

A SPECTRUM OF APPROACHES TO HEALTH INFORMATION INTERACTION: FROM AVOIDANCE TO  
VERIFICATION

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SUGGESTED RUNNING HEAD:  
SPECTRUM OF APPROACHES TO HEALTH INFORMATION

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## **A spectrum of approaches to health information interactions:**

### **From avoidance to verification**

#### ABSTRACT

People respond to illness in a range of ways, and take different approaches to engaging with health information throughout the course of their illness. This study describes and explains the variety of approaches to health information taken by patients on hemodialysis. Ethnographic observations (156 hours) were conducted in three hemodialysis clinics, and semi-structured interviews about health information were held with 28 patients. Demographic data were collected. Data were analyzed qualitatively. We found a spectrum of five approaches to health information: *avoiders*, who close themselves off from health information; *receivers*, who encounter information in the dialysis clinic but do not seek it out; *askers*, who only pose questions about health to their healthcare providers but otherwise do not seek; *seekers*, who actively look for health information both in and out of the clinic; and *verifiers*, who seek information and triangulate it among multiple sources. Trust in healthcare providers and coping sociality differed across approaches. Findings indicate that health information should be provided to patients using strategies tailored to their preferences and existing approaches to information interaction.

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## INTRODUCTION

Hemodialysis is a treatment for end-stage renal disease (ESRD), which occurs when one's kidneys are no longer working properly. It cannot be cured, but it can be treated with dialysis or a kidney transplant. Sixty-three percent of patients with kidney failure in the United States receive dialysis treatment in a hemodialysis clinic (United States Renal Data System, 2018), which requires patients to visit a clinic three days a week for approximately four hours each visit where they are connected to a dialysis machine that filters their blood (National Kidney Foundation, 2001). Hemodialysis patients experience frequent health crises, with three emergency room visits and almost two hospitalizations per patient-year on average (United States Renal Data System, 2018). Kidney failure and dialysis are stressful experiences, and patients on dialysis typically face ongoing health-related challenges and periods of stability punctuated with periods of decline (Jablonski, 2004).

Patients with ESRD have many information needs, including medical questions about treatment options, interpretation of test results, and dietary and fluid restrictions (Ormandy, 2008). They also have psychosocial concerns, such as whether they will be able to work, how to navigate social relationships and activities, and the desire to know how their life will change if and when they begin dialysis (Orsino, Cameron, Seidl, Mendelsohn, & Stewart, 2003). After the initial shock of diagnosis has passed, patients report developing new information needs that are largely psychosocial, such as how to manage uncertainty or cope with their compromised health, throughout the illness trajectory (Martin, Stone, Scott, & Brashers, 2010). Patients also seek

information about their treatment and illness from healthcare providers (HCPs), who are critical sources of information for medical questions in ESRD (Ormandy, 2008). However, trust in healthcare providers varies among patients (Armstrong et al., 2008), and may affect information interaction (Richardson, Allen, Xiao, & Vallone, 2012; Veinot, Campbell, Kruger, & Grodzinski, 2013).

While patients often gain psychosocial information about dialysis by experiencing dialysis and living in the information world of a dialysis clinic (Veinot, Meadowbrooke, Newman, Zheng, & Perry, 2010), some express the desire to visit clinics and meet with other patients before beginning dialysis in order to understand the process (Iles-Smith, 2005). Patients' desire for information provided by social peers has also been observed in other studies on kidney disease, and is present throughout the disease trajectory (Costello, 2017). Notably, in-center hemodialysis regularly puts patients in social situations with other patients (Costello, 2017). Peer-based information may help patients to manage emotions related to their conditions (Xiao, Sharman, Rao, & Upadhyaya, 2014), which has implications for their methods of coping with stress. Further, information seeking in kidney disease has been linked to sense-making (Godbold, 2013), medical decision-making (Winterbottom, Bekker, Conner, & Mooney, 2012), and patient empowerment (Costello, 2016). An understanding of how dialysis patients engage with health information will allow for the development of educational interventions to empower dialysis patients in coping with and making decisions about their care. Critically, understanding potentially-variable patterns of this information engagement can assist in the development of

interventions that are appropriate to each patient. Interventions that deliver tailored health information have been shown to increase patient comprehension (Kreuter, Strecher, & Glassman, 1999), patient satisfaction (Nguyen, Smets, Bol, Loos, & Van Weert, 2018) and improve health behaviors (Williams-Piehota, Schneider, Pizarro, Mowad, & Salovey, 2003). But such interventions typically focus on tailoring only the content of messages. Researchers have called for more nuanced approaches to tailoring based on the information preferences of patients, such as source and source presentation, rather than simply focusing on content (Nguyen et al., 2018). In kidney disease specifically there is a need for translational health information interventions that focus on adapting educational materials and that leverage the existing social networks of patients (Tuot et al., 2014). Design of such interventions would also be aided by understanding how trust in healthcare providers and other social relationships, such as with patient peers, may factor into patterns of hemodialysis patients' information interactions.

Therefore, the objectives of this study is to identify the approaches that patients on in-center hemodialysis take to interacting with health information, and to describe the social coping strategies and trust in healthcare providers observed in each approach. In this study, health information interaction includes: (1) Strategies for avoiding or seeking health information; (2) Preferences for and selection of health information sources; (3) What health information is used for.

## LITERATURE REVIEW

### *Health information styles*

The concept of patient empowerment, defined as “a process through which people gain greater control over decisions and actions affecting their health” (World Health Organization, 1998, p. 6) is an increasingly vital goal of healthcare both in the United States and throughout the world. Health information interaction is a necessary component of patient empowerment (Ende, Kazis, Ash, & Moskowitz, 1989; Roberts, 1999). Because empowerment has a positive effect on health outcomes (Trummer, Mueller, Nowak, Stidl, & Pelikan, 2006), many health interventions focus on fostering empowerment via information, either in the provision of information or in encouraging patients to actively seek out information on their own. In dialysis care, for example, educational interventions demonstrate that patient education can have a positive effect on health outcomes (e.g., Mason, Khunti, Stone, Farooqi, & Carr, 2008), and high levels of health information literacy in patients with kidney disease have been linked to greater self-efficacy, improved access to care, and lower mortality rates (Devraj et al., 2015).

For such interventions to positively impact all patients, however, it is necessary to understand how patients engage with health information (Noar, Benac, & Harris, 2007). Early research in health information interaction demonstrates that, broadly, people either seek or avoid health information; these two general styles have been conceptualized in the literature as “monitoring” and “blunting” (Baker, 1996). While theories in this domain acknowledge a continuum of information styles among patients, they often focus on those who are “actively interested in managing information and [who] intentionally engage cognitive and other resources toward that end” (Afifi & Weiner, 2004, p. 170). The active approaches of purposeful seeking and avoidance

are well-established in the literature (Brashers, Goldsmith, & Hsieh, 2002). Of course, a range of information styles exist (Bawden & Robinson, 2011). Individual variations in cancer information seeking, for example, cluster in five patterns: intense seekers, who look for as much information as possible; complementary seekers, who want to add to what they already know; fortuitous seekers, who consult other patients for health information; minimal seekers, who do not look for information on their own; and active avoiders, who find the experience so stressful that they actively avoid cancer information (Lambert, Loiselle, & Macdonald, 2009a, 2009b).

These clusters have not yet been examined in other health contexts, and “to date, distinct health-related information-seeking preferences have been understudied and underreported” (Loiselle, 2019, p. 5). Like patients with other health conditions, dialysis patients may either seek or avoid health information (Bonner & Lloyd, 2012). However, their small sample size (n=5) likely obscures the extent of variability in information styles present in this population. Triangulating data about health information interactions from multiple sources may afford the opportunity to uncover a larger range of information styles. This may be particularly true in dialysis, where patients are exposed to the information world of the clinic regularly (Veinot et al., 2010). We therefore ask:

RQ1: What varied approaches do people on hemodialysis take if and when they interact with health information?

*Influence of social coping strategies on information interaction*



A great deal of research exists that characterizes similarities and differences in information style, but this work is limited by being contextually bound, and is therefore perhaps “best regarded as [an indicator] of interesting avenues for further investigations, particularly for direct attempts at correlation of information behavior with [individual] traits” (Bawden & Robinson, 2011, p. 134).

Two individual traits that are often explored are personality and cognitive style, but few studies have examined how information behavior is related to social interaction or other social traits.

Health information interaction can be understood as a coping activity, and coping is often a social act that can occur in social environments. In addition, many stressors have interpersonal components, and coping efforts often require interpersonal interaction or have social consequences (Dunahoo, Hobfoll, Monnier, Hulsizer, & Johnson, 1998). The same is true of information interaction, especially when it is understood as a coping strategy for managing illness uncertainty. Although existing research has separately considered the social and interactive nature of both coping and information interaction, these concepts have not yet been considered in concert. Dialysis is an ideal site of inquiry for this investigation, as it requires patients to have regular, frequent social and informational interactions with healthcare providers and other patients, and the porous boundaries of the clinic allow for information interaction outside its walls (Veinot et al., 2010; Veinot & Pierce, in press). Like many chronic health conditions, ESRD is also shaped by social factors, such as perceived and enacted social support, family caregiver dynamics, and the role of healthcare providers and other patients; in dialysis patients, social support is associated with increased patient satisfaction, better quality of life, and

decreased hospital admissions (Plantinga et al., 2010). But unfortunately, isolation is a common issue for ESRD patients throughout the illness trajectory (Kierans, 2005). Extreme fatigue, dialysis treatment schedules, and the fear of burdening others makes it difficult for patients to socialize with friends or to continue education or employment (Tong et al., 2009). The social networks of patients on dialysis tend to get smaller over time; however, as friends and work colleagues drift away, the number of family members in one's network remains stable (Neumann, Lamprecht, Robinski, Mau, & Girndt, 2018).

We therefore consider the social dimension of coping and information interaction together by examining information style through the lens of social coping theory. Social coping theory demonstrates that coping strategies do not exist only on a spectrum of *passive* to *active*; they also have a social dimension ranging from *antisocial* to *prosocial* (Hobfoll, Dunahoo, Ben-Porath, & Monnier, 1994). The social coping framework de-emphasizes individual emotions experienced while coping (e.g., uncertainty management arising from information seeking or avoidance) and instead focuses on socio-behavioral strategies employed by participants in their social interactions. Examples of activity and sociality derived from the theoretical framework are listed in Table 1.

*Table 1. Examples of activity and sociality in social coping theory.*

<b>Activity (active/passive)</b>	
<i>Very active</i>	Aggressive Holds ground in decision-making Takes charge of situations

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	Tenacious
<i>Somewhat active</i>	Depends on self and personal strengths Evaluates choices, but doesn't hesitate too long Trusts instincts
<i>Somewhat passive</i>	Cautious Deals with things as they come Does things to distract self from problems Thinks "better safe than sorry"
<i>Very passive</i>	Feels resigned Hopes problems will go away on their own Moves on to other things due to lack of hope Retreats from problems

**Sociality (prosocial/antisocial)**

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<i>Prosocial</i>	Checks with others to see what they would do Flexible Helps others in similar situations Solves problems in a group
<i>Asocial</i>	Allows others think they are in control Depends on self but takes others' opinions into account
<i>Antisocial</i>	Catches others off-guard Does not consider the needs/feelings of others Independent

We also examine information seeking and social coping behavior in terms of trust in others, which may impact the sociality of information interactions. Patients are more likely to seek out health information from people they trust, for trust in people can extend to trust in the information they produce (Sztompka, 1999). Prior research shows that trust influences health information source selection (Costello, 2017; Veinot, Campbell, Kruger, & Grodzinski, 2013), and trusted sources are more relied upon than untrusted sources in health-decision making. Furthermore, in cancer patients, trust in HCPs has been shown to lead to avoidance of other

information (Germei & Schulz, 2014); it is has also been shown to be a mediator of uncertainty in illness (Mishel & Braden, 1988).

Most studies focus on the role that interpersonal interactions play as sources for health information (e.g., Afifi & Weiner, 2004); in contrast, we focus on the general social strategies participants take when interacting with others, as well as their level of trust in others, in order to potentially inform how we understand the multiple dimensions of information interaction approaches in health behaviors. Therefore, we ask:

RQ2: Do social coping strategies and trust in others relate to the varied approaches people on hemodialysis take when they interact with health information, as identified in RQ1? If so, how?

## METHODS

### *Data collection*

#### *Observations*

We conducted a multi-sited ethnography at three outpatient hemodialysis clinics (one urban, one suburban, and one rural) in a Midwestern state from 2009-2010. Ethnographic observation was conducted for 156 hours in the three clinics (51–53 hours per clinic); the researcher adopted a non-member role (DeWalt & DeWalt, 2002). Oral informed consent was obtained from 173 patients for the observations. Because dialysis occurred in thrice-weekly “shifts” in morning and afternoon at study clinics, we triangulated data (Flick, 2007) by observing clinic activity in mornings and afternoons and on different days of the week. We observed interactions in the two main patient care regions of the clinics: the waiting room and the dialysis room. Informal

interviewing (DeWalt & DeWalt, 2002) was conducted intermittently to clarify evolving understandings. During observations, the researcher kept “jottings” from which in-depth field notes were later constructed (Emerson, Fretz, & Shaw, 1995). Observations concluded when saturation was achieved in each site.

### *Interviews*

In-depth, semi-structured interviews (Hesse-Biber, 2006) were conducted with 28 of the observed patients. Interviews, which averaged 2 hours and 28 minutes, focused on their experiences of hemodialysis, their methods of coping with illness, their information interactions both inside and outside of the clinic, and their social interactions both inside and outside of the clinic. Interviews were audio-recorded, transcribed verbatim, and verified. Patients also completed a brief demographic survey at the interview. Participants were theoretically sampled (Schensul & LeCompte, 2013) based on clinic observations, in which variability in patient behavior was noted. Behaviors ranged from full engagement (active conversations with other patients and staff) to moderate engagement (quiet but actively observing activity in the clinic) to detachment (neither interacting with nor observing others). Interviews were conducted in the dialysis clinic, as patients dialyzed. Pseudonyms were assigned to each participant for analysis.

### *Demographic Survey*

Interview participants completed a survey that indicated their exact age, their gender (male/female), their race/ethnicity (White, Black, Asian/Pacific Islander, Native American, Hispanic/Latino), and their education level. As shown in Table 2, the mean age of participants

was 67, and most (64.2%) were white. Participants were roughly equally proportioned by gender and by education level. The Institutional Review Board of the University of Michigan approved the study.

*Table 2. Demographic characteristics of participants.*

	<b>Total (n=28)</b>
<b>Age (Mean (S.D.))</b>	67.1 (12.3)
<b>Years on dialysis</b>	4.5 (4.9)
<b>Race/Ethnicity (n (%))</b>	
White	18 (64.2%)
Black	8 (28.6%)
Asian	1 (3.6%)
Native American	1 (3.6%)
<b>Gender</b>	
Female	13 (46.4%)
Male	15 (53.6%)
<b>Education level</b>	
High school or less	13 (46.4%)
Beyond high school	14 (50%)
<b>Clinic</b>	
Rural	10 (35.7%)
Suburban	8 (28.6%)
Urban	10 (35.7%)

### *Data analysis*

Interview data and field notes were analyzed qualitatively using emic/etic coding and the constant comparative method, moving from open coding to focused coding as the research progressed (Miles & Huberman, 1994). Our research draws on the constructivist tradition, addressing questions about the causes, consequences, and conditions under which certain information interactions occur, with a focus on the cognitive-affective processes our participants

undergo as they make sense of the world (Charmaz, 2014). As is common in qualitative analysis, sensitizing concepts—including information interactions (e.g., information styles, source selection, and information use), social coping, and trust in healthcare providers—were identified and shaped the analysis as it progressed. To address RQ1, the researchers inductively analyzed interview responses about and in-clinic observations of health information experiences and encounters, guided by the existing literature on information styles, including discussions about what health information (if any) participants exchanged with friends, family members, and healthcare providers; what sources they used for health information; where they encountered and searched for health information; and whether and how they used health information.

To answer RQ2, at the close of each interview participants were asked a series of questions about the people they mentioned during the interview, including the amount and frequency of contact, social support exchanged, health information exchanged, and closeness of the relationship. These responses and related interview and observation data were analyzed deductively using social coping theory (Table 1) to determine the activity and sociality of the information approaches identified in RQ1. Interview responses and in-clinic observations were inductively analyzed to assess trust in HCPs.

Analytic memos were created to track the analysis as it moved up the analytic chain from coding to grouping the codes into categories and constructs related to the patterns of health information interaction described by participants. In naturalistic research, traditional verification techniques, such as intercoder reliability statistics, are not used. Instead, trustworthiness is the goal for

naturalistic, interpretive studies (Lincoln & Guba, 1985). Peer debriefing and memoing are both accepted methods for enhancing the trustworthiness of analysis; in this study, the research team met biweekly throughout the first year of analysis to discuss the results as they progressed. These meetings included discussions about the research process, related sensitizing concepts, and negative cases.

## RESULTS

### ***RQ1: Health information interaction approaches***

Participants take five distinct approaches to interacting with health information; these approaches can be arranged along a spectrum according to the amount of interactivity, which is defined by the number and type of sources consulted in the information seeking process (Figure 1).

**Avoiders** close themselves off from health information and often rely on a proxy to manage illness information. **Receivers** encounter health information in the dialysis clinic rather than seeking health information. **Askers** pose questions to their HCPs, but otherwise do not seek out health information. **Seekers** engage in active information acquisition both in and out of the dialysis clinic. **Verifiers** seek health information from multiple sources, comparing and contrasting it in order to verify what they have learned.

In general, most of the strategies for information seeking, the source/locations of information sought, and information use that are reported by participants with lower amounts of activity are also used by all patients with higher levels of activity; these are listed using italics in Figure 1. For example, seekers get information using the same methods used by receivers and askers (like



receivers, they listen to clinic interactions or otherwise encounter information in the clinic; like askers, they ask questions of HCPs); they also add strategies, such as consulting external sources, such as books, classes, and workshops offered by the clinic or by the National Kidney Foundation. The exception is avoiders; the strategies they use to interact with health information (such as relying on a healthcare proxy) are not reported by other participants. The following section describes each approach in detail.

<b>Avoiders</b>	<ul style="list-style-type: none"><li>• <b>Seeking</b> N/A.</li><li>• <b>Sources</b> Proxies.</li><li>• <b>Use</b> N/A.</li></ul>
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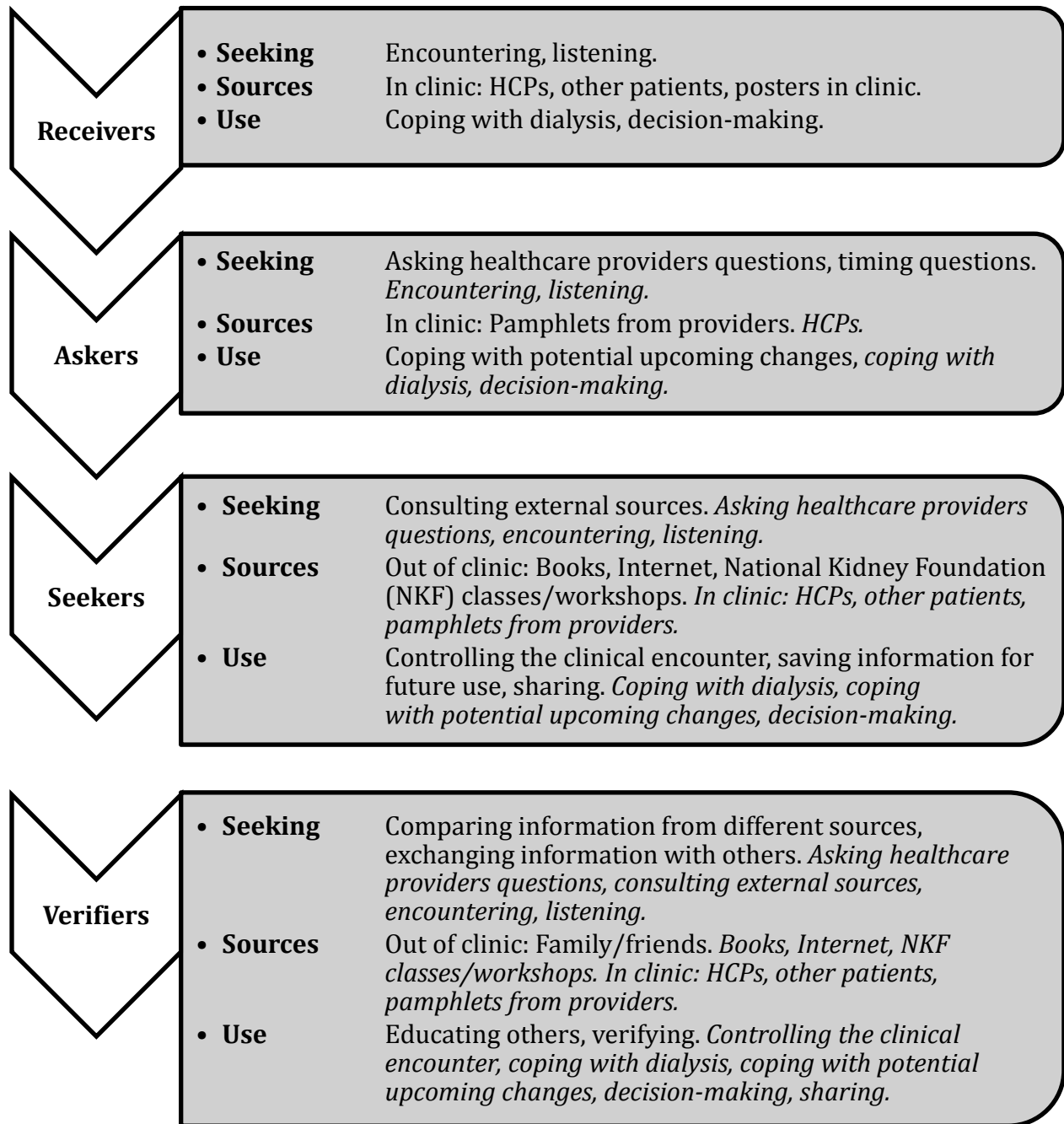


Figure 1: A spectrum of approaches to health information interaction.

*Avoiders*

Avoiders do not seek out health information, nor do they discuss using health information in their daily lives. They also do not pay attention during their dialysis treatment, preferring instead to watch television or sleep. Avoiders report feeling disengaged and disillusioned about their condition, and they absorb little during interactions with HCPs; they were observed not asking questions when given new medications or when asked by providers if they had questions.

Clayton says: *“Really, nobody’s explained to me what’s going on, but I guess there isn’t really much explanation to it.”* He says that rather than seeking out information, *“you just...suffer your way through it.”* For example, during physician rounds, Clayton told his physician that he was not feeling well on dialysis, but he did not seek information about reasons for his condition; he instead accepted the physician’s lack of follow-up regarding his concerns:

*Physician: “How are you feeling on dialysis?”*

*Clayton: “OK, not great.”*

*Physician: [inaudible]*

*Clayton: “It’s OK, I guess.”*

*Physician: “How is your breathing? Let’s listen.” [Physician listens with the stethoscope at the patient’s back for a minute, then speaks.]*

*Physician: “Sounds pretty good.”*

*Clayton: “OK.”*

*[Physician leaves]*

In the clinic, avoiders don’t turn to other patients for health information. They may make small talk with other patients, but, as David says, *“The subject [of kidney disease] don’t ever come up.”* Adam describes: *“Most [of the other patients] don’t have any mutual things going on. You run in here, get your treatment, go your merry way.”* They are disengaged with dialysis; by

extension, and perhaps by necessity, they often have a proxy in their social network that coordinates their care in general. For example, David says that he was “*out of his mind*” when he started dialysis, and that caused him to avoid information about the disease, or even diagnosis: “*I was probably [sick for awhile] but I didn’t tell anybody.... [My wife] noticed...that I wasn’t well and she took me to the doctor. She brought me.*”

### *Receivers*

In contrast to avoiders, receivers do engage with health information, but only information that they encounter in the clinic. Health information is “*already there,*” (a phrase used by several receivers); and receivers say that if they need new information it will be provided for them—often before they even know they need it. Henry explains: “*I take information, of course, all the time, and I get pamphlets, so, I usually read those.*” While he pays attention to the results of his blood tests and other tests, he doesn’t ask questions about them: “*If [the doctor] came around here, everything’s perfect. He’ll shake my hand and say ‘How are you?’ and he’ll listen to my lungs and heart, ‘See you next time.’ Same way with the dietician, she comes around, and I don’t, no questions.*” Here, Henry demonstrates the passive strategy of receivers: he is cautious and deals with information when it comes to him. Receivers like Henry get health information from a variety of sources in the clinic: HCPs, other patients, clinic-provided literature, and posters on walls. Patricia says: “*...they have a little something out on the bulletin board about not shortening your dialysis time. So, that’s how I figured...I better keep going as long as I can....*” She learns dietary information from the bulletin board and from a monthly laboratory

report. For receivers, the clinic is an information world, and interactions within the clinic convey enough information to meet their needs. Theresa explains that she received information from the clinic when she first began dialysis, which she read: *“they gave us some hints, you know, on things to do and not do, and that was helpful.”*

Receivers focus on keeping their kidney disease *“under control”* and on *“coping”* with dialysis by following the doctor’s instructions. When asked if he has questions for his doctors, Henry says: *“...everything seems to be going alright, so I just cope with it.”* Patricia says that she doesn’t have questions *“As long as it can be kept under control.”* Again, this demonstrates receivers’ somewhat passive and cautious attitude toward information. Reflecting this, in a conversation with another patient, Patricia indicates her tolerance for uncertainty regarding her impending surgery:

*Keith: “Hey, how’s your fistula working?”*

*Patricia: “Well, I’m having surgery again.”*

*Keith: “Oh, where at?”*

*Patricia: “Umm. . . . [pauses] They’re going to move it to a new place.”*

*Keith: “And the reason they thought to do that now?”*

*Patricia: “I don’t know. Between [nephrologist NAME] and them, it’s a big puzzle!”*

*Keith: “When are they doing the surgery?”*

*Patricia: “Oh, pretty soon.”*

#### *Askers*

Askers actively seek out health information from HCPs in the clinic; as George says, *“You’re doing what you’re supposed to be doing and you need any questions answered, you talk to the*

*people that's doing it.*" They inquire about things that are happening to them during their treatment. For example, Betty asked about her blood pressure each time it was taken:

*[Betty is gazing straight in front of her while the technician takes her standing blood pressure; technician is standing by the dialysis machine, watching the monitor; after a minute, she speaks]*

*Technician: "OK, go ahead and have a seat."*

*[Betty sits down carefully]*

*Betty: "What's my blood pressure?"*

*Technician: "165 over 73—that's very good."*

*Betty: "I'm happy about that."*

For askers, an important part of information seeking is timing questions appropriately; they tend to ask their questions in-clinic, when the opportunity arises. This strategy is somewhat passive, as it requires that providers approach them, allowing them to deal with information as it comes. Sadie describes: *"How I found out about different things was...talking to... the nurses. We would ask questions about... 'Why you got to go three or four hours?' or... 'Why is it they have a graft or a fistula?'"* Askers seek out information primarily from HCPs, but they also receive information without asking, via the clinic's "informing routines" (sources like pamphlets or handouts from the dietician), as described in the section on receivers (Veinot et al., 2010). Like receivers, askers do not seek information outside the clinic. When asked if she might ever use the Internet for health information, Betty says: *"I have not had any questions that [my HCPs] didn't answer for me.... Really!"* Information is often deemed irrelevant or not useful by askers if it does not come from healthcare providers. Cathy says that before she started her treatment, her

daughter-in-law gave her information that she found online about dialysis: *“She told me I was a candidate for dialysis... way back. I didn’t believe it, but it come to pass.”*

Askers seek out information primarily when they are monitoring their health status or making health-related decisions. For example, Gail was considering home hemodialysis at one point, and she says: *“I talked to the social worker here [about it]...she gave me information and I read all that and then one of the nurses from that unit came over and sat down and we talked about it.”*

Like Gail, Betty is likely to ask questions of providers when there are potential or actual changes in her treatment. She doesn’t currently have questions for her doctor, but she says, *“I might in the future,”* since she recently started a new drug.

#### *Seekers*

Unlike askers and receivers, seekers see information acquisition as an active, deliberate act that occurs both in and out of the dialysis clinic: *“When I was first diagnosed,”* Mary says, *“I drove the Kidney Foundation nuts with them sending me packages of information.”* Seekers actively look for information during times of decision-making and illness transitions. Myron says, *“If I had to...go through any more...something serious...I would [look for information and support] because...every now and then I do need a little help.”* Laura uses the Internet to find information about kidney disease and shares her findings with other patients and friends; the Internet is a popular source for seekers, but they also consult print sources, such as booklets and NKF pamphlets. Seekers typically also seek out health-related information from other people—HCPs, friends, and family members. Like askers, seekers ask questions of their HCPs in the clinic: *“I*



*asked different questions [back when I first started dialysis. The technicians] told me different things about it, the temperature...I will ask questions,*” says Donald. Like receivers and askers, seekers also encounter health information: *“Any place, any time I hear something, somebody talk about dialysis, or kidney disease...my ears open up,”* says Donna. Myron describes the same behavior: *“Every time...somebody...talking about dialysis or kidney failure, I’m all ears...”*

Seekers use information to manage their health, to understand their treatment, and to control clinical encounters or influence their care. For example, Lewis describes: *“You’ve got to learn this machine... That machine is going to tell you everything that’s gonna happen to you... they’ve already clumped us all into one group. Learning the machine is your way of individualizing yourself.”* He also says that his information seeking helps differentiate him from other patients and can be used as a tool to control the clinical encounter: *“When I started suffering is when I started saying, ‘Wait a minute, hold on, how much fluid you taking off today?’”* In addition to looking for health information from a variety of sources, seekers also share information with other patients, and they may encourage them to also seek out health information on their own. Lewis explains: *“When I see a new person, my main thing is always to tell them, ‘Learn everything you can about this procedure.’ That’s going to be the key to comfort. That’s going to be the key to survival.”*

#### *Verifiers*

Like seekers, verifiers engage in a wide variety of information seeking behaviors: asking questions of their providers, encountering health information in the dialysis clinic, and

exchanging and sharing health information with other patients. For example, Gary gets information from multiple sources to make decisions about his health: “[*If I had to make a decision about my treatment*] I’d get a bunch of answers so I could make a decent decision in my head... the more information I can get, the better it is.” In addition to these behaviors, verifiers routinely consult multiple sources in order to develop knowledge and to check the accuracy of what they are learning, which differentiates them from seekers. Keith says,

*I looked up all kinds of aspects of [kidney disease]. And side effects .... some reports I could understand. Some, I don’t know what the heck they were talking about.... All of them had something. And then the more you read something, then you start understanding what the other person is talking about.*

Another reason that verifiers seek out health information is to verify or ask questions about recommendations made by healthcare providers. They may even print out information from the Internet and bring it to the clinic to discuss. When Sabine was having trouble with neuropathy, she went online after speaking with her doctor: “...he gave me a prescription for sleeping pills. Well, I’m not taking sleeping pills. So, next time went to see him, I said, “Look, I got on the Internet... he said, (gasps) threw up his hands like this (gasps), “Don’t ever go on the Internet for that!” Despite this recommendation, she continues to verify health information, not just online but with friends, family, and other HCPs. Similarly, when Edith was asked what she does with information she gets from her doctor, she says, “I... go talk to my daughter...she’s in the medical field.” Verifiers primarily assess credibility by repetition across sources: “when you go on the Internet, and you look up information... [and] you go someplace else... and they’re all saying the same thing...somebody got to be telling the truth about something.” To double-check

the information they have about their health, some verifiers may also monitor their dialysis machine's display during treatment, thus checking the accuracy of their clinical records:

*Keith: ...when I was in the hospital, they said the number was 1.8. But then when I got here later, they said it was 2.23. What's in my chart?"*

*Nurse: "Well...if that's the number they gave you, then that's what'll be in the system."*

*Keith: "The hospital seems like they're saying something different."*

*[Nurse walks over to the rack of chart books, pulls one out, and brings it back]*

*Nurse: "So that was on the 17th? We got 2.23?"*

*Keith: "Yeah."*

*Nurse: "And they got 1.8?"*

*Keith: "Yeah, I think."*

*Nurse: "Huh. And here that is, too. Well, 1.9."*

*Keith: "Oh, that was it, 1.9."*

*Nurse: "Not sure why theirs is in here. Maybe it got transferred into our system?"*

*Keith: "Would that happen?"*

*Nurse: "I'm not sure. I'll look into it for you."*

*Keith: "Thanks."*

The primary function of verification is to assess the quality and accuracy of a particular piece of information, but it is also used to translate or make sense of information, to satisfy curiosity, and to foster learning. Verifiers have confidence in their abilities to find and evaluate information:

*"You can always find the resources," Crystal says. "It's always out there." Gary says that he uses information to make choices about his health: "Basically to me it's like playing a game, being able to know what you need to do to fit all the parameters. And it took awhile for me to figure that all out... from my own experience, reading, seeing what you go through here."*

*Summary of interaction approaches*

Five approaches to health information interaction were identified and described, and we arranged these approaches on a spectrum according to interactivity, from low/no interactivity with information to high interactivity (Figure 1). The spectrum begins with the lowest interactivity approach: *avoiders* do not engage with health information and may have proxies do this for them. Moving along the spectrum of interactivity, next there are *receivers*, who report encountering all the health information they need in clinic without the need to search for more. *Seekers* actively acquire information in and out of clinic. Finally, the approach at the highest end of the scale is that adopted by *verifiers*, who describe seeking out health information from multiple sources in order to validate its credibility. As interactivity increases, participants consult more sources in a wider variety of locations, and most of the strategies used by participants with less interactive approaches are also used by the more interactive participants, who simply add additional strategies to their approach.

***RQ2: Activity, sociality and trust***

Coping strategies like health information interaction are not just *active* or *passive*; they also have a social component and can be *prosocial*, *asocial*, or *antisocial*. Examples of these strategies, derived from the model of social coping, are listed in Table 1. In this section, we discuss the activity and sociality of the approaches identified in RQ1. We also consider the role that trust in one's healthcare provider may play in influencing health information interaction. To facilitate discussion, the activity and sociality of each approach was qualitatively mapped using violin plots in Figures 2 and 3. Violin plots are useful for visualizing differences between categories in

small-n datasets; the length of the plot demonstrates the range of datapoints, and the width of the plot illustrates the density (based on the number of participants) at that point. For example, Figure 2 demonstrates that avoiders are variably active, with a range from very passive to very active. Figure 3 shows their tendency towards antisociality, with a range from antisocial to moderately prosocial with most participants at the antisocial or moderately antisocial level.

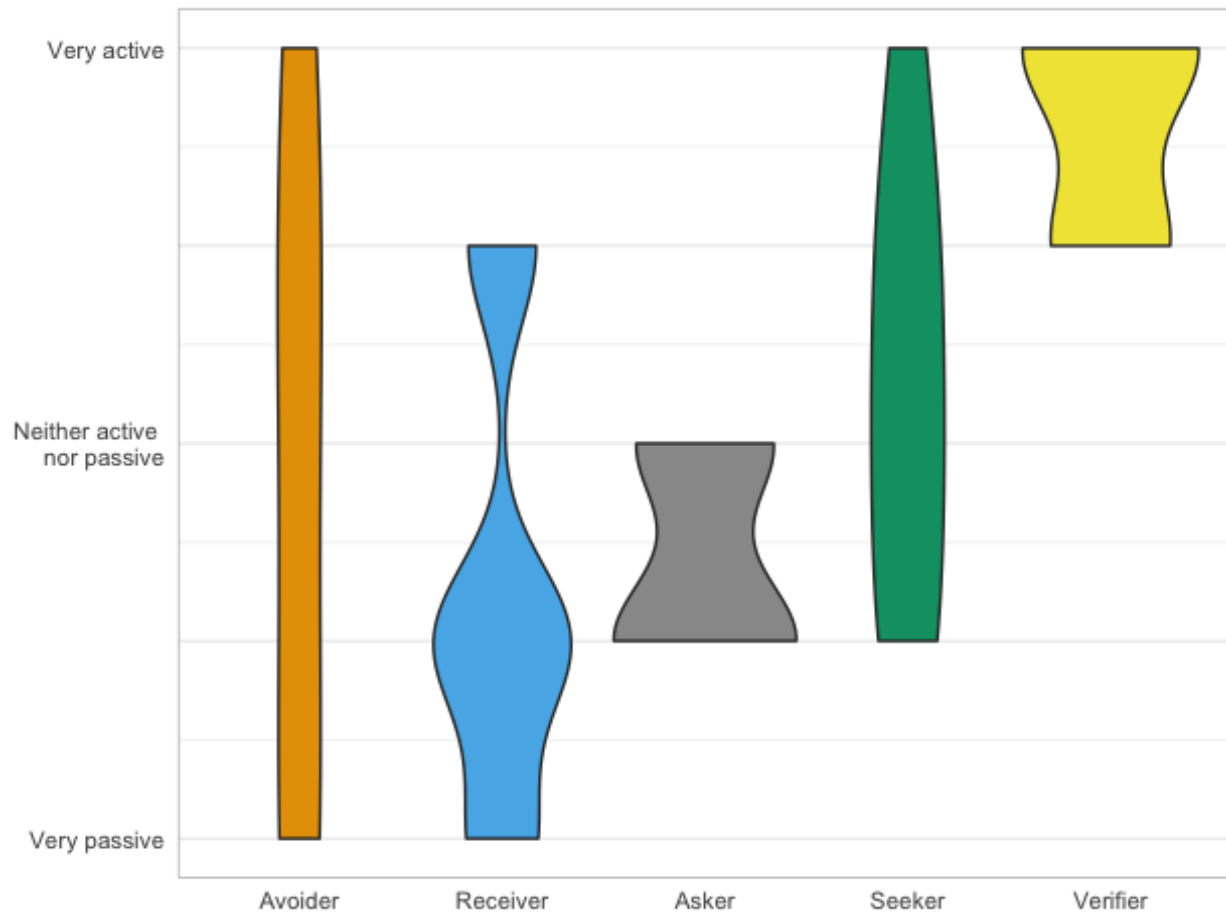


Figure 2: Activity of each approach.

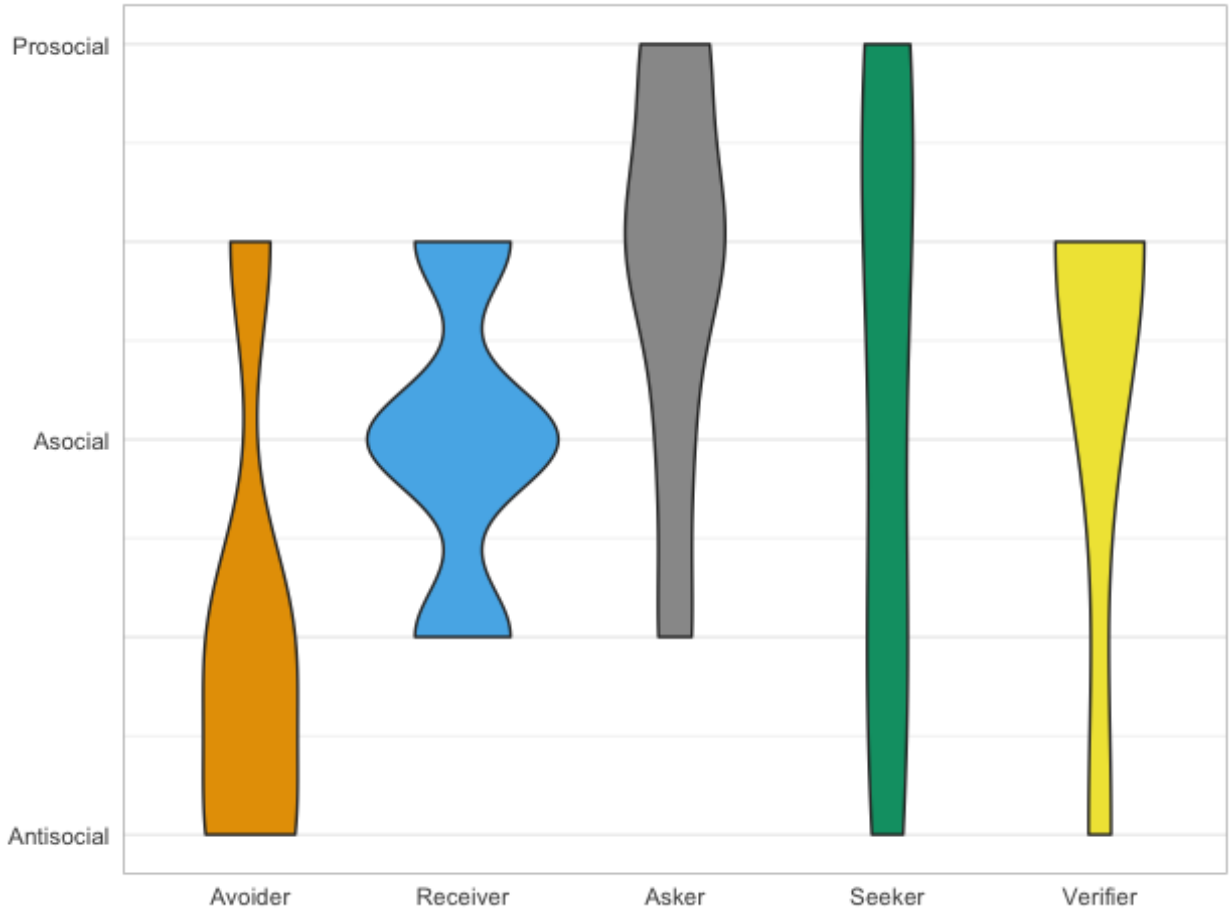


Figure 3: Sociality of each approach.

*Avoiders*

Avoidance is variably active and antisocial, and avoiders employ instinctive, avoidant strategies when interacting with health information. Often, a caregiver manages their care. As their moderate antisociality demonstrates, avoiders do not value this labor, calling it unimportant and unnecessary. Avoiders are not particularly assertive; they do not advocate for their own care, instead deflecting substantive discussion or even ignoring healthcare providers altogether in the

clinic. For example, in the following exchange, Calvin deflects the nurse's questions by joking in a manner that social coping theory describes as both instinctive and avoidant:

*Nurse: Stomach bothering you again?*

*Calvin: Wait a minute, I can pick up my telephone.*

*Nurse: Who you gonna call?*

*Calvin: I don't know. Ghostbusters! (all three laugh)*

As previously described, avoiders may ignore their care altogether, preferring uncertainty. For example, David's wife had to take him to the doctor in order for him to be diagnosed. His avoidance of the doctor before his diagnosis may reflect avoiders' tendency to distrust the healthcare system. Avoiders have low trust in HCPs in part because they strongly believe providers are more motivated by profit than by patient care; the health insurance system and the for-profit dialysis care model further erode trust in the medical system. Calvin says: "*They get paid every time they hook me up.*" Adam posits that providers care about money more than their patients: "*He'll go by and say, 'How are you,' and keep right on a-going, and I'll get a bill for \$400.*" This lack of trust in the medical system, which (for avoiders, at least) partly stems from the for-profit dialysis model, extends more broadly to distrust in the information they receive from HCPs; this is demonstrated in the following exchange between the interviewer and Calvin:

*Calvin: I asked [the nurse] what happened, and he was telling me that my blood pressure dropped...*

*Interviewer: Do they ever tell you anything about what might be causing that? Do you ever think about—*

*Calvin: They don't know that.*

*Interviewer: Oh, they don't know?*

*Calvin: I'm saying.*

*Interviewer: You think maybe they don't.*

*Calvin: I'm thinking they don't know.*

*Interviewer: Yeah? Do you ever think about trying to get an answer to that question some other way besides—?*

*Calvin: What other way am I going to get an answer, even from the doctors? They'll still say the same thing.... They all trained by the same master. (laughs)*

*Interviewer: So, for you, if the doctor can't answer it, what do you do?*

*Calvin: There's no other place to go.*

### *Receivers*

Receivers are somewhat passive and asocial; they prefer to have health information given to them directly or to glean it in the clinic through observation. They are cautious, and they rely on others, usually HCPs, to create a careful plan for their health. For example, when Theresa is asked about what she would do if she had a new symptom, she says: *"I really don't have much worry about that...I don't know it, somebody has to tell me."* She also describes the somewhat passive approach of receivers: *"I didn't want any [information about kidney disease]. I didn't want any of it because I didn't want to have to know it."* However, throughout her interview she discusses reluctantly engaging with health information when it is given to her by HCPs, distinguishing this approach from that of an avoider. Receivers say that they trust their HCPs; specifically, they trust that providers will give them information at the appropriate time. Carol says that one of the reasons she does not ask questions of her HCPs is that *"I would think they would tell me what to do, the nurses and the doctors, you know, with kidney disease."*

### *Askers*

Askers are fairly passive with a tendency towards prosociality; in addition to using all the other strategies used by less-engaged patients, they prioritize what social coping theory calls *social joining* by engaging in friendly, chatty encounters with HCPs and other patients. They are



somewhat passive in their information behaviors, for they are careful to time their information activities so as to not disturb providers with questions outside of existing clinical encounters. For example, a friend of Betty's asked her questions about an upcoming treatment, "*I had no answers for her.... She said, 'Oh, [your doctor] doesn't answer any questions, does he?' I said, 'Well, I did ask.... And he said, 'Well, I can't tell ya right now.'*" Rather than seek information from another source, Betty waited for an answer from her HCP, a trusted source.

Askers demonstrate high trust in HCPs. As Wayne says, "*They're the experts.... Because they always answer my questions really very well, the two doctors.*" Here, Wayne describes how trust is maintained during information interactions—the doctors address his questions thoroughly, building and strengthening trust. Betty corroborates: "*I have not had any questions that they didn't answer for me.*" Of his questions, Odel says: "*Mostly if it's something I want, or am concerned about, I talk to the doctor when he come around.*" However, he notes that asking questions can be difficult because HCPs are busy: "*You've got to catch him fast if you want to say something because he's in a real hurry, it seem like.*"

#### *Seekers*

Seekers are somewhat active and variably social; social coping theory would describe them as *cautious*. They use information to make decisions after carefully evaluating their choices. While they seek support from family, friends, and other patients, they ultimately make their own health decisions. They also extend social support to other people in their network, especially other patients. For example, they may serve as a source of health information for other people in the

clinic: “A lot of [the other patients] will come to me and ask me questions,” says Donna. “I’ve even had a nurse come and ask me questions. Because I...do so much reading.” Donna occasionally looks up information for other clinic patients online and brings it in to them when asked.

In accordance with their variable sociality, seekers use information to control the clinical encounter. As Lewis says, learning everything one can about dialysis is “*the key to survival.*” Here, Lewis places the onus of survival on the patient, demonstrating some level of distrust in the clinical encounter. Seekers are careful about which HCPs to trust, when to trust them, and what information to trust them with. In some cases, trust is called into question, usually due to unexpected medical issues or complications. This lack of trust then may extend to a lack of trust in information from that provider or other providers like them: “[My doctors] had already screwed up once,” explains Donald. “Now you begin to wonder, is this right? This may be a screw-up, too.... Whatever you are doing to me or for me, I will watch it.”

#### *Verifiers*

Verifiers are very active and tend towards prosocial; they not only seek and triangulate information on their own, they also have a take-charge attitude and hold their ground when interacting with others. For example, Sabine’s doctor told her to stop taking a certain blood pressure medication because of side effects, so she has been looking for information about how to control her blood pressure without medication. She spoke with several doctors, went online, and is considering multiple options. Like other verifiers, she is prosocial and seeks support from

others in the form of information and advice, checking with family, friends, and HCPs to see what they know or what they might do in a particular situation. Verifiers stress the importance of interacting with other people; for example, Gary notes that a prosocial approach is useful for coping:

*It's hard enough going through this, let alone talking about it.... I see that some people have a harder time [with dialysis] than other people, and I think that has a lot to do with it. They'd rather be private to themselves.... I do see a number of people that don't listen. They think they know more than the doctor, which is not a good idea.*

Here, Gary describes the delicate social tightrope that verifiers walk with respect to health information: a need to be social and to engage with other people, particularly providers, while also respecting the expertise and knowledge of those providers.

Like avoiders, verifiers describe a low level of trust in the medical system and in HCPs. James echoes the financial concerns of avoiders, saying, *“If you were to ask my opinion of some of the head honchos that make the big decisions here, I don't have a very high opinion of them. They make big bucks.”* However, when verifiers say they don't trust HCPs, it is usually because they find them dismissive, particularly of information that verifiers bring in to discuss. Crystal says,

*It is helpful to know what your symptoms are and what kidney disease is all about because of all the things physically that I was going through.... And you go to the doctor and you say, “Hey, look, I think this is what's going on,” or “In the past week, this happened, or this....” Didn't no one want to say [to me], “You have kidney, you're about to, going into kidney failure.*

Similarly, when Sabine brought information she found online to her doctor, she felt chastised for using the Internet. As previously discussed, she describes that she felt that her provider dismissed

the information she found online or that she learned from hearing other patients' personal experiences with kidney disease, even if that information was personally relevant and useful for her.

*Summary of activity, sociality, and trust*

Activity, sociality, and trust vary among the five approaches to health information interaction (Figure 2). According to the model of social coping, *avoiders*, *seekers*, and *verifiers* all take an active approach to health information, while *receivers* and *askers* are more passive. Only *avoiders* are antisocial, while *askers* and *verifiers* are more prosocial and *receivers* are asocial. Trust also varies; it is lowest at the extreme ends of the spectrum (*avoiders* and *verifiers*) and highest in the middle (*askers*).

#### DISCUSSION

Our analysis reveals that our participants interact with health information in five increasingly interactive approaches; each approach generally includes and broadens the previous stage's seeking methods, sources consulted, and information use. The activity and sociality of these approaches varies, as does the level of trust that participants have in their healthcare providers. This study thus offers three key contributions: (1) its detailed characterization of the variability of information interaction approaches in this context; (2) the identification of the sociality of these approaches; (3) the role that trust in one's healthcare provider may play in patients' approach to health information.

The information interaction approaches identified in this study differ from those found in prior research on health information interaction styles (e.g., Baker, 1996; Bonner & Lloyd, 2012; Case, Andrews, Johnson, & Allard, 2005; Lambert et al., 2009b, 2009a; Nelissen, Van den Bulck, & Beullens, 2017). We identify more categories than prior work in this domain, with the exception of one cancer-based study (Lambert et al., 2009a, 2009b). Some of the approaches identified in their study, which focused specifically on information seeking strategies, are similar to those identified in our work. For example, intense information seekers are similar to verifiers, and fortuitous information seekers are analogous to receivers (Lambert et al., 2009a). They also found support for a range of avoidant strategies; however, they do not describe an approach similar to askers (Lambert et al., 2009b). To our knowledge, no prior research has identified the asker approach to information interaction, either in or out of health. Additionally, our work reveals more interaction with health information at a mid-level of activity (e.g., *receivers* and *askers*); this may reflect our participants' ongoing contact with HCPs and the chronicity of their condition, which may be characterized by periods of stability that correlate to less active information seeking (Chen, 2016). We also identify nuances at the more interactive end of the spectrum, distinguishing verifiers from seekers based on their assessment of health information via confirmation across multiple sources, their prosociality, and their lower trust in HCPs.

Our findings extend prior typologies, including those of Lambert and colleagues, with its greater attention to activity, sociality, trust, and information use than has been elucidated in prior related work. For example, although Lambert et al. (2009b, 2009a) identified five approaches to cancer

information interaction, some of which map to the approaches found in our study, they did not specifically study sociality and found only one passive approach. However, they do note that the most silent and least interactive focus group members in their study also demonstrated minimal information-seeking preferences, which aligns with our finding that avoiders are antisocial and receivers are asocial. They also found that the least active information seekers expressed high trust in their oncologists, a finding that is in contrast with our findings, which demonstrate that avoiders do not trust their healthcare providers. We also identify differences in sociality among participants, finding that participants with more active approaches to health information are qualitatively more social than those who are avoidant. Therefore, in our study, more information interactivity is associated with more social and active coping strategies. Our research contributes to a growing understanding of health information interactions as contextually-based social activities, not as simple functions of internal or cognitive factors (Johnson & Case, 2012). Our findings support the need for more research into the role of sociality beyond its narrow application to source selection in health information behavior.

Uniquely, we found that patients at both ends of the spectrum—those with the most and least interactive approaches—also have the lowest levels of trust in HCPs. This contradicts a research synthesis in cancer, which found higher trust in patients who avoided health information (Germei & Schulz, 2014). Notably, our observation and inclusion of the *verifier* approach also differs from prior studies; this difference may be related to the hemodialysis context in the US, where patients are often skeptical of the for-profit nature of their dialysis care (Costello, 2016).

The issue of healthcare provider trust is therefore a key factor in health information interaction that should be investigated in future research.

### ***Implications for practice***

With a more nuanced understanding of the variability of patient activity, sociability, and trust, practitioners can gear information resources to the approaches we know dialysis patients actually use. There is a large body of literature that demonstrates that tailoring health messages is linked to health behavior change, especially in cases in which information is tailored to several of patients' theoretically-grounded behavioral characteristics, such as attitude and social support (Noar, Benac, & Harris, 2007). Moreover, there is a pressing need for individualized educational interventions in ESRD that account for the needs, values, and preferences of patients (Green & Boulware, 2016). Our study provides more theoretical support for future health information interventions, offering multiple interrelated constructs that authors can use to tailor information provision. Like prior researchers, then, we advocate for providing information to patients in a manner that is tailored to their information interaction patterns and underlying preferences (Czaja, Manfredi, & Price, 2003; Nelissen, Bulck, & Beullens, 2017; Williamson & Manaszewicz, 2002). Our research could be used to theoretically underpin health information interventions for this particular patient population, using the identified approaches to health information interactions, social coping, and trust. The next step for such work is to further test and operationalize the identified styles, with the aim of creating a validated survey instrument that could be used to assess patient preferences for tailoring information in health interventions.

This would add to a growing interest in developing translational interventions in kidney disease and dialysis that target education and disease self-management (Tuot et al., 2014). In the next section, we outline some examples of such interventions.

Avoiders do not want to engage in health information interactions, and despite their relative antisociality they often rely on proxies who manage their care. They also have a low amount of trust in healthcare providers. To develop trust with avoiders, HCPs could consider preparing for dialysis-specific communication challenges by participating in workshops designed to improve doctor-patient relationships in dialysis (Green & Boulware, 2016). Reinforcing the autonomy of avoiders may also be one way for HCPs to develop trust with this group. HCPs should also still provide opportunities for avoiders to engage with health information, but with the recognition that providing health information to their proxies may also be appropriate. We suggest assessing the information style of proxies and tailoring health information to match their style in the case of avoiders.

Although there is a trend toward patient empowerment and shared health decision-making (Johnson & Case, 2012), our findings indicate that this model of care is not appropriate for every dialysis patient. Receivers prefer health information that comes to them in the clinic, and their relative passivity and moderate trust in healthcare providers makes them excellent candidates for traditional modes of health information delivery: frequently updating clinic posters, providing informational flyers in waiting rooms, and sending regular newsletters to patients are useful ways to provide health information to receivers.



Askers, as well, may prefer a more traditional approach to healthcare. This approach to health information—seeking out health information by only asking questions of HCPs—was previously not identified in the literature. Our identification of this approach may be due to the context of in-center hemodialysis, which puts patients into regular contact with other patients and with HCPs. We do not know whether or not this behavior exists only in patients who have regular contact with their HCPs, or if it is a general approach that many people take to health information. Understanding whether this particular category is transferrable to other contexts is therefore necessary. Nevertheless, practically, HCPs in dialysis clinics should make sure to give askers space and time to ask questions, and may plan to linger at their chairs for a few minutes to provide such an opportunity. Since they are fairly social, askers on dialysis may also be good candidates for either online or face-to-face patient peer support groups, especially those that are moderated by HCPs (Taylor, Gutteridge, & Willis, 2016).

Seekers will engage with health information outside of the clinical setting, and these information interactions can be supported by healthcare providers by acknowledging this activity and discussing it with them directly. This is particularly important for building and maintaining trust with seekers, who have moderate trust in HCPs, particularly since the quality of social interactions with providers plays a vital role in how much people who seek information outside of the clinical encounter trust them (Lu, Xu, & Wallace, 2018).

Verifiers are fairly social and are very active in their care; they fit the general definition of an “empowered” patient (Trummer et al., 2006). Although they are fairly social and active, they

have low trust in HCPs. Working to establish a relationship of trust with verifiers is therefore important. HCPs should be willing to have discussions with verifiers about health decision-making and the rationale underlying those decisions. Out of respect for their interest and engagement, HCPs could encourage verifiers to bring in information for verification; or, they could provide supplementary reading to verifiers. Since trust begets trust, involving them in patient advocacy programs or patient peer support groups as patient navigators may be another way to develop trust with this group. Verifiers like educating other patients about how to interact with health information about kidney disease and are therefore good candidates for selecting as patient navigators, who have been demonstrated to improve patient care in translational interventions for ESRD patients (Jolly et al., 2015).

This spectrum of approaches may also hold promise for tailoring information both within and beyond health contexts. To do so, future research should operationalize this spectrum through the development and validation of a summated rating scale for use in this and similar contexts. Health combines cognitive, affective, and somatic experiences and is personally salient for most individuals. The approaches we identified, therefore, may exist in other situations that are personally meaningful; disruptive or transitional; and where experts or professionals exist and are fairly accessible, as is the case in healthcare generally and dialysis specifically. For example, this spectrum may hold for other similar health conditions like cancer with frequent chemotherapy treatments, or in transitional and situated health contexts like in antenatal classes. Outside of health, the spectrum may be found in personally meaningful situations that unfold

over a period of time, such as religious practice (Gorichanaz, 2016), home buying (Savolainen, 2010), or crises (Westbrook, 2009). The variety of approaches we identified may not be present in acute health situations, or in health conditions that are more stigmatized than kidney disease as stigma likely impacts social coping and trust. Future research, therefore, should further test the transferability of this spectrum to information interactions in other contexts both in and out of health.

### ***Limitations***

First, we interviewed patients at only one point in time. A longitudinal analysis may identify potential variation across time among hemodialysis patients. Moreover, our sample may be affected by selection bias, since participants had to agree to be interviewed during their dialysis sessions. Because they were situated next to other patients and their healthcare providers during the interviews, social desirability bias may also be a factor in this data collection technique. Finally, it is not clear whether results are transferable beyond a hemodialysis context, since the clinic environment may have shaped information interactions approaches within them; for example, perhaps information encountering was possible because of the clinics' informing routines (Veinot et al., 2010).

### CONCLUSION

Patients on hemodialysis take multiple approaches to interacting with health information; these approaches can be arranged on a spectrum from avoidance to verification. Level of activity, sociality, and trust in HCPs differ across these approaches. Participants at both extreme ends of

the spectrum (*avoiders* and *verifiers*) both have low trust in HCPs and are moderately active in their approach to health information interaction. They differ, however, in their sociality; *avoiders* are antisocial, while *verifiers* are prosocial. In contrast, *receivers* and *seekers* are asocial and exhibit a fair amount of trust in their HCPs, but as the names imply, *seekers* are more active information seekers than *receivers*. Finally, *askers* are prosocial and have a high level of trust in their HCPs. A key contribution of this work is its nuanced understanding of health information interaction. These findings can and should be used to tailor health information interventions. Moreover, the dimensions of activity, sociality, and trust can assist in identifying patients likely to engage in each approach and in designing information systems and services that address their specific requirements.

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A SPECTRUM OF APPROACHES TO HEALTH INFORMATION INTERACTION: FROM AVOIDANCE TO  
VERIFICATION

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SUGGESTED RUNNING HEAD:  
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## **A spectrum of approaches to health information interactions:**

### **From avoidance to verification**

#### ABSTRACT

People respond to illness in a range of ways, and take different approaches to engaging with health information throughout the course of their illness. This study describes and explains the variety of approaches to health information taken by patients on hemodialysis. Ethnographic observations (156 hours) were conducted in three hemodialysis clinics, and semi-structured interviews about health information were held with 28 patients. Demographic data were collected. Data were analyzed qualitatively. We found a spectrum of five approaches to health information: *avoiders*, who close themselves off from health information; *receivers*, who encounter information in the dialysis clinic but do not seek it out; *askers*, who only pose questions about health to their healthcare providers but otherwise do not seek; *seekers*, who actively look for health information both in and out of the clinic; and *verifiers*, who seek information and triangulate it among multiple sources. Trust in healthcare providers and coping sociality differed across approaches. Findings indicate that health information should be provided to patients using strategies tailored to their preferences and existing approaches to information interaction.

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## INTRODUCTION

Hemodialysis is a treatment for end-stage renal disease (ESRD), which occurs when one's kidneys are no longer working properly. It cannot be cured, but it can be treated with dialysis or a kidney transplant. Sixty-three percent of patients with kidney failure in the United States receive dialysis treatment in a hemodialysis clinic (United States Renal Data System, 2018), which requires patients to visit a clinic three days a week for approximately four hours each visit where they are connected to a dialysis machine that filters their blood (National Kidney Foundation, 2001). Hemodialysis patients experience frequent health crises, with three emergency room visits and almost two hospitalizations per patient-year on average (United States Renal Data System, 2018). Kidney failure and dialysis are stressful experiences, and patients on dialysis typically face ongoing health-related challenges and periods of stability punctuated with periods of decline (Jablonski, 2004).

Patients with ESRD have many information needs, including medical questions about treatment options, interpretation of test results, and dietary and fluid restrictions (Ormandy, 2008). They also have psychosocial concerns, such as whether they will be able to work, how to navigate social relationships and activities, and the desire to know how their life will change if and when they begin dialysis (Orsino, Cameron, Seidl, Mendelsohn, & Stewart, 2003). After the initial shock of diagnosis has passed, patients report developing new information needs that are largely psychosocial, such as how to manage uncertainty or cope with their compromised health, throughout the illness trajectory (Martin, Stone, Scott, & Brashers, 2010). Patients also seek information about their treatment and illness from healthcare providers (HCPs), who are critical sources of information for medical questions in ESRD (Ormandy, 2008). However, trust in healthcare providers varies among patients (Armstrong et al., 2008), and may affect information

interaction (Richardson, Allen, Xiao, & Vallone, 2012; Veinot, Campbell, Kruger, & Grodzinski, 2013).

While patients often gain psychosocial information about dialysis by experiencing dialysis and living in the information world of a dialysis clinic (Veinot, Meadowbrooke, Newman, Zheng, & Perry, 2010), some express the desire to visit clinics and meet with other patients before beginning dialysis in order to understand the process (Iles-Smith, 2005). Patients' desire for information provided by social peers has also been observed in other studies on kidney disease, and is present throughout the disease trajectory (Costello, 2017). Notably, in-center hemodialysis regularly puts patients in social situations with other patients (Costello, 2017). Peer-based information may help patients to manage emotions related to their conditions (Xiao, Sharman, Rao, & Upadhyaya, 2014), which has implications for their methods of coping with stress. Further, information seeking in kidney disease has been linked to sense-making (Godbold, 2013), medical decision-making (Winterbottom, Bekker, Conner, & Mooney, 2012), and patient empowerment (Costello, 2016). An understanding of how dialysis patients engage with health information will allow for the development of educational interventions to empower dialysis patients in coping with and making decisions about their care. Critically, understanding potentially-variable patterns of this information engagement can assist in the development of interventions that are appropriate to each patient. Interventions that deliver tailored health information have been shown to increase patient comprehension (Kreuter, Strecher, & Glassman, 1999), patient satisfaction (Nguyen, Smets, Bol, Loos, & Van Weert, 2018) and improve health behaviors (Williams-Piehota, Schneider, Pizarro, Mowad, & Salovey, 2003). But such interventions typically focus on tailoring only the content of messages. Researchers have called for more nuanced approaches to tailoring based on the information preferences of patients, such

as source and source presentation, rather than simply focusing on content (Nguyen et al., 2018). In kidney disease specifically there is a need for translational health information interventions that focus on adapting educational materials and that leverage the existing social networks of patients (Tuot et al., 2014). Design of such interventions would also be aided by understanding how trust in healthcare providers and other social relationships, such as with patient peers, may factor into patterns of hemodialysis patients' information interactions.

Therefore, the objectives of this study is to identify the approaches that patients on in-center hemodialysis take to interacting with health information, and to describe the social coping strategies and trust in healthcare providers observed in each approach. In this study, health information interaction includes: (1) Strategies for avoiding or seeking health information; (2) Preferences for and selection of health information sources; (3) What health information is used for.

## LITERATURE REVIEW

### *Health information styles*

The concept of patient empowerment, defined as “a process through which people gain greater control over decisions and actions affecting their health” (World Health Organization, 1998, p. 6) is an increasingly vital goal of healthcare both in the United States and throughout the world. Health information interaction is a necessary component of patient empowerment (Ende, Kazis, Ash, & Moskowitz, 1989; Roberts, 1999). Because empowerment has a positive effect on health outcomes (Trummer, Mueller, Nowak, Stidl, & Pelikan, 2006), many health interventions focus on fostering empowerment via information, either in the provision of information or in encouraging patients to actively seek out information on their own. In dialysis care, for example, educational interventions demonstrate that patient education can have a positive effect on health



outcomes (e.g., Mason, Khunti, Stone, Farooqi, & Carr, 2008), and high levels of health information literacy in patients with kidney disease have been linked to greater self-efficacy, improved access to care, and lower mortality rates (Devraj et al., 2015).

For such interventions to positively impact all patients, however, it is necessary to understand how patients engage with health information (Noar, Benac, & Harris, 2007). Early research in health information interaction demonstrates that, broadly, people either seek or avoid health information; these two general styles have been conceptualized in the literature as “monitoring” and “blunting” (Baker, 1996). While theories in this domain acknowledge a continuum of information styles among patients, they often focus on those who are “actively interested in managing information and [who] intentionally engage cognitive and other resources toward that end” (Afifi & Weiner, 2004, p. 170). The active approaches of purposeful seeking and avoidance are well-established in the literature (Brashers, Goldsmith, & Hsieh, 2002). Of course, a range of information styles exist (Bawden & Robinson, 2011). Individual variations in cancer information seeking, for example, cluster in five patterns: intense seekers, who look for as much information as possible; complementary seekers, who want to add to what they already know; fortuitous seekers, who consult other patients for health information; minimal seekers, who do not look for information on their own; and active avoiders, who find the experience so stressful that they actively avoid cancer information (Lambert, Loiselle, & Macdonald, 2009a, 2009b).

These clusters have not yet been examined in other health contexts, and “to date, distinct health-related information-seeking preferences have been understudied and underreported” (Loiselle, 2019, p. 5). Like patients with other health conditions, dialysis patients may either seek or avoid health information (Bonner & Lloyd, 2012). However, their small sample size ( $n=5$ ) likely obscures the extent of variability in information styles present in this population. Triangulating

data about health information interactions from multiple sources may afford the opportunity to uncover a larger range of information styles. This may be particularly true in dialysis, where patients are exposed to the information world of the clinic regularly (Veinot et al., 2010). We therefore ask:

RQ1: What varied approaches do people on hemodialysis take if and when they interact with health information?

***Influence of social coping strategies on information interaction***

A great deal of research exists that characterizes similarities and differences in information style, but this work is limited by being contextually bound, and is therefore perhaps “best regarded as [an indicator] of interesting avenues for further investigations, particularly for direct attempts at correlation of information behavior with [individual] traits” (Bawden & Robinson, 2011, p. 134).

Two individual traits that are often explored are personality and cognitive style, but few studies have examined how information behavior is related to social interaction or other social traits.

Health information interaction can be understood as a coping activity, and coping is often a social act that can occur in social environments. In addition, many stressors have interpersonal components, and coping efforts often require interpersonal interaction or have social consequences (Dunahoo, Hobfoll, Monnier, Hulsizer, & Johnson, 1998). The same is true of information interaction, especially when it is understood as a coping strategy for managing illness uncertainty. Although existing research has separately considered the social and interactive nature of both coping and information interaction, these concepts have not yet been considered in concert. Dialysis is an ideal site of inquiry for this investigation, as it requires patients to have regular, frequent social and informational interactions with healthcare providers and other patients, and the porous boundaries of the clinic allow for information interaction

outside its walls (Veinot et al., 2010; Veinot & Pierce, in press). Like many chronic health conditions, ESRD is also shaped by social factors, such as perceived and enacted social support, family caregiver dynamics, and the role of healthcare providers and other patients; in dialysis patients, social support is associated with increased patient satisfaction, better quality of life, and decreased hospital admissions (Plantinga et al., 2010). But unfortunately, isolation is a common issue for ESRD patients throughout the illness trajectory (Kierans, 2005). Extreme fatigue, dialysis treatment schedules, and the fear of burdening others makes it difficult for patients to socialize with friends or to continue education or employment (Tong et al., 2009). The social networks of patients on dialysis tend to get smaller over time; however, as friends and work colleagues drift away, the number of family members in one's network remains stable (Neumann, Lamprecht, Robinski, Mau, & Girndt, 2018).

We therefore consider the social dimension of coping and information interaction together by examining information style through the lens of social coping theory. Social coping theory demonstrates that coping strategies do not exist only on a spectrum of *passive* to *active*; they also have a social dimension ranging from *antisocial* to *prosocial* (Hobfoll, Dunahoo, Ben-Porath, & Monnier, 1994). The social coping framework de-emphasizes individual emotions experienced while coping (e.g., uncertainty management arising from information seeking or avoidance) and instead focuses on socio-behavioral strategies employed by participants in their social interactions. Examples of activity and sociality derived from the theoretical framework are listed in Table 1.

[Insert Table 1 here.]

We also examine information seeking and social coping behavior in terms of trust in others, which may impact the sociality of information interactions. Patients are more likely to seek out health information from people they trust, for trust in people can extend to trust in the information they produce (Sztompka, 1999). Prior research shows that trust influences health information source selection (Costello, 2017; Veinot, Campbell, Kruger, & Grodzinski, 2013), and trusted sources are more relied upon than untrusted sources in health-decision making. Furthermore, in cancer patients, trust in HCPs has been shown to lead to avoidance of other information (Germeni & Schulz, 2014); it is has also been shown to be a mediator of uncertainty in illness (Mishel & Braden, 1988).

Most studies focus on the role that interpersonal interactions play as sources for health information (e.g., Afifi & Weiner, 2004); in contrast, we focus on the general social strategies participants take when interacting with others, as well as their level of trust in others, in order to potentially inform how we understand the multiple dimensions of information interaction approaches in health behaviors. Therefore, we ask:

RQ2: Do social coping strategies and trust in others relate to the varied approaches people on hemodialysis take when they interact with health information, as identified in RQ1? If so, how?

## METHODS

### *Data collection*

#### *Observations*

We conducted a multi-sited ethnography at three outpatient hemodialysis clinics (one urban, one suburban, and one rural) in a Midwestern state from 2009-2010. Ethnographic observation was conducted for 156 hours in the three clinics (51–53 hours per clinic); the researcher adopted a non-member role (DeWalt & DeWalt, 2002). Oral informed consent was obtained from 173

patients for the observations. Because dialysis occurred in thrice-weekly “shifts” in morning and afternoon at study clinics, we triangulated data (Flick, 2007) by observing clinic activity in mornings and afternoons and on different days of the week. We observed interactions in the two main patient care regions of the clinics: the waiting room and the dialysis room. Informal interviewing (DeWalt & DeWalt, 2002) was conducted intermittently to clarify evolving understandings. During observations, the researcher kept “jottings” from which in-depth field notes were later constructed (Emerson, Fretz, & Shaw, 1995). Observations concluded when saturation was achieved in each site.

#### *Interviews*

In-depth, semi-structured interviews (Hesse-Biber, 2006) were conducted with 28 of the observed patients. Interviews, which averaged 2 hours and 28 minutes, focused on their experiences of hemodialysis, their methods of coping with illness, their information interactions both inside and outside of the clinic, and their social interactions both inside and outside of the clinic. Interviews were audio-recorded, transcribed verbatim, and verified. Patients also completed a brief demographic survey at the interview. Participants were theoretically sampled (Schensul & LeCompte, 2013) based on clinic observations, in which variability in patient behavior was noted. Behaviors ranged from full engagement (active conversations with other patients and staff) to moderate engagement (quiet but actively observing activity in the clinic) to detachment (neither interacting with nor observing others). Interviews were conducted in the dialysis clinic, as patients dialyzed. Pseudonyms were assigned to each participant for analysis.

#### *Demographic Survey*

Interview participants completed a survey that indicated their exact age, their gender (male/female), their race/ethnicity (White, Black, Asian/Pacific Islander, Native American,

Hispanic/Latino, and their education level. As shown in Table 2, the mean age of participants was 67, and most (64.2%) were white. Participants were roughly equally proportioned by gender and by education level. The Institutional Review Board of the University of Michigan approved the study.

[Insert Table 2 here.]

### ***Data analysis***

Interview data and field notes were analyzed qualitatively using emic/etic coding and the constant comparative method, moving from open coding to focused coding as the research progressed (Miles & Huberman, 1994). Our research draws on the constructivist tradition, addressing questions about the causes, consequences, and conditions under which certain information interactions occur, with a focus on the cognitive-affective processes our participants undergo as they make sense of the world (Charmaz, 2014). As is common in qualitative analysis, sensitizing concepts—including information interactions (e.g., information styles, source selection, and information use), social coping, and trust in healthcare providers—were identified and shaped the analysis as it progressed. To address RQ1, the researchers inductively analyzed interview responses about and in-clinic observations of health information experiences and encounters, guided by the existing literature on information styles, including discussions about what health information (if any) participants exchanged with friends, family members, and healthcare providers; what sources they used for health information; where they encountered and searched for health information; and whether and how they used health information.

To answer RQ2, at the close of each interview participants were asked a series of questions about the people they mentioned during the interview, including the amount and frequency of contact, social support exchanged, health information exchanged, and closeness of the relationship. These

responses and related interview and observation data were analyzed deductively using social coping theory (Table 1) to determine the activity and sociality of the information approaches identified in RQ1. Interview responses and in-clinic observations were inductively analyzed to assess trust in HCPs.

Analytic memos were created to track the analysis as it moved up the analytic chain from coding to grouping the codes into categories and constructs related to the patterns of health information interaction described by participants. In naturalistic research, traditional verification techniques, such as intercoder reliability statistics, are not used. Instead, trustworthiness is the goal for naturalistic, interpretive studies (Lincoln & Guba, 1985). Peer debriefing and memoing are both accepted methods for enhancing the trustworthiness of analysis; in this study, the research team met biweekly throughout the first year of analysis to discuss the results as they progressed. These meetings included discussions about the research process, related sensitizing concepts, and negative cases.

## RESULTS

### *RQ1: Health information interaction approaches*

Participants take five distinct approaches to interacting with health information; these approaches can be arranged along a spectrum according to the amount of interactivity, which is defined by the number and type of sources consulted in the information seeking process (Figure 1).

**Avoiders** close themselves off from health information and often rely on a proxy to manage illness information. **Receivers** encounter health information in the dialysis clinic rather than seeking health information. **Askers** pose questions to their HCPs, but otherwise do not seek out health information. **Seekers** engage in active information acquisition both in and out of the

dialysis clinic. **Verifiers** seek health information from multiple sources, comparing and contrasting it in order to verify what they have learned.

In general, most of the strategies for information seeking, the source/locations of information sought, and information use that are reported by participants with lower amounts of activity are also used by all patients with higher levels of activity; these are listed using italics in Figure 1. For example, seekers get information using the same methods used by receivers and askers (like receivers, they listen to clinic interactions or otherwise encounter information in the clinic; like askers, they ask questions of HCPs); they also add strategies, such as consulting external sources, such as books, classes, and workshops offered by the clinic or by the National Kidney Foundation. The exception is avoiders; the strategies they use to interact with health information (such as relying on a healthcare proxy) are not reported by other participants. The following section describes each approach in detail.

[Insert Figure 1 here.]

### *Avoiders*

Avoiders do not seek out health information, nor do they discuss using health information in their daily lives. They also do not pay attention during their dialysis treatment, preferring instead to watch television or sleep. Avoiders report feeling disengaged and disillusioned about their condition, and they absorb little during interactions with HCPs; they were observed not asking questions when given new medications or when asked by providers if they had questions.

Clayton says: *“Really, nobody’s explained to me what’s going on, but I guess there isn’t really much explanation to it.”* He says that rather than seeking out information, *“you just...suffer your way through it.”* For example, during physician rounds, Clayton told his physician that he was



not feeling well on dialysis, but he did not seek information about reasons for his condition; he instead accepted the physician's lack of follow-up regarding his concerns:

*Physician: "How are you feeling on dialysis?"*

*Clayton: "OK, not great."*

*Physician: [inaudible]*

*Clayton: "It's OK, I guess."*

*Physician: "How is your breathing? Let's listen." [Physician listens with the stethoscope at the patient's back for a minute, then speaks.]*

*Physician: "Sounds pretty good."*

*Clayton: "OK."*

*[Physician leaves]*

In the clinic, avoiders don't turn to other patients for health information. They may make small talk with other patients, but, as David says, "*The subject [of kidney disease] don't ever come up.*" Adam describes: "*Most [of the other patients] don't have any mutual things going on. You run in here, get your treatment, go your merry way.*" They are disengaged with dialysis; by extension, and perhaps by necessity, they often have a proxy in their social network that coordinates their care in general. For example, David says that he was "*out of his mind*" when he started dialysis, and that caused him to avoid information about the disease, or even diagnosis: "*I was probably [sick for awhile] but I didn't tell anybody.... [My wife] noticed...that I wasn't well and she took me to the doctor. She brought me.*"

### *Receivers*

In contrast to avoiders, receivers do engage with health information, but only information that they encounter in the clinic. Health information is "*already there*," (a phrase used by several receivers); and receivers say that if they need new information it will be provided for them—often before they even know they need it. Henry explains: "*I take information, of course, all the time, and I get pamphlets, so, I usually read those.*" While he pays attention to the results of his blood tests and other tests, he doesn't ask questions about them: "*If [the doctor] came around here, everything's perfect. He'll shake my hand and say 'How are you?' and he'll listen to my*

lungs and heart, 'See you next time.' Same way with the dietician, she comes around, and I don't, no questions." Here, Henry demonstrates the passive strategy of receivers: he is cautious and deals with information when it comes to him. Receivers like Henry get health information from a variety of sources in the clinic: HCPs, other patients, clinic-provided literature, and posters on walls. Patricia says: "...they have a little something out on the bulletin board about not shortening your dialysis time. So, that's how I figured...I better keep going as long as I can...." She learns dietary information from the bulletin board and from a monthly laboratory report. For receivers, the clinic is an information world, and interactions within the clinic convey enough information to meet their needs. Theresa explains that she received information from the clinic when she first began dialysis, which she read: "they gave us some hints, you know, on things to do and not do, and that was helpful."

Receivers focus on keeping their kidney disease "under control" and on "coping" with dialysis by following the doctor's instructions. When asked if he has questions for his doctors, Henry says: "...everything seems to be going alright, so I just cope with it." Patricia says that she doesn't have questions "As long as it can be kept under control." Again, this demonstrates receivers' somewhat passive and cautious attitude toward information. Reflecting this, in a conversation with another patient, Patricia indicates her tolerance for uncertainty regarding her impending surgery:

*Keith: "Hey, how's your fistula working?"*

*Patricia: "Well, I'm having surgery again."*

*Keith: "Oh, where at?"*

*Patricia: "Umm. . . . [pauses] They're going to move it to a new place."*

*Keith: "And the reason they thought to do that now?"*

*Patricia: "I don't know. Between [nephrologist NAME] and them, it's a big puzzle!"*

*Keith: "When are they doing the surgery?"*

*Patricia: "Oh, pretty soon."*

### Askers

Askers actively seek out health information from HCPs in the clinic; as George says, “*You’re doing what you’re supposed to be doing and you need any questions answered, you talk to the people that’s doing it.*” They inquire about things that are happening to them during their treatment. For example, Betty asked about her blood pressure each time it was taken:

*[Betty is gazing straight in front of her while the technician takes her standing blood pressure; technician is standing by the dialysis machine, watching the monitor; after a minute, she speaks]*

*Technician: “OK, go ahead and have a seat.”*

*[Betty sits down carefully]*

*Betty: “What’s my blood pressure?”*

*Technician: “165 over 73—that’s very good.”*

*Betty: “I’m happy about that.”*

For askers, an important part of information seeking is timing questions appropriately; they tend to ask their questions in-clinic, when the opportunity arises. This strategy is somewhat passive, as it requires that providers approach them, allowing them to deal with information as it comes. Sadie describes: “*How I found out about different things was...talking to... the nurses. We would ask questions about... ‘Why you got to go three or four hours?’ or... ‘Why is it they have a graft or a fistula?’*” Askers seek out information primarily from HCPs, but they also receive information without asking, via the clinic’s “informing routines” (sources like pamphlets or handouts from the dietician), as described in the section on receivers (Veinot et al., 2010). Like receivers, askers do not seek information outside the clinic. When asked if she might ever use the Internet for health information, Betty says: “*I have not had any questions that [my HCPs] didn’t answer for me.... Really!*” Information is often deemed irrelevant or not useful by askers if it does not come from healthcare providers. Cathy says that before she started her treatment, her daughter-in-law gave her information that she found online about dialysis: “*She told me I was a candidate for dialysis... way back. I didn’t believe it, but it come to pass.*”

Askers seek out information primarily when they are monitoring their health status or making health-related decisions. For example, Gail was considering home hemodialysis at one point, and she says: *“I talked to the social worker here [about it]...she gave me information and I read all that and then one of the nurses from that unit came over and sat down and we talked about it.”*

Like Gail, Betty is likely to ask questions of providers when there are potential or actual changes in her treatment. She doesn't currently have questions for her doctor, but she says, *“I might in the future,”* since she recently started a new drug.

### *Seekers*

Unlike askers and receivers, seekers see information acquisition as an active, deliberate act that occurs both in and out of the dialysis clinic: *“When I was first diagnosed,”* Mary says, *“I drove the Kidney Foundation nuts with them sending me packages of information.”* Seekers actively look for information during times of decision-making and illness transitions. Myron says, *“If I had to...go through any more...something serious...I would [look for information and support] because...every now and then I do need a little help.”* Laura uses the Internet to find information about kidney disease and shares her findings with other patients and friends; the Internet is a popular source for seekers, but they also consult print sources, such as booklets and NKF pamphlets. Seekers typically also seek out health-related information from other people—HCPs, friends, and family members. Like askers, seekers ask questions of their HCPs in the clinic: *“I asked different questions [back when I first started dialysis. The technicians] told me different things about it, the temperature...I will ask questions,”* says Donald. Like receivers and askers, seekers also encounter health information: *“Any place, any time I hear something, somebody talk about dialysis, or kidney disease...my ears open up,”* says Donna. Myron describes the same behavior: *“Every time...somebody...talking about dialysis or kidney failure, I'm all ears...”*

Seekers use information to manage their health, to understand their treatment, and to control clinical encounters or influence their care. For example, Lewis describes: *“You’ve got to learn this machine... That machine is going to tell you everything that’s gonna happen to you... they’ve already clumped us all into one group. Learning the machine is your way of individualizing yourself.”* He also says that his information seeking helps differentiate him from other patients and can be used as a tool to control the clinical encounter: *“When I started suffering is when I started saying, “Wait a minute, hold on, how much fluid you taking off today?”* In addition to looking for health information from a variety of sources, seekers also share information with other patients, and they may encourage them to also seek out health information on their own. Lewis explains: *“When I see a new person, my main thing is always to tell them, ‘Learn everything you can about this procedure.’ That’s going to be the key to comfort. That’s going to be the key to survival.”*

#### *Verifiers*

Like seekers, verifiers engage in a wide variety of information seeking behaviors: asking questions of their providers, encountering health information in the dialysis clinic, and exchanging and sharing health information with other patients. For example, Gary gets information from multiple sources to make decisions about his health: *“[If I had to make a decision about my treatment] I’d get a bunch of answers so I could make a decent decision in my head... the more information I can get, the better it is.”* In addition to these behaviors, verifiers routinely consult multiple sources in order to develop knowledge and to check the accuracy of what they are learning, which differentiates them from seekers. Keith says,

*I looked up all kinds of aspects of [kidney disease]. And side effects .... some reports I could understand. Some, I don’t know what the heck they were talking about.... All of them had something. And then the more you read something, then you start understanding what the other person is talking about.*

Another reason that verifiers seek out health information is to verify or ask questions about recommendations made by healthcare providers. They may even print out information from the Internet and bring it to the clinic to discuss. When Sabine was having trouble with neuropathy, she went online after speaking with her doctor: “...*he gave me a prescription for sleeping pills. Well, I’m not taking sleeping pills. So, next time went to see him, I said, “Look, I got on the Internet... he said, (gasps) threw up his hands like this (gasps), “Don’t ever go on the Internet for that!”* Despite this recommendation, she continues to verify health information, not just online but with friends, family, and other HCPs. Similarly, when Edith was asked what she does with information she gets from her doctor, she says, “*I... go talk to my daughter...she’s in the medical field.*” Verifiers primarily assess credibility by repetition across sources: “*when you go on the Internet, and you look up information... [and] you go someplace else... and they’re all saying the same thing...somebody got to be telling the truth about something.*” To double-check the information they have about their health, some verifiers may also monitor their dialysis machine’s display during treatment, thus checking the accuracy of their clinical records:

*Keith: ...when I was in the hospital, they said the number was 1.8. But then when I got here later, they said it was 2.23. What’s in my chart?”*

*Nurse: “Well...if that’s the number they gave you, then that’s what’ll be in the system.”*

*Keith: “The hospital seems like they’re saying something different.”*

*[Nurse walks over to the rack of chart books, pulls one out, and brings it back]*

*Nurse: “So that was on the 17th? We got 2.23?”*

*Keith: “Yeah.”*

*Nurse: “And they got 1.8?”*

*Keith: “Yeah, I think.”*

*Nurse: “Huh. And here that is, too. Well, 1.9.”*

*Keith: “Oh, that was it, 1.9.”*

*Nurse: “Not sure why theirs is in here. Maybe it got transferred into our system?”*

*Keith: “Would that happen?”*

*Nurse: “I’m not sure. I’ll look into it for you.”*

*Keith: “Thanks.”*

The primary function of verification is to assess the quality and accuracy of a particular piece of information, but it is also used to translate or make sense of information, to satisfy curiosity, and to foster learning. Verifiers have confidence in their abilities to find and evaluate information: “*You can always find the resources,*” Crystal says. “*It’s always out there.*” Gary says that he uses information to make choices about his health: “*Basically to me it’s like playing a game, being able to know what you need to do to fit all the parameters. And it took awhile for me to figure that all out... from my own experience, reading, seeing what you go through here.*”

#### *Summary of interaction approaches*

Five approaches to health information interaction were identified and described, and we arranged these approaches on a spectrum according to interactivity, from low/no interactivity with information to high interactivity (Figure 1). The spectrum begins with the lowest interactivity approach: *avoiders* do not engage with health information and may have proxies do this for them. Moving along the spectrum of interactivity, next there are *receivers*, who report encountering all the health information they need in clinic without the need to search for more. *Seekers* actively acquire information in and out of clinic. Finally, the approach at the highest end of the scale is that adopted by *verifiers*, who describe seeking out health information from multiple sources in order to validate its credibility. As interactivity increases, participants consult more sources in a wider variety of locations, and most of the strategies used by participants with less interactive approaches are also used by the more interactive participants, who simply add additional strategies to their approach.

#### ***RQ2: Activity, sociality and trust***

Coping strategies like health information interaction are not just *active* or *passive*; they also have a social component and can be *prosocial*, *asocial*, or *antisocial*. Examples of these strategies,

derived from the model of social coping, are listed in Table 1. In this section, we discuss the activity and sociality of the approaches identified in RQ1. We also consider the role that trust in one's healthcare provider may play in influencing health information interaction. To facilitate discussion, the activity and sociality of each approach was qualitatively mapped using violin plots in Figures 2 and 3. Violin plots are useful for visualizing differences between categories in small-n datasets; the length of the plot demonstrates the range of datapoints, and the width of the plot illustrates the density (based on the number of participants) at that point. For example, Figure 2 demonstrates that avoiders are variably active, with a range from very passive to very active. Figure 3 shows their tendency towards antisociality, with a range from antisocial to moderately prosocial with most participants at the antisocial or moderately antisocial level.

[Insert Figure 2 here.]

[Insert Figure 3 here.]

### *Avoiders*

Avoidance is variably active and antisocial, and avoiders employ instinctive, avoidant strategies when interacting with health information. Often, a caregiver manages their care. As their moderate antisociality demonstrates, avoiders do not value this labor, calling it unimportant and unnecessary. Avoiders are not particularly assertive; they do not advocate for their own care, instead deflecting substantive discussion or even ignoring healthcare providers altogether in the clinic. For example, in the following exchange, Calvin deflects the nurse's questions by joking in a manner that social coping theory describes as both instinctive and avoidant:

*Nurse: Stomach bothering you again?*

*Calvin: Wait a minute, I can pick up my telephone.*

*Nurse: Who you gonna call?*

*Calvin: I don't know. Ghostbusters! (all three laugh)*



As previously described, avoiders may ignore their care altogether, preferring uncertainty. For example, David's wife had to take him to the doctor in order for him to be diagnosed. His avoidance of the doctor before his diagnosis may reflect avoiders' tendency to distrust the healthcare system. Avoiders have low trust in HCPs in part because they strongly believe providers are more motivated by profit than by patient care; the health insurance system and the for-profit dialysis care model further erode trust in the medical system. Calvin says: "*They get paid every time they hook me up.*" Adam posits that providers care about money more than their patients: "*He'll go by and say, 'How are you,' and keep right on a-going, and I'll get a bill for \$400.*" This lack of trust in the medical system, which (for avoiders, at least) partly stems from the for-profit dialysis model, extends more broadly to distrust in the information they receive from HCPs; this is demonstrated in the following exchange between the interviewer and Calvin:

*Calvin: I asked [the nurse] what happened, and he was telling me that my blood pressure dropped...*

*Interviewer: Do they ever tell you anything about what might be causing that? Do you ever think about—*

*Calvin: They don't know that.*

*Interviewer: Oh, they don't know?*

*Calvin: I'm saying.*

*Interviewer: You think maybe they don't.*

*Calvin: I'm thinking they don't know.*

*Interviewer: Yeah? Do you ever think about trying to get an answer to that question some other way besides—?*

*Calvin: What other way am I going to get an answer, even from the doctors? They'll still say the same thing.... They all trained by the same master. (laughs)*

*Interviewer: So, for you, if the doctor can't answer it, what do you do?*

*Calvin: There's no other place to go.*

### *Receivers*

Receivers are somewhat passive and asocial; they prefer to have health information given to them directly or to glean it in the clinic through observation. They are cautious, and they rely on others, usually HCPs, to create a careful plan for their health. For example, when Theresa is asked about what she would do if she had a new symptom, she says: "*I really don't have much*

worry about that...I don't know it, somebody has to tell me." She also describes the somewhat passive approach of receivers: "I didn't want any [information about kidney disease]. I didn't want any of it because I didn't want to have to know it." However, throughout her interview she discusses reluctantly engaging with health information when it is given to her by HCPs, distinguishing this approach from that of an avoider. Receivers say that they trust their HCPs; specifically, they trust that providers will give them information at the appropriate time. Carol says that one of the reasons she does not ask questions of her HCPs is that "I would think they would tell me what to do, the nurses and the doctors, you know, with kidney disease."

#### Askers

Askers are fairly passive with a tendency towards prosociality; in addition to using all the other strategies used by less-engaged patients, they prioritize what social coping theory calls *social joining* by engaging in friendly, chatty encounters with HCPs and other patients. They are somewhat passive in their information behaviors, for they are careful to time their information activities so as to not disturb providers with questions outside of existing clinical encounters. For example, a friend of Betty's asked her questions about an upcoming treatment, "I had no answers for her.... She said, 'Oh, [your doctor] doesn't answer any questions, does he?' I said, 'Well, I did ask.... And he said, 'Well, I can't tell ya right now.'" Rather than seek information from another source, Betty waited for an answer from her HCP, a trusted source.

Askers demonstrate high trust in HCPs. As Wayne says, "They're the experts.... Because they always answer my questions really very well, the two doctors." Here, Wayne describes how trust is maintained during information interactions—the doctors address his questions thoroughly, building and strengthening trust. Betty corroborates: "I have not had any questions that they didn't answer for me." Of his questions, Odel says: "Mostly if it's something I want, or am

*concerned about, I talk to the doctor when he come around.*” However, he notes that asking questions can be difficult because HCPs are busy: *“You’ve got to catch him fast if you want to say something because he’s in a real hurry, it seem like.”*

### *Seekers*

Seekers are somewhat active and variably social; social coping theory would describe them as *cautious*. They use information to make decisions after carefully evaluating their choices. While they seek support from family, friends, and other patients, they ultimately make their own health decisions. They also extend social support to other people in their network, especially other patients. For example, they may serve as a source of health information for other people in the clinic: *“A lot of [the other patients] will come to me and ask me questions,”* says Donna. *“I’ve even had a nurse come and ask me questions. Because I...do so much reading.”* Donna occasionally looks up information for other clinic patients online and brings it in to them when asked.

In accordance with their variable sociality, seekers use information to control the clinical encounter. As Lewis says, learning everything one can about dialysis is *“the key to survival.”* Here, Lewis places the onus of survival on the patient, demonstrating some level of distrust in the clinical encounter. Seekers are careful about which HCPs to trust, when to trust them, and what information to trust them with. In some cases, trust is called into question, usually due to unexpected medical issues or complications. This lack of trust then may extend to a lack of trust in information from that provider or other providers like them: *“[My doctors] had already screwed up once,”* explains Donald. *“Now you begin to wonder, is this right? This may be a screw-up, too.... Whatever you are doing to me or for me, I will watch it.”*

### *Verifiers*

Verifiers are very active and tend towards prosocial; they not only seek and triangulate information on their own, they also have a take-charge attitude and hold their ground when interacting with others. For example, Sabine's doctor told her to stop taking a certain blood pressure medication because of side effects, so she has been looking for information about how to control her blood pressure without medication. She spoke with several doctors, went online, and is considering multiple options. Like other verifiers, she is prosocial and seeks support from others in the form of information and advice, checking with family, friends, and HCPs to see what they know or what they might do in a particular situation. Verifiers stress the importance of interacting with other people; for example, Gary notes that a prosocial approach is useful for coping:

*It's hard enough going through this, let alone talking about it.... I see that some people have a harder time [with dialysis] than other people, and I think that has a lot to do with it. They'd rather be private to themselves.... I do see a number of people that don't listen. They think they know more than the doctor, which is not a good idea.*

Here, Gary describes the delicate social tightrope that verifiers walk with respect to health information: a need to be social and to engage with other people, particularly providers, while also respecting the expertise and knowledge of those providers.

Like avoiders, verifiers describe a low level of trust in the medical system and in HCPs. James echoes the financial concerns of avoiders, saying, "If you were to ask my opinion of some of the head honchos that make the big decisions here, I don't have a very high opinion of them. They make big bucks." However, when verifiers say they don't trust HCPs, it is usually because they find them dismissive, particularly of information that verifiers bring in to discuss. Crystal says,

*It is helpful to know what your symptoms are and what kidney disease is all about because of all the things physically that I was going through.... And you go to the doctor and you say, "Hey, look, I think this is what's going on," or "In the past*

*week, this happened, or this....” Didn’t no one want to say [to me], “You have kidney, you’re about to, going into kidney failure.*

Similarly, when Sabine brought information she found online to her doctor, she felt chastised for using the Internet. As previously discussed, she describes that she felt that her provider dismissed the information she found online or that she learned from hearing other patients’ personal experiences with kidney disease, even if that information was personally relevant and useful for her.

#### *Summary of activity, sociality, and trust*

Activity, sociality, and trust vary among the five approaches to health information interaction (Figure 2). According to the model of social coping, *avoiders*, *seekers*, and *verifiers* all take an active approach to health information, while *receivers* and *askers* are more passive. Only *avoiders* are antisocial, while *askers* and *verifiers* are more prosocial and *receivers* are asocial. Trust also varies; it is lowest at the extreme ends of the spectrum (*avoiders* and *verifiers*) and highest in the middle (*askers*).

## DISCUSSION

Our analysis reveals that our participants interact with health information in five increasingly interactive approaches; each approach generally includes and broadens the previous stage’s seeking methods, sources consulted, and information use. The activity and sociality of these approaches varies, as does the level of trust that participants have in their healthcare providers. This study thus offers three key contributions: (1) its detailed characterization of the variability of information interaction approaches in this context; (2) the identification of the sociality of these approaches; (3) the role that trust in one’s healthcare provider may play in patients’ approach to health information.

The information interaction approaches identified in this study differ from those found in prior research on health information interaction styles (e.g., Baker, 1996; Bonner & Lloyd, 2012; Case, Andrews, Johnson, & Allard, 2005; Lambert et al., 2009b, 2009a; Nelissen, Van den Bulck, & Beullens, 2017). We identify more categories than prior work in this domain, with the exception of one cancer-based study (Lambert et al., 2009a, 2009b). Some of the approaches identified in their study, which focused specifically on information seeking strategies, are similar to those identified in our work. For example, intense information seekers are similar to verifiers, and fortuitous information seekers are analogous to receivers (Lambert et al., 2009a). They also found support for a range of avoidant strategies; however, they do not describe an approach similar to askers (Lambert et al., 2009b). To our knowledge, no prior research has identified the asker approach to information interaction, either in or out of health. Additionally, our work reveals more interaction with health information at a mid-level of activity (e.g., *receivers* and *askers*); this may reflect our participants' ongoing contact with HCPs and the chronicity of their condition, which may be characterized by periods of stability that correlate to less active information seeking (Chen, 2016). We also identify nuances at the more interactive end of the spectrum, distinguishing verifiers from seekers based on their assessment of health information via confirmation across multiple sources, their prosociality, and their lower trust in HCPs.

Our findings extend prior typologies, including those of Lambert and colleagues, with its greater attention to activity, sociality, trust, and information use than has been elucidated in prior related work. For example, although Lambert et al. (2009b, 2009a) identified five approaches to cancer information interaction, some of which map to the approaches found in our study, they did not specifically study sociality and found only one passive approach. However, they do note that the most silent and least interactive focus group members in their study also demonstrated minimal

information-seeking preferences, which aligns with our finding that avoiders are antisocial and receivers are asocial. They also found that the least active information seekers expressed high trust in their oncologists, a finding that is in contrast with our findings, which demonstrate that avoiders do not trust their healthcare providers. We also identify differences in sociality among participants, finding that participants with more active approaches to health information are qualitatively more social than those who are avoidant. Therefore, in our study, more information interactivity is associated with more social and active coping strategies. Our research contributes to a growing understanding of health information interactions as contextually-based social activities, not as simple functions of internal or cognitive factors (Johnson & Case, 2012). Our findings support the need for more research into the role of sociality beyond its narrow application to source selection in health information behavior.

Uniquely, we found that patients at both ends of the spectrum—those with the most and least interactive approaches—also have the lowest levels of trust in HCPs. This contradicts a research synthesis in cancer, which found higher trust in patients who avoided health information (Germeni & Schulz, 2014). Notably, our observation and inclusion of the *verifier* approach also differs from prior studies; this difference may be related to the hemodialysis context in the US, where patients are often skeptical of the for-profit nature of their dialysis care (Costello, 2016). The issue of healthcare provider trust is therefore a key factor in health information interaction that should be investigated in future research.

### ***Implications for practice***

With a more nuanced understanding of the variability of patient activity, sociability, and trust, practitioners can gear information resources to the approaches we know dialysis patients actually use. There is a large body of literature that demonstrates that tailoring health messages is linked

to health behavior change, especially in cases in which information is tailored to several of patients' theoretically-grounded behavioral characteristics, such as attitude and social support (Noar, Benac, & Harris, 2007). Moreover, there is a pressing need for individualized educational interventions in ESRD that account for the needs, values, and preferences of patients (Green & Boulware, 2016). Our study provides more theoretical support for future health information interventions, offering multiple interrelated constructs that authors can use to tailor information provision. Like prior researchers, then, we advocate for providing information to patients in a manner that is tailored to their information interaction patterns and underlying preferences (Czaja, Manfredi, & Price, 2003; Nelissen, Bulck, & Beullens, 2017; Williamson & Manaszewicz, 2002). Our research could be used to theoretically underpin health information interventions for this particular patient population, using the identified approaches to health information interactions, social coping, and trust. The next step for such work is to further test and operationalize the identified styles, with the aim of creating a validated survey instrument that could be used to assess patient preferences for tailoring information in health interventions. This would add to a growing interest in developing translational interventions in kidney disease and dialysis that target education and disease self-management (Tuot et al., 2014). In the next section, we outline some examples of such interventions.

Avoiders do not want to engage in health information interactions, and despite their relative antisociality they often rely on proxies who manage their care. They also have a low amount of trust in healthcare providers. To develop trust with avoiders, HCPs could consider preparing for dialysis-specific communication challenges by participating in workshops designed to improve doctor-patient relationships in dialysis (Green & Boulware, 2016). Reinforcing the autonomy of avoiders may also be one way for HCPs to develop trust with this group. HCPs should also still



provide opportunities for avoiders to engage with health information, but with the recognition that providing health information to their proxies may also be appropriate. We suggest assessing the information style of proxies and tailoring health information to match their style in the case of avoiders.

Although there is a trend toward patient empowerment and shared health decision-making (Johnson & Case, 2012), our findings indicate that this model of care is not appropriate for every dialysis patient. Receivers prefer health information that comes to them in the clinic, and their relative passivity and moderate trust in healthcare providers makes them excellent candidates for traditional modes of health information delivery: frequently updating clinic posters, providing informational flyers in waiting rooms, and sending regular newsletters to patients are useful ways to provide health information to receivers.

Askers, as well, may prefer a more traditional approach to healthcare. This approach to health information—seeking out health information by only asking questions of HCPs—was previously not identified in the literature. Our identification of this approach may be due to the context of in-center hemodialysis, which puts patients into regular contact with other patients and with HCPs. We do not know whether or not this behavior exists only in patients who have regular contact with their HCPs, or if it is a general approach that many people take to health information. Understanding whether this particular category is transferrable to other contexts is therefore necessary. Nevertheless, practically, HCPs in dialysis clinics should make sure to give askers space and time to ask questions, and may plan to linger at their chairs for a few minutes to provide such an opportunity. Since they are fairly social, askers on dialysis may also be good candidates for either online or face-to-face patient peer support groups, especially those that are moderated by HCPs (Taylor, Gutteridge, & Willis, 2016).

Seekers will engage with health information outside of the clinical setting, and these information interactions can be supported by healthcare providers by acknowledging this activity and discussing it with them directly. This is particularly important for building and maintaining trust with seekers, who have moderate trust in HCPs, particularly since the quality of social interactions with providers plays a vital role in how much people who seek information outside of the clinical encounter trust them (Lu, Xu, & Wallace, 2018).

Verifiers are fairly social and are very active in their care; they fit the general definition of an “empowered” patient (Trummer et al., 2006). Although they are fairly social and active, they have low trust in HCPs. Working to establish a relationship of trust with verifiers is therefore important. HCPs should be willing to have discussions with verifiers about health decision-making and the rationale underlying those decisions. Out of respect for their interest and engagement, HCPs could encourage verifiers to bring in information for verification; or, they could provide supplementary reading to verifiers. Since trust begets trust, involving them in patient advocacy programs or patient peer support groups as patient navigators may be another way to develop trust with this group. Verifiers like educating other patients about how to interact with health information about kidney disease and are therefore good candidates for selecting as patient navigators, who have been demonstrated to improve patient care in translational interventions for ESRD patients (Jolly et al., 2015).

This spectrum of approaches may also hold promise for tailoring information both within and beyond health contexts. To do so, future research should operationalize this spectrum through the development and validation of a summated rating scale for use in this and similar contexts. Health combines cognitive, affective, and somatic experiences and is personally salient for most individuals. The approaches we identified, therefore, may exist in other situations that are

personally meaningful; disruptive or transitional; and where experts or professionals exist and are fairly accessible, as is the case in healthcare generally and dialysis specifically. For example, this spectrum may hold for other similar health conditions like cancer with frequent chemotherapy treatments, or in transitional and situated health contexts like in antenatal classes. Outside of health, the spectrum may be found in personally meaningful situations that unfold over a period of time, such as religious practice (Gorichanaz, 2016), home buying (Savolainen, 2010), or crises (Westbrook, 2009). The variety of approaches we identified may not be present in acute health situations, or in health conditions that are more stigmatized than kidney disease as stigma likely impacts social coping and trust. Future research, therefore, should further test the transferability of this spectrum to information interactions in other contexts both in and out of health.

### *Limitations*

First, we interviewed patients at only one point in time. A longitudinal analysis may identify potential variation across time among hemodialysis patients. Moreover, our sample may be affected by selection bias, since participants had to agree to be interviewed during their dialysis sessions. Because they were situated next to other patients and their healthcare providers during the interviews, social desirability bias may also be a factor in this data collection technique. Finally, it is not clear whether results are transferable beyond a hemodialysis context, since the clinic environment may have shaped information interactions approaches within them; for example, perhaps information encountering was possible because of the clinics' informing routines (Veinot et al., 2010).

## CONCLUSION

Patients on hemodialysis take multiple approaches to interacting with health information; these approaches can be arranged on a spectrum from avoidance to verification. Level of activity, sociality, and trust in HCPs differ across these approaches. Participants at both extreme ends of the spectrum (*avoiders* and *verifiers*) both have low trust in HCPs and are moderately active in their approach to health information interaction. They differ, however, in their sociality; *avoiders* are antisocial, while *verifiers* are prosocial. In contrast, *receivers* and *seekers* are asocial and exhibit a fair amount of trust in their HCPs, but as the names imply, *seekers* are more active information seekers than *receivers*. Finally, *askers* are prosocial and have a high level of trust in their HCPs. A key contribution of this work is its nuanced understanding of health information interaction. These findings can and should be used to tailor health information interventions. Moreover, the dimensions of activity, sociality, and trust can assist in identifying patients likely to engage in each approach and in designing information systems and services that address their specific requirements.

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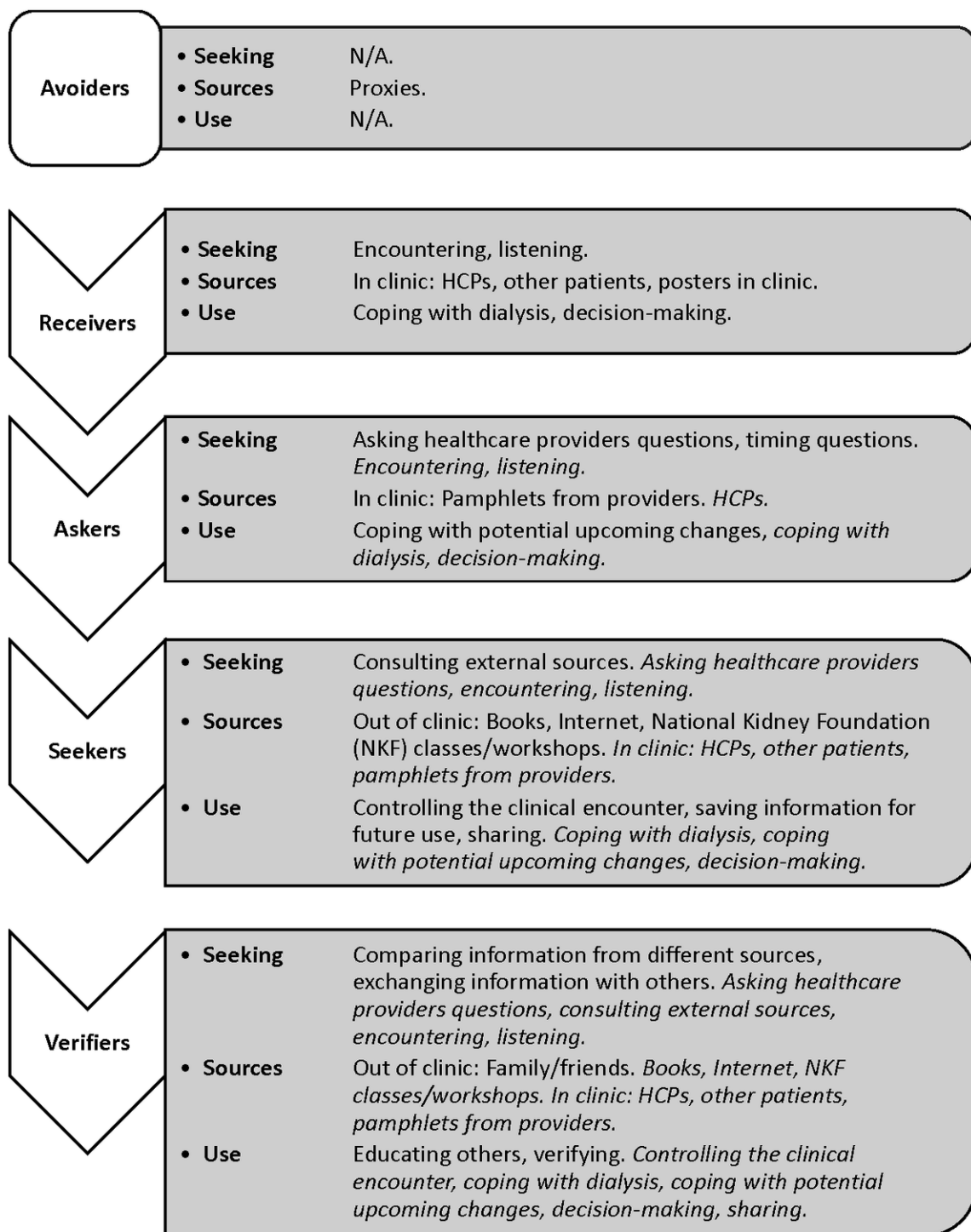
Table 1. Examples of activity and sociality in social coping theory.

Table 2. Demographic characteristics of participants.

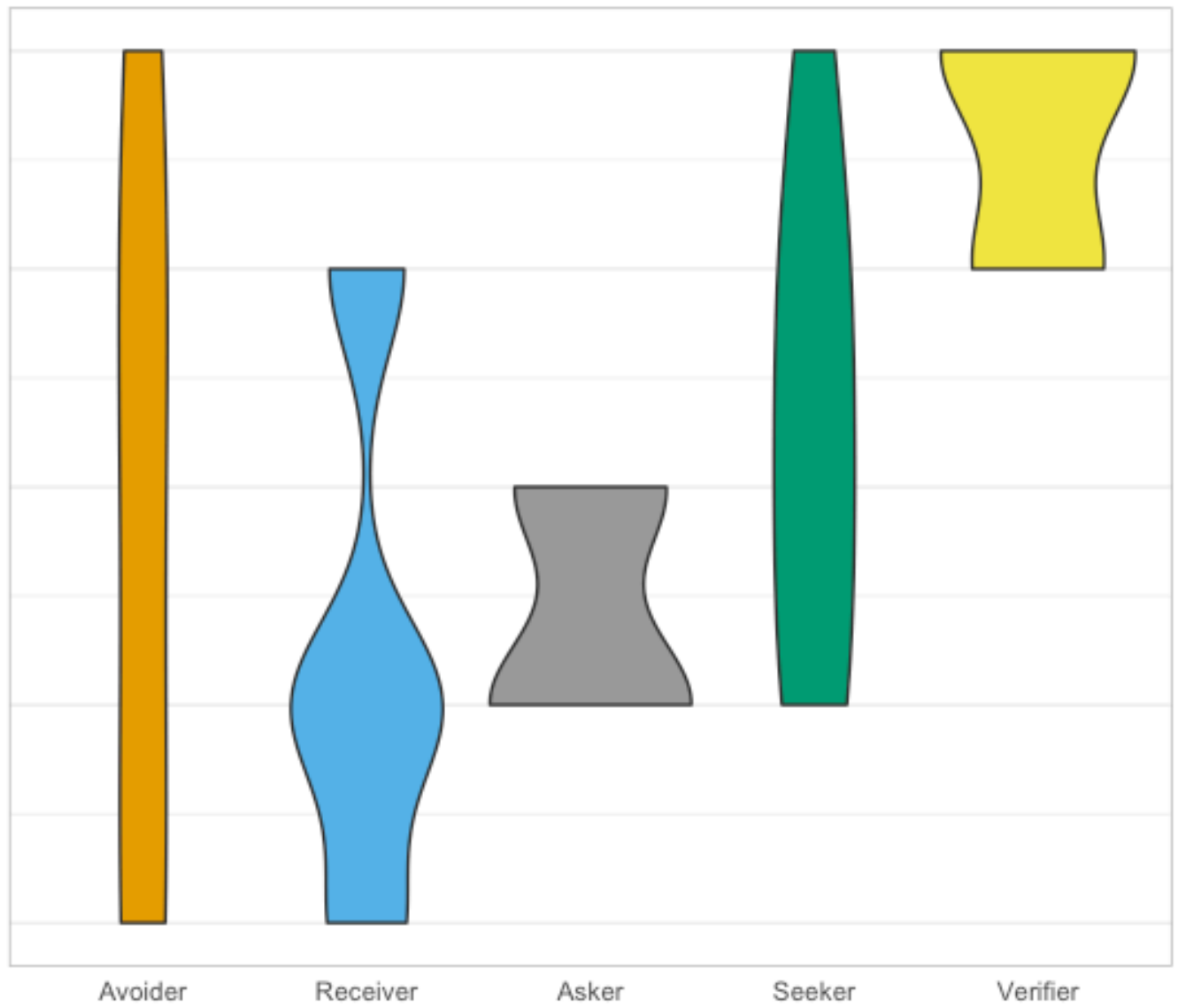
Figure 1: A spectrum of approaches to health information interaction.

Figure 2: Activity of each approach.

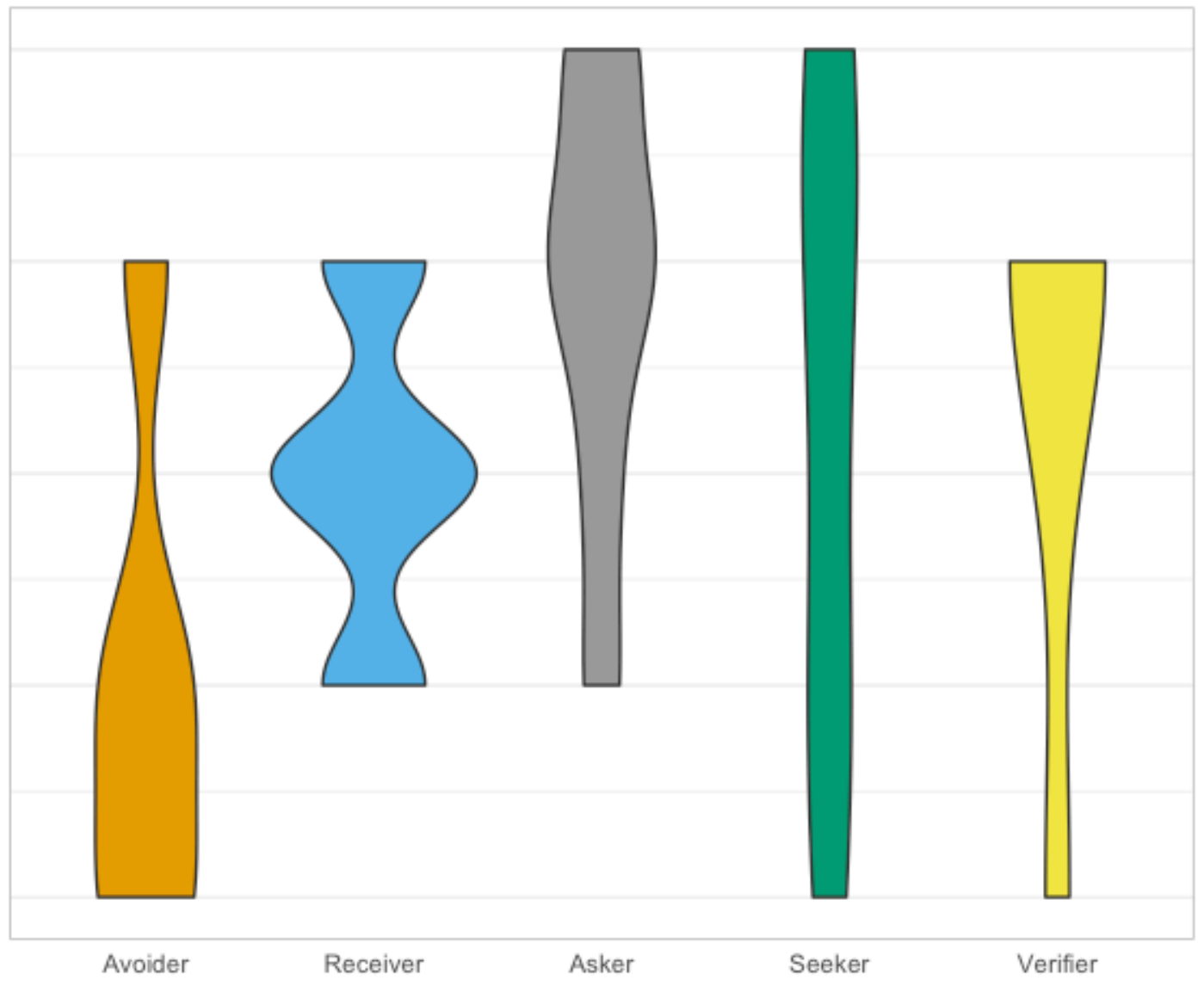
Figure 3: Sociality of each approach.



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ASI\_24310\_Figure-2\_Activity.tiff



ASI\_24310\_Figure-3\_Sociality.tiff

Table 1. Examples of activity and sociality in social coping theory.

<b>Activity (active/passive)</b>	
<i>Very active</i>	Aggressive Holds ground in decision-making Takes charge of situations Tenacious
<i>Somewhat active</i>	Depends on self and personal strengths Evaluates choices, but doesn't hesitate too long Trusts instincts
<i>Somewhat passive</i>	Cautious Deals with things as they come Does things to distract self from problems Thinks "better safe than sorry"
<i>Very passive</i>	Feels resigned Hopes problems will go away on their own Moves on to other things due to lack of hope Retreats from problems
<b>Sociality (prosocial/antisocial)</b>	
<i>Prosocial</i>	Checks with others to see what they would do Flexible Helps others in similar situations Solves problems in a group
<i>Asocial</i>	Allows others think they are in control Depends on self but takes others' opinions into account
<i>Antisocial</i>	Catches others off-guard Does not consider the needs/feelings of others Independent

Table 2. Demographic characteristics of participants.

	<b>Total (n=28)</b>
<b>Age (Mean (S.D.))</b>	67.1 (12.3)
<b>Years on dialysis</b>	4.5 (4.9)
<b>Race/Ethnicity (n (%))</b>	
White	18 (64.2%)
Black	8 (28.6%)
Asian	1 (3.6%)
Native American	1 (3.6%)
<b>Gender</b>	
Female	13 (46.4%)
Male	15 (53.6%)
<b>Education level</b>	
High school or less	13 (46.4%)
Beyond high school	14 (50%)
<b>Clinic</b>	
Rural	10 (35.7%)
Suburban	8 (28.6%)
Urban	10 (35.7%)