

“Tricky to get your head around”: Information Work of People Managing Chronic Kidney Disease in the UK

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ABSTRACT

People diagnosed with a chronic health condition have many information needs which healthcare providers, patient groups, and resource designers seek to support. However, as a disease progresses, knowing when, how, and for what purposes patients want to interact with and construct personal meaning from health-related information is still unclear. This paper presents findings regarding the information work of chronic kidney disease patients. We conducted semi-structured interviews with 13 patients and 6 clinicians, and observations at 9 patient group events. We used the stages of the information journey – recognizing need, seeking, interpreting, and using information – to frame our data analysis. We identified two distinct but often overlapping information work phases, ‘Learning’ and ‘Living With’ a chronic condition to show how patient information work activities shift over time. We also describe social and individual factors influencing information work, and discuss technology design opportunities including customized education and collaboration tools.

CCS CONCEPTS

• Human-centered Computing → Human computer interaction (HCI); HCI theory, concepts and models

KEYWORDS

Information work; chronic kidney disease; sensemaking; meaning making; information journey; patient self-management

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1 INTRODUCTION

“each [chronic] illness confronts patients and their families with the same spectrum of needs: to alter their behaviour; to deal with the social and emotional impacts of symptoms, disabilities, and approaching death; to take medicines; and to interact with medical care over time.”

– Edward H. Wagner & Trish Groves, *British Journal of Medicine* [84]

Nearly 17.5 million adults in the United Kingdom (UK) have one or more chronic conditions [18] that they will have to manage for the rest of their lives. To learn about and plan for an uncertain medical and social future, patients find and utilize health information resources (e.g., healthcare providers, patient peers, and online and paper-based information) [63]. Patients and their families are encouraged to use information resources to gain awareness of the benefits and challenges of future treatment options and to assist in collaborative decision-making with healthcare providers. However, this process often requires substantial patient effort to learn, discuss, and make decisions about their future as a person with a chronic illness. Thus, to better support individual’s health-related decision-making activities, we must better understand the breadth of patient *information work*.

HCI researchers have long been interested in understanding health self-management practices in the context of chronic illness (e.g., [4,34,45,57,75,76]). Within this space, researchers are also extending our conceptual understanding of information work. Strauss et al. [78] define information work in the healthcare context as “the quest for, the receiving of, and the passing of information.” This broad definition encompasses a variety of information-related activities such as identifying problems

[70], sensemaking [65,82], and collaboration [68]. For instance, Büyüktür and Ackerman discuss the importance of collaboratively aligning the information work practices and perspectives of care providers and patients [11]. Similarly, other researchers have studied aspects of information work including patient-provider communication [48], nurse navigators [35], family information-sharing [6], and management of verbal and written communication during cancer care [41]. However, there has been less focus on how information work for self-management *shifts over time* in chronic care.

There has also been growing interest in developing technologies to better support health information work such as online health communities (e.g. [33,51,88]) and mobile health applications (e.g. [36,55]). However, a focus on improving technologies is only part of the solution. We also need to help patients manage information overload [11] and the emotional aspects of information work [12] when medical issues are severe. Therefore, we still need to better understand patient's information work practices and *when* and *how* to best present information to patients and their families in order to support their decision-making goals. To do this, we explore patient information work activities and motivations through a temporal lens.

In this study, we utilized qualitative methods to examine the information work of patients managing chronic kidney disease (CKD) in the UK. CKD is an example of a complex health condition that demands significant engagement from the patient and their family, presents a variety of information needs, and has several online and offline information resources [19,54,60]. We conducted semi-structured interviews with patients and care providers at two hospitals and observed CKD patient group events, to study patient information work activities in these settings. We describe their information work including the barriers participants encounter and their resource preferences.

We contribute to the HCI literature by extending prior work on self-management and the lived experience of chronic conditions by focusing on a particular aspect of self-management, information work, specifically how patient's information work activities unfold over time. We do this in three ways. First, we describe how patient information work shifts between two phases which we label "Learning" and "Living With." These two phases enable us to consider the ecology and social context of information resources as well as the temporal dimension of information work as activities change over time. These phases can also overlap and reoccur as a patient continues their long-term treatment. Second, we contribute to a

deeper understanding of patient meaning making (interpreting the personal relevance of information and applying it to one's own health context) by defining this activity and showing how it is an important complement to sensemaking work. To effectively conduct meaning making, we show how collaboration with others is key to supporting patients through emotional and informational barriers. Third, we identify a reason patients engage in information work that has rarely been discussed: patients conceptualizing their "future normal" selves in order to make treatment decisions that best fit their goals for the future. Through this research, we aim to inform design of information resources that are linked to the shifting nature of patient information work.

2 RELATED WORK

In this section we provide a brief overview of the chronic kidney disease context, and then summarize key literature about patient information work, sensemaking, and meaning making.

2.1 Chronic Kidney Disease

Chronic kidney disease (CKD) describes abnormal kidney function and/or structure. CKD patients are roughly divided into three categories: (1) "Pre-dialysis" patients who often have declining kidney function but are not yet facing critical kidney failure; (2) ESRD (end-stage renal disease) patients who require renal replacement therapy (RRT) or palliative care; and (3) transplant patients. Ideally, patients with CKD are provided with information about treatment choices, so that they can be prepared for dialysis [33]. CKD patients are also likely to be managing comorbid conditions including diabetes or heart disease [21].

Pre-dialysis patients are usually aware of their declining kidney function, but have not yet reached ESRD. Before people reach ESRD, a key decision they must make with their healthcare team is their future method of dialysis or supportive care. Clinical nephrology guidelines recommend shared decision-making around this crucial question [27]. Dialysis removes bodily toxins through artificial means and maintains fluid and biochemical balance as failing kidneys lose their capacity to do so. Methods include hemodialysis, where blood is pumped from the patient, passed through an artificial kidney (the dialysis machine) and returned to the patient; and peritoneal dialysis, where the peritoneal membrane in the abdomen is used to filter out toxins through a surgically implanted catheter. These treatments take place several times a week.

For RRT patients, there may be flexibility in treatment location depending on their ability to self-care. For

hemodialysis, some patients receive their treatment at the hospital dialysis unit (in-center patients), and others conduct their treatment entirely self-sufficiently at home [67] including peritoneal dialysis patients.

Finally, patients may receive a matched kidney transplant, which may enable them to return to their previous activities as normal. However, they will need to continue to take immunosuppressant pills every day to maintain kidney function.

2.2 Patient Self-management & Information Work

A large body of work has focused on understanding the self-management practices of individuals managing chronic disease (e.g. [7,15,74]). Broadly defined, self-management is “the day-to-day tasks an individual must undertake to control or reduce the impact of disease on physical health status” [15]. Many HCI researchers have stated the importance of patient’s collaborative work with clinicians [34,51] and informal caregivers [57,80] to support learning and ongoing self-management. An important aspect of self-management work involves acquiring, understanding, and using information. This paper focuses on the information work area of the self-management literature.

Patients often conduct information work collaboratively with healthcare providers, patient peers, and family members. Collaboration helps patients to make sense of complex illnesses and to locate distributed healthcare system resources. For example, a survey of HIV patient information work found that 80% of patients had experience giving advice telling others where to find care-related information [63]. Similarly, cancer patients reported the importance of bringing another person (often a family member or friend) to the clinic with them to ask questions and take notes on their behalf when they felt ill [41].

While collaborative patient information work activities are widespread, HCI researchers have noted that the practices and guiding assumptions about information work held by healthcare practitioners, patients, and family members are often distinct from each other. In studies of breast cancer, these diverse viewpoints have created discrepancies in health information sharing preferences among patients, doctors, and other health service staff [37]. In the bone marrow transplant context, at varying times, patients experienced information overload (too much information), under-load (too little information), misalignments and breakdowns between stakeholders [11]. However, while challenges in information work have been identified, it is less clear how information work practices and preferences may shift over time. Knowing how and at

what point in time patients seek to gather and interpret information is an important first step to aligning the currently misaligned perspectives with healthcare providers.

Researchers have investigated and designed for aspects of the information work of CKD patients largely through technology-based self-management solutions. For young adult and adolescent CKD patients, researchers investigated the feasibility of online social support technologies to address their needs. Zheng et al. [89] describe how CKD treatment options often introduce radical changes to patient lifestyles. Through a web-based prototype platform, their objective was to “help YAs [young adults] develop ‘new normal’ lives, restore social identities, and regain confidence in school and work.” However, Bers et al. [8] found that children preferred to engage in online environments without any kidney disease related information. Abeer [1] and Laverman [45] discussed how digital self-management systems can lead to greater health awareness for patients and caregivers, and Costello [16] described how patients search for kidney donors online. However online platforms are unlikely to serve all patient needs, particularly because, as Diamantidis and Becker [21] note, individuals with CKD “who are frequently older and of lower socio-economic status and health literacy are often not in the target markets of IT providers and vendors.”

Beyond technology-focused research, some work has been conducted regarding the information practices of CKD patients during hospital dialysis sessions. Veinot et al. [83] observed peer- and provider-led education processes with ongoing threads of “escapism and gentle banter.” Through this gentle information exchange, illness and treatment become more tolerable. However, the authors also note that these information work routines can be disrupted by major health events, for instance receiving a kidney transplant, experiencing a new health crisis, or coming to distrust their care providers. Thus, understanding the wider patient information work context including both online and offline resources and patients’ evolving needs can create broader inspirations for thinking of the future of information resource design for CKD patients. While many of the above papers encompass aspects of information identification and use, they focus on how people use information as part of their broader health management practices, and do not foreground the information work aspects of self-management as it shifts over time in chronic care.

2.2.1 Temporal Lenses. We have limited knowledge about how patient information work behaviors unfold and shift

over time as people gain knowledge and experience managing their condition. Researchers and medical professionals often situate information work within the stages of the patient care pathway. For cancer patients experiencing a disease group with a complex treatment path, Eschler et al. [17] noted that information work activities were often tied to the stage of treatment (e.g. pre-diagnosis, in-treatment, survivor, among others). Also using this treatment stage perspective, Jacobs, Mynatt, and Clawson [29] describe the importance of ‘just-in-time’ education to target relevant information to the current health stage of each breast cancer patient. For healthcare providers, knowing when to provide information to patients in a way that helps them prepare for upcoming treatment stages, but also not be overwhelmed by information, is a pressing question [54].

Another perspective on patient information work over time is focused on iterative experience(s) and learning. These researchers present information behavior models that cycle through stages of patient learning and processing, but are not specifically tied to stages of disease. For example, Büyüktür and Ackerman [11] describe stages of crisis, steady states, and transitions in the information work activities of Bone Marrow Transplant patients. Their conceptual view highlights how information work activities are tied to the medical and emotional experience of treatment and often do not fit a specific routine of daily practice. Others have focused on patient information needs as they evolve over time in technology-mediated contexts such as online communities [23] and tablet computing [36]. However, while understanding how patients search for and discuss different questions over time in these contexts is useful, these studies, by their nature, leave out the experiences of patients who do not have access to or have had negative past experiences with technology tools.

2.3 Sensemaking and Meaning Making

A key information work process, for someone whose life is directly affected by information, is transitioning from a general understanding of some information to applying that information within one’s personal context. We refer to these activities as “sensemaking” and “meaning making” respectively, to facilitate a discussion of this important transition in understanding, whilst recognizing that the definitions of both terms in the literature are often broad and overlapping. Sensemaking has been defined in many ways, including “the deliberate effort to understand events” [43], using data to arrive at an appropriate understanding of a specific situation [24], and as “a motivated, continuous effort to understand connections (which can be among

people, places, and events) in order to anticipate their trajectories and act effectively” [42]. The goal of this activity is to gain understanding of a certain topic. As people make sense of information, they place new knowledge into a framework for categorization and fill gaps [20].

Sensemaking is closely linked to another process: *meaning making*, a term used in HCI to describe artistic [62] and educational [86] processes. In the context of health, we define meaning making as internalizing understanding in terms of what it means for the individual personally. Through meaning making, patients create personal meaning of information and events through emotional processing activities and shifts in personal beliefs, goals, and perceptions of the world [64]. While sensemaking can be more intellectual, meaning making relates to the embodied experiences [13] and values of patients. A recent meta-analysis compiled outcomes of meaning making including acceptance of one’s condition, and perceptions of growth or positive life changes, among others [64]. These outcomes can be powerful in shaping future information work and understanding of oneself as a chronic disease patient.

Although Genuis & Bronstein [28] do not use the language of meaning making, they describe patient activities that result in finding a “new normal” state. In their model, when patients encounter symptom-related “gaps” that are outside their normal life experience, this causes interference with cognitive and emotional processing, complicating health management. This dissonance stimulates patients to engage in information behaviors including expressing information needs, seeking, and using information to make sense, and also personal meaning, of the new information relative to their personal experience.

Emotional processing is an important component of meaning making. Researchers note connections between frantic information work and intense emotional work [11] and describe emotion as affecting information work [83]. Others describe the emotional aspects inherent to self-care [5,12,39] but few specifically locate when and how emotion plays out during a patient’s information journey.

2.4 Summary

In summary, patient information work encompasses a wide variety of activities that are often collaborative. Challenges arise when perspectives of patients and healthcare staff are misaligned regarding when and how patients conduct their information work. Patient information work including

sensemaking and meaning making may shift over time, but it is unclear when and how best to present information to patients and their families to support their decision-making and self-management.

3 METHODS

We conducted semi-structured interviews with 13 patients, one caregiver, and 6 healthcare practitioners during a year-long study in the UK. We complemented the interviews with field observations of 9 CKD events such as patient group meetings that included caregivers. All research was conducted in the United Kingdom within the context of the National Health Service (NHS) and received ethical clearance from the NHS Health Research Authority reference number 16/NE/0174.

3.1 Sites

Data were collected at two large hospital sites, their satellite renal units, and several kidney patient events. One hospital was based in London, serving the local metropolitan population, and the other was in York, serving the city and surrounding population. Patient event sites were accessed opportunistically at the invitation of community members. Observations were conducted at 2 dialysis units, 2 patient organization conferences, 3 local patient group meetings, 1 patient group education session, and one UK Parliament funding meeting. In the dialysis units, some patients managed significant parts of their own treatment (“shared care”); specialist nurses managed the dialysis of others.

3.2 Participants

Participants were recruited in-person across the two sites (Tables 1. & 2.) with the support of two lead nephrologists (coauthors 3 and 4). 12 hemodialysis patients were interviewed in-person in the renal unit as they were receiving their dialysis treatment. One interview included the patient’s caregiver who was seated near the patient during dialysis treatment. Additionally, one patient was receiving pre-dialysis information but did not yet need dialysis; he was interviewed by phone. Two participants requested to not be audio recorded. During all interviews, copious field notes were taken. Interviews with six healthcare practitioners were recorded. A group interview with three specialist nurses and one-on-one interviews with the other listed healthcare providers were also conducted and recorded.

3.3 Data Collection & Analysis

An interview guide was used during all interviews addressing topics relating to digital technology use,

information-seeking practices, and use of online social support technologies. We asked patients contextualized questions based on their timeline of disease management experience. For instance, we asked “Since when you first knew about having kidney failure and then especially over

Table 1. Patient (and caregiver) study participants

Pseudonym	Age	Gender	Location	Stage
Mark	61	Male	York	Pre-Dialysis
Nancy	77	Female	London	ICH*
Henry	35	Male	London	ICH
Sumit	69	Male	London	ICH
Daniel	45	Male	London	ICH
Andrew + (Sarah)	56 + (53)	Male + (Female)	London	ICH + (Caregiver)
Jane	78	Female	York	ICH
Andrei	46	Male	York	ICH
Wally	74	Male	York	ICH
Dawn	43	Female	York	ICH
Francesca	70	Female	York	ICH
Mary	54	Female	York	ICH
Charlie	28	Male	London	ICH

* ICH = In-center Hemodialysis

Table 2. Healthcare provider study participants

Pseudonym	Role	Gender	Location
Beth	Specialist Renal Nurse	Female	York
Katie	Specialist Renal Nurse	Female	York
Michelle	Specialist Renal Nurse	Female	York
Leah	Social Worker	Female	York
Emma	Specialist Renal Nurse	Female	London
Carlie	Specialist Renal Nurse	Female	London

the past two years, was there information that you wish you had known in the process?” We closed each interview by asking about future information needs. During provider interviews, providers described their work with patients across various stages of CKD management. Observations provided a broader social and political context to this research. During observations, we focused on the questions and concerns of patients in various treatment stages. Field notes were taken of all observation sessions.

Our analysis began using a bottom-up inductive thematic analysis. Following the Braun & Clarke approach [10], we analyzed the 102 pages of transcribed interviews and field notes using thematic analysis to identify themes across the dataset. When we asked healthcare practitioners about their current problems and patients about their current questions, many of the answers grouped around major patient treatment decisions such as dialysis and transplants. We then grouped relevant quotations and observations according to their stage on the CKD patient pathway continuum; from this, it became evident that there were distinct phases of information work activities. From

there, we developed axial codes and deepened and contextualized the themes.

During this process, we realized that the *Information Journey* [9] framework, including its four stages – recognizing need, seeking, interpreting and validating, and using information – fit our data well as a deductive framing, helping us to temporally organize participant information work activities. The model is cyclical and recognizes that there may be multiple cycles of information acquisition, comprehension and use. In the Findings section, we apply this model across the two phases of information work (which evolved from our thematic analysis) to structure our thematic account of the information work of the patients. To conclude our analysis, we returned to inductive analysis to interpret which activities in our data aligned with each information journey stage within our Learning and Living with phases.

4 FINDINGS

Through our analysis, we identified patient information work activities that fit two broad phases: “Learning,” and “Living With” a chronic condition. These phases highlight how patient information work activities shift over time. Within each phase, we describe the four stages of a patient’s information journey [9]. These stages showcase the motivations behind patient information work activities. Not all stages are explored to the same level of detail; we focus our analysis on the most pertinent stages of each information journey, particularly where patients experience the greatest challenges in their information work.

4.1 Learning about Chronic Illness

4.1.1 Recognizing Need. Patients begin the Learning phase by experiencing an information work trigger. Potential triggers include receiving a diagnosis, deciding on a dialysis treatment, or changing treatment. As described earlier, CKD is a complex condition that requires patients to not only understand the function of the kidneys and the details of kidney disease including its prognosis, but also the general treatment trajectories for CKD.

The Learning phase is characterized by uncertainty regarding the future. Care teams (nephrologist, specialist nurse, and other healthcare providers) provide information to help patients decide on the treatment that will best fit into a patient’s life. The type of treatment is an important consideration for the patient and their family members to make together. Therefore, careful thought here will help a treatment better fit the goals and expectations of patients and promote effectiveness of long-term care [54].

Patients and family members are expected to use information resources such as paper pamphlets to begin learning, to enable collaborative decision-making regarding treatment options. Depending on the stage and rate of the kidney deterioration, a key decision patients will need to make is which renal replacement therapy to use (e.g. hemodialysis or peritoneal dialysis).

4.1.2 Information Seeking: Accessing Resources. Information resources provide education about medical issues related to having CKD and the routines and challenges of managing CKD in day-to-day life. Patients discussed occasionally seeking paper-based and online informational resources. However, more often, *people* were their first source to address care-related questions for personalization of information and comfort of the interaction [87].

Patients, especially those with co-morbid conditions, described the importance of speaking with care team members to gather personalized information. Francesca described the appeal of asking questions to her patient care team (nephrologist, specialist nurses, and other providers):

“you can ask questions pertinent to you in particular rather than just general stuff. I’m quite a complicated case with not just renal failure [but also another chronic condition]”

Francesca viewed her care team as her main source of accurate, personalized information because of their knowledge of her comorbid health conditions.

Patients also preferred the comfort and adaptability of human interactions. Jane described how she prefers to talk with her nephrologist who can help her understand topics though multiple means including drawing. *“I can remember once asking what your parathyroid gland was. And he drew me a picture.”* She also noted how her doctor would make small talk and ask about her life outside of her illness management: *“And [he’ll] say...what have you been doing? Have you been gardening?”* She enjoyed the comfort of these conversations within the sometimes stressful healthcare environment.

Conversely, a number of patients discussed negative experiences going online to find health-related information. Mary described her first (and only) online search:

"I decided after I'd had a look [online] not to do it again because there's that much information on there, and I didn't understand enough about what was wrong with me, and I thought well, I could be reading anything and scaring myself to death and it might not be something that's concerning me."

This illustrates an experience shared by many patients who went online and were overwhelmed with the quantity of results and skeptical of the personal applicability of the health information they found online.

Patients conducted information work with three main types of human resources: care team members, friends and family members, and patient peers. Among care team members, patients viewed the nephrologist as the best source for accurate health information. However, Wally noted the challenges of gaining access to the nephrologist: *"Sometimes it's a bit of a problem to get hold of a doctor, because they're rather busy and our paths do not meet."*

Nurses, however, focused on education, adherence to care-related behaviors, and gaining the buy-in of family or caregiver(s). Andrei described why he reaches out to the specialist nurses:

"my first port of call would always be the nurses here. Because the nurses are always telling you in layman's terms. Whereas sometimes doctors...can be a bit too technical; a bit too medical speaking."

Andrei found his interactions with the renal specialist nurses to be successful because they provided practical, hands-on information.

Patients also collaborated with their friends and family members to gain speedy answers and emotional support. Francesca described having her sons help her search for information online: *"I'm not terribly good at the Internet. I'll look up on Google or something, or my sons help me."* Part of the work of accessing family members and friends for support is determining who in their social circle to ask for support based on factors such as levels of technology literacy, busyness, and related medical knowledge.

Peers are viewed as useful to discuss the lived experience of the condition and to help patients to think about their future. Dawn described how she desires to seek information from patient peers both offline and online regarding a potential kidney and pancreas transplant:

"[I will] find information from people who have had the double kidney and a pancreas transplant. See when they had it. See how long it took them to recover. What their future is now. What were the really drastic side effects? ...I

will probably start going online. And probably go into, if Facebook's got a renal page, go on there. And just read the stories ...And speak to actual people who have had these transplants...It's not just the statistics, right? ...You'd like to have statistics and also go in search of people who can tell you their story. And about how they feel. And how long it lasted."

Many patients echoed Dawn's sentiments about the importance of informal discussions with patient peers to gather information.

4.1.3 Interpreting: Sensemaking, Meaning Making, and Emotional Barriers. Once information has been acquired, patients must come to an intellectual understanding of the information (sensemaking) and then construct meaning from it in their personal situation (meaning making). However, the early days of becoming a patient are often emotionally difficult for individuals, family members, and caregivers, yet this a critical period for understanding and decision-making.

4.1.3.1 Sensemaking and Meaning Making. Patients begin interpretation by understanding information; this may occur as patients read medical education information or engage in activities such as an educational meeting run by the Kidney Patient Association at one of the hospitals in the study. For this annual meeting, the association had gathered a panel of healthcare practitioners for a patient-led Q&A session. The panelists included a transplant surgeon, a nephrologist, a dermatologist who specialized in supporting immuno-suppressed individuals, and a head of renal nursing. The audience included about 42 patients and their family members.

A patient asked, "What type of fruits can we eat?" The nephrologist discussed that most fruits were fine, but to avoid peaches and other stone fruits, bananas, and tomatoes because these are all high in potassium. He noted that patients should think about making incremental changes to their diets rather than radically cutting out items. He described this philosophy as, "do small things forever, versus big things for a short amount of time."

The patient who asked the question wanted to know how to adapt their diet in the context of their condition. The nephrologist answered by describing the implied medical rationale (potassium is a difficult element to filter out of weak kidneys) behind cutting types of food out of the person's diet. The nephrologist also suggested a slow integration of this advice to support sustainable diet change. He gave a general explanation of why certain types of food were not beneficial. This helped the patient to better understand the situation intellectually, supporting their

sensemaking work. However, the patient has to then apply this information to their personal context (meaning making). For example, if the patient really enjoyed bananas, this new knowledge could mean a major shift from previous eating habits.

In the transition from sensemaking to meaning making, problematic aspects of health decisions may only become apparent when patients begin their treatment process and the decision becomes personally meaningful. A Specialist Nurse for young people, Carlie, describes a relatively common process where patients will go through the medical and logistical procedures for a treatment, spend two to three weeks on the new treatment, and then realize the treatment is not working out for them. *“All of a sudden their brain unfogs and they ring me and go ‘blah’ with lots of questions,”* she said. Carlie further noted that it is harder to help patients once they have started on a specific treatment path because medical surgeries such as creating a buttonhole fistula for hemodialysis treatment may have already been conducted. She shared an example of one patient who called her to discuss what he had realized was an issue with his treatment. She described how he told her: *“I need to take three buses to get to [the dialysis unit location]...it’s dark outside, my parents are away in [a foreign country].”* This patient realized after starting treatment that for him, this treatment plan was not going to be a personally viable one.

4.1.3.2 Emotional Barriers. However, before meaning making activities can occur, most patients must first address emotional barriers including dealing with the initial shock of their diagnosis and coming to terms with declining health status. Patients and their families face the brunt of emotional effects during the Learning phase while at the same time being pushed by health professionals to make long-term treatment decisions. Emotional issues are exacerbated by the current ways in which information is delivered: many information resources are provided in rapid succession, leading some patients to complain of information deluge. One participant at a Kidney Patient Association monthly meeting described how, even though she *“had a lot of leaflets”* providing information, the initial period for her was *“tricky...to get your head around”* as she sought to interpret the stack of information in front of her. Another participant also felt overwhelmed by emotions and information, noting that she felt like she, *“was just thrown in at the deep end.”*

Some patients struggled to make informed decisions while they were feeling ill and undergoing medical procedures. Andrei described how he passively accepted

medical recommendations because he was overwhelmed with comorbid conditions and did not know which disease information to prioritize first.

“There seems to be plenty of information if you want to know it...But I mean at first, because I’d developed heart problems at the same time, because I’d taken on so much fluid and I’d left it too long to go to the doctor’s...it’s just been a...sort of like a rafter...Whatever the doctors or nurses said...I would just think, fine.”

Beth, a specialist nurse, described a provider’s perspective of patients in Andrei’s state – they passively accept their doctor’s recommendations without learning about their condition or participating in treatment decision-making:

“They’ll bury their heads in the sand. They’ll do what their doctor tells them, but they’re not really ready to take [information] on board, not ready to consider what we’re asking them at this stage.”

While medical staff can make treatment decisions on behalf of the patient, this passive approach to information work may hamper optimal treatment by decisions that are made too late. Delays in information work can lead to clinically adverse outcomes. If a patient does not engage in effective self-care activities, their kidney function can deteriorate to such a level that they end up in hospital and are put on immediate hemodialysis treatment. Katie, a specialist nurse, described the danger of patients remaining in denial of their condition:

“Some patients will have a lot of problems when they won’t accept it, and they won’t do anything and they end up crashing [kidney functions dropping to a dangerous level].”

Patients who successfully overcame their emotional barriers did so with the help of their care team and family. Dawn faced strong emotional barriers that she had to overcome because of her family history of CKD (her father had the condition). She described the support she received from both her care team and family members and how she was able to change her thinking:

“[The doctor] was saying, you can still do these things. Just because I’ve got renal failure, [that] doesn’t mean I can’t do it. So now I’ve got it in my head right, it’s me first and then it’s renal disease afterwards, you know. It’s not going to ruin my life. It’s not going to run it.”

She also described working with her husband to find needed information. He was able to present information to her in a way that highlighted how her CKD experience would be different from that of her father.

“My husband actually went online and looked up renal disease. Because, at first, I just didn't want anything to do with it...he'd print it all for me and, say ‘just read this.’ And I found myself reading it. And I was thinking, okay, it has changed from when my dad had it. And that's when I started to get more active looking at stuff.”

Interpreting information is a challenging activity for patients. Transitioning between sensemaking and meaning making and overcoming emotional barriers through collaboration with others allows them to make these transitions.

4.1.4 Using Information. Patients use the interpreted information to learn how to manage their condition to keep themselves as healthy as possible (e.g. eating approved food and exercising) and to operationalize the logistics of their self-care (e.g. coordinating transportation to and from the hospital for treatment and getting to know their care team) [21]. These interpretations are used to make decisions about types of dialysis treatment [60].

Once patients learn approaches to manage their condition, they can put them into practice. Henry described the role of his medical care team in helping him learn about his condition and conduct proper management behaviors over time:

“From the beginning [of diagnosis] you meet nurses, you meet dieticians and they talk to you [about] how to go along with it, so initially you don't put all of them into practice, but as time goes on you begin to do your best to.”

Henry shared a specific example: *“The nurses tell you if your potassium is high you need to cut these kind of foods, you need to stop eating this.”* This illustrates how care-related information is used to inform behavior change.

Following initial learning and acceptance, patients settle into their routines of self-management activities and move into the “Living With” phase of information work.

4.2 Living With a Chronic Illness

As patients move from the Learning phase into the Living With phase, information work becomes more routine. Patients are more certain about how the next day, week, and year will look as they continue similar treatment routines and develop a better understanding of how to utilize information resources. Characteristics of this phase include moving toward a long-term perspective and monitoring and vigilance information behaviors.

4.2.1 Recognizing Need. In this phase, triggers for information work become routinized. Routines may include looking at blood test results after each checkup. Some

patients make information work a part of their everyday activities and do not need a specific trigger to continue to read about and discuss their condition. These patients conduct information work motivated by their ongoing engagement with their own health management, in contrast to the external triggers (e.g. clinician-prompted reading and discussion) during the Learning phase described above.

Several participants had CKD along with other health problems. These patients described the importance they placed on ongoing information work because of comorbid health conditions and the need to communicate with multiple care teams. When seeking information, Andrew, a patient with both CKD and bladder cancer, and his wife, Sarah, often communicated with members of multiple care teams. Andrew described this challenge in the context of an upcoming bladder surgery: *“I am about to have a very complicated situation dealing with different disciplinary teams – in different hospitals.”* Sarah, who often communicates with medical practitioners on her husband's behalf stated, *“My questions have, on occasion, saved his life.”* She noted the importance of being aware of ongoing information to facilitate interacting with multiple care teams at the same time.

4.2.2 Information Seeking: Tracking Routines & Avoidance. During the Living With phase, many patients utilize a routine (practiced) approach to seeking information. For CKD patients, blood test results provide valuable insight into the functioning of their kidneys. Some patients check their results in the online Patient View system [90] continuously and use the numbers to assess the current health and functioning of their kidneys. Mark, a pre-dialysis patient, states, *“The most critical things for me are the blood results, because they determine everything else that happens.”* For Mark, his biometrics determine when he will need to start dialysis, so he tracks them closely. Other patients leave the tracking of their blood test results to the renal staff. These patients may be less inclined to follow their results because they do not want to watch their kidney function decline, or they do not understand their results. For example, Andrei talks about why he does not use the patient page to view his blood test results:

“I have been on that renal page where you can check your records. But I only used it only a couple of times. Because I look at it and I'm none the wiser, anyway. When after I've read it I look at it and think – would a doctor understand any of this? ...Half the stuff I don't understand.”

Andrei went on to say that he feels very comfortable leaving the information management of his medical results

in the hands of the hospital staff. For many of the in-center hemodialysis patients in this study, there is little incentive beyond personal curiosity to review the results of tests, because nurses take this responsibility. Therefore, not all patients engage in active tracking of their own health metrics.

Other patients described their goal to avoid dwelling on their health condition. Daniel said he was not looking for care related information because he was satisfied with his current situation:

“I said this is enough for me...I get the best treatment. It's comfortable. So I don't want any more [information], and I think that this stage [this is] enough for my life.”

Patients also described avoiding health-related information specifically to focus on the good parts of their life. Nancy described this line of thinking:

“when I'm out of here, I try to forget about it...I think one must look at the good things when you have a bad thing...So I try and enjoy my grandchildren, my great-grandchild is going to be born and things like that and separate it from...being here.”

Information avoidance behaviors may be carried out as a psychological defense mechanism by an individual patient facing a lifetime of managing a difficult disease [79].

4.2.3 Interpreting: Vigilance Activities. In the Learning phase, much of the information work revolved around transitioning from sensemaking to meaning making. However, in the Living With phase, the focus is on vigilance. Based on past negative interactions with the healthcare system, some participants were wary of potential problems and miscommunications with their care providers. Consequently, they described how part of their information work, as phrased by Andrew and Sarah, was to act “as a check on the healthcare system.” These patients carefully monitor communications between healthcare practitioners and ask specific questions about new medications and routines.

Mark described monitoring information sent from his nephrologist to his pharmacist. He had twice emailed his nephrologist for clarification about orders, motivated by a past miscommunication with adverse effects. Back then, he had been prescribed bicarbonate medication and the letter to the pharmacist detailed only one month of prescription. The nephrologist then had a major accident, and over the 18 months that he was absent, Mark developed bad acidity. When his nephrologist returned, he realized that Mark's prescription was supposed to be ongoing and not stopped.

This mistake made Mark wary of fully trusting the actions of his healthcare providers.

Andrew and Sarah also described the need to monitor the actions of healthcare providers. Andrew described several experiences of being handed medication that he is allergic to by nurses, so he knew that he needed to take extra care to read the label and inquire about what he was receiving. He said, “*I'm constantly offered penicillin which I'm allergic to.*” The couple worried that doctors could miss potential adverse drug reactions. Sarah said, “*we want to be an extra check in the process.*” She shared her concern about being able to continue caring for her husband: “*As we get older and more tired, we are likely to make mistakes.*” Constant vigilance activities were important to this couple, but they recognized the exhausting toll of that these activities could take over time.

4.2.4 Using Information. Not all routinely gathered information is directly actionable. Tracking glomerular filtration rate (GFR) of the kidney (a measure of kidney function) or tracking levels of phosphate in blood tests, for example, enables a patient to maintain awareness of their health status over time, but does not necessarily require decision or action. Thus, information work with the goal of staying on top of ongoing health status enabled patients to verify a continuation of their normal state. However, if information work in this phase uncovered information that did not meet expectations (e.g. a significant drop in GFR), this would trigger action such as contacting their healthcare providers.

5 DISCUSSION

In the Findings section, we detailed information work activities and challenges. In this section, we turn our attention to themes related to the information work described in the previous section.

5.1 Temporal Dimensions of Information Work

Temporality helps to structure an individual's work. Discussing organizational work, Strauss states, “Anyone who works in organizations thinks – has to think – of his or her work, and of the organization itself, in temporal terms” [78]. Similarly, we can consider the information work of individuals in temporal terms [59]. For instance, researchers have examined the role of rhythms and routines to better understand the information behavior of individuals [69]. We found that temporal characteristics also overlaid the information work of patients in our study. We use the Learning and Living With phases to capture these characteristics.

These two phases orient us toward the different information activities that patients carry out over time. Specifically, the Learning phase is focused on understanding what information resources they may need, reducing uncertainty, and highlighting key decisions that have to be made (and the information that may be needed to make those decisions). As patients move from the Learning to Living With phase, their information needs change and focus on longer-term goals. Furthermore, patients are often more familiar with relevant information resources and can better track their medical information.

While the Living With phase follows the initial Learning phase, it is important to note that these phases may re-occur and overlap (Figure 1). Patients, throughout their years of treatment, shift between activities related with learning new things about their condition and the more routine work of management. Patients may engage in both phases at the same time. For instance, several participants conducted routine information activities (e.g. looking at blood test results), whilst seeking information to understand kidney transplants to be ready to receive a kidney if one became available. These patients, therefore, conducted the work of both phases in parallel.

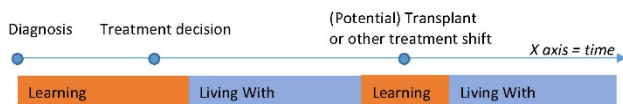


Figure 1. Illustration of Learning and Living With Phase reoccurrence

Understanding these temporal characteristics allows us to consider when it would be most useful for patients to receive certain information, and when certain types of resources need to be made available to patients.

5.2 Sensemaking, Meaning Making, and the Importance of Collaboration

The transition between sensemaking and meaning making is an important aspect of successful patient information work. Previously, HCI researchers have described sensemaking as a process enabling people to reach a conceptual understanding of a topic through both individual and collaborative actions [24,31,51,66]. This study highlights the importance of the next step after sensemaking – personally applying the information within an individual’s specific health context (meaning making [64]). Regarding patient health, meaning making addresses two questions: what does this information mean in my personal context, and how do I apply it in my thinking and activities? This application of information is tied to

personal values and belief systems [64] and is a process of internalizing a health situation.

Most information resources presented in our study were set up to support sensemaking rather than meaning making. This often resulted in feelings of overwhelming work for patients. As patients seek to reduce uncertainty by learning about their condition, they try out various resources (e.g., online, care team staff, patient peers) and determine which are most useful to help them answer questions about their care. Education sessions with health specialists, informational books and binders, and dialysis machine training programs were all seen as useful resources; however, patients can struggle with too much information, as reported for the bone marrow transplant process [11]. These sensemaking resources help patients to understand their condition, but do not help people to understand themselves – especially their personal values and goals for the future. As described in the Findings, barriers to meaning making include managing an overload of information and coping with the intense emotions that can accompany diagnosis.

Collaboration with others enables patients to overcome these barriers to meaning making and aids in information interpretation. While researchers have long studied the benefits of collaboration in information work such as finding information that would normally be difficult to find [26], and finding more useful information [73], in our study, we also found that patients collaborated to find information personalized to their specific health context and to enjoy a more comfortable social interaction. This resonates with findings of other research regarding the utility of incorporating social scaffolding into technology systems for individuals managing chronic illness [50]. Talking to others helped participants to reduce fear and better plan for the future. Home visits by nurses and conversations with patient peers were viewed as helpful because these conversations enabled information to be contextualized to the individual. For example, during a home visit, a nurse can quickly assess what treatment options may best fit the capabilities of a patient and their family members as well as the patient’s current living situation.

The distinction between sensemaking and meaning making is useful for us to consider. If patients are turning to other people for assistance with meaning making processes, this suggests unmet patient needs. Technology and other resource design may need to devote more attention to assisting patients in the application of information within their lives.

5.3 Low & High Monitor Information Workers

In our study, we found that different patient information behaviors emerged strongly in the Living With phase. Patients often have individual preferences which guide their information work goals and activities. Researchers have begun to categorize these preferences into different groups of information workers. For instance, Schneider et al. [71] developed a framework of information workers that separates them into four different groups: controllers, collaborators, cooperators and avoiders. Others discuss these differences in terms of who patients think should be responsible for the information work [17]. Ancker et al. [3] found that some individuals with multiple chronic conditions perceived that healthcare providers should take responsibility for information management; other patients felt that they themselves should have the primary responsibility for their own information work.

Our participants also held differing views about their role in monitoring their health information. Patients could be categorized into two groups: high- and low-monitors. “High-monitor” workers were patients who created routines of frequent information-seeking. We highlight these behaviors in the Findings as monitoring and vigilance (section 4.2.3). These patients always wanted to know their current health information. For other patients (“low-monitors”), once the basics of kidney disease and treatment were mastered, they reduced information work activities in their daily lives. Instead, they depended on their information being largely managed by their healthcare providers.

Differences in behaviors are likely to be rooted in personal values, experiences, and self-efficacy [47]. For example, low-monitors describe refocusing their day-to-day attention to happier aspects of their lives. The information work context for most of the patients in this study was the hospital dialysis unit, noted by Veinot et al. [83] as particularly information-rich. Patients could clearly see nurses and other care team staff attending to information work activities. In this context, low-monitor patients emphasized their confidence in the medical staff of the unit. This confidence may also reflect a lack of trust in their own knowledge or decision-making capabilities in the often complex process of kidney care and treatment. Additionally, self-reported depression rates among CKD patients are high [32]. These challenges can lead to patients wanting to focus on happier aspects of their lives and reinforce the low-monitoring behavior.

Reflective analysis of past actions, found by Mamykina et al. [50] to be an important learning avenue for diabetes

patients, is a type of analysis that high-monitor patients are more likely to perform than low-monitor patients. High-monitor patients described their intensive information behaviors as being motivated by negative past healthcare experiences such as mistakes made by a healthcare practitioner that led to adverse health outcomes. Their reflections on negative encounters plays an important role in their current information activities. In addition, while we did not gather information about participants’ socioeconomic status or education level, several of the high-monitor patients in our study described backgrounds in biochemistry or nursing which may make it easier for them to comprehend and be invested in ongoing information work activities.

5.4 Anticipating the “Future Normal”

To consider which treatments might best fit their lives, participants often conceptualized what their life might look like in the future. Researchers have found that patients when planning for the future seek information about expected survival rates [22], yet maintain hope by anticipating an active future life [40]. Genuis & Bronstein [28] described a process where gaps between what a patient knows and their current symptoms motivate information work activities. The goal of patient information work, they assert, is to reach a “new normal” state, an intellectual or emotional acceptance of the situation and behavioral coping. We found that patients *think ahead* to what their baselines and activities will be like in the future. They not only gather information to address their current needs but also to better anticipate what their day-to-day life, both medically and non-medically, would look like in the future. We call this activity constructing their *future normal*.

Patients construct their future normal using both social and medical information to identify which care pathways best fit their life priorities. Huh and Ackerman [34] discuss the role of peer support in helping users to anticipate future health needs. Peer support can be a crucial avenue to help create future normal conceptualizations. For example, a future where a patient chooses home dialysis will put the work of dialysis setup largely in the patient’s (or caregiver’s) hands because the treatment would be conducted in their own home. This would create work for the patient. However, the benefits of taking on this extra work may include the possibility to sleep during dialysis and save time-consuming travel to and from the hospital. Home dialysis may be a better decision for people who want to continue working during the day, rather than conducting in-center hemodialysis during working hours.

Visualizing and planning for a particular future normal does not always lead to that state. For example, patients may make decisions based on a desired future normal such as the ability to quickly obtain a kidney transplant, but there may be medical aspects that are out of their control. Uncertain and unknown medical outcomes can have a tremendous impact on the future, so patients can be ideally prepared for different future normals, and be equipped to respond to potentially unforeseen situations through further sensemaking and meaning making.

5.5 Implications for Design

We conducted this study to further understand characteristics of patient information work, particularly how needs and experiences shift over time (see Table 3.).

Table 3. Characteristics of Information Work Phases

Phase	Characteristics
Learning	<ul style="list-style-type: none"> • Uncertainty (process) • Information deluge • Key decisions to be made • High Emotions
Living With	<ul style="list-style-type: none"> • Long-term perspective (more certain) • Different resource needs of high- and low-monitor patients • Routine information maintenance activities • Emotional Acceptance

To better support patient information work, we suggest (1) customized education and (2) support for collaborative information interpretation.

5.5.1 Customized Education. Rethinking the design of patient education may ameliorate challenges with information deluge and distrust of online information. Our findings highlight the potential to design customized education to help patients understand the types of information they need at specific stages and phases of their self-management experience. Specifically, we suggest helping them as they move between the phases (e.g. Living With to Learning and back to Living With).

Our findings make clear that a patient's information work encompasses a variety of activities including finding resources with personalized information, meaning making, and then integrating what they have learned into their daily practices. By segmenting these activities into manageable steps, the deluge of information and decisions that need to be made may become less overwhelming. Some researchers have sought to improve patient education through multimedia delivery [25,81]; however, our findings suggest that the educational content itself should be revisited. As Meloncon [52] notes, patient education materials should

attend to the nuances of a patient's health and social context. A customized curriculum where patients read information and complete open-ended challenges to explore options at a pace that is comfortable could enable adequate time to digest information, thereby increasing a patient's participation in their care [46,61]. Recognizing the expertise of patients [77] and caregivers [72] through system aspects such as journaling [76] or logging information may also be useful for such collaborative systems that foster customized education.

As described in the Findings, many patients, especially those managing comorbid conditions, were skeptical of the applicability of digital information sources to their personal, often complex, health situations. Participants also struggled to know which information to trust, for example, when conducting Google searches. Indeed, research has shown that there are significant biases in online health information retrieval, on the part of both the searcher and the search engine [85]. Given participant experiences of overwhelming information during online search, education on how to find and judge the quality of information online, and how to read medical information may be useful. Using an information management resource to connect patients to quality online information resources [14], and enable them to think critically about what they read, may be useful for some patients. Sota et al. [74] propose a novel design for CKD patient blood test results over time with an overlay showing whether the participant is stable, deteriorating, or improving. This may assist patients in making sense of information that was previously difficult to understand.

5.5.2 Collaborative Interpretation. This study highlights the value of designing to involve other people, particularly for low-monitor patients who may engage in information avoidance behaviors. Healthcare providers and patient peers are key resources to share information personalized to the patient's health context through comfortable, emotionally-supportive interactions [30]. This is important for low-monitor patients because as we describe in our findings and as has also been previously reported [45], people are often overwhelmed during online information search and report difficulty in trusting information found online [44].

Support for collaborative search and interpretation activities [2,26] may be particularly useful for this group of patients. However, unlike calls to design for a shared locus of control with providers [29] it is unlikely that low-monitors would take advantage of information resources that would require sustained individual participation (e.g., a health portal, online community, or patient forum).

Indeed, benefitting from these type of online resources requires considerable work to build and maintain support networks and manage their self-presentation [56].

Therefore, another potential solution for this group may be to reduce focus on purely technical solutions and instead support collaboration with other people who have the background to best answer a patient's questions. For instance, connecting care team members and patient peers to patients can support their imagining of a future that is different from their current situation. Care team members can provide details about the likelihood of future events, and patient peers can speak about the lived experience of potential treatment options.

High-monitor patients in our study actively used online information resources including the Patient View system [90] to keep on top of their blood test results. Thus, interpretation work forms an important information work activity for this group of patients, as has been found in other research [4]. Awareness of current health status in order to engage in collaborative discussions with clinicians is important for these patients. Therefore, they are likely to be active users of health portals and other online information resources. Several researchers have investigated the potential of Personal Health Records [38,49,71,80] which may be of particular interest to this group of patients to organize their health information. For instance, given the long-term nature of chronic illness management, technology supports such as recording physician dialogue for capture and reply at a later time [53] may be useful. Our data confirm that one size does not fit all, and that an ecology of digital and physical resources is needed to address people's individual requirements.

6 LIMITATIONS

Since interviews took place in two hospitals, the majority of patient participants were in-center dialysis patients. Consequently, we were not able to interview patients who conducted their dialysis at home. One of our inclusion criteria was English proficiency, so this work does not address the information needs of people who need additional language support. Additionally, this study only covers the experiences of people within the UK NHS. Further studies could investigate these issues in different national healthcare contexts.

7 CONCLUSION

This study highlighted the dynamic shifts that occur in information work activities as patients progress in their medical treatment and understanding of CKD. We described and discussed the two phases that organize

patient information work activities: 'Learning' and 'Living With.' Within the Learning phase, we highlight sensemaking and meaning making activities as patients interpret care-related information, and show the importance of human resources to accomplish these processes. In the Living With phase, we show how information activities become routinized and how behaviors shift based on individual preferences, resulting in high- and low-monitor behaviors. Finally, we discuss a rationale behind much patient information work: patients conceptualizing their "future normal" selves in different future scenarios in order to make best-fit treatment decisions. Through this research, we encourage the HCI community to continue to investigate these issues to inform future design of information resources for people who experience and manage chronic conditions.

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