



REGULAR PAPER

The individual in multiple interacting activity systems: IT-supported diabetes management

IT-supported
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Abstract

Purpose – The purpose of this paper is to examine how pregnant women with type 1 diabetes integrate new information technology (IT) into their health management activities, using activity theory as an analytical framework.

Design/methodology/approach – The research is a multiple case design, based on interviews with 15 women with type 1 diabetes who were pregnant, considering pregnancy, or had recently given birth. A thematic analysis, sensitised by activity theory, was used to analyse the data.

Findings – Health management in this setting involves negotiations and contradictions across boundaries of interacting activities. Participants play an active role in managing their health and using new IT tools in particular ways to support their health management. Using new technologies creates both opportunities and challenges. IT-enabled healthcare devices and other information systems open up new treatment possibilities, but also generate new contradictions between interacting activity systems.

Research limitations/implications – The research was conducted with a small sample in a specific context of health management. Further research is needed to extend the findings to other contexts.

Practical implications – Healthcare providers need to accommodate a bottom-up approach to the adoption and use of new technologies in settings where empowered patients play an active role in managing their health.

This research was funded by the Australian Research Council (grant DP0880699). The authors thank Virginia Hagger and Renza Scibilia of Diabetes Australia, Victoria for assisting with the recruitment of participants, and the women and healthcare professionals who agreed to be interviewed for this research. The authors are also grateful to the editor and anonymous reviewers for their valuable feedback on an earlier version of this manuscript. The authors dedicate this paper to the memory of the colleague and friend, Professor Steve Howard (1961-2013) of the University of Melbourne. Steve joined the University of Melbourne in 2000, and over the next decade his leadership transformed the research agenda of the Department of Information Systems. Steve established the Interaction Design Laboratory, served as Head of Department from 2007-2010, and was the inaugural Director of the Melbourne School of Information in 2012. His scholarship, intellectual insights, and generous mentoring of staff and students were widely recognised in the University, and he was internationally renowned as a leading scholar in his field of research.



Originality/value – The findings highlight opportunities to further develop activity theory to accommodate the central role that individuals play in resolving inherent contradictions and achieving alignment between multiple interacting activity systems when incorporating new IT tools into health management activities.

Keywords Alignment, Technology adoption, E-health, Activity theory

Paper type Research paper

Background

Information technologies (IT) are playing an increasingly central role in healthcare and long-term health management across a range of settings. Individuals are now actively using the Internet to learn about diseases and identify strategies to improve health (Fox, 2011). There is a growing body of research within the field of e-health, covering a range of issues, including electronic patient records (e.g. Hayrinen *et al.*, 2008), the design of IT to support patient-physician communications (Gonzales and Riek, 2013), patients' use of online communities and social media for support, empowerment, and knowledge-sharing (Johnston *et al.*, 2013; Liu *et al.*, 2013), and broad design considerations involving patient autonomy and empowerment (Fitzpatrick, 2011; Storni, 2010). While e-health research typically focuses on the possibilities offered by new technologies, it is important to recognise that new technologies can change health management in both positive and challenging ways. The processes by which individuals incorporate new technologies into their health management, and the subsequent impact new IT tools have, can only be fully understood by taking into account the broader contexts in which health technologies are used (Aarhus and Ballegaard, 2010; Fitzpatrick, 2011; Moen *et al.*, 2007). In this paper, we examine how patients with a chronic condition have integrated specific IT-enabled healthcare devices, along with more generic information systems, into their everyday lives.

New technologies offer great potential for empowering patients and enhancing healthcare. To realise this potential, however, innovations need to be effectively integrated with health management processes and systems in the broader healthcare setting. IT-enabled healthcare innovations are often boundary-spanning in the sense that their adoption depends on the co-adoption of related technologies, and the transformation of practices and processes between patient, doctor and other healthcare providers. Today, many patients no longer see themselves as passive care recipients. Instead, they take ownership of their health, seek out information about their condition, compare healthcare providers, and in general take a more active role in their treatment than in the past (see, e.g. Fitzpatrick, 2011; Storni, 2010). This can lead to tensions and differences of opinion about treatment scenarios between the patient, family, doctor, specialists, and hospitals.

Our study examines the use of IT-enabled health technologies by women with type 1 diabetes who, at the time of the research, were pregnant, considering pregnancy, or had recently given birth. During the study, the women's health management was in a state of considerable transformation due to both pregnancy – or planning for pregnancy – and the use of new technologies, such as IT-enabled insulin pumps (often referred to as smartpumps). We take a holistic approach, using activity theory to examine the context in which new technologies are integrated into, and transform, our participants' health management. Our approach aimed to gain insight into the challenges or tensions involved in integrating new technologies into long-term health management. Activity theory is particularly helpful for considering the role of tools and technologies across complex settings and identifying the inherent tensions between separate activity systems. However, in the current healthcare landscape of

empowered patients, our findings suggest that activity theory may need to evolve to accommodate the central role that highly motivated individuals play when seeking to achieve specific objectives across multiple interacting activity systems. The women we interviewed proactively negotiated technology use and worked to overcome tensions within and between the different social contexts that are pertinent to diabetes management (e.g. home, work, healthcare settings). This central orchestrating role of the individual is not usually apparent in activity theory analyses of traditional healthcare settings. We conclude with some ideas on how this role could be theorised as part of multiple interacting activity systems in the context of integrating new IT tools into empowered patients' long-term health management.

IT and type 1 diabetes

A complex condition such as diabetes – which requires ongoing measurement of blood sugar levels, adjustments to insulin dosages, and attention to diet and exercise – provides a ripe setting for the potential use of IT to empower patients (Wynne, 2008). Type 1 diabetes is an auto-immune condition characterised by fluctuations in blood glucose levels, controlled by diet, exercise and insulin. Serious health consequences can occur when patients frequently experience hypo- and hyperglycaemia (extremely high or low blood sugar levels) (Chitayat *et al.*, 2009). Traditionally diabetes patients administered frequent injections of insulin via syringes and, more recently, insulin pens. Today many patients conduct their insulin therapy through IT-enabled smartpumps that typically include bolus calculators (i.e. they can calculate the amount of insulin required), and can be set to inject highly specific doses of insulin at regular intervals (Australian Institute of Health and Welfare, 2012; Lenhard and Reeves, 2001). Many of these devices include continuous glucose monitors (CGMs) that are used to accurately and regularly record patients' blood sugar levels. Without CGMs, patients must manually test blood sugar levels and keep records of the results. Current CGM devices enable patients to record the data from their glucose monitors electronically, so patients and their doctors can identify trends in blood sugar fluctuations (Chitayat *et al.*, 2009). While the primary functionality of these healthcare technologies are to administer insulin and record blood sugar levels, they include embedded information systems, with considerable functionality to record, display and transmit large volumes of fine-grained electronic data. They can also be seen contrastingly as tools to engender patient compliance and as tools for patient empowerment and self-management (Storni, 2010).

Pregnancy, or planning for pregnancy, introduces new challenges for patients with type 1 diabetes. To ensure a healthy pregnancy, women with type 1 diabetes are normally advised to achieve stable blood sugar levels for at least three months prior to pregnancy, while fluctuations during pregnancy can seriously affect the health of both mother and unborn child (Wollitzer *et al.*, 2010). Morning sickness and tiredness make it difficult for women to effectively manage their diet and exercise. Consequently there is much interest in the potential use of new technologies to support pregnant women with diabetes (e.g. Chitayat *et al.*, 2009; Wollitzer *et al.*, 2010). However, the need for a high level of self-management in diabetes care can limit the effective use of technologies such as smartpumps, which involve a significant learning curve and require substantial support from patients' healthcare teams (Hirsch, 2010). Smartpumps are expensive. To fund the device patients must first satisfy the requirements of health insurance companies, which delays adoption and creates challenges for the patient (Scheepers *et al.*, 2011). Further, the smartpump is a highly personal and visible technology that can evoke emotional reactions and body image concerns (Ritholz *et al.*, 2007).

In order to understand the role of technologies in supporting and transforming diabetes management, it is necessary to examine the social setting in which health technologies are used. Activity theory, with its emphasis on tools as mediators of activity within social systems, provides a useful lens to examine the socio-cultural context of personal health management (Moen *et al.*, 2007).

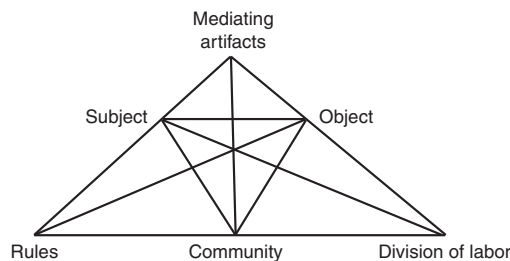
Activity theory for analysing IT in health management

Activity theory is a broad framework that provides an analytical perspective on complex social systems. Developed from the work of Russian psychologists such as Vygotsky (1978), the version of activity theory commonly used today (the second generation) describes purposeful activity as a social structure, represented by the triangular model in Figure 1 (Engeström, 1987). According to this framework, activity is driven by an object or motive, achieved through the use of tools and mediated by rules (both formal rules and implicit regulations or established ways of doing things). Activity is collective, involving a community: members of the community all play a role in working towards the object, and achieving the outcome.

A core argument of activity theory is that all activity is mediated by the use of tools. It has therefore been widely used in information systems research to examine technology use in organisational settings (e.g. Crawford and Hasan, 2006; Hasan and Pfaff, 2012; Waycott, 2005). Hasan and Pfaff (2012), for example, employed activity theory to explain why two organisations experienced different outcomes when they integrated wikis into their knowledge management work. Activity theory has also been used as a theoretical framework for information systems design (e.g. Bødker and Klokmose, 2012; Kaptelinin and Nardi, 2006; Mursu *et al.*, 2007), to identify tensions and analyse activity to inform the development of new healthcare tools (e.g. Bardram and Doryab, 2011; Luukkonen *et al.*, 2011), and to evaluate the impact of new technologies in healthcare settings (e.g. Hasu and Engeström, 2000). Healthcare is a particularly complex social setting, with numerous stakeholders and established practices governing how activities are carried out. In a professional context, new IT can create considerable disruption to the way healthcare is delivered, and activity theory provides a holistic framework for analysing the disturbances that occur (see Hasu and Engeström, 2000).

Interacting activity systems, contradictions, and knotworking

Human activity is social, constantly evolving and always interconnected with other activities or social systems that share a common object, or motive (Kuutti, 1996). In the context of healthcare, this common object might be the improved health of the patient.



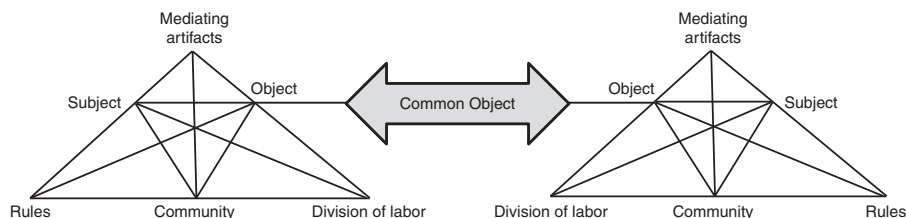
Source: Engeström (1987)

Figure 1.
Activity system
framework

To capture the notion of intersecting activity systems, Engeström (2001) proposed that the analytical perspective of activity theory should be extended to include a network of interacting activities (Figure 2). For Engeström, this version of activity theory (the third generation) requires that researchers analyse at least two interconnected activity systems.

One of the central tenets of activity theory is that there are always contradictions, or tensions, within and between activity systems. Contradictions “manifest themselves as problems, ruptures, breakdowns, clashes” (Kuutti, 1996, p. 34). The notion of contradictions derives from activity theory’s roots in Marxist philosophy, in which capitalism is said to contain primary contradictions “between the use value and exchange value of commodities. This primary contradiction pervades all elements of our activity systems” (Engeström, 2001, p. 137). In healthcare, patients represent a commodity, and doctors may be expected to see as many patients as possible to achieve a cost-effective service, but also have a duty of care and are expected to adequately diagnose and prescribe treatment. Secondary contradictions occur between two or more components in an activity system; for example, when a new tool clashes with existing rules or established practices. Tertiary contradictions represent conflict between an existing activity system and its culturally more advanced form and therefore involves some upheaval during the evolution of an activity system – for example, as new rules or practices are formed to accommodate a new tool. Quaternary contradictions are tensions between intersecting activity systems that occur when co-existing activities (e.g. activities of physicians and patients) have conflicting objectives, rules, or divisions of labour.

Activity systems are said to be in a constant state of development or transformation, and evolve through the introduction and resolution of contradictions. For Engeström (2007), activity systems are also transformed through a horizontal, collaborative process that he termed knotworking. During this process, separate but related activity systems become tied together, untied and retied in knots of collaborative work (Engeström and Sannino, 2010). As Greig and colleagues explained, the metaphor of knots represents “temporary entanglements of inter-organisational” work groups (Greig *et al.*, 2012, p. 306). A key element of knotworking is that “no single actor has the sole, fixed authority – the center does not hold” (Engeström, 2007, p. 24). Knotworking, in other words, has a flat, non-hierarchical structure. This perspective, then, favours a holistic and decentralised view of organisations and social systems, and does not account for the role that individuals might play in initiating collaboration and transforming activities. Despite this, Engeström has noted that changes in activity systems “must be initiated and nurtured by real, identifiable people, individual persons and groups” (Engeström and Kerosuo, 2007, p. 340). A common criticism of activity theory, however, is that it does not sufficiently address the role of individuals



Source: Engeström (2001)

Figure 2.
Interacting activity
systems

in activity systems (Roth, 2009; Sannino, 2011), or the role of individual experience in understanding users' encounters with technology (McCarthy and Wright, 2004).

Patients in health management activities

Much of the research using activity theory to analyse healthcare systems has been conducted by Engeström and colleagues, in a programme called developmental work research (e.g. Engeström, 2001, 2007; Engeström and Sannino, 2010). The focus of this program has been on organisational systems; therefore, this research has primarily focused on understanding the experiences of healthcare professionals, with patients typically examined as objects, rather than subjects of the activity (e.g. Engeström, 2007). Where self-management is key to effective healthcare, it seems imperative that patients' perspectives are included in an activity theory analysis, particularly when seeking to understand the role of technologies in supporting and transforming health management. There are many instances of healthcare transformations that involve new collaborations and emerging practices at the organisational level, and policy reform at societal level (see Greig *et al.*, 2012). However, in situations when individual patients can choose to adopt and use personal technologies to support their health management, as is the case for those with type 1 diabetes, transformations in the activity system may be seen most clearly by, and have the greatest impact on, the patient. Accordingly, in this work we sought to emphasise the patient's perspective, and this shaped the data gathering and analysis approaches.

Research method

We utilised a multiple-case research design for the study (Yin, 2003). The case study method is ideally suited to the exploration of new phenomena (in this instance use of IT-enabled smartpumps) in a particular context (in this instance, diabetes care). To complement the earlier mentioned healthcare systems research with its focus on healthcare practitioners (Engeström, 2007), we chose the unit of analysis to be the individual patient. Each interviewee was an individual woman with type 1 diabetes, who was either pregnant, planning to be pregnant, or had recently given birth. We chose to focus on individual women with type 1 diabetes as they are revelatory in terms of their highly specialised care needs. This makes them highly reliant upon health professionals and family support, creating a set of multiple interacting activity systems that are relevant to the analysis. The multiple-case design yielded opportunities for literal replication (Yin, 2003) in analysing how women incorporated (or planned to incorporate) new IT-enabled health technologies into the multiple interacting activity systems that contribute to their health management.

For data collection, we utilised approaches commonly associated with ethnographic research (Creswell, 2007). One of the authors spent extended periods of time in the field, meeting with diabetes educators, attending diabetes advocacy group meetings, and immersing herself in the daily activities of women living with type 1 diabetes. Through in-depth interviews (Kvale, 1996) we obtained detailed understanding of the use of information and healthcare technologies by the participants, and their life histories and lived experience in the broader context as they managed their diabetes.

Participants

Participants were recruited through a local diabetes support organisation. This recruitment was supplemented using a snowball sample technique and attendance at diabetes pregnancy support events, where researchers distributed information about

the project to the attendees. Participants were selected to cover a range of life stages relevant to the research (i.e. pregnant, planning for pregnancy, or recently pregnant), as well as different stages of smartpump adoption/use. Table I provides pseudonyms used to identify interviewees, background information about each participant (not all participants provided their age), and status regarding smartpump adoption/use. One participant (Lisa) had decided not to adopt the smartpump at this stage because she was happy using insulin pens. Another participant (Veronica) no longer used a smartpump because she found it increased her anxiety following a stillbirth, and the technology was not well supported by her local hospital. The sample was necessarily small because of the uniqueness of this healthcare setting and the in-depth nature of the research.

Data collection

The interviews were conducted using a semi-structured interview guide developed by the team and checked with colleagues prior to deployment to test for rigour and relevance. The interview guide covered broad topics, including: history of diabetes diagnosis and treatment, pregnancy status, and use of smartpumps and other technologies. Interviews were conducted at the interviewees' home, workplace or other setting. The interviews included discussions about participants' experiences of pregnancy and miscarriage in the context of a chronic illness, and therefore required sensitivity from the interviewers. Each interview lasted for one hour or longer, and was audio-recorded and later transcribed.

Data analysis

The analysis followed an iterative process of coding, reviewing, recoding, and interpreting the data (Boulton and Hammersley, 2006). We were primarily interested in

Interviewee (pseudonym)	Age	Pregnancy status	Smartpump adoption/use
Lisa	–	Planning pregnancy	Not using a smartpump
Fiona	32	Considering pregnancy in the next few years	In the process of adopting smartpump
Claire	–	Planning for pregnancy	In the process of adopting smartpump
Emma	30	Pregnant with first child	Uses smartpump
Janet	32	9-month-old baby conceived through <i>in vitro</i> fertilisation (IVF); planning to have another baby	Uses smartpump
Vanessa	–	One child; planning to have another baby	Uses smartpump
Susan	40	15-month-old child; planning to have another baby	Uses smartpump
Kathryn	36	18-month-old child; pregnant with second baby	Uses smartpump
Jessica	29	4-month-old baby	Uses smartpump
Eloise	31	Considering pregnancy	Uses smartpump and CGM
Rebecca	27	Pregnant with first child	Uses smartpump
Rachel	37	Trying to conceive through IVF	Uses smartpump
Amy	28	8-month-old twins	Uses smartpump
Bronwyn	31	20-month-old child	Uses smartpump
Veronica	39	One child; recent still-birth; planning for another pregnancy	Previously used smartpump

Table I.
Pseudonyms and background information about interviewees

gaining an overall picture of participants' diabetes management, with a focus on understanding how participants used (or didn't use) smartpumps and other tools to achieve their goals, and identifying the interactions and contradictions between different activity systems. The data were analysed thematically through a close reading of the interview transcripts (Miles and Huberman, 1994). The first author examined the interview transcripts to identify the tools, rules, community, and division of labour involved in the core activity system of individual health management. For each interviewee, a rough activity system model was drawn up and a written summary of the activity prepared. This analysis was discussed at a team level for reliability. We then compared and contrasted the activity systems that interviewees described in order to identify common and salient features of the core activity. These are summarised in the findings section below.

The first author then examined the transcripts to identify other activity systems that interacted with the core activity, along with their rules, tools, division of labour, community, and any areas of tension that interviewees described. The tensions were noted as evidence of contradictions. Typically these were quaternary contradictions, or conflict between interacting activity systems. Again, for each interviewee we prepared a written summary describing the multiple activity systems and their contradictions. These summaries were then compared and contrasted and discussed within the research team. From this analysis, common intersecting activities and contradictions emerged. These are described below.

Findings

Here, we report the findings of the analysis, beginning with an outline of the core activity system: the patients' health management. We then describe the different activity systems that interacted with this core activity, focusing on: healthcare provision, pregnancy healthcare, hospital systems, and workplace, families and home life, which in the interests of space are discussed together. Throughout, we present extracts from the data to highlight how participants integrated new IT tools into these activity systems and the impact new tools had on contradictions or tensions between intersecting activities.

Health management for women with type 1 diabetes

The activity of diabetes management was in a state of transformation for our participants. The motive of the activity had changed, from the general objective to maintain health and manage their diabetes, to a more pressing concern about being healthy enough to contemplate pregnancy and to have a healthy baby.

The mediating tools included physical artefacts and technologies, such as insulin pumps or pens, as well as education about diabetes management. Many interviewees talked about the central role that education played in the activity, from their first encounters with diabetes in the early days following diagnosis. Health professionals typically educated patients, but the women proactively sought other sources of information when they felt that they had insufficient knowledge. Resources on the Internet were important in enabling women to learn about new strategies and tools available to help manage their diabetes.

The activity system was governed by rules, including established practices for testing blood sugar levels, modifying insulin doses, managing diet and exercise, and recording and sharing information with health professionals. These practices changed over time as the health management activity evolved. In particular, pregnancy, or planning for pregnancy, modified the rules substantially, making it important for

women to test their blood sugar levels more frequently, to keep accurate and comprehensive records, and to share this information with their health professionals. In some cases, IT were used to accommodate these new rules (e.g. some women reported using e-mail during pregnancy to regularly share information with their health professionals).

The community grew during pregnancy, with additional health specialists needed. The patient's partner and family members were also important and some participants had actively sought to broaden their community through engagement with other pregnant women with type 1 diabetes. For instance, Rachel described taking part in a discussion forum on a diabetes website:

There's a thread, somebody started it last year sometime, about older women with type 1 having babies. We're all really active on there talking and discussing. That has been absolutely vital for me to be able to go there and hear about the two women that are both pregnant at the moment, the woman that's just had a baby, and they're all late 30s (Rachel).

Other interviewees identified a gap in their community: they felt they would have benefited from being able to share experiences and knowledge with other pregnant women with type 1 diabetes.

A clear division of labour governed the roles that different community members played. Typically the patient took a proactive role in managing her healthcare, influencing healthcare professionals and educating partners and family members (e.g. "I think she [endocrinologist] takes her cues from me" – Kathryn). These roles are discussed further below, in an analysis of the interactions between the different activity systems.

A network of interacting activities

Following the initial analysis of the core health management activity, we extended the analysis to include the multiple interacting activity systems that contribute to the patients' health management. The key interaction occurred between the patient's and health professionals' activity systems, and this will be the focus of our discussion. The other activity systems in the network included pregnancy healthcare, hospital systems, workplace activities, and family or home activities.

Healthcare provision

Our interviewees were highly motivated individuals who needed to carefully manage their health to achieve positive outcomes, particularly when facing pregnancy. Many of our interviewees talked about their efforts to achieve positive outcomes for their healthcare. This often involved achieving alignment between the way their healthcare professionals operated and their own preferences for managing diabetes. Some women described a well-functioning activity network, where the patient and a community of health professionals worked collaboratively. Others identified tensions between the two activity systems, describing their difficulties sharing information with endocrinologists, or gaps in the tools and resources that were made available to support their health management. Fiona, for instance, found that her endocrinologist followed rigid rules, which clashed with her preferences to be in charge of (and knowledgeable about) her own health management:

I've been told it's all about the haemoglobin A1c with the endocrinologist. They get special – you know, rewards and stuff if they have all their patients in the right zone or whatever. [...] But he changes my insulin and he doesn't sort of tell me why (Fiona).

Here we see an example of a quaternary contradiction, with the rules of healthcare provision conflicting with Fiona's health management activity. A recurring theme in our interviews was that women felt they needed to have control over their own health management. Fiona experienced tension when there was conflict between her preference for autonomy and the paternalistic practices of her healthcare provider. This need for control was often manifested in the way participants proactively used technologies and interacted with health professionals to make decisions that would transform the activity system. Eloise described how she actively sought support from her endocrinologist to adopt an insulin pump:

I went to my endo [endocrinologist] and I said "I want to go on the pump." He didn't really want me to go on a pump, and I said "no, I want to go on the pump. Put me on the pump. Make it happen." That's how I kind of treat my endo, as the facilitator when I need him to do stuff that I can't do. That's how the relationship works and he's good. He has a bit of faith in me (Eloise).

Participants expected endocrinologists, diabetes educators, and other health professionals to play the role of facilitators rather than managers. When reality fell short of this expectation, they took action to resolve this contradiction. Fiona felt she had never been properly educated about managing diabetes ("everyone involved just sort of stood back"). She resolved this by attending courses and seeking information on the Internet, which led to learning about insulin pumps:

I just jumped on the Internet and looked up some information, contacted some of the companies that produce the pumps. They had information sessions [...] So I went along and got all the information (Fiona).

She then took it upon herself to educate her doctor (general practitioner) about the pumps and was in the process of finding a new pro-pump endocrinologist at the time of the interview. In other words, she planned to swap one healthcare provision activity system with a system that would be more aligned with her own health management.

Many women described conflict between the detailed information that health professionals requested and their own preferences for an *ad hoc* approach to recording and analysing blood sugar levels (e.g. "Recording your blood sugar is just a pain [...] and most people do it like the week before you go to see the endocrinologist" – Vanessa). Some interviewees used IT to overcome this conflict. For instance, Susan uploaded information from her smartpump to a secure web site, which she then shared with her diabetes educators:

You can sort of plug it [the pump] into a computer, get all the results off. This website sorts it all out into a chart so you can see any trends fairly easily. [...] The nurse educators at [the hospital] have that password and information. So they log in, they do a print off, and then when I arrive at the hospital I've got mine and they've got theirs [record] (Susan).

Those who did not have access to these tools saw a need for technologies that would provide better support for record keeping and information sharing. Here, there is an opportunity for new tools to resolve existing contradictions between activity systems, but our research suggests that realizing this opportunity is not straightforward.

Pregnancy healthcare

Women planned for pregnancy by seeking out information (e.g. attending information seminars) and discussing their plans with their health professionals. Maintaining tight

control over blood sugar levels became a key priority, which influenced the decision to use a smartpump: “At the moment I’m looking at changing my therapy to an insulin pump, with the thought to have a baby in the not too distant future” (Claire).

During pregnancy, the diabetes health management activity evolved to accommodate new, stricter rules. Women reported being more pedantic and disciplined about recording blood sugar levels and sharing information with their health professionals:

I was testing my blood sugars probably 10 times a day [during pregnancy]. Testing every couple of hours pretty much (Jessica).

This is just a few weeks’ worth [of paperwork] in here. [...] But this is intense because I’m pregnant. I was always doing at least half as much work for the last 17 years but just not with the same accountability seeing the doctor every week (Emma).

Participants found IT particularly useful during this time. Being able to e-mail information to health professionals made it easier to cope with new expectations about information sharing. Jessica described her practices as follows:

I can upload [...] all the data from the pump on to my computer and share that with the diabetes educator [...] Which was fantastic when I was pregnant because I’d upload on to the computer, email my educator and say have a look at my data. Then she’d look at it and email me back and say you know, “do this, do that” [...] I was in contact with her probably once or twice a week while I was pregnant – purely remotely (Jessica).

The healthcare community expanded during pregnancy to include obstetricians, midwives, nurses and, in some cases, new diabetes healthcare professionals who were experienced in dealing with pregnancy. Some interviewees encountered health professionals who were experienced in dealing with pregnancy and childbirth, but did not know enough about type 1 diabetes. There were clearly contradictions between the rules of the pregnancy/childbirth activity system and the patients’ health management activity. Emma, for instance, described the difficulties she experienced with healthcare professionals who were unfamiliar with type 1 diabetes: “They only know type 2 and gestational, because that’s what’s common. It’s so frustrating.” Emma was 33 weeks pregnant at the time of the interview and did not expect to receive adequate healthcare during childbirth, so was training her husband to manage her diabetes and use the pump:

I can’t depend on the nurses to keep a really good eye on me, so I’m training [my partner] as much as I can. [...] The fact is [my partner’s] probably going to be taking more care of my pump and my blood testing than the nurses will be on the day [of the birth] because the nurses are so clueless [about diabetes] sometimes (Emma).

Here we see evidence of the proactive role a highly motivated patient has taken to manage a contradiction between her diabetes management and the pregnancy healthcare system. Emma was aware that the objectives and procedures of pregnancy healthcare, which focused on pregnancy and childbirth, may not align with her own diabetes management, hence the need to develop a workaround: training her partner to use the pump and effectively manage her diabetes while she was in labour.

Hospital activity systems

Some interviewees also encountered contradictions between their own health management practices and the rules or established practices of hospital healthcare systems, outside of pregnancy and diabetes care. Contradictions between hospital care

and diabetes self-management were exacerbated by the use of new technologies. Eloise described the difficulties she experienced when undergoing surgery for a shoulder injury. She was told by a nurse that her smartpump could not be supported during surgery:

The educator came in and said “no, you can’t wear a pump. Actually I don’t have training in a pump. I’m not comfortable with this situation” (Eloise).

This proved extremely difficult for Eloise: she had to determine how to manage her diabetes, using insulin shots rather than the smartpump, while fasting for surgery. She then had to rely on her husband to refit the smartpump immediately after surgery, because professional support was unavailable.

In this case the new tool – the smartpump – clearly created a conflict between the patient’s established practices for managing her diabetes and the expectations of hospital staff members who were unfamiliar with this approach. This was a tertiary contradiction for the hospital activity system, which had not fully evolved to accommodate the new technology. Veronica, who lived in a rural setting, also described insufficient support from the hospital for her use of the smartpump. She had been instructed to call the hospital if she had a high reading but when that happened, she was unable to get sufficient advice from the hospital staff. In the end, Veronica discontinued using the smartpump. In both these cases there was a potential for serious consequences from the conflict between patients’ health management tools and practices and the support provided by the hospital. This was also the case when participants’ health management intersected with their work, family, and home life, as described below.

Workplace, families and home life as interacting activity systems

Participants described the care they took in negotiating the contradictory scenarios and tensions that occurred when diabetes management intersected with work activities and home life. For instance, as a teacher at a special school, Rebecca felt she needed to be quite careful about displaying the tools that she used to manage her diabetes, particularly the smartpump:

I’ve got kids at school who, when they see it [the pump] they poke it and try and pull it off and stuff like that. So if I hide it, then I know that it’s safe (Rebecca).

Eloise’s role as a professional cyclist clearly impacted on her choices regarding health technologies. At the time of the interview, she was using a wireless insulin pump, made from disposable materials, that was only available in the USA. She had spent some time on the professional cycling circuit in the USA and her sponsors had provided her with the pump. Previously she had used a non-disposable pump; she would take it off when racing for fear of damaging the pump if she crashed. There was a contradiction, then, between the tool she used for diabetes management and the rules of her professional practice, which involved high speed and risk of damage should an accident occur.

The social structure of family and home life also affected the way participants managed their health. Many of the women we spoke to had been diagnosed with diabetes during childhood. Initially, their families and home life exerted significant influence over the way their diabetes was managed; this changed as they grew up and moved away from home. Often this involved a transitional period as they moved through adolescence and young adulthood, when they were less likely to take their

health management seriously (e.g. “I thought I was indestructible”). Over time, however, they learned to manage their diabetes independently. Some women described a contradiction between the way their parents approached diabetes and their own health management goals and preferences. They found that moving out of home enabled them to exert more control:

I found when I lived at home as a kid they'd buy ice cream and frozen chips. You'd come home from school and there'd be nothing to eat except ice cream and [fast food]. When you're in control of your own shopping trolley [...] your diet can change dramatically (Susan).

I came from a family that was very “[she’s] not a diabetic, she’s a child with diabetes” and that sort of thing [...] Now that I’ve taken on board this is actually a really important part of my life, then my health’s better and I’m more open about it with people (Vanessa).

Partners also played a central role in helping the interviewees manage their diabetes, often influencing their decisions to adopt new tools, e.g.: “He came with me when I got the pump put on and so he knows as much if not more than me” (Janet). The women we spoke to clearly relied on an extended community of both family members and health professionals to help manage their diabetes, although their role as advocates of their own health management remained central. This finding reinforces the idea that diabetes pervades all aspects of a patient’s life, suggesting that a holistic analysis of the broader context of diabetes management is appropriate for examining the role health technologies play in this activity. We discuss the theoretical and practical implications of our findings below.

Discussion

IT transformed the way the women in our study managed their diabetes, creating opportunities for improved interactions with members of the healthcare community, but also highlighting tensions or exacerbating contradictions between interacting activity systems. One of the most notable findings to emerge from our research is that the women we interviewed were active in learning about the tools and resources available to support their health management, and choosing to adopt new technologies to suit their own established practices. Existing research has shown that new technologies can be empowering for patients with chronic conditions (e.g. Aarhus *et al.*, 2009; Fitzpatrick, 2011; Johnston *et al.*, 2013; Storni, 2010). Our research extends this, suggesting that highly motivated patients with chronic conditions may be already empowered, choosing to use technologies in particular ways to suit their own established practices. This study contributes to a growing body of literature that is concerned with understanding the complexities involved in integrating personal health technologies into long-term health management (e.g. Aarhus and Ballegaard, 2010; Fitzpatrick, 2011; Moen *et al.*, 2007; Storni, 2010). By applying an activity theory lens to examine the socio-cultural context in which smartpumps were used, we have furthered understanding in this area. Previous research has illustrated the complex social and physical spaces into which new technologies must become integrated when used by patients with chronic conditions (Aarhus and Ballegaard, 2010; Fitzpatrick, 2011; Storni, 2010). Our research provides further insight to help understand these complexities, highlighting the contradictions that occur between interacting activity systems and the effort patients go to in order to achieve alignment between those activities. Again, the proactive role of the highly motivated individual was clearly apparent. This finding has both theoretical and practical implications, highlighting a need to incorporate individual perspectives in

analyses of healthcare systems, and providing insight into how new IT tools are integrated into healthcare activities.

Individuals as micro activity systems – a focus on alignment

Activity theory provided a useful analytical perspective to consider the diversity of interactions in this study. While our empirical focus was on the patient, we found evidence of multiple activity systems, each with its own objectives, tools, rules and divisions of labour. We observed several contradictions both within and between the interacting activity systems. The practices of some of the endocrinologists did not align with the participants' own preferences for recording and sharing information electronically, and hospital staff members were sometimes unfamiliar with the new smartpump technology.

Participants in this study tried to align their objectives with those of other activity systems in different ways. Some interviewees actively sought new healthcare professionals when the practices of their current healthcare team did not meet their own preferences. This effectively means substituting one activity system with another, to achieve a more overall-aligned network. We propose the label alignment, rather than Engeström's (2007) notion of knotworking, to describe this process. Knotworking suggests a collaborative process involving actors from two or more activity systems working towards common objectives. For us, alignment involves a highly motivated individual purposefully working to overcome contradictions between separate activity systems. Alignment may involve collaborative knotworking, but also more directed, unilateral attempts by the individual to achieve outcomes across interacting activities.

Our findings point towards further consideration of activity theory to accommodate the role of highly motivated individuals in multiple interacting activity systems. The current healthcare landscape has seen a shift towards greater patient knowledge and empowerment, with increased use of technologies that move healthcare away from hospital and institutional care settings into the personal domain of patients and their families (Fitzpatrick, 2011). While activity theory provides a valuable holistic framework for examining the socio-cultural context in which new IT tools are used in formal healthcare settings, highly motivated individuals can also be seen as micro activity systems, with a particular set of objectives, tools, rules, community and division of labour. Conducting analyses of these micro activity systems alongside more holistic analyses could lead to more analytical precision when examining specific interactions and conflicts within interacting activity systems. This is particularly pertinent in the context of long-term health management. Individuals with chronic disease are both the subjects and objects of care, negotiating their health management and the tools they use across the boundaries of multiple activity systems.

Personal IT in a complex healthcare landscape

Healthcare technologies for managing chronic and pervasive conditions must be incorporated into multiple settings, creating challenges for the patient. Like Aarhus and Ballegaard (2010), our study shows patients engaging in "a negotiating process that pushes and shapes boundaries" (p. 1224). Applying the lens of activity theory, we have highlighted the contradictions that need to be overcome in order for new healthcare technologies to be used effectively across settings. Our research focused on unique participants who were highly motivated to use IT tools to achieve positive health outcomes. Highly motivated patients are not only empowered by new

technologies: they proactively seek to achieve alignment when integrating new IT into their personal and complex healthcare landscapes.

While we have examined a particular context of health management, the notion of the individual as central in integrating IT tools across activities could usefully inform analyses in other contexts. Today many individuals own personal technologies which they use at home, but also take to the office, leisure settings and other places. As such, employers, service providers and other institutions have to consider if, and how, to accommodate such non-affiliated use (Scheepers and Middleton, 2013) as part of their traditional computing landscapes. Storni (2010) illustrated that user appropriation of new technologies is accepted and embraced in some contexts, but is often considered deviant in the context of healthcare. Like Storni, our study suggests that some user appropriation is necessary for personal IT tools to be effectively integrated into long-term health management. Extending Storni's argument, we have demonstrated that this involves not only using the technology in particular ways to suit personal practices, but also modifying multiple activity systems in order to accommodate the technology across settings. Healthcare providers and technology designers must recognise the complexities involved in integrating new health technologies into long-term healthcare.

Limitations of this study

This study examined a particular healthcare context in which the activity was in a state of transformation, due to pregnancy or planning for pregnancy. Our findings need to be interpreted with this specific context in mind. Further research is required to examine whether analyses of micro activity systems would be valuable in other healthcare settings. Our study is based on a small sample, but this was necessary given the highly specific nature of the healthcare activity we examined. Nevertheless, the interviews provided rich detail about participants' lives and experiences, an approach recommended for research into personal technology use in complex healthcare settings (Moen *et al.*, 2007).

Conclusion

The study reported in this paper demonstrated that changes in this healthcare activity system were largely initiated by a central, highly motivated individual: the patient. The study also examined the broader context within which healthcare occurs, including interactions with other individuals and activity systems. By applying an activity theory lens to understand this socio-cultural context, we extend previous research on personal IT use in similarly complex healthcare settings (Aarhus *et al.*, 2009; Aarhus and Ballegaard, 2010; Storni, 2010). Our findings show that highly motivated patients play an active role in managing their health, aligning different interacting activity systems and using technologies in particular ways to support their health management. In contemporary society, many patients are knowledgeable and resourceful individuals who are taking ownership over their healthcare. Analytical frameworks of healthcare systems would therefore benefit from a more prominent focus on empowered individual patients. We propose that these individual(s) could be theorised as micro activity systems in their own right. The role of the active and highly motivated patient in healthcare settings also needs to be taken into account when planning the introduction of new IT tools. Healthcare providers may need to accommodate a bottom-up approach to the adoption and use of new technologies, adapting their own practices to fit in with patients' approach to adoption and use of new technologies.

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Further reading

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