

Understanding the value of PatientView for enabling self-care practice in Chronic Kidney Disease

Summary

Background: Individual responsibility and self-care are seen as ways to overcome some of the challenges for long-term health care provision. Patients are being encouraged to take an active role in their health care and access to health information via a web-based, patient-facing portal is an innovative way to engage in self-care. PatientView was developed to allow patients with kidney disease access to parts of their health record. It is thought that the use of PatientView will improve self-care activity but there is little evidence to support this claim.

Objective: To gain an understanding of how patients with kidney disease use PatientView in their self-care practice.

Participants: 6 users and 4 non-users of PatientView.

Design: Qualitative, semi-structured interviews and participant observation.

Approach: A practice-based approach was used to collect qualitative data to better understand how patients use PatientView in daily life to enable self-care. Participants were invited to 'show the researcher' how they use PatientView and to describe how they translated the information into actions of self-care. Inductive analysis was used to identify themes.

Results: The analysis identified four key themes which are non-linear inter-related. These themes are that PatientView forms part of a broader, existing understanding of health and health care practice for patients. Patients engage with PatientView because it supports ways of knowing that are of direct importance to self-care activity. Patients interact with PatientView and translate the information they gain from using it into actions that support self-care. A consequence of engaging with PatientView is that patients can involve their family more in their care and this helps to reduce the burden on health care professionals.

Conclusion: Patient interactions with PatientView are inter-related, multi-dimensional and differ according to the individual's positioning within a continuum of care. Nonetheless these interactions can be captured and doing so provides a basis for understanding of how patients create and sustain opportunities for care through information technology.

Keywords

Chronic Illness, Patient Portal, Health Record, Self-care, Technology

Introduction

An aging population and longer life expectancy have resulted in an increasing proportion of the population living with chronic health conditions (Barlow *et al.* 2002; Rogers *et al.* 2011) such as Chronic Kidney Disease (CKD). Concerns about the increasing economic burden this represents have resulted in a high level of interest in the need to find innovative ways to provide and support those with chronic health conditions (Ausili *et al.* 2014). This has been reflected in health care policy through increased emphasis on the role of individuals in taking responsibility for their own health and on promoting a corresponding need for patient empowerment (Foot *et al.* 2014).

The concept of self-care has been identified as one approach to increasing patient involvement and empowerment. However, there are variations as to its definition resulting in several terms, such as self-management, self-monitoring, and self-activation, being used interchangeably (Godfrey *et al.* 2011). For the most part, self-care is a multifactorial concept (WHO 1998) and includes a variety of activities designed to support and maintain one's own health which are influenced by environmental and socioeconomic factors (Department of Health 2005; WHO 1998). For those with long term conditions the changing requirements of self-care have been viewed as forming part of a 'continuum of care' (Godfrey *et al.* 2011; Barnes 2012) as opposed to a more linear, deterministic view of necessarily increasing dependency. For instance, within CKD, there is much 'hidden work' (Rogers *et al.* 2011; Unruh and Pratt 2006) such as monitoring, management of diet and fluid intake, the taking of multiple medications as well as many other aspects of health care management (Godfrey *et al.* 2011), which change over time, therefore requiring an ability to continually adapt self-care activity (Blickem *et al.* 2011). In this context, use of a web-based patient portal, such as PatientView, is viewed as a means of enabling patients to make informed choices that can support ongoing self-care through offering them access to health information contained in their medical record (NHS England 2015; RIXG 2010).

Web-based portals that allow patients to access medical information such as test results are being increasingly implemented at national, regional and hospital levels (Ammenwerth 2018; Baldwin *et al.* 2017). Whilst there are portals and mobile phone based applications which allow access to records for specific patient populations, such as people accessing primary care and others are available for for specific health conditions such as cancer, diabetes and HIV in certain parts of the country, other systems such as PatientView, provide all patients at national level with access to elements of their health record, such as blood test results.. Although portal interfaces and the timeliness of information that portals provide have improved there remain serious concerns regarding

their under-use and the extent to which patient access to health records *alone* can be equated with patient empowerment (Ammenwerth 2018). Web-based portals are used internationally and much of the early research demonstrating the impact of technology within health care has come from America. For example, Hassol et al (2004) aimed to assess how patients valued access to their electronic health record and the effect of web-based communication and Zhou et al (2007) demonstrated a reduction in patient-clinician visits when a secure messaging system was introduced within primary care.

Whilst both pieces of research showed that patients had a positive attitude towards accessing their electronic health record, they did not illustrate the benefit and value this held for patients. Instead, they concentrated on the differences in opinions between health care professionals and patients and their preferred methods of communication. Zhou et al (2007) commented that patients showed a preference for email communication whereas letters and telephone conversations were preferred by physicians.

Much of the American research into the use and uptake of electronic health care systems has concentrated on measurable and economic outcomes. The focus appears to highlight improvements in efficiency and cost savings as opposed to the importance of these systems for patients. Such positivist methods of evaluation fail to evaluate the changes in care that are of importance to those using the systems, the staff and the patients (Darking *et al.* 2014), instead 'practice-centred' approaches of evaluation are advocated to allow for attention to the routines of the care given.

Patient View (or Renal Patient View as it was originally known) was piloted in 2004 and was the first example in the UK of a web-based portal (in any disease area) that provided access to patient records held in a hospital IT system (Mukoro 2012). It was developed by the Renal Patient Exchange Group (RIXG) whose membership included people from across the renal community, including patients and their carers. Intended for patients living with CKD who had been referred to hospital to receive specialist care (typically at CKD stages 3-5), Patient View continues to provide up-to-date blood test results to patients at over 90% of Renal Units in the UK (PatientView 2018). Within PatientView latest blood tests are presented with the facility to view historical results graphically, as a line graph, enabling patients and their carers to see trends over time. They can also see line graphs next to one another to show, for example, the effects of anaemia on eGFR (Royal College of Physicians 2015).

Evidence of improved health outcomes following use of PatientView is limited, partly due to it only having been widely implemented since 2008. Studies tend to focus on usage measures such as uptake, sustained use, or self-reported outcomes such as patients reporting that PatientView helped them to look after themselves better and that they valued the information it gave them (Bartlett *et al.* 2012; Woywodt *et al.* 2014; Phelps *et al.* 2014). There is therefore little evidence to support the rationale that self-care is facilitated by the implementation and use of a patient portal. Without knowing how patients include patient portal use within their daily self-care activities, it is more difficult to explain their relevance and benefit to patients and argue for the resources needed to develop such technologies.

However, there are no qualitative studies and therefore detailed analysis of *how* PatientView enables actions of self-care is currently absent from the literature. Consequently there is a lack of theorisation of care as socially situated and embodied 'practice'.

In contrast to traditional qualitative health research, which privileges individual thoughts and reasoning, practice-based approaches allow for the foregrounding of 'knowing' and 'doing' (Pols 2014). This positioning allows for the exploration of the complex and embedded processes (Maller 2015) involved in gathering, understanding and making use of information from PatientView in everyday life. It enables care to be seen as a form of knowing and a form of 'doing' or practice that occurs within a specific context and includes interactions between people, IT, bodies, emotions, food, medication, ethical sensibilities, health professionals, health systems and carers. 'Knowing' in this sense is not treated solely as a cognitive activity, just as care is not treated as an effective response or solely technical procedure. They are social practices that are materially and socially shaped through interaction with a time and place, otherwise known as a situation or environment (Buch and Anderson 2015). Knowing and care are therefore conceptualised as sets of practices that are in constant dialogue with one another within situations that unfold over time (Pols 2014). In the example presented here, PatientView forms a potential 'way of knowing' for renal patients. This research therefore takes a 'dialectical practice theory approach', described by Monteiro and Nicolini (2015) which centres upon the development and interactions of two or more practices; in this case the use of a web-based patient portal and the actions of self-care.

Based on this theoretical framework, this research explores both PatientView users' and non-users' engagement with self-care, and seeks to answer the research question:

'How and to what extent do patients with kidney disease value the use of PatientView in their self-care practice?'

Methods

A qualitative, practice-based approach that draws on ethnographic methods, specifically semi-structured interviews and participant observation and a focus on day-to-day life, was used to explore and support understanding of how the use of technology and activities of self-care inter-relate. Ethnographic methods differ from other social science methods because they encourage attentiveness to artefacts, values and beliefs and how people interact with and express these in their day-to-day lives (Leslie *et al.* 2014). This enabled a focus on the processes through which PatientView supported patients to practice care. For those not using PatientView it enabled a focus on the practices that took the place of PatientView use in their lives.

An opt-in process was used to recruit participants from an adult kidney unit on the South East coast of England during September 2015 – February 2016. Inclusion/exclusion criteria are detailed in Box 1.

Box 1- Inclusion Criteria

Inclusion Criteria

Participants must be:

- Aged over 18 years
- Require long-term treatment for CKD, either haemodialysis, peritoneal dialysis, transplantation or be classified as needing specialist nephrology care
- Have capacity to give informed consent

Exclusion Criteria

- Patients with Acute Kidney Illness that does not require long-term nephrology care
- Those under the age of 18 years
- Those who do not have capacity to give informed consent
- Those who are unable to have a conversation in English

A convenience sampling method was used with an original target of 10 PatientView users and 10 non-users. Non-users as well as users were recruited in order to understand the extent to which people who do not use PatientView can be understood to not value the technology *per se* or whether, for example, they simply do not engage in self-care or do not know of the technology. When answering the research question, this adds important analytical dimension to the understanding of how the technology is (and is not) valued.

A convenience sample was appropriate because practice-based approaches do not assume that demographic characteristics will act as a determinant of behaviour at the outset. They suspend concern with this point until it is seen if such characteristics act as determinant 'in practice'. A small sample size is appropriate in qualitative research in which the emphasis is on a depth of engagement in human interactions and rich description. Data collection must be proportionate to the effort required to analyse such data which also calls for a depth of empirical and theoretical engagement.

(Table 2)..

Ethical Considerations

Prior to commencing the study, the researcher met with committee members of the local Kidney Patient Association (KPA) to review the layout and wording of patient information sheets, consent forms and the proposed questions for the semi-structured interviews. Changes in format and grammar were made accordingly and all documents were written in plain English.

An opt-in recruitment process which took place over 5 months was used to ensure that participants were not subject to coercion and that their participation was voluntary (World Medical Association 2008) particularly as the researcher had previously worked in the clinical area and maybe known to them. PatientView users were recruited through: posters displayed in the renal unit; a letter of invitation from the PatientView administrator; an advertisement in the KPA newsletter. Non-users were recruited through 1.) handing out a letter of invitation and information sheet being handed to patients on the haemodialysis ward by a dialysis nurse and 2.) a receptionist handing the same materials to patients attending outpatient appointments. In all cases, the researcher was not involved in the distribution of recruitment materials. Interested potential participants were asked to contact the researcher therefore ensuring un-coerced opt-in.

In ethnographic and practice-based research, researcher involvement in or knowledge of an environment is understood as having a constructive effect on the research process rather than being viewed as responsible for creating research bias (Lesley *et al.* 2014). The researcher is able to understand and contextualise what participants say and do in a way that a researcher who did not know the context might well be unable to do. The extent to which the researcher is an 'insider' or 'outsider' is an area of interest for ethnographers (Neyland 2009). For example, in this case the researcher was a renal nurse, but not a renal patient, therefore her knowledge of the patient experience was as a nurse. To engage fully with patient experience she had to focus on allowing their knowledge and experience to take precedence and her own to become secondary.

Ethical approval for the research was sought and gained from the university research and ethics and governance committee, the National Research Ethics Committee and the local NHS Trust Research and Development Department. Written, informed consent was gained from each participant, prior to the interview being conducted.

Data Collection

Qualitative data were collected using a series of open-ended questions during semi-structured interviews conducted at a location suitable to the participant, for example, a quiet room within the kidney unit or patient's home. The interviews were recorded using a digital recorder with the participant's consent. The interviews with users of PatientView were supported by participant observation where participants were invited to 'show the researcher' how they use PatientView 'in the way they normally would'. The researcher made handwritten field notes of these observations which were used in conjunction with the interview data during analysis. Typically, patients would show the researcher which screens they tended to use, point out results they were especially interested in and support descriptions of key events or 'moments in time' within their care by using the cursor 'show' where these were visible on a particular line graph.

Interview Questions

The participants were asked some introductory questions to describe how they looked after themselves and about their use of technology in general, daily life. This was to gain some background data about what the participants understood about self-care and whether technology use was already part of their daily routine. For those that were non-users of PatientView, further questions focused on how they gained information about their illness and how they used this information to look after themselves better. These questions enabled the researcher to understand the different ways in which patients seek out information and how this may lead to actions of self-care.

For users of PatientView, follow-up questions were asked to gain greater in-depth knowledge about how they used the technology, the screens that they looked at and to describe what was important about the information that they saw displayed. Examples of some of the questions are given in Box 2.

Box 2 – Examples of questions asked in the semi-structured interviews

In this research I'm asking patients about 'self-care', that is the care that patients take responsibility for, perhaps with help from friends or family, rather than the care they receive from a health professional. Can you tell me about how you "care" for yourself?

Please can you show me the screens that you look at most frequently?

Can you tell me why these screens are important to you? What do they tell you?

Participant observation

In conjunction with the interviews, users of PatientView were also asked if they would 'show the researcher' how they use PatientView and to describe how they translated the information into actions of self-care. This encouraged the participants to practically demonstrate their use of PatientView which in turn enabled an understanding of how patients 'do' self-care, what enables them to sustain or change their self-care practice and why this is important.

Data analysis

The interview transcripts and notes from the participant observations were analysed using inductive, thematic analysis, whereby themes emerge directly from the data as opposed to deductive content analysis which is reliant on the frequency of the identified themes. Inductive analysis takes into consideration the context of the data and is compatible with practice-based methodology.

Braun and Clarke's (2006) six stage method of thematic analysis was used to identify codes from the transcripts which were then grouped into themes. These themes were further reviewed and redefined by rereading the transcripts alongside the handwritten field notes.

Table 3. Six stage method of thematic analysis as applied to data

Step	Theoretical Process	Aim	Process within the study
Familiarisation with data	<p>Transcription of recorded interviews, reading and re-reading</p> <p>Making notes of thoughts.</p> <p>Checking the transcription against the audio recording</p>	<p>Immersion in the data</p> <p>Identifying interesting words/phrases</p> <p>Confirming accuracy of the transcription against the recording</p>	<p>Researcher conducted the interviews and observations, so had initial knowledge of the content. Through transcribing and re-reading, the researcher became increasingly familiar with the data and wrote some thoughts and notes about meanings and patterns that appeared of interest.</p>
Creating first codes	<p>Systematically identifying characteristics of the data set, producing codes to represent the data</p>	<p>Identifying features of the dataset that are of interest</p> <p>Helps to organise elements of the data into groups</p>	<p>The researcher colour-coded (using highlighter pens) particular segments of data which were of relevance. Some data was coded more than once, therefore had several colours</p>
Identifying themes	<p>Grouping the codes into possible themes, identifying all data relevant to each possible theme.</p>	<p>Identification of broader themes which consist of groups of codes.</p> <p>Thoughts about the relationships between the themes, identifying main and sub themes</p>	<p>Codes highlighted in each colour were copied onto Post-it notes and placed together on sheets of paper. The researcher re-read the codes and identified possible theme headings for each set of codes.</p>
Revising themes	<p>Reviewing the themes against identified codes and the data set.</p>	<p>To check there is a pattern from the coded data which supports the identified themes.</p>	<p>The codes were reread against the transcribed interview to ensure the theme was supported. Underlying relationships between the themes were considered.</p>

	Producing a thematic map.	Confirming that the individual themes relate clearly back to the entire data set	
Outlining and specifying themes	Continuing review of the themes, creating definitions and names for the themes.	Description of the essence of the themes, discussing what is interesting and reflecting on why this is so	The codes were reviewed again to identify what it was that was said or observed that made it of significance to the identified theme,
Writing a report	Extracting examples from the data to illustrate the identified themes. Relating the themes and data back to the research question and literature review	To use data extracts to illustrate the identified codes and themes in a logical way so that they can support and give evidence to the research question	The identified themes were discussed using quotes and extracts from the transcribed interviews and observations as evidence. Each theme has been analysed separately but with appreciation that they are linked and interwoven and that each theme has influence within another.

Data from interviews with non-users were of relevance to stages 4 and 5. The reasons they gave for not using PatientView and the relationship between non-use and self-care added different dimensions to understanding when, how and to whom PatientView was experienced as valuable to self-care. Data from handwritten notes taken during observations was particularly relevant in stages 2 and 3 'Identifying' and 'Revising' themes. Moments in the interview where the patient chose to reinforce their description by demonstrating a particular of sequence of actions on the computer were given a specific code. They were taken as an example where IT-enabled, self-care practice facilitated a set of practices that reinforced key relationships that supported patient self-care.

Trustworthiness of data

This research has been conducted in a local NHS Kidney Unit where the researcher works, and it is acknowledged that issues associated with power, subjectivity and role conflict (Humphrey 2012) may have implications for this study. However, it is also recognised that insider research is an appropriate approach to take when there is a need to understand the context of the situation which the research seeks to explain (Hewitt-Taylor 2002). It is argued that, for this research, it is appropriate to be an insider researcher because this affords depth and richness to the data (Hewitt-Taylor 2002) which is supported by the researcher's prior clinical knowledge and which enables a greater understanding (Bonner and Tolhurst 2002). This in turn enhances the analysis of the self-care practices described in the interviews and performed during the participant observation. Ethical safeguards ensure that potential disadvantages of insider research are mitigated against. An ethnographic orientation ensures that the researcher is engaged in a continuous, reflective process that constantly questions the power dynamics involved in creating knowledge. Notes from observations and recorded post-interview served as a form of reflective practice that was integrated into the analytical process

supporting further reflection on tensions inherent in disclosing details of everyday life.

The use of participant observation in conjunction with the interviews permits an openness to the research (Elliot 2015), and the credibility of the themes identified from the interviews can be reinforced by linking them to interview responses and the practices observed (Bonner and Tolhurst 2002). Patients 'did' rather than just 'said they did' and so the relationship between words and deeds could be opened up to further enquiry.

Findings

Despite 5 months of recruitment effort a total of 10 participants, 6 users of PatientView and 4 non-users of PatientView were recruited. Demographic details are shown in Table 1. The demographic data indicates that the non-users of PatientView in this sample are older than the users of PatientView which may have implications for how the more elderly population are supported with self-care activity.

Table 1 - Sample Population Demographic Data

	Number	Gender		Median age (age range)	Renal Modality	
		M	F			
Users of PatientView	6	4	2	54	Haemodialysis	4
					Peritoneal Dialysis	0
					Transplant	2
					Non RRT	0
Non-Users of PatientView	4	4	0	63	Haemodialysis - 4	

This sample is similar to the overall demographics of the local unit in that there are proportionately more males enrolled for PatientView use than females. The median age range of the participants in the study is comparable to that of the overall median age range of PatientView users in the local unit, although the age range from the unit was between 18-92 years.

The analysis identified four key themes which are not linear but interact and are entwined with one another:

Theme 1: Extending existing practice

PatientView forms part of a broader, existing understanding of health and health care practice for patients

Theme 2: Supporting ways of knowing

Patients engage with PatientView because it supports ways of knowing that are of direct importance to self-care activity

Theme 3: Translating information into practice

Patients interact with PatientView and translate the information they gain from using it into actions that support self-care

Theme 4: Engaging family and carers

A consequence of engaging with PatientView is that patients can involve their family more in their care and this helps to reduce the burden on health care professionals.

Theme 1: Extending existing practice

Use of PatientView formed part of patients' existing, normative understanding of their own health and health care. For example, below, a patient describes their personal position on how they understand their own health and care.

"...everything I *can* do for myself lands on *my* shoulders [emphasis added]." (Interview 9).

There is a clear sense of ownership and responsibility in this example that, as a sentiment, was shared amongst the 6 users of PatientView. They each drew a distinction between 'care of self' and 'care received from others'. There was common recognition that kidney disease was *their* illness, for them to live with on a daily basis (Barlow *et al.* 2002; Rogers *et al.* 2011).

One interviewee articulated this, saying:

"...I'm thankful for the help and care that I get from specialists.... but it's not their problem, it's *my* problem" (Interview 4)

whilst another expressed the need for *him* to have 'control' over his outcomes rather than health care specialists (Interview 5).

Nonetheless, care practices and the normative beliefs that underpin them can change over time and are situation-specific. For instance, one participant said that whilst he was receiving haemodialysis in a privately-run haemodialysis unit (not in the research locality) he was:

"...totally distant from my treatment..." (Interview 6)

because there was no flexibility or invitation to be involved within his care. He stated:

"I just did what I was told" (Interview 6)

and although he had access to PatientView, he didn't use it because he did not feel involved in the decisions that affected his care or treatment.

He went on to describe that there was a completely different attitude to care at his current treatment centre, where he has been encouraged to ask questions and be more involved by looking up his blood results on PatientView, to the extent that he says that he now sees himself as:

"...completely in charge of my treatment..." (Interview 6).

PatientView forms part of an existing, broader understanding of health and health care practice for patients. Specifically, patients' normative understanding of what is valuable in their self-care is shaped by the care environment and the normative social practices within that environment (Maller 2015). In the example above, the patient did not know that PatientView *could* be valuable within their own self-care until they found themselves in a new care environment. Such change and the rationale that underlies it can be 'hard to measure'. It is clear nonetheless within patient descriptions of their previous and current self-care practice that PatientView use can be of value to self-care practice particularly when supported by the care environment.

For the non-users of PatientView, the responsibility for health care was more clearly aligned with health care professionals. In response to questions about how they got information about their kidney disease, they described being more inclined to wait until they were told by health care professionals about their blood results and any related changes that were needed to their care:

"I think all the time you are feeling well...you don't bother...they've not said anything, everything must be alright" (Interview 8)

whilst another stated:

"...I know if there's anything I need to look out for, they'll tell me" (Interview 10).

In this case, the support offered by healthcare professionals is valued alongside a capacity to be *less involved* in looking up and responding to blood results. Within the continuum of care experienced by people living with chronic conditions (Godfrey *et al.* 2011; Barnes 2012) being able to vary the level of responsibility taken is important, particularly at points when the burden of hospital visits is significant, as it is when patients require haemodialysis.

Theme 2: Supporting ways of knowing

Participants identified that the ability to seek out information was of value because it gave them the opportunity to prepare themselves and their family for changes to their care:

"I don't want to suddenly wake up one day and they say today you've got to dialyse...I would rather know what's coming.... it's far better to have information...even if it's distasteful" (Interview 4).

For non-PatientView users, interaction with health care staff was the key source of information gathering. Importantly there was no evidence to suggest that they were less engaged in self-care just that they are more selective about what it is they want to know.

Patients engage with PatientView because it supports ways of knowing that are of direct importance to self-care activity. For example, users of PatientView consistently demonstrated their use of the blood results tables and graphs visible within the portal and each described these as being screens that they frequently accessed. The importance of these screens was illustrated during the observations, for example, when a rise in phosphate level was observed, one participant recalled how he had thought about changes that he could make to his diet whereas another described asking about antibiotics when her CRP was raised.

This illustrates how the information gained was seen as empowering (Blickem *et al.* 2011), enabling participants to make choices that were of value within their self-care practice. However, 'knowing' as a dimension of 'doing' or 'knowing what to do' was not the only reason participants gave for wanting to gather knowledge. An important focus for some was the ability to be *prepared* for future events. Daily life for those with CKD requires them to be able to frequently deal with changing circumstances (Blickem *et al.* 2011).

Theme 3: Translating information into practice

Patients described how they made connections between their physical symptoms, blood results and physiological changes within their bodies. Understanding and making sense of these connections enabled them to take action and make alterations to their self-care activities (Pols 2014). The observational notes gave evidence to the use of graphical data as being particularly important with participants 'pointing out' specific levels on the graphs and recalling how they 'felt':

"...down here I was down at 92 and I felt dreadful..." (Interview 4);

"...Because when you are in the low point, there, you know about it... you'd just be tired, really tired..." (Interview 6).

One participant illustrated the degree of complexity of self-care actions in relation to his potassium levels. This involved observing from graphs that he saw on PatientView that his potassium was 'out of range' followed by reflection about how he had physically felt at the time. These connections enabled him to see possible links between the abnormal laboratory results and his symptoms and he began to think about what he could 'do' to change this.

As a direct consequence of the information he gained from PatientView, this participant started eating a banana during the last part of his dialysis session which resulted in his potassium level being within the normal range and an improvement in his symptoms. Patients also described how knowing their blood results enabled them to be prepared for clinical appointments at which they could reflect on symptoms and results with their clinician.

Non-users of PatientView were less likely to make connections between symptoms and actions they had taken. However, they were still very involved in their self-care describing practices through which they watched their diet and fluid intake or how they set up their own dialysis machine prior to a session. These activities are of no less value and in the case of setting up the dialysis machine are clear examples of technology-engaged, self-care. . Maybe this is because non-users of PatientView do not utilise information given to them to manage their self-care in the same way as those that use PatientView.

Patients interact with PatientView and translate the information they gain from using it into actions that support self-care. Moser (2011) views information as being just one aspect of the self-care process. She suggests that self-care is not only dependent on what information a patient *has* but on how patients handle information and what they do with it consequently.

Theme 4: Engaging family and carers

A consequence of engaging with PatientView is that patients can involve their family more in their care and this helps to reduce the burden on health care professionals. The extent of family involvement in self-care varied amongst the participants, which was to be expected due to differing personal circumstances. Some stated it was their choice not to include family members in their use of PatientView, whilst for others sharing information with their carers and family members, particularly partners, was an integral part of their self-care activity (Foot *et al.* 2014).

It was evident from one account that PatientView use had become an embedded part of shared daily life which benefitted their relationship:

“...my wife is very positive to this... [she] wants to be involved and is interested...it [kidney disease] brings a lot of stress and pressure into relationships at times...[and] we find it very helpful...” (Interview 4).

Another described how interactions with PatientView enabled her to explain problems with her kidneys by showing her family the graphs of her blood results.

A further consequence of engagement with PatientView and therefore broader care networks was a perceived reduction in reliance on healthcare staff to provide information that patients described:

“...hopefully it unloads them [staff] a bit from people like me that would like to know...” (Interview 4).

Being able to reduce the burden for health care professionals is part of a normative understanding of health and health care delivery that in interviews was linked with individual acceptance of ownership for health.

In contrast, non-users of PatientView did not discuss the involvement of family and friends in their care despite being asked if family and friends were involved in their self-care activities. Even when non-users were given information relating to their diet or fluid intake, they did not mention any discussions with family members. This is an area which could be explored more in future research.

Discussion

By describing and demonstrating how they use PatientView, participants have described the 'hidden work' as identified by Unruh and Pratt (2006) involved in making self-care practice part of daily life and sustaining this over time. In the case of PatientView users this work includes finding new ways to stay engaged in care, gathering information, translating it into action and engaging families and carers. At some points PatientView made patients feel less reliant on healthcare professionals, and whilst they valued the care and advice given by health care professionals, they framed their kidney disease as being *their* problem to manage, seeing themselves as responsible for the choices they make (Barlow *et al.* 2002).

At other times participants felt that use of PatientView deepened their engagement, helping them to relate symptoms to results and enabling them to prepare and think through questions to address during clinical appointments. The analysis revealed how the practice of understanding how to act in response to changes in blood test results is a practice produced through trial and error coupled with ongoing conversations with clinicians, peers and family members. These practices supported PatientView users in their preparedness whereby patients not only enacted changes to their current self-care practices, but also valued the opportunity to plan ahead and prepare for engagement in future activities of self-care.

The findings [identified in Theme 1](#) suggest that patients valued the use of PatientView differently according to their normative understanding of health and healthcare. [Some participants discussed the importance of personal and family responsibility throughout their illness whereas another illustrated that the ethos of the care setting influenced the extent of his ability to be involved in his care. These examples demonstrate that](#) historical experiences of health services, home circumstances and personal position have an influence within what is (for people living with CKD) a continuum of care as described by Barnes (2012). Within that continuum, the value of PatientView was that it simultaneously afforded opportunities for both independence and inter-dependence which could be realised or withdrawn from accordingly (see Figure 1).

Contrary to what might be expected, patients who did not use PatientView were also actively engaged in self-care. However, finding out and interpreting blood test results was a practice they specifically preferred to engage in with health care professionals.

Figure 1 describes the different patterns of self-care practice that were in evidence and positions them within a continuum of care during which a patient

may feel more or less engaged in their own care at different points in time, depending on the circumstances they find themselves in. Use of technology is described in the context of patient willingness or capacity to self-care within this continuum. The self-care practices of PatientView users are grouped together in the top half of the Figure 1 and those of non-users at the bottom. Each circle represents one of the four themes identified in the findings section. All practices are located within a continuum of care in which patients feel more or less able to cope and therefore be active in their self-care at different points in time.

Figure 1 Self-care practices and a continuum of care



This research contributes to the body of evidence suggesting that technology has a role in supporting patient empowerment (Ammenwerth *et al.* 2012; Anjouat *et al.* 2007). However, research on empowerment tends to focus on measures of individual experience that reduce context to the inclusion of one or two variables. We argue that shifting research design and conceptual focus away from empowerment to *what it is that patients' value* – that is what they normatively strive to include, develop, focus on, prioritise - within their own care, enables strategies for self-care to be more clearly articulated. It also allows the underpinning 'logic of care' (Mol 2008) that the patient is using to understand and present their actions to come to the foreground.

Limitations

This research was conducted at one kidney unit and only a small sample of patients participated in interviews and observation. Furthermore, the

convenience sampling approach used means that the study has not represented the views of patients from all renal modalities and all age groups. Despite a small sample, the study has provided new and useful insights into this currently under-researched topic.

Whilst the research design methodology used does not offer representativeness or generalisability, issues of confirmability and transferability could be overcome by further work in other kidney units or with other patient groups, such as those with diabetes, who now have access to PatientView. In addition, although this research has discussed carers and their role within patient self-care, carers were not included as participants which is a limitation of the study.

Implications for Practice

This research is important for ongoing investigations into the role of technology for supporting self-care. By shifting research design and conceptual focus away from empowerment to *what it is that patients value*, strategies for understanding how self-care can be supported are made visible. Many of these strategies are focussed around relationships highlighting the fact that it is not technology *per se* that patients value, but rather the capacity technology offers to facilitate and strengthen the relationships that support them to self-care. Patient educators, clinicians and other members of staff responsible for implementing PatientView or increasing uptake may find this outcome from the research can support engagement efforts. Findings may also be relevant to patient portal designers who are seeking to codesign technology with patient groups (Marent *et al.* 2018).

Conclusion

This research considers how the 'doing' of self-care through the use or non-use of technology is influenced by what individual's value within their life and this in turn influences how PatientView becomes embedded, or not, within daily life. PatientView users took the position that they were *responsible* for their health and this position was supported by interaction with PatientView which in turn produced *ways of knowing* that supported their self-care practice. By taking a practice approach that privileges understanding of the *doing* of self-care, it is possible to recognise the interactions through which knowing and self-care become possible.

Engagement with PatientView involves intricate and entwined practices that encourage patients to seek out information which can be translated into self-care actions that patient's value. Identifying these actions as practices bring to light the complicated hidden work enacted by patients with CKD and what can be done to support patients to feel active in *sustaining their own* health. Practices that support *preparedness* - having the opportunity to reflect and plan

ahead - were valued by users of PatientView. The value of having knowledge which supports practices of choosing *when* to act and how is a feature of self-care and technology use that would benefit from further investigation. All of these practices were enhanced by the sharing of care that PatientView enables, allowing family members to become involved and participate in care in ways which enhances relationships.

What is valued by patients has been shown to be inextricable from the context of individual situations and situations in which they live and this has been shown to have an influence upon technology use and self-care activity. By positioning CKD within a continuum of care, it is recognised that there are times when patients are unable to cope with such complexity, preferring instead to rely on care from health professionals. Within that continuum, the value of PatientView was that it afforded opportunities for both independence and inter-dependence.

On this basis we would argue that IT enabled self-care should not be conflated with self-sufficiency, but with enhanced opportunities for engaging in a broad range of self-care practice.

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Conflict of Interest

No conflict of interest has been declared by the author(s).

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