

Impact of patient-provider communication on online health information behaviors in chronic illness

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ABSTRACT

This study analyzes the role that patient-provider communication has in shaping online health information seeking in patients diagnosed with chronic kidney disease [CKD]. Data were collected and analyzed over two years using grounded theory methods; the findings presented in this study are a subset of the results from this larger study. Twelve participants, all diagnosed with CKD, were each interviewed twice for a total of 24 interviews; the posts they made to three different online support groups were also harvested. Data were analyzed using the constant comparative method until theoretical saturation was reached. There are multiple factors related to patient-provider communication that influence online health information seeking, including dismissive responses from providers, the type of information need, time pressure, information overload, the healthcare system, and the desire to verify or crosscheck information by consulting multiple sources. These results highlight the importance of effective communication between people diagnosed with CKD and their healthcare providers, as these interactions impact online health information behavior. In particular, providers should foster an open attitude towards online health information seeking; they should also encourage patients to verify information found online.

KEYWORDS

Doctor-patient communication, information seeking behavior, online support groups.

INTRODUCTION

Patients living with lifelong health conditions often search for information about their health throughout their illness trajectory (Johnson & Case, 2012), and many patients diagnosed with chronic conditions are increasingly turning to the Internet for health information (Fox & Duggan, 2013). However, there have been few studies that specifically examine how interactions with healthcare providers may shape online health information seeking. This study examines how patient-provider communication impacts online health information behavior.

These results are part of a two-year grounded theory study examining health information seeking and personal health information disclosure in online support groups by patients

diagnosed with CKD. In grounded theory, there is no central research question or hypothesis; instead, a process, practice, or behavior is explored in detail, and multiple facets of interest emerge and evolve as the research progresses (Glaser & Strauss, 1967). In this study, online health information behavior is the phenomenon of interest. Chronic kidney disease was chosen as the illness context, as it is a non-stigmatized chronic illness that is increasing in prevalence in the United States (Coresh et al., 2007; NIDDK Clearinghouses Publication Catalog, 2012).

LITERATURE REVIEW

In general, patients prefer to get information from their healthcare providers (Fox & Duggan, 2013; Gollop, 1997; Lenz, 1984). However, in practice they are more likely to go online to seek health information before talking with their provider, both for more general health questions (Volkman et al., 2014) and for concerns related to chronic issues (Marrie, Salter, Tyry, Fox, & Cutter, 2013). Although people seeking health information prefer channels that exhibit social presence (Johnson & Case, 2012), it can be expensive and time-consuming to visit the doctor. Access to sources also matters greatly: people with less access to flexible resources like the Internet are more likely to consult their providers for health information (Manierre, 2015). The context of the information need also plays an important role: patients are likely to ask healthcare providers about technical issues, such as prescription interactions and symptoms; they turn to other, more personal channels when they have more personal information needs, like coping strategies (Fox, 2011).

Although to this researcher's knowledge there are no direct-observation studies of kidney patients trying to elicit information from care providers, many studies do allude to the struggles that patients have in obtaining information from their providers. For example, dialysis patients in an interview study have noted that they don't know what to ask their doctors and nurses, citing a lack of time and the barrier of medical vocabulary used by nephrologists and dialysis technicians (Anderson, Devitt, Cunningham, Preece, & Cass, 2008). Others in this study said that they wanted to know why they got sick, but that asking care providers yielded no satisfactory answers, a finding echoed in another more recent study of patients diagnosed with CKD in stages I through IV (Lopez-Vargas et al., 2014). Unfortunately, a confounding issue is the low health literacy in patients diagnosed with CKD or ESRD (end-

stage renal disease); this is present throughout the illness trajectory and has been found in several studies (Devraj et al., 2015; Fraser et al., 2013; Miller-Matero, Hyde-Nolan, Eshelman, & Abouljoud, 2015). It is difficult, therefore, to know whether or not patients do not try to elicit information from their providers or if they do not understand the information that is provided to them by providers.

Interestingly, although online health information seeking is an activity that providers are aware patients undergo, there is little literature to date that describes the impact that patient-provider communication has on online information seeking. Instead, most of the research in this area focuses on how the relationship with providers is changed as a result of online health information seeking. Some studies show that providers feel threatened when patients bring information in from the Internet (Dedding, van Doorn, Winkler, & Reis, 2011). Others demonstrate that providers often react negatively when patients bring online health information in to appointments, potentially jeopardizing the patient-provider relationship (Rupert et al., 2014). The current study focuses on the impact of patient-provider communication on online health information seeking, demonstrating the consequences of the patient-provider relationship on information behavior online.

METHODS

The data presented in this study were gathered as part of a two-year constructivist grounded theory study with two sources of data: semi-structured interviews and forum posts made to one of three online support groups (OSGs) focused on CKD. Twelve participants between the ages of 25 and 70 and diagnosed with CKD were recruited using public messages posted by the researcher on four OSGs. Each participant was interviewed twice, for a total of 24 interviews that each lasted 100 minutes on average. The interviews resulted in 40 total hours of audio, which were transcribed by the researcher. A pseudonym was assigned to each participant at the time of transcription. With permission, threads containing posts made to the OSGs by 11 of the 12 participants were scraped. There are 1,847 total threads in the dataset. The posts were also coded alongside the interview data. At the completion of the second interview, participants were sent a \$75 gift card as a token of appreciation for their time.

Data were analyzed qualitatively using grounded theory methods (Charmaz, 2014). The researcher began by coding line-by-line; then, codes were grouped into thematic categories and theoretical constructs were created to describe those categories. As new data were collected, the constant comparative method of analysis was employed to group codes into constructs. Memos were written throughout the analysis process to track the development of codes, categories, and constructs over time. These memos also alerted the researcher to several questions about the process of evaluating other patients as information sources; to fill these gaps, theoretical sampling began after six participants had been interviewed. Data collection and

analysis were performed until theoretical saturation was reached. The analysis was verified using several methods, including data triangulation, member checking, and peer de-briefing. To help prevent deductive disclosure of participants, data sources are not identified in the results; data originate both from forum posts and from interviews.

RESULTS AND DISCUSSION

This section provides an overview of how patient-provider communication impacts online health information seeking in patients with CKD. Dismissive interactions, suitability of information topic, time pressure, overload, the healthcare system, and verifying information through crosschecking are all addressed.

There are many different types of healthcare providers discussed in the data, including dialysis technicians, emergency technicians, dieticians, social workers, nurses, general practitioners, nephrologists, and other specialists. Participants describe a variety of interactions with these providers. Interactions include, but are not limited to:

- Pre-dialysis check-up appointments with nephrologists;
- Meeting with various providers in the dialysis clinic, including technicians, dieticians, social workers, and nephrologists;
- Visits to other healthcare specialists for comorbidities;
- Appointments with dieticians to discuss the pre-dialysis or dialysis diet;
- Post-transplant annual visits with nephrologists.

During these interactions, participants say that they mostly receive information from their doctors and other providers about their CKD. The provider, not the participant, largely guides these interactions, although participants do discuss asking their providers questions and sharing information they find online with their doctors as a way to verify, or *crosscheck*, what they have found. Research has shown that the patient/provider interaction during appointments is very provider-heavy; that is, the relationship is asymmetrical, with the provider receiving more information than patients (McNeilis, 2001). Unfortunately, many participants describe feeling dismissed by their healthcare providers when they do ask questions; it is often this type of negative reaction that spurs further information seeking online. Although negative interactions with providers are a recurring theme in the data, this does not indicate that participants are receiving poor care. In fact, many participants discuss having very positive relationships with their providers, despite sometimes experiencing negative interactions with them.

Dismissive interactions

Dismissal of a patient's concerns by a health care provider comes in a variety of forms, and participants use words like *nonchalant*, *dismissive*, and *ill-considered* to describe these interactions. Sherri, who is on the cusp of Stage III CKD,

describes feeling dismissed during her first nephrology visit—a visit that was recommended by her primary care doctor:

I went to a renal specialist at the local university hospital, the best people in the area. And it was horribly disappointing. Bottom line, they don't suggest that [you] do anything until Stage IV. "You look fine, you feel fine, continue eating what you feel like! When you start dumping protein in your urine, then you can worry." And this is a respected expert on kidneys.

This advice is the opposite of the advice she received from her primary care doctor, who told her to eat a low-protein diet and to watch her sodium intake. When asked if she might get a second opinion, she says:

I went back to my primary care physician and I said, I've got so many excellent resources online, and I've got the dietician to help me, and I've got my PCP monitoring me every three months to see whether any of the key indicators are moving in a bad direction, or potentially in a good direction.... I feel comfortable managing things with her as long as things are stable. If they start deteriorating I'll go find another specialist.

Here, Sherri describes a reaction that many participants also have when they feel dismissed by a provider: using other resources, including the Internet, to find information. Sherri does not only go online to look things up, however – she has a dietician, a PCP that she is comfortable with, and trusted online resources. This illustrates that participants do not just turn to the Internet with health questions when they feel dismissed by a provider: the Internet is one of many resources that they use to answer questions about their health. In fact, participants often see the Internet as a helpful resource for enhancing communication with their providers. For example, when I ask Amy what she is looking for when she searches for information about CKD online, she says: "to gain more understanding of what [my doctors] were trying to say, [so] that I have more knowledge to be able to ask more knowledgeable questions in the future."

A dismissive or negative attitude from a provider can also impact what participants share with that provider, either as a given interaction continues, or in subsequent interactions. For example, Jacob travels frequently to lobby state and national legislators for better kidney care. He is on in-center dialysis, and is "a bit of a hard stick." Technicians unfamiliar with him were taking nearly two hours to successfully insert the needles for dialysis into his arms, causing him great pain and disrupting his schedule. So he talked to his favorite technician at his usual clinic, Tim, and Tim gave him incredibly precise instructions about how to stick his fistula. Another technician, Rita, also jumped in and gave some additional advice about it. Jacob also took several photographs to share with the technicians, but when

he got to the center, he decided that felt a bit like "overkill" so he just gave them the verbal instructions: "I'm like, ok, I'm ready for this. So I went to the new site and I gave them that instruction." Unfortunately, Jacob's technicians still had lots of difficulty sticking him:

I said you needed to use the inch and a quarter needle right here, and they said, "Oh, well we haven't tried that one yet." And I'm like, "You don't even listen to me!" Very often, they're not ready for patients to tell them what, as a technician, they think they already know.... Very often they won't listen to me. They heard me, they listened to me, they heard what I was saying and then totally ignored it.

Jacob never showed them the pictures: "It was a case of where I intellectually detached from it and I just kind of like, 'Ok, fine, when you guys find it, you let me know.' I got kind of tired of that because it *hurts*." In this instance, Jacob decided to stop sharing information with his providers because of their dismissive response, although he plans to do differently in the future: "I'll get better at it. I'll get more involved," he says. This is a particularly telling statement from an individual who lobbies Congress and is a champion of patient empowerment. Like in other situations described by participants, Jacob takes on the responsibility of being dismissed by his providers – he says that he believes that if he were more involved, a "better" patient—one who shares more readily with his providers—he would perhaps not have had a difficult and painful experience dialyzing at this center. This is corroborated in the literature: patients are more willing to disclose information to providers when their providers seem engaged – nodding, using animated facial expressions, and smiling are all things that doctors can do to promote patient disclosure; turning away, breaking eye contact while speaking, and verbally dismissing patient concerns all cause patients to disclose less (Duggan & Parrott, 2001).

Nina also explains that sometimes, it is not that her providers are dismissive – it's that they don't know the answers to her questions:

When I first got my diagnosis, and I said, well, what's the prognosis, and the nephrologist said, "I have no idea." [Laughs].... It was the beginning of my enlightenment. When you actually start using the medical system you realize it's not what you thought it was. It's not, here, take this pill; it's not, here, have this operation; it's a lot of lab tests and waiting.... Your expectations get – you have to readjust them.... They're not going to always get it right. And the doctors are trying and they're working—to a certain extent, they're working in the dark, like you are at the beginning. They only know so much.

Nina has a rare genetic form of CKD; this, she says, contributes to her doctors knowing less than they might

about other forms of the illness. This is one of the reasons that she says that she turns to the Internet to look for information specifically about her particular etiology of CKD. In fact, there are many reasons that participants give for going online for health information rather than consulting with their providers. Brent describes some of these reasons:

I go [to the forums] fishing for people who are looking for information... and then I provide it... And I see it as an indication of mainly, their medical teams are just not giving them the information that they're asking for. Or, they're just afraid to ask these questions of them.... There's a lot of, I get a lot of – a number of people have got kind of what I would consider innocent questions. I mean, maybe they didn't ask their medical team. Or maybe they're just curious and more comfortable with this forum. Right? There are other people who are complaining bitterly that they're not getting the answers from their medical teams. They don't have the access. How do you get that information without making an appointment? They don't want to spend the money or the time to get an appointment. So they're using this [forum] to try to get answers.

Here, Brent touches on several factors that limit interactions with providers that come from the patient: the cost of appointments, which was an oft-cited concern for most of the participants in the United States; the amount of time it takes to attend a doctor's appointment, which includes travel time (requiring its own separate set of logistics and often a support system, since many participants cannot drive); and the type of questions that people are able to ask providers, which may be limited due to embarrassment or because the limited amount of time with a doctor impacts the number and type of questions people are able to ask. Questions that are curiosities may not be important enough to bring up during the limited time participants have with providers.

Unsuitable topics for providers

There are questions that participants have that providers aren't able to answer; these questions are mostly experiential in nature. Examples of these questions that have been posed in online support groups include: "What does a biopsy feel like?" "How do you keep living your life while you're waiting for the call [for a kidney from the deceased donor list]?" and "Does your spouse eat a renal-friendly diet with you? If not, how do you handle it?" Providers do not have the ability to answer questions about experience, making the role of online support groups very valuable to participants in this study. Providers also do not generally provide emotional support. Joan describes:

I don't think there's enough validating people's feelings in general. This whole thing is so medicalized. And your doctors are concerned about

your numbers and that's pretty much where their involvement ends. There's a whole other half, and that is your emotional half. And I just, I really don't think that that's stressed enough.

This is a common theme in discussions with participants, on the forums, and in the literature about chronic care. Although empathy is a necessary component of effective doctor-patient communication, a distance between patients and providers exists and is propagated as a function of the medical system (Haque & Waytz, 2012). This process may lead people to search for emotional support elsewhere, as they cannot receive it from their care providers.

There are also some issues that providers do not bring up with patients, such as the option of hospice or palliative care. For example, when he met with a social worker to discuss his treatment options, Steve mentioned hospice to her:

She goes, "Do you know what your treatment options are?" And I was like, "Yeah, in-center hemodialysis, nocturnal in-center dialysis, home hemodialysis, peritoneal cyclor, peritoneal manual exchange, transplant, and hospice" - and nobody *ever* says hospice. She was like, "Woah! My gosh!" And I'm like, "That's an absolute choice! That we have!" But that's one they never talk about.

Gretchen, who lives in Australia, relates a similar experience in her dialysis training – the trainer told the group of people in the pre-dialysis seminar "that if we decided not to do dialysis, they would take care of us, and know that there was another way. They didn't have to do dialysis. The woman next to me perked up at this, not realizing that the other way was palliative care." In both cases, the participants had to infer that hospice was an option and they had to approach their providers to discuss it first. In fact, a recent meta-analysis reports that providers often do not discuss palliative care with patients before dialysis is initiated (Fassett et al., 2011). However, providers are willing to discuss discontinuing dialysis and palliative care when patients ask about it directly. For example, Jacob decided at one point to discontinue dialysis due to severe depression: "I was just inches away, I had already prepared everything; I was ready to quit dialysis completely. I was *so* unhappy." He went to the social worker at his dialysis clinic, who convened a meeting with the nephrologist and the office manager at the clinic: "They talked to me for a little while, not a whole lot of pressure, just talking to me. And then she had the doctor ready to go, I went back in the exam room and he came in a couple minutes later, everything's happening very quickly. [And then I realized] 'Oh wait, Jacob, this is not just you doing something to yourself.'" Jacob decided to continue his dialysis treatments after that meeting.

Interestingly, the data shows that interactions with providers do not greatly influence disclosure of personal

health information in online support groups. For example, when Laura told her doctors about starting a website for CKD patients, their reaction was mostly positive; however, as she says, “They told me I wasn’t allowed to reference the hospital itself, or any of the staff that works at the hospital. As long as it was all about me and my experience with failing kidneys and on dialysis, and it wasn’t hospital specific, then I was okay to do it.” I ask her if they explained why, and she says, “I guess it’s because of the fear of any bad PR. That’s what I said anyway. I said I wouldn’t. I just said, just so you know, I would never speak badly about the hospital or any of the staff. The website wasn’t as a form of complaining. It was more of a form of positivity and supporting other people and making them feel that they’re not alone, and that there’s someone else that understands.” Candice explains that “what I say online is my business, and I’m not sure it’s really something the doctor wants to hear about. There’s so much else to get through when I’m there in terms of topics that I want to know about and what he needs from me.”

Time pressure

Although some specific topics are either thought of as off-limits or as ones that cannot be addressed by providers, multiple participants say that time pressure is the primary reason that they can’t get as much information out of their providers as they would like, so they turn to the Internet to supplement these interactions. This finding is also a popular complaint in general, noted both in the popular media (Varney, 2012) and in the scholarly literature (Gulbrandsen et al., 2012; Sampson et al., 2013). In these situations, participants in this study say that they often turn to the Internet as a source for information. Brent expounds on this:

It’s a time element—you only have so much time to see a doctor. Unless you go in there with a script, and even then they’re probably not, they probably don’t have that much time for you. It’s a 15-minute consultation. You can usually cover, maybe a couple of topics. So they leave it to something like the posts on the DaVita website, to get answers.

As a salient example of this issue, here is what happened to Steve after being released from the hospital – where he had been diagnosed with ESRD and had been placed on emergency dialysis:

I had, like, a billion questions. And the first month, the doctor would come through [the dialysis clinic] and spend literally five to seven seconds with each patient. And I was like, *woah*. So I called his office, and I said, “I would really like an appointment in-office. I’ve got a lot of questions.” And they’re like, “Ok! Here’s an appointment in a month and a half.” I’m like, “A month and a half! I’m like, I’m really, I don’t know what’s going on. I-I-I really have a lot of questions, this is really,

you know, important to me.” And they said, “Hold on; let me talk to the doctor.” And they said, “Oh, we talked to the doctor, he doesn’t need to see you right away.” A month and a half.

Steve went online to ask whether or not this was customary, and he quickly switched nephrologists after learning from other patients with CKD that this provider’s behavior was not standard; he could get more support from his providers as he navigated his diagnosis and treatment.

Overload

Because visits with healthcare providers are so short, participants frequently mention feeling overloaded when they see their doctor. Travis explains:

You go into a doctor’s office and you start talking, they give you all kinds of information and it’s kind of information overload. So for me I said, well, I’m going to go, I went on the Mayo Clinic website. I want, anything, I put in kidney issues, to see what popped up.

For Travis, the nature of the doctor’s visit—it’s short, rapid-fire, and does not allow him time to process information—drives him to go online for health information. Joan actually does not use her providers as an information resource due to how much anxiety she has when visiting the office. She explains that “it’s not something you want to be reminded of” and that going to the nephrologist’s office, or having her blood drawn every month, is “a constant reminder that you’re kind of in a fragile condition and it can be very perilous and, it’s a scary thing to be constantly reminded of your mortality.” Visiting providers is particularly difficult for Joan, because, as she says, “I have never spoken to anyone who deals with CKD patients who has EVER painted a rosy picture. My nephrologist flat-out told me that FSGS is ‘a horrible disease.’” When asked about discussing dialysis options with her nephrologist, she says:

I hated going to the nephrologist. I hated, hated, hated the whole process of having to get labs done, and then waiting that horrible, horrible week, until you go get the results, and you have absolutely no idea. No idea.... So when I went to get my results, if I saw that my creatinine was still at a certain level, and my [glomerular filtration rate] was still above 20, I just wanted to get out of there. I didn’t want to discuss dialysis with him. I just wanted. Out. And I could breathe a sigh of relief and come home, and in my own time, when my nerves I thought could take it, then I would go online and do my research myself.

Like Travis, Joan goes online so that she can process the information on her own time and at her own pace. Candice, too, discusses how overloaded she feels at her doctor’s appointments, largely because she—like many patients—is unable to process medical terminology at a rapid pace:

They start using terminology that only doctors understand and the general populous don't. That's what I mean. That happens in the doctor's. They'll start to speak and forget that that patient does not understand your lingo.... some of that is still over me and I don't understand what those words mean.... This is beyond me, too much. Then, I go to the Mayo Clinic [website] and back to WebMD where I can understand what they're saying. They put it in a way that takes all of the big words and puts them into people words.

Therefore, some of the participants in this study go online to search for information as a way to manage information overload and as a method for learning things that their doctors "can't or won't tell them," as Nina says. Amy, too, searches for information online as a way to better understand her interactions with healthcare providers: "First thing I do when I come from any of the doctors I see is sit down and Google and stuff to see, to get more understanding, so that the next time I go I have more understanding to be able to ask better questions." This is an example of crosschecking, or consulting multiple sources for information as a way to verify information and as a way to gain clarity about what the information means. Crosschecking will be explicated in more detail below.

Healthcare system

The dismissive attitude that so many participants mention is also directly related to the healthcare system in the United States. This may not be as much of an issue in countries with healthcare systems that are not based on a private health insurance model; both Gretchen and Laura are in countries that use a single-payer healthcare model, and they both remark that their experiences seem very different from the experiences shared by most members on the forums.

In the United States, providers spend less than 15 minutes on average with patients, and the healthcare system is not focused on preventive care (Farley, Dalal, Mostashari, & Frieden, 2010). As Jacob observes, "They're just going complaint to diagnosis, or complaint to treatment, and not really sharing the diagnoses or what the issues are going to be." In fact, there are multiple examples in the data of participants losing access to health insurance and subsequently losing function of their kidneys. For example, when one of the participants lost his health insurance due to his divorce, he was unable to continue paying for his blood pressure medication or for his annual visits to the doctor. He discontinued taking his medication and his blood pressure rose again, and within six months he was diagnosed with ESRD. He tells me that he did not know that high blood pressure caused kidney failure. Another participant lost his kidney transplant because he was unable to pay for his antirejection medications; he is now back on dialysis.

In both of these examples, there were clear communication breakdowns between participants and their respective

providers. A larger focus on preventive care—particularly for patients who already have issues like high blood pressure, pre-diabetes, and a history of kidney issues – may be necessary, as illustrated by the stories told by the participants in this study. Unfortunately, there is a dearth of research on information exchange and communication during follow-ups after treatment initiation—not just in CKD, but in other chronic illnesses as well (e.g., Bakker, Fitch, Gray, Reed, & Bennett, 2001). As Jacob says, "All I was told [for 40 years] was, 'Well, you've got suspicious things going on with your kidneys.' It wasn't until my kidneys failed that I finally started going backwards and piecing the puzzle together.... Nobody really sat me down and told me what was happening." Because of this, Jacob became a dialysis patient advocate.

Furthermore, the healthcare system in the United States is highly fragmented. This also influences information behaviors. As Nina says, "the body works together as a whole, but our medical system tries to break us down into some kind of production line or something and that's not how the body works." For example, participants may not see the same doctors every time they visit. Amy explains: "Unfortunately because of my insurance I see a lot of residents, and they rotate in and out and so you don't have much continuum of care with them. Depending on who comes in, sometimes they listen to you, sometimes they don't." Research shows building a relationship with a specific provider over time enhances communication between the patient and the provider (e.g., Katz, McCoy, & Sarrazin, 2014; Piette, Schillinger, Potter, & Heisler, 2003), and participants who visit teaching hospitals or who are on Medicare say that they feel that they are at a disadvantage because they lack continuity with their providers.

Steve posits that providers don't discuss hospice with patients "because then they don't make money. It's a business. Dialysis is a business, and hospice terminates that income for that person. That is my true belief." This is unfortunately substantiated by the medical literature (e.g., Cabin, Himmelstein, & Woolhandler, 2014), and is likely one of the reasons that in-center hemodialysis is the most popular modality in the United States. Steve expands: "I know that in-center hemodialysis is the hardest on your body. But it's a business. They try to get as many people in and out of the chairs as possible." In fact, Jacob also mentions feeling like the patients were treated like "cattle" at his first dialysis clinic; he says this feeling greatly contributed to his depression and was a large factor when he considered stopping dialysis. Robert, too, discusses this issue: "unfortunately, in-center dialysis is warehouse dialysis. It is a production line." Both Robert and Jacob switched dialysis clinics because of their poor treatment; all three men have considered going on home hemodialysis, but none of them have care partners at home and are therefore ineligible for at-home hemodialysis at this time. Robert, however, is on nocturnal dialysis in a clinic, and he

finds this experience to be vastly preferable to in-center hemodialysis during the day.

The “business” of dialysis is a common thread on the forums and in interviews; it elicits a visceral, emotional response when people discuss it: “Dialysis, it’s about the money. It’s about following the money and it’s a big business. How do you take that out of it? I don’t know. What are you going to do, you’ve got a total of 400,000 now, patients on dialysis. It’s only going to get bigger, and they’re only going to profit more,” one participant explains. Another says, “It’s this for-profit type of setup. It’s unbelievable.” Another participant says, with anger in his voice: “In-center dialysis is the patient-centered way of care? Hah. It’s the PROFITABLE way of delivering care!” For-profit dialysis organizations, both large and small, provide at least 81% of dialysis care in the country (US Renal Data System, 2014).

Crosschecking information

Participants often consult multiple sources as a way to verify information. Gretchen calls this *crosschecking*, and all participants engage in this activity in one form or another. Crosschecking is a routine activity that participants report carrying out with almost all of the information they receive about CKD. In fact, Gretchen is clear that the activity is agnostic as to the source: “After you read a couple of somebody’s posts and you can crosscheck on Google or with your doctor or whatever. Then you can get the gist of, yes, they seem to know what they’re talking about and the risk of their post.” Therefore, it does not only occur with information from providers; participants also describe crosschecking information from one online source with information from other online sources; they also may check information from the doctor with online sources as well. In this section, causes of crosschecking related to patient-provider interactions will be discussed, examples of the activity will be presented, and the consequences of the behavior will be addressed.

One motivating factor for crosschecking information from a provider is a dismissive response from that provider. For example, Joan lived with “discomfort or downright pain” in her arm after her fistula was placed. As she describes on the forum: “There has not been a single day where my arm has not felt like it was being burned, being pricked, being bruised, or being pinched. Even as I type this, FOUR YEARS LATER it aches.” After receiving a pre-emptive transplant, Joan decided to look into fistula ligation—although she may someday still need it if her transplant ceases to function. The standard practice in the United States is to keep the fistula without tying it off in case it is needed again in the future (Aitken & Kingsmore, 2014). She inquired about this at an appointment with her GP for an unrelated issue:

And he said, “You know, you might want to think about tying that off.” And I said, “Yeah, but what if I need it? What if my transplant fails?” And he

said, “Well, that’s a risk you have to take.” And I thought, “You know? That’s a little bit nonchalant.”

Joan then consulted the forums, went to her nephrologist after that was suggested by other patients online, and eventually met with a vascular surgeon in order to determine what to do. She had the fistula ligated and, as she describes her decision on the forums: “My arm has been bothering me for four years now, and the very idea that a 15 minute procedure performed as day surgery could ‘make this all go away,’ as he put it, delights me. Most nights the whole area between my armpit and my elbow just aches. I thought this was all part of it, that it was the nature of this particular beast, but I was mistaken.” Had her doctor not initially replied in a nonchalant manner, Joan may have continued to put off asking on the forums and eventually other providers about her fistula, which was not only causing her pain but was putting her at risk for cardiac failure.

Many participants use their doctors as a source for crosschecking information they find online; this activity is, in fact, common for many patients with chronic illnesses (Morahan-Martin, 2004). It does not just occur when participants have negative interactions with providers. For example, Steve says, “My doctor knows exactly which forum I get most of my information from. And I print articles – I don’t understand a lot of the chemistry, so I will print articles that I found on the forums and have him explain them to me.” Sherri, too, brings articles from medical journals to her doctor; she also has read articles with the doctor during her visits:

In a couple of situations, she pulled up an article right on her computer and we read it together and discussed it. She printed out the reference list so I could go look up some of the, not only that article, so I could have my own copy, but all the major researchers that this author was citing, I could kind of find out what they’re doing and look at some of the key terms.

This indicates that Sherri not only crosschecks what she finds online with her provider, but that this activity spurs further searching and learning on her own. In fact, multiple participants say that their providers encourage them to use the Internet to search for health information: Amy’s doctor “pushed” her to read the National Kidney Foundation website, and one resident that Nina spoke with encouraged her use of the Internet for health information:

I said something like “I know you doctors probably hate this, when people come in talking about something they read on the Internet,” and he was very surprising. He said, “No, no. That’s *fine*,” he said, and he was very, like, encouraging. And that kind of surprised me.

In fact, participants in this study report that their providers typically respond positively to online information, but with a cautionary tone: “They tell me to be careful of what I read, but they’re still willing to answer my questions and either validate what I’m saying or giving me the reasons why what I read may not be for me,” says Amy. Encouraging patients to crosscheck information found online with the doctor is recommended in the literature (McMullan, 2006).

Importantly, participants stress that the information they get from providers has primacy in decision-making and self-care. As Amy says:

It’s not like what I read, I will follow that instead of what my doctors say. It just guides me more into exploring with my doctor, maybe, alternative things. I don’t use it as a Bible for, “This is what my healthcare should be doing.” It’s just, I use it for a basis to examine what’s going on in my life.

Travis, too, explains that he does not apply what he reads online to his own care before consulting with a provider:

There was something not too long ago and someone had some, “Oh! I cured my kidney problems and all this stuff and I was taking these holistic stuff and all these herbs and everything!” And I’m going, “Eh – (laughs) – I don’t think I’ll try that.” If I did, I’d still want to check with my doctor, because I have all the faith in trust in them.

Relatedly, many participants also mention running across misinformation about curing kidney disease online; the word “herb” is often present in these discussions, used as shorthand for information about holistic, homeopathic, or naturopathic treatments. Kidney disease cannot be cured; it can only be managed, so this information is erroneous and often dangerous. Amy expands:

Several nights a week I get a suggested post on Facebook on “37 days to healthy kidneys.” I tried to read it sometime and it was so outrageous. I get a lot of information on Facebook like that. And – yeah, right. I know doctors want to make money, but I can’t believe that if there was a way to [cure CKD] that doctors wouldn’t be jumping on the bandwagon!

It is clear that Amy is inherently skeptical of this type of information because it seems, as Candice puts it, “too good to be true.” Amy also says: “I have a high regard to the medical people. I don’t necessarily know that they’re always right, but I trust them more than the people that all they want to do is pawn off herbs on you.” In fact, Jacob says outright: “That herb stuff is total, unsubstantiated bullcrap. And I make a point, when I see that kind of stuff, I make a point to make sure that I reply.” Robert replies directly to a user on the forums who asks about herbal supplements to increase function; he says: “I suggest you read the following. No negativity, just a dose of reality.

Good luck.” This is followed by a list of six reputable links, and ends his comment with: “Also suggest you do an extensive SEARCH [here on the] message boards.” Here, Robert gently refutes the medical efficacy of herbal supplements by providing links to reputable sources online rather than confronting the person who asked the question.

Many participants are careful about refuting misinformation online. Sherri explains:

Well, what I’ve been doing from day one, is just ignoring it because what happens if you, even in any kind of a mild way, if you contradict a fanatic, they just get angry. They’re not open to any thoughts or ideas.... I don’t want to have to fight with people because I want to save my energy for all the things that I’m trying to do for myself. Their doctors can fight with them.

In these instances, Steve, Gretchen, and Sherri all pinpoint the importance of medical advice given by qualified healthcare providers in their discussions on refuting bad information they see online. This is in line with something that Amy says: “A lot of people post on these sites questions that should be answered by doctors, not by me.” This echoes Brent’s sentiment discussed earlier in this article: that many people go online with questions that are best answered by providers. Here, participants describe teaching other patients information literacy skills by explaining the process of crosschecking online health information with providers to them.

In fact, participants see the information they get on the forums as recommendations or as a jumping-off point; nearly all of them discuss the importance of verifying online information with their healthcare providers before making any decisions or changing their care. Travis explains: “I’m not just going to jump into something just because somebody says, ‘Oh, I tried this and it worked.’ Like I said, before I do that, I’d rather – as Reagan used to say – ‘Trust and verify.’” This process is a common thread throughout the data and is a finding that extends our understanding of how the type of information sought online might impact verification behaviors more generally (Flanagin & Metzger, 2000).

CONCLUSION

There are several factors that shape informational interactions with healthcare providers, as explicated in the data. First, many participants describe feeling dismissed by providers, especially when their information needs are complex or unusual or are related to curiosities rather than necessary information. There are also many topics that patients feel are unsuitable for providers: particularly sensitive or embarrassing questions and palliative care or hospice are all topics that participants mention as being difficult to discuss with providers. Time pressure, information overload, and the healthcare system also shape online health information behaviors.

It is important to determine the transferability of these findings to other illness contexts. While the results presented here are not intended to be generalizable due to the research methods used, the factors of patient-provider communication that influence online health information seeking uncovered in this analysis should be tested in other illness contexts and using other methods of data collection and analysis. For example, a large-scale survey study of the factors identified here could be employed. Another potential study could examine the role of Internet information in patient-provider interactions through a systematic review of the existing literature.

These results highlight the importance of effective communication between people diagnosed with CKD and their healthcare providers. They also demonstrate the relationship between online health information seeking and patient-provider communication. General strategies for effective communication with patients, particularly taking patient concerns seriously and developing an ongoing dialogue with patients is advice that is often repeated in the literature (e.g., Berry, 2006) that corroborates some of the findings presented here. Moreover, many participants feel that interactions with providers specifically regarding the communication of treatment options could be improved. In particular, multiple participants say that they learned about alternative options to in-center dialysis online—not from their healthcare providers. This aligns with the literature in this area, which shows that patients are often unaware that they have options when they initiate dialysis (Mollicone, Pulliam, & Lacson Jr, 2013). More comprehensive patient education is warranted with for CKD treatment options.

Providers can also actively encourage patients to crosscheck information by looking to see if it is repeated across sources. Although participants report crosschecking nearly all of the information they get from any source—stressing in particular that they do not implement anything they have read about online without first discussing it with a trusted provider—this activity may not always occur. Therefore, providers should encourage patients to verify information found online, especially when that information may be used to make treatment decisions. In this study, participants who felt dismissed by providers were less likely to use them as sources for crosschecking in future interactions, highlighting the necessity of a welcome attitude towards information seeking online.

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