**Abstract:** The health literacy concept is often limited to descriptions of a patient’s functional relationship with text. This description does not acknowledge the range of information sources that people draw from in order to make informed decisions about their health and treatment. A socio-cultural understanding of the practice of health literacy and the construction of the health information landscape is described, and draws from two studies of people with two different but complex and life-threatening conditions.
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The health information practices of people living with chronic health conditions: Implications for health literacy

Abstract:
The health literacy concept is often limited to descriptions of a patient’s functional relationship with text. This description does not acknowledge the range of information sources that people draw from in order to make informed decision about their health and treatment. A socio-cultural understanding of the practice of health literacy and the construction of the health information landscape is described, and draws from two studies of people with two different but complex and life-threatening chronic health conditions, chronic kidney disease (CKD) and human immunodeficiency virus (HIV). Health information is experienced by patients as a chronic health condition landscape, and develops from three information sources; namely epistemic, social and corporeal sources. Participants in both studies used activities that involved orienting and sharing activities to understand the landscape that was used to inform their decision-making. These findings challenge the traditional conceptions of health literacy and suggest an approach that views the landscape of chronic illness as being socially, physically and contextually constructed. This suggests recasting health literacy away from a sole interest in skills and towards understanding how information practices facilitate people becoming health literate.

Keywords: Information literacy, health literacy, Chronic Kidney Disease, human immunodeficiency
The health information practices of people living with chronic health conditions: Implications for health literacy

Introduction

In this paper we will argue that health literacy is a socially derived health information practice that connects people to ways of knowing, and enables them to draw from a range of information sources to inform the decisions that they make. Descriptions of health literacy (Speros, 2004; Nutbeam, 2008) focus on the interaction between the individual and text and the development of a range of information skills. However, health literacy is far more complex than these descriptions. Recent approaches have suggested that functional and baseline information skills associated with health literacy should not be viewed in isolation from the social and cultural context (Mårtensson and Hensing 2012).

The approach advocated in this paper rests on the premise that chronic health conditions (the focus of this study) enact the whole person into an information landscape that is socially, physically and contextually constructed. This requires a recasting of health literacy. Away from a sole interest in skills that focus on acquiring understanding (typically but not only) through text, and towards acknowledging that the ability to understand chronic illness and make decisions in relation to it, requires that patients draw from information that is also derived from social sources (through interaction with others) and corporeally through the body. Becoming health literate is, therefore, a situated social practice.

The aim of this paper is to recast health literacy as a complex social practice that emerges through the social and embodied information work done by participants who are situated by a chronic health condition. In this respect health literacy and the capacity to be recognised as health literate are understood as critical outcomes of health information practice in which information practices are defined as:

An array of information related activities and skills, constituted, justified and organised through the arrangements of a social site and mediated socially and materially with the aim of producing shared understanding and mutual
agreement about ways of knowing and recognising how performance is enacted, enabled and constrained in collective situated action (Lloyd, 2011: 285).

In this paper the term chronic health condition is an overarching term used to encompass chronic disease, chronic illness and disability. Chronic conditions are those involving a long course in their development or their symptoms, and these conditions account for a high proportion of illness, disability, hospitalisation, and deaths globally (World Health Organization, 2009). The diagnosis of a chronic health condition constitutes a significant health event and creates a disruption to the biography of people (Bury, 1982) because it constitutes a rethinking of identity and recasting of knowledges.

This paper will draw from the information literacy field to explain the findings which emerged from two recent studies that sought to understand the information landscape of chronic health conditions from the perspective of people who are experiencing living with either Chronic Kidney Disease (CKD) or Human Immunodeficiency Virus (HIV). Until recently the information literacy field has tended to focus on the functional aspects of information literacy (i.e. the development of skills) and here the synergies with the current view of health literacy are most obvious. More recently however, information literacy research in everyday and workplace settings has recast information literacy as a socio-cultural practice, and it is from this perspective that health literacy can also be recast.

**Literature Review**

Outside the health field, there is a broad and substantial corpus of research literature in the library and information science and education fields that explores the role of information literacy in relation to learning in the workplace, education and everyday life including health (e.g. Bruce, 1997; Limberg, 2000; Johannisson and Sundin 2007; Sundin 2008; Yates, Stoodley, Partridge, et al (2012). Simply put, health literacy is an example of information literacy contextualised; it is therefore a significant expression of the importance of information literacy. Both bodies of literature have the potential to enhance and enrich the information literacy and health literacy debate,
particularly as recent research into this area extends the notions of information literacy, which the health literacy field advocates (Yates, Partridge and Bruce, 2009).

**Information literacy**

First coined by Paul Zurkowski in 1974, information literate people were described as “people trained in the application of information resources…they have learnt techniques and skills for utilising a wide range of information resources as well as primary sources for moulding information solutions to their problems” (p.6). In the library and information science and education fields, information literacy is deeply connected with learning and is driven by two main approaches. The dominant information skills approach focuses on development of baseline information skills whereby the individual can “recognise when information is needed and have the ability to locate, evaluate and use the needed information” (ALA, 2000: 2).

More recently, a socio-cultural perspective has gained currency and represents a discursive shift in thinking about information literacy. It is this approach that may benefit the evolving understanding of health literacy. This approach is more closely focused on understanding how becoming informed and a competent user of information is a social, material and corporeal practice that is mediated through interactions within a social setting (Lloyd, 2005; Tuominen, Savolainen and Talja, 2005). Information literacy practice, as with all practices, is therefore “socially bound to a specific context and activity setting” (Talia and Lloyd, 2010, p. xii).

From a socio-cultural perspective, which underpins this current research, information literacy is not context independent, but is a social practice that reflects the ontological and epistemological conditions that shape a particular setting and its ongoing practices (Lloyd, 2010) and is embedded in social and material relations of the site (Lloyd 2005: Tuominen, Savolainen and Talja, 2005). Information literacy is something that occurs not only through a relationship with text, but in the space created between “thought and text” (Barton and Harman 1999: 3). For Tuominen, Savolainen and Talja (2005:337), literacy essentially means, “being able to enact in practice the rules of argumentation and reasoning that an affinity group in a specific knowledge domain considers good or eloquent”. Subsequently from this socio-cultural approach information literacy emerges as a practice that is composed of a
constellation of information related activities and information skills that are sanctioned and legitimised by the setting. These activities do not necessarily connect a person with information from textual sources, but may connect them with important and significant sources that cannot be articulated or expressed in written form (Lloyd, 2006).

The socio-cultural perspective broadens information literacy practice research because it focuses research attention towards understanding how:

- information is enable and contested within a setting;
- the modalities (sources) are deemed credible and authoritative;
- information skills are operationalised; and
- to ‘go on’ in a particular setting (Lloyd, 2011: 292).

A central feature of the information literacy practice approach is recognition of the information landscapes which are act as the communicative space created by the shared experiences of people in interaction and with the signs and symbols of their setting. Three broad modalities are central to the information landscape, each representing different sources of information. First, the epistemic modality represents a space of canonical knowledge, which is rule driven, reproducible, objective and easily expressed in written form. Second, the corporeal modality represents physical (bodily) information that is created as the result of performing or practicising as part of everyday living. This type of information is experiential and embodied. The final modality is represented through the social modality. The space created by the nuanced and implicit information that is closely related to being together or being in a familiar situation, and which is difficult to express in written form.

**Health Literacy**

Health literacy is an expression of information literacy in context. Health literacy like other forms of information literacy is a situated practice and the way it is practised reflects the setting through which it emerges. In the field of health the concept of health literacy is connected with literacy across the spectrum from functional literacy (reading and writing) to numeracy. Current gaps in research have been identified as disparities in health literacy, and health literacy and technology (Paasche-Orlow,
Wilson and McCormack, 2010). Definitions of health literacy focus on the individual developing skills, competencies and the ability to understand information that is being disseminated by medical, nursing or allied health professionals (Berkman, Davis and McCormack, 2010). Notably the focus concentrates on specific textual formats and forms (e.g. text, graphs, CD’s and websites). A review of definitions of health literacy mainly emanating from the US, (AMA Ad Hoc Committee on Health Literacy, 1999; Nutbeam 2008; US Department of Heath and Human Services, 2010) suggest a focus on the individual developing skills or competencies that will enable them to access and understand written disseminated information. This approach to the concept of literacy suggests a technicist perspective or bolted on approach, where literacy is understood as a “tool or a conduit for performance, a means of encoding and decoding information, a generic skills or key competency” (Searle, 2003: 61). More recently, a review of the literature by Mårtensson and Hensing (2012) has reported that the concept is polarised within the health field (as it is in the library and information science field). In addition to the functional approach, these authors have identified another interactional approach which emphasises the complexity of the context and the need for the individual to develop skills that will enable them to interact with “social and cultural contexts” (p.158).

The idea that health literacy can be measured echoes similar calls in the information literacy field (Catts, 2000). It also suffers the same issues and challenges as information literacy measurement. Namely what is being measured? and, What does this measurement mean? How are measurements constructed and whose knowledge are authorised? Is it an individual’s ability to apply a set of information skills in response to a problem (bearing in mind that health literacy includes functional literacy while information literacy does not)? If health literacy is a static concept then at what point would a person be measured? The ability to read is not a measure of comprehension nor is it the ability to evaluate the information that is obtained from searching the Internet or from talking to another person or listening to the narratives of others people who are living with a chronic health condition. Additionally, the current health literacy debate focuses solely on the textual experience of participants and fails to acknowledge the importance of information that is produced, reproduced and circulated and accessed in ways that are not articulated or expressed textually, but are nonetheless critical to participants’ information needs.
Study Focus

The two studies drawn from for this paper were informed by the same research design, methodological approach, and research questions. Philosophically both studies were informed by the concepts of Habermas’ communicative action and Schatzki’s practice theory. First, Habermas’ theory of communicative action (1989) suggests that there are two dimension; a lifeworld as a place of communicative action and a system, a place for instrumental action. Second, Schatzki’s practice theory (Schatzki, 2002) develops an understanding how social life is constituted and transformed through practices that occur within a field of practice. Together these approaches enable us to understand how people develop information practices such as health literacy. Both studies sought to: 1) describe the types of information practices and skills employed by people who were diagnosed with a chronic health condition (i.e. CKD or HIV) to inform judgments about their health and its complex treatment regimen; and 2) understand the range and type of information sources used by patients. All authors of the paper were investigators on both studies. Human Research Ethics Committees from hospitals and universities provided ethical approval for each study.

The first study was conducted with 10 people with CKD, aged between 38-72 years, all living in Brisbane; and the second involved eight people living with HIV (PLwHIV) aged between 42-65 years, who were living in San Francisco. Voluntary informed consent was obtained from participants prior to data collection, and data was de-identified through the use of pseudonyms.

Purposive sampling was used by both studies to recruit participants. Data collection involved semi-structure interviews using the same questions that focused on understanding the modalities of information used; identifying the information skills people used to understand their chronic health condition and its treatment; and the role of health professionals in providing information. Interviews also allowed the researchers to clarify participants’ answers and to encourage participants to expand on their responses. Interviews lasted approximately 40 minutes, were audio recorded for subsequent verbatim transcription, and were undertaken by two of the authors. Each transcription was checked against the audio recording for accuracy prior to using a
modified thematic analysis technique (Liampittong and Serry, 2010). The data was not pooled from each study at this stage but the three researchers involved met for three days to set the protocols for analysis and to develop the coding sheets that would be employed. Initially two transcripts (1 for each study) were coded and then compared between the researchers to ensure that coding protocols were understood. After which all researchers each independently coded the transcripts for both studies. Following this, the researchers worked together to group similar codes and then to identify themes within each study. We then undertook a process of synthesising the themes from each study to develop highly conceptualised meta-themes. Finally, through a collaborative process of analysis, the meta-themes were evaluated for the most appropriate fit with the original data. The next section presents the emergence of a chronic health condition information landscape.

**Landscape of chronic health conditions**

The findings of the study suggest that an individual’s initial experience of the chronic health landscape is a corporeal experience - as the result of symptoms which create uncertainty and the need to become informed about short and long term options, treatment regimens, and illness progression. In both studies a diagnosis of a complex chronic health condition created its own information landscape, situated within the large meta-landscape of health. In learning to navigate both the medicalised landscape and the one associated with their condition, individuals engage with specific discourses related to health care and information provision and they must develop ‘ways of knowing’ (Lloyd, 2006) which will allow them to understand how information is situated, and how it is produced, reproduced, circulated, disseminated, and accessed. This is a dynamic process where people are enacted into the chronic health conditions setting through their interaction with information via their relationships with others who are drawn into this landscape (as peers), through their association with healthcare providers (e.g. doctors, nurses, social workers) or social affiliation (family members, friends).

**Information Modality**

The term information modality is used to represent the broader category of information that may be made up of similar categories of information or similar
sources, that represent a certain type of space (e.g. textual space, social space, physical space). Each modality acts as a site of knowledge, and mediates the enactment of specific activities related to knowledge construction by creating different accounts of learning

**Drawing from corporeal and embodied sources**

Becoming and then being chronically ill, is a physical experience, and the corporeal modality is a central space in the landscape of all the participants reported in this study because it acts as a site of embodied and physical experiences. This centrality lies not only in terms of a person’s initial experience that alerts them to illness, but draws upon their everyday living with that chronic condition and in their engagement with the healthcare settings associated with their treatment. Participants reported their bodies acted as reference points for their illness and their awareness of changes prompted the need to interact with a range of other information landscapes associated with their chronic health condition to locate sources of information that could alleviate uncertainty.

> If I have something in my body, going on in my body, I can research it. I show it to my doctor and address my concern ...so I kind of feel better you know? Especially if it’s nothing to worry about (Donald, HIV)

A participant with CKD describes how their symptoms alerted them to a potential problem and connected them to the CKD landscape.

> I felt really run down.... While I was waiting for that appointment I got onto the Internet and start to know all about polycystic kidney disease and what it was all about...When I eventually go to see the doctor he said I need to explain all about what’s going to happen and I said “ That’s ok, I already know” (Daphne, CKD)

**Connecting epistemic sources: Adhering**

Adhering describes the participants’ agreement to stick to the recommendations made by a health professional. For participants in both studies the epistemic modality is composed of codified information, largely disseminated by doctors or through the reading of prescriptions or information pamphlets and connected with often complex
treatment regimens. In the CKD study participants reported receiving a package of information which included print information and a DVD which outlines the various options of renal replacement treatment (e.g. haemodialysis, peritoneal dialysis or kidney transplantation). Daphne who suffers CKD, highlighted the importance of adhering to codified knowledge if I followed all the instructions I had a chance of a reasonable life (Daphne, CKD).

Similarly in the HIV study the epistemic landscape was constructed for people by the medical profession.

– you know, me and the doctor, we all the communicate really well. What I need to do, what kind of medication I need to take, whatever I have to do for my health, you know. …. (Martin, HIV)

In both studies, all participants viewed the specialist (CKD or HIV) doctor as the health authority, and they adhered (as best as they could) to the treatment regimens that were required.

Social Sources

In the social modality, information was shaped by people in ongoing interaction with each other. For people living with HIV, the discussion and dissemination of information was largely through social groups. These groups were important sources of experiential information gained through the lived experience, where people who had managed HIV could draw from their experiences in support of those more recently diagnosed.

...we talk about it and how to, you know – how to survive it, you know, when you want to live a long life, you know, you have to take medication, you have to do this, you have to do that. We always have to keep yourself, you know, healthy, the first priority (Martin, HIV)

For CKD patients, nurses were viewed as mediators and interpreters of medical information provided by nephrologists. Consulting a nurse ensured information was understood in relation to the blood results, medications and plans for the management of their CKD. Rodger (CKD) expressed a common sentiment “it would have to be the nurses explaining what is going on”. In this respect the information work of nurses
was aimed at developing concordant relationships between the patient and the complex treatment regimen.

**Health information Practices**

Having briefly described the information landscape, we now turn to a description of the activities that constitute health information practice for both groups. We then consider these implications in relation to health literacy. The diagnosis of chronic health conditions requires that people engage with an array of activities that will enable them to become oriented towards the disease and its progress and allow them to make informed decisions in relation to their treatment options. The development of effective and sustainable health information practice enables patients to gain some control, to become situated emically (in relation to the information) and to situate others (i.e. family and friends, colleagues) outside the illness etically (external to the information). From this perspective health information practices are understood holistically as foundational to the process of meaning making about illness. Firstly in relation to adherence, where information is mediated through the epistemic modality; secondly in relation to other people with chronic health conditions who act a source of community and; lastly their families and friends for whom patients must construct and negotiate the environments on their behalf to inform their external understanding. The studies identified orienting, sharing and creating as activities which people employed in order to connect with the information landscape.

**Orienting**

Participants used information to orient themselves and others towards the chronic health condition landscape. In doing so they were negotiating the reality of their illness and constructing a new identity. They learned to navigate the landscape on their own behalf and to mediate on behalf of significant others (families, friends, colleagues), enabling those who interacted with the chronic health condition to become situated.

Orienting was an activity that people engaged to recognise and then identify information that may be relevant to their conditions and the affordances furnished by other people or by technology that connected them with information. Orienting allowed participants to locate and map the wide range of information sources (social,
corporeal and epistemic) associated with their chronic condition and its management. These sources could then be drawn upon to inform their decision-making. One participant describes how prior to his diagnosis he did not recognise information related to his condition, once diagnosed his awareness changes.

*before I found out I was positive I didn’t look at the brochures, .I just take it and throw it away. And then after I find out that I am positive, I have been reading it every time they give it to me”*(Craig, HIV)

Evaluation of potential new sources was seen as an important part of this orientation, and it allowed participants to ground their decision-making and thus work more effectively with healthcare practitioners. Information sharing between peers (about treatments, about new information, about experiences, about daily living with disease); drawing from their own embodied experiences and the experiences of others contributes to the ability to become oriented. In addition, seeking guidance and advice from nurses and drawing from epistemic sources all contribute to the orientation experience.

Having a chronic health condition also impacts on family and friends, who orbit the periphery of the landscape as *outsiders with deep attachments*. This term reflects the idea that while family and friends are closely connected to the person with a chronic condition, they can never truly understand the embodied experience, because they do not share it corporeally. Participants of both studies reported the need to orient significant others toward an understanding of their health condition. A participant with CKD tells the story of how she draws her employer into the chronic health conditions landscape

*She says “exactly what happens? And her face was like “You’re kidding me. Oh I didn’t realise that”* (Shirley, CKD)

Participants reported repacking and mediating information so that family and friends could understand the experience. These activities are principally aimed at drawing others into the peripheral orbit of the chronic health landscape. For instance one CKD participant reported the activity of creating menus to cater for changed dietary conditions could be used to draw the family into the landscape.
Jim says we’ve got pizza tonight and I said ‘I can’t eat pizza’. [Jim said] ‘Oh we’ll give you a weight watchers meal mum’. …They’re learning (Joan, CKD)

**Information sharing**

The sharing of information was another activity undertaken to connect with the chronic condition. In these studies information sharing was identified as profession sharing, or peer sharing. In sharing information participants’ drew from other peoples experiences of the three information modalities. In both studies, information sharing acted to orient others, to develop peer relationships and intersubjective understanding, as a form of information evaluation, as a mechanism for mediation, and a process of circulation and reproduction. A hierarchy of sharing was discernible as participants actively demarcated the types of information that could be shared.

**Professional sharing**

Participants described professional sharing, as occurring between nurses and patients with participants reporting that nurses were able to draw from their own clinical and experiential knowledge to interpret doctors medical advice; “I guess they are able to simple it down and explain things (Tony, CKD)”. The professional knowledge held by nurses was viewed by participants as being grounded in their experiences of the setting and an understanding of the chronic condition landscape and its elements. This allows nurses to paint a picture (Robert, CKD) for patients and act as a bridge between the patient and the doctor. Nurses were viewed by all participants in both the studies as being easier “to talk to” and to be able to “explain what was going on...they spend all their time here, they hear a lot of patients, so I kind of trust them, you build up a rapport with your nurse...I found them comforting…. I trusted my nurse. He will say you can do that…but he lets you make up your own mind” (Robert, CKD).

**Peer to peer information sharing**

Information sharing among peers was seen as an important activity. It allowed participants to share experiential information; keep up-to-date with fellow sufferers and provided an avenue for learning that could contribute to self-care. When discussing the importance of sharing information, Shirley (CKD) expressed a common sentiment “I think that’s what people need is actually someone who has gone through it”. Sharing information is seen affectively, as way of expressing your solidarity and care.
for others with the same chronic illness. “[We shared] how to care for yourself and the side effects of medication and how to handle it” (Shirley). In addition to fulfilling a need to connect with fellow suffers on an emotional level, information sharing had practical applications and participants commonly describe the sharing of textual information “one patient showed me a book from another hospital” (Shirley, CKD).

**Creating**

Both studies revealed that information practices were not solely constructed around the activities that enabled access (orienting) or dissemination of information (sharing) but also facilitated creating knowledge that was specific to the participants and that acted to situate the participants in the landscape. In the CKD study, participants reported creating scrapbooks of recipes and information about CKD, which they shared with others.

*I’ve got scrapbooks of notes about kidney disease and different treatments* (Peter, CKD)

Another in discussing the collecting of information suggested it would be great to collate all the information

*It would be nice to have a reference book or kidney bible* (Peter, CKD)

The idea of creating an archive of information that could be shared was also expressed in the HIV community with many participants reporting that they actively cut out newspaper articles and medical reports about potential new treatments, side effects. Notices about friends who have died were also collected and passed around to keep the community abreast about these. The gathering of information via newspapers and magazine clipping and then disseminating them was recognised by participants as contributing to the knowledge base and learning of the HIV community … “sometimes I cut out newspapers I will show it to them. It says new research, they found something….So I am more like helping them out” (Craig, HIV).

**Discussion: Recasting health literacy**

The concept of health literacy is considered by some authors (Berkman, Davis, McCormack, 2010) to be a relatively fixed concept, that emphasises functional
literacies such as reading, writing and numeracy. While these are important, the approach that is advocated here is more holistic and focused towards understanding how patients use information to situate themselves and to inform their decision making in relation to the day-to-day management of their chronic illness. This approach has implications for health literacy researchers.

Understanding the health literacy of people with chronic health conditions requires researchers to: first understand how the information landscape is constructed when there is a diagnosis of a chronic disease; second to understand the relationship between the various modalities of information that are constructed and called into play as a consequence of the changed biography of the person; third describe the activities that enable access to information; and finally to consider how skills are operationalised in relation to the domains of knowledge that are sanctioned by a setting. The studies reported here have focused on the first three aspects.

The experiences reported by participants in both studies, indicate that patients in addition to use of text, draw from and use a wide range of information and participate in a number of activities to inform and manage their understanding of their chronic health condition. This finding is supported in studies conducted in other contexts such as the workplace where emergency services personnel draw from a wide range of information sources including their bodies to help inform their practice (Lloyd 2009) and in studies of student information use which explored the use of visual information resources (Lundh and Limberg, 2012). Patients are not only active seekers and users of information, but are also sharing information with others suffering the same condition, or with people who form part of the patients’ immediate community (e.g. family, friend, work colleagues). The role of information sharing in patient-patient interaction has also been explored by Birkelund and Søndergard Larsen (2012) who suggest that the sharing of information is important because it provides strategies for living and coping with illness (p. 5) and acted as way of accessing and acquiring expert knowledge not from the health care professionals but from other patients because of the similar bodily experiences.

Interestingly, patients in the current studies also revealed that they are not only consumers of information, but also active creators of information, an activity they
undertake for family and friends in order to orient them towards their changed health (and more wider social) circumstances. In this instance, creating information takes the form of modifying and interpreting existing information in order to make it more accessible to people who remain on the periphery of the landscape, but whose participation and support is critical. It can also be understood as a way of connecting family members to the medical discourses that now surround and regulate patients’ lives. An example of this in the present study relates to the creation of scrapbooks and the collection of recipes by patients to orient family members. There is a synergy with this process and that of the concept of communities of practice (Lave and Wenger, 1991) whereby novices are drawn from the peripheral of practice, however as family members lack the embodied experiences of the patient, they lack a full understanding of this experience, hence the need for mediation.

Patients also identified their physical bodies as first-hand sources of information about the lived experience of chronic illness. The corporeal ground as source of information and catalyst for learning has been identified by authors in a number of other fields (e.g. workplace learning Becket and Morris, 2001; Somerville and Lloyd, 2006; in education, Fenwick 2003; and in aged care nursing Somerville and Bernoth 2001). Similar findings have been identified by Bonner and Lloyd (2011), but in relation to nurses working bodies as a source and site of embodied knowledge that can only be drawn upon at the moment of practice. In the present study, awareness of changes in the body alerted patients to possible new avenues that could be researched.

**Recasting health literacy**

Health literacy is a complex social practice and research into this field requires a greater emphasis on sociological and embodied aspects that impact and influence the information experience. The current studies, while representing a small slice of research, appear to indicate that health literacy is a situated information practice that engages patients with information on a number of levels. Firstly in relation to content about illness and, secondly information about the structure and discourses of a particular setting through which illness is managed and medicalised. Participants in the study demonstrated that they complement the epistemic sources which provide the instructions, rules and norms that patients must follow to have a ‘reasonable life’ with other sources, specific to the situation to inform them (e.g. social and corporeal). A
more holistic approach to health information practice acknowledges that the
information landscape is a specific construction created by the altered biography that
occurs when a diagnosis of chronic illness is made. It is therefore possible to be
health literate in one context but not to be in another (Mårtensson and Hensing, 2012).
Similar findings have also been identified in workplaces studies (Lloyd, 2005) and
school based studies (Herring, 2010) suggesting that the issue of transfer should also
be considered in relation to health literacy.

Recasting of health literacy as an outcome of health information practice
acknowledges that the information experience of a chronic health condition is
produced by a number of information modalities that participants must learn to
recognise and access in order to inform them about their chronic illness. In doing so
they are able to make informed decisions about their options in relation to treatment.
In the studies reported here, the interaction that occurs between people, their bodies,
and their settings provides a considerable range of information which is used to
inform the decision making process. This approach emphasises the flow of
information and range of sources that construct the landscape and the activities and
skills required to connect with knowledge from a wide range of sources in order to
make appropriate decisions about health (Mårtensson and Hensing, 2012)

Consequently to become informed and to maintain a level of control in relation to
everyday living and medical settings, participants must draw from corporeal, social
and epistemic modalities which represent the spaces of their information landscape.
Participants must learn to navigate the paths in order to understand their chronic
health conditions experiences and position themselves to make informed decisions.
This recasting of the chronic health experience acknowledges that other information
modalities act as critical sites of knowledge from which to draw information. This
in turn suggests that people engage with a range of activities that will enable them to
develop ways of knowing.

This research presented here has raised a number of questions that warrant further
investigation such as:
• how are the health information landscape of people with chronic health
  conditions shaped;
• how does living with a chronic health condition ground the information experience of people;
• what are the sources of information that compose the health landscape; and,
• how do people develop information practices that will inform their decision-making

Limitations
There are some limitations to the studies from which this paper emerges. The findings reflect the particular time and contexts in which the studies took place and while the findings are not generalisable to a wider population, the findings may resonate with other people with either CKD or HIV. We also employed several strategies to minimise the limitations including establishing agreement between all authors with analytical processes; individual coding of each transcript prior to moving to higher levels of thematic analysis; and a detailed check with the original transcripts following meta-coding of both studies.

Conclusion
A health information practice approach to understanding health literacy opens up a new area of enquiry by focusing on people developing the capacity to work with information in the context of health issues, management of treatment and in relation to others who are engaged in the same health related information landscapes. This approach emphasises concordance and resilience by empowering individuals to understand the nature of the health information landscape and to draw from it information to inform their decision making. Both studies are grounded in the information experience of participants. Together, the findings highlight the complex and multimodal information landscapes that are bought into play when people are diagnosed with serious life-limiting health conditions, which require them to resituate and reposition themselves in relation to their illness and the range of people and artefacts that are required to maintain health. We have suggested that, in order for participants to understand their illness and for them to make informed decisions, they must have access to information through a range of modalities. Understanding chronic health conditions is not just confined to engagement and understanding of information provided to them by health professionals, but is also constituted through an awareness
of the body and the bodies of others as embodied knowledge and of social sources of information.
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