-
13. Nurse	1	1	0	0	1	0	0	1	3	0	1	1	-	-
14. Transplant Doctor	0	0	0	0	0	0	0	2	2	0	0	0	0	-

assessing whether providers engaged in specific communication during the most recent visit (i.e., explained things, listened, spent time, and respectful). Our findings, focused on dissatisfaction, revealed that not only do patients reflect on several similar concepts found in CAHPS when seeking healthcare for a CCD (i.e., communication, spending time with patient), but also reveals several new concepts such as whether the patient believes their healthcare provider is well informed about diagnosing and treating their disease, the lack of emotional support displayed by healthcare providers towards patients in dealing with the burdens of their CCD, the perception that providers and patients may have misaligned priorities when it comes to care, and finally, perceptions that care was not coordinated well among different healthcare providers and that healthcare mistakes were made. This type of nuanced information gained from focusing on patient dissatisfaction would not be captured with scales like CAHPS, meaning that hospitals and healthcare providers may not be aware that these patient perceptions exist, or they are not using measures that capture this information accurately.

Additionally, this study focused on patients' integrated experience in seeking care for their CCD, rather than focusing on a single encounter with a healthcare provider or hospital stay. As such, this study revealed that patients can identify specific episodes where dissatisfying experiences occur but can *also* reflect on their healthcare experiences cumulatively. This cumulative or integrated approach focused on the healthcare received for a CCD can offer unique information not captured in an approach which focuses on a single encounter. For example, recall this example of *patient perceptions of poor care delivery/therapy* provided in the Findings section:

“First I was told I had pancreatitis, then crohns, then ovarian cysts, then if I was a drug user. They stumbled upon the PKD by accident after many years.” (Participant 42)

This participant is reflecting not on a single episode, but rather reflecting on the dissatisfying experience of continued misdiagnosis. Note how the participant uses the term “they” to discuss the general collection of healthcare providers seen for the CCD, and how the participant mentioned it took “many years.” Now, imagine if one of the encounter-specific measures was given to this patient after seeing the doctor who finally gave a correct diagnosis. The patient may have reported high satisfaction given that the disease was finally identified and a diagnosis given! However, the data would be incomplete as it would not have captured the lengthy struggle and dissatisfaction this patient experienced with the healthcare system before finally being given a correct diagnosis.

Lastly, the results from this study should be interpreted in light of the sample used. PKD patients may experience different types and amounts of dissatisfaction with their healthcare than patients with other types of CCDs. However, despite this article focusing solely on one disease, there is evidence that patients with other CCDs (e.g., diabetes, arthritis, epilepsy, etc.) engage in similar chronic disease management behaviors and have frequent healthcare visits, and therefore are likely to have similar healthcare experiences.³⁶ Additionally, this data only represents patients' retrospective reflections on their care experiences and was gathered using an online, open-ended questionnaire. Future work should continue to explore the phenomena of patient dissatisfaction with other disease populations, as well as examine the interaction that takes place between providers and patients when a patient expresses or experiences dissatisfaction.

Implications for Patient Care Experiences

Providers who see patients with CCDs would do well to remember that patients may see multiple providers over time and may have unique support needs compared to other patient populations. Helping patients to see the integration of their healthcare across multiple providers in a supportive way can be one step toward addressing dissatisfying experiences. For example, providers could adopt a “reflective practice” technique,³⁷ by structuring individual appointments in this way:

1. Begin with asking patients to “tell me about your last appointment where you talked about your condition.” This will help patients bridge the gap between healthcare encounters and ensure that the provider knows about any other appointments the patient had.
2. During the appointment, encourage patients to share any and all information or concerns they have about their CCD, including any emotional or mental burdens they have faced. Patients may not always know what information is important to share, but providers can gather better and more complete information by encouraging the patient to share what she or he thinks is important. Many of the sources of dissatisfaction uncovered in the current study are directly or indirectly due to gaps in communication, so encouraging more open exchange of information may help to address some of these concerns.
3. End the appointment by summarizing what was discussed. Patients can be provided with a written summary to share with their other providers, or providers can prepare patients to discuss their condition with others by asking them, “we have discussed quite a bit today, what will you share with your [insert care provider name or loved one here] following our discussion here today?” This question will help prime the patient for their next care appointment and may be useful in identifying possible

sources of dissatisfaction or misunderstanding from the current appointment.²⁷

Conclusion

Patients with CCDs experience various sources of dissatisfaction when seeking healthcare. Healthcare providers treating these unique patients need to ensure that they not only deliver good healthcare in a single appointment, but also be aware that this patient population may have unique burdens related to their CCD that may lead them to feel dissatisfied with the care they receive. Patients with CCDs may see multiple healthcare providers over many years, and their experiences with the healthcare system may be better understood from an integrated approach that places the patient's collective healthcare experience at the center, rather than focusing on whether patients are satisfied with a single physician or hospital stay. The reflective practice technique provided in this paper is just one method of improving patient-provider communication. Future work should continue to identify other sources of patient dissatisfaction and ways to mitigate it.

References

- Richmond VP, Smith RS Jr, Heisel AD, McCroskey JC. The association of physician socio-communicative style with physician credibility and patient satisfaction. *Communication Research Reports*. 2002;19(3):207-215.
- Fenton, JJ, Jerant AF, Bertakis KD, Franks P. The cost of satisfaction: A national study of patient satisfaction, health care utilization, expenditures, and mortality. *Archives of Internal Medicine*. 2012;172(5):405-411.
- Joshi S, McMacken M, Kalantar-Zadeh K. Plant-based diets for kidney disease: A guide for clinicians. *Am J Kidney Dis*. 2021; 77(2):287-296. doi:10.1053/j.ajkd.2020.10.003
- Street RL Jr, Makoul G, Arora NK, Epstein RM. How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient Education and Counseling*. 2009;74(3):295-301. doi: 10.1016/j.pec.2008.11.015.
- Ong LM, Visser MR, Lammes FB, de Haes JC. Doctor-patient communication and cancer patients' quality of life and satisfaction. *Patient education and counseling*. 2000;41(2):145-156. doi: 10.1016/s0738-3399(99)00108-1.
- Brown JB, Stewart M, Ryan BL. Outcomes of patient-provider interaction. In Thompson TL, Dorsey AM, Miller KI, Parrot R, eds. *Handbook of Health Communication*. Mahwah, NJ: Lawrence Erlbaum Associates, Inc.; 2003:141-161.
- Hall JA, Dornan MC. What patients like about their medical care and how often they are asked: A meta-analysis of the satisfaction literature. *Social Science & Medicine*. 1988;27(9):935-939. doi: 10.1016/0277-9536(88)90284-5.
- Clever SL, Jin L, Levinson W, Meltzer DO. Does doctor-patient communication affect patient satisfaction with hospital care? Results of an analysis with a novel instrumental variable. *Health Services Research*. 2008;43(5p1):1505-1519. doi: 10.1111/j.1475-6773.2008.00849.x.
- Dutta-Bergman MJ. The relation between health-orientation, provider-patient communication, and satisfaction: An individual-difference approach. *Health Communication*. 2005;18(3):291-303. doi: 10.1207/s15327027hc1803_6.
- Haskard KB, DiMatteo MR, Heritage J. Affective and instrumental communication in primary care interactions: Predicting the satisfaction of nursing staff and patients. *Health Communication*. 2009;24(1):21-32. <https://doi.org/10.1080/10410230802606968>.
- Schmid Mast M, Hall JA, Roter DL. Disentangling physician sex and physician communication style: Their effects on patient satisfaction in a virtual medical visit. *Patient Education & Counseling*. 2007;68(1):16-22. doi: 10.1016/j.pec.2007.03.020.
- Trant AA, Szekeley B, Mougalian SS, et al. The impact of communication style on patient satisfaction. *Breast Cancer Res Treat*. 2019;176(2):349-356. doi: 10.1007/s10549-019-05232-w.
- Agency for Healthcare Research and Quality. About CAHPS. <https://www.cahps.ahrq.gov/about-cahps/index.html> Published 2015. Accessed November 2022.
- Wanzer MB, Booth-Butterfield M, Gruber K. Perceptions of health care providers' communication: Relationships between patient-centered communication and satisfaction. *Health Communication*. 2004;16(3):363-384. doi: 10.1207/S15327027HC1603_6.
- Epstein RM, Street RL Jr. Patient-centered communication in cancer care: Promoting healing and reducing suffering. Bethesda, MD: National Cancer Institute; 2007.
- Harvey PW, Petkov JN, Misan G, et al. Self-management support and training for patients with chronic and complex conditions improves health-related behaviour and health outcomes. *Australian Health Review*. 2008;32(2):330-338. doi: 10.1071/ah080330.
- Nolte E, McKee M. Integration and chronic care: A review. In Nolte E, McKee M, eds. *Caring for People with Chronic Conditions: A Health System Perspective*. England: McGraw-Hill; 2008:64-91.
- Stange KC. The problem of fragmentation and the need for integrative solutions. *Annals of Family Medicine*. 2009;7(2):100-103. doi: 10.1370/afm.971.
- Lee AV, Moriarty JP, Borgstrom C, Horwitz LI. What can we learn from patient dissatisfaction? Analysis of

- dissatisfying events at an academic medical center. *J HOSP Med.* 2010;5(9):514-520. doi: 10.1002/jhm.861.
20. Sitzia J, Wood N. Patient satisfaction: a review of issues and concepts. *Soc Sci Med.* 1997;45(12):1829-1843. doi: 10.1016/s0277-9536(97)00128-7.
 21. Sevick MA, Traith JM, Ling BS, et al. Patients with complex chronic diseases: Perspectives on supporting self-management. *Journal of General Internal Medicine.* 2007;22(Suppl 3):438-444. doi: 10.1007/s11606-007-0316-z.
 22. Rich E, Lipson D, Libersky J, Parchman M. Coordinating care for adults with complex care needs in the patient-centered medical home: Challenges and solutions. Rockville, MD: Agency for Healthcare Research and Quality; 2012.
 23. Schoen C, Osborn R, How SKH, Dotty MM, Peugh J. In chronic condition: Experiences of patients with complex health care needs, in eight countries, 2008. *Health Affairs.* 2009;28(1):w1-w16. doi: 10.1377/hlthaff.28.1.w1.
 24. Wilson PD. Polycystic kidney disease. *New England Journal of Medicine.* 2004;350(2):151-164. doi: 10.1056/NEJMra022161.
 25. National Kidney Foundation. *Polycystic kidney disease.* <https://www.kidney.org/atoz/content/polycystic>. Published 2015. Accessed November 2022.
 26. Kidney Disease Improvindh Global Outcomes. KDIGO 2012 clinical practice guideline for the evaluation and management of chronic kidney disease. *Kidney International Supplements.* 2013. 3(1):19-62.
 27. Welch JL, Meek J, Bartlett Ellis RJ, Ambuehl R, Decker BS. Patterns of healthcare encounters experienced by pateints with chronic kidney disease. *Journal of Renal Care.* 2017;43(4): 209-218. <https://doi.org/10.1111/jorc.12200>.
 28. Ng JHY, Luk BHK. Patient satisfaction: Concept analysis in the healthcare context. *Patient Educ Couns.* 2019;102(4):790-796. doi: 10.1016/j.pec.2018.11.013.
 29. Sonis JD, White BA. Optimizing patient experience in the emergency department. *Emerg Med Clin North Am.* 2020;38(3):705-713. doi: 10.1016/j.emv.2020.04.008.
 30. Krippendorff K. *Content analysis: An introduction to its methodology.* 2nd ed. London: Sage Publications; 2004.
 31. Brann M, Mattson M. Toward a typology of confidentiality breaches in health care communication: An ethic of care analysis of provider practices and patient perceptions. *Health Communication.* 2004;16(2):231-251. doi: 10.1207/S15327027HC1602_6.
 32. Montini T, Noble AA, Stelfox HT. Content analysis of patient complaints. *International Journal for Quality in Health Care.* 2008;20(6):412-412. doi: 10.1093/intqhc/mzn041.
 33. Jangland E, Gunningberg L, Carlsson M. Patients' and relatives' complaints about encounters and communication in health care: Evidence for quality improvement. *Patient Education & Counseling.* 2009;75(2):199-204. doi: 10.1016/j.pec.2008.10.007.
 34. PKD Foundation. Living with PKD. <http://www.pkdcure.org/learn/adpkd/living-with-pkd-questions> Published 2015. Accessed November 2022.
 35. Agency for Healthcare Research and Quality. About CAHPS. <http://www.ahrq.gov/cahps/About-CAHPS/index.html> Published 2016. Accessed Novmber 2022.
 36. Miller WR, Lasiter S, Bartlett Ellis R, Buelow JM. Chronic disease self-management: A hybrid concept analysis. *Nursing Outlook.* 2015;63(2):154-161. doi: 10.1016/j.outlook.2014.07.005.
 37. Schön DA. *The reflective practitioner: How professionals think in action.* United States: Basic Books;1993