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Integration of devices into long-term condition management: a synthesis of qualitative studies

CLAIRE GATELY*, ANNE ROGERS*, SUSAN KIRK† and ROSALIND MCNALLY‡

*Primary Care Research Group, School of Community Based Medicine, The University of Manchester, Williamson Building, Oxford Road, Manchester, M13 9PL, UK
†School of Nursing, Midwifery and Social Work, University of Manchester, University Place, Oxford Road, Manchester, M13 9PL, UK
‡National Primary Care Research and Development Centre, The University of Manchester, Williamson Building, Oxford Road, Manchester, M13 9PL, UK

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Background: Understanding peoples’ responses to and ability to incorporate technology for managing long-term conditions into their everyday lives is relevant for informing the development and implementation of new technologies as part of future long-term condition management in domestic environments. Future research and theory building can be facilitated by the synthesis of existing qualitative studies.

Methods: A systematic search for qualitative studies of health technologies at home was undertaken on OVID CINAHL, OVID Medline and CSA databases for the period 1996–2006. Studies (n = 12) that met the inclusion criteria were synthesized and their analyses subjected to qualitative meta-synthesis.

Findings: Analyses clustered into five themes: (1) managing multiple uncertainties; (2) the reconstruction of identity; (3) the struggle to remain autonomous while allowing dependence; (4) coming to terms with living a technology-assisted life; and (5) the usability of devices. These translated into a line of argument synthesis in which technology takes on the status of a personified ‘other’ around which a set of personal and relational attributions are subsequently constructed. These allow the extension of existing illness work to incorporate new technologies.

Conclusions: Ambivalence about the value of technologies that are designed to assist with the management of a long-term condition reflects experiences of the disruptive effects of health technologies on personal identities and strategies of managing illness. At the same time, they are highly valued because they provided new opportunities to complete aspects of illness work that were previously impossible.

Keywords: Long-term conditions, Meta-synthesis, Self-Care, Technologies

BACKGROUND

The use of health technologies in domestic settings has increased in the last 15 years. They are viewed by policy-makers as important elements in enabling people to self-care, and as having the potential to reduce utilization of services (such as admission and treatment in hospital settings) and enhance the experiences of service users by maintaining access to healthcare resources. They also allow the provision of care to be shifted from traditional health services into the home, e.g. enabling people to be discharged earlier from hospital and be monitored from home. This view of the transformative effects of new technology tends to assume a priori that the patient’s life will be enhanced by the introduction of these new arrangements. The successful introduction of devices to aid the management of long-term conditions is viewed as...
predominantly a technological process, and the user is assumed to be an active participant in its mobilization. This process can shift the roles and responsibilities for care from health professionals to the patient.\textsuperscript{3,4} However, such assumptions are not necessarily grounded in knowledge about the variety of ways in which people may engage with, adapt and integrate new forms of technology in their everyday lives, or the social-contextual influences that may inhibit or promote this process. We know from studies of illness experience that the latter is a dynamic iterative process that draws on a person’s biography, ongoing experiences and social worlds.\textsuperscript{5,6}

We are concerned with the ways in which health technologies are implemented and integrated in the home. We start from the premise that integrating a technology is not simply about its functional aspects but relates to users’ ability to incorporate it into their everyday lives. Using an approach informed by meta-ethnography, we develop a line of argument about the likely response of patients to the introduction of a self-care device into the home.

**METHODS**

Meta-synthesis is a technique for the systematic reinterpretation of qualitative studies. It allows new insights and understandings to emerge through a process of a re-conceptualization of themes.\textsuperscript{7} It is increasingly used in the health field\textsuperscript{8–10} using a variety of techniques.\textsuperscript{7,11–13} This study draws upon the methods developed by Noblitt and Hare,\textsuperscript{7} but also takes into account Dixon-Woods’ recent contributions to qualitative synthesis.\textsuperscript{13}

**The Scope of the Review**

This meta-synthesis examines existing studies concerning patient responses to different devices and technologies across a range of long-term conditions. The identification of relevant literature was based on three stages of searching:

1. Initial exploratory searches to examine the size, scope and definitions employed in the area.
2. Further searching and screening to refine the inclusion criteria and narrow the topic focus.
3. A set of final searches focused on a number of specific appliances and devices.

A broad search was used initially to search for qualitative studies of the application of technology to chronic disease self-care. The focus of the search grew progressively more specific as we refined the study to concentrate on the experiences of adults (see Fig. 1 for inclusion and exclusion criteria). A flow-chart (Fig. 2) shows the number of records identified and eliminated at each stage.

In the first phase, searches of OVID CINAHL, OVID Medline and CSA were carried out for the period 1996–2006. The search strategy combined a number of terms in order to identify qualitative research, chronic diseases and health technologies used to support self-care. Citation and related records searches of PubMed and Web of Knowledge were also performed to follow links to and from papers identified by the authors (CG, AR, SK) as being highly relevant. The electronic contents pages of key journals were also scanned for the same time period. This identified 2489 articles.

In the second phase, searches of the same databases were carried out for publications by key authors in the field and specific areas relating to specific devices. The results of searches conducted for a previous meta-synthesis\textsuperscript{10} were also re-scanned. This resulted in a further 2422 articles being identified. Initial record screening was conducted by RM, reducing the number of records to 346. The authors CG, AR and SK met to further screen against the inclusion criteria. This reduced the number of records to 38. A copy of the full text was then obtained for these citations, which were then
The authors then met to discuss their assessments and reach consensus. For example, exclusions were made if the study conclusions were not qualitative (e.g. qualitative methods were used to develop or gain insight for the development of a measurement tool), or if they did not provide sufficient details of the results (e.g. results...
were descriptive and superficial). Finally, eight studies met our inclusion and quality criteria. During meetings, the authors returned to the scope of the review and an earlier discussion regarding the meaning of the term self-care device. This led to a further set of searches being conducted that employed the same methods outlined in stage 1, but focused on specific devices.

FIG. 2. Identification of relevant literature for inclusion in the meta-synthesis.
Sample search strategies for all phases of searching can be obtained from the authors. At this stage, to refine our search, index terms were used for highly relevant papers identified in earlier stages and methodological terms that stage 1 showed lacked sensitivity were eliminated. This resulted in a further 2025 records being identified, which were further scanned by the librarian (RM) for relevance. Sixty potentially relevant records were identified from this stage, and a member of the research team (CG) scanned the abstracts, filtering out records that did not satisfy the inclusion and exclusion criteria. From the 60 citations, 13 appeared to meet the inclusion criteria. A copy of the full text was then obtained and evaluated. Finally, four papers met both inclusion and quality criteria.

Sample, Data Extraction and Interpretation

The final sample for the meta-synthesis consisted of 12 qualitative studies published between 1996 and 2006. Table 1 gives details of the methodological characteristics of the papers and provides the context for the interpretations of each study. The selected papers were read repeatedly in order to understand each study. Lists of the original authors’ interpretations, explanations and key concepts were constructed for each paper and were treated as data. Several meetings were held where the authors identified emerging themes. Data extraction stopped when no new themes were emerging. This information was translated into a grid where each column represented a paper and each row the concepts as they applied to the paper. These constructs were then integrated into a line of argument (LOA) synthesis, leading to the generation of a synthesizing argument. The results of the meta-synthesis are summarised in Table 2.

RESULTS

Twelve studies were identified in the literature searches: transvenous internal cardioverter defibrillator (ICD); long-term dialysis; non-invasive oxygen therapy; self-blood glucose monitoring and urine testing; antibiotic intravenous therapy, parenteral nutrition, peritoneal dialysis and oxygen therapy; mechanical ventilation; home ventilation; and colostomy. Analyses of these papers clustered them into five themes: (1) managing multiple uncertainties; (2) the reconstruction of identity; (3) the struggle to remain autonomous while allowing dependence; (4) coming to terms with living a technology-assisted life; and (5) the usability of devices.
<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Discipline</th>
<th>Device</th>
<th>Sample</th>
<th>Data collection</th>
<th>Qualitative research design/analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Burke (1996)</td>
<td>Nursing</td>
<td>Transvenous internal cardioverter defibrillator</td>
<td>New patients (n = 24)</td>
<td>Repeated in-depth interviews</td>
<td>Grounded theory/constant comparative method</td>
</tr>
<tr>
<td>Curtin et al. (2002)</td>
<td>Nursing</td>
<td>Long-term dialysis</td>
<td>Patients (n = 18)</td>
<td>Semi-structured interviews</td>
<td>Descriptive/content analysis</td>
</tr>
<tr>
<td>Ingadottir and Jonsdottir (2006)</td>
<td>Nursing</td>
<td>Non-invasive oxygen therapy</td>
<td>Patients receiving (n = 6)</td>
<td>Interviews with patients and families</td>
<td>Thematic and narrative analysis</td>
</tr>
<tr>
<td>Lawton et al. (2004)</td>
<td>Health services research</td>
<td>Self-blood glucose monitoring and urine testing</td>
<td>Newly diagnosed diabetics (n = 40)</td>
<td>Repeated in-depth interviews</td>
<td>Grounded theory/constant comparative method</td>
</tr>
<tr>
<td>Lehoux (2004)</td>
<td>Sociology</td>
<td>Antibiotic intravenous therapy, parenteral nutrition, peritoneal dialysis and oxygen therapy</td>
<td>Patients (n = 16), carers (n = 6), observations of professionals’ visits (n = 16)</td>
<td>Biographical interviews and observations of nursing visits</td>
<td>Symbolic interactionism</td>
</tr>
<tr>
<td>Lindahl et al. (2003)</td>
<td>Nursing</td>
<td>Mechanical ventilation</td>
<td>Patients (n = 13)</td>
<td>Longitudinal interview</td>
<td>Phenomenological-hermeneutic approach inspired by Ricoeur (1976)</td>
</tr>
<tr>
<td>Lindahl et al. (2006)</td>
<td>Nursing</td>
<td>Home ventilation</td>
<td>Patients (n = 10)</td>
<td>Life world and narrative interview conducted as conversations about everyday life</td>
<td>Phenomenological-hermeneutic approach developed by Lindseth and Norberg (2004)</td>
</tr>
<tr>
<td>Manderson (2005)</td>
<td>Sociology</td>
<td>Colostomy</td>
<td>Patients (n = 34)</td>
<td>Unstructured interviews and written responses to questions where travel is an issue</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Peel et al. (2004)</td>
<td>Health services research</td>
<td>Self-blood glucose monitoring</td>
<td>Patients (n = 40)</td>
<td>Repeated interviews ((\times 2)/constant comparative method)</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>Polaschek (2003)</td>
<td>Nursing</td>
<td>Renal dialysis</td>
<td>Males (n = 6)</td>
<td>Interviews ((\times 3 \text{ per respondent}))</td>
<td>Critical interpretation</td>
</tr>
<tr>
<td>Ring and Danielson</td>
<td>Nursing</td>
<td>Long-term oxygen therapy</td>
<td>Patients (n = 10)</td>
<td>Interviews/van Kaam (1959)</td>
<td>Phenomenology</td>
</tr>
</tbody>
</table>
involved ventilator-dependent patients living at home, and found that although people were grateful for the technology for prolonging their lives, individuals possessed a heightened awareness that it would be ever-present for the rest of their lives (echoing the notion of Polaschek\(^{24}\) of the ‘ongoingness’ of dialysis). The authors observed that participants were conscious of their body’s frailty, living in the constant shadow of death and feeling vulnerable to technological failure, and having to wait for help if it failed. Like the respondents in the paper of Curtin \textit{et al.},\(^{17}\) people coped by ‘striving to live in the present’ and not worrying about the future; just as the respondents in Polaschek’s study\(^{24}\) hoped for a transplant, the people in this study wished that the future would bring technological advances offering a more ‘promising dimension’ to their life.

### TABLE 2. Main results from the meta-synthesis

<table>
<thead>
<tr>
<th>Synthesis of main findings</th>
<th>Line of argument synthesis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Managing multiple uncertainties</strong></td>
<td>Adaptation, accommodation and integration of a technology are an extension of identifying and living life with a chronic condition</td>
</tr>
<tr>
<td>Heightened awareness of health deteriorating</td>
<td></td>
</tr>
<tr>
<td>Continuous feelings of uncertainty about the future</td>
<td></td>
</tr>
<tr>
<td>New vulnerability to technological failure</td>
<td></td>
</tr>
<tr>
<td>Living in hope of technological advances</td>
<td></td>
</tr>
<tr>
<td>Technology imposed a routine that facilitated a sense of control and certainty</td>
<td></td>
</tr>
<tr>
<td><strong>The reconstruction of identity</strong></td>
<td>The integration of a technology or device into the user’s life world can be viewed as an extension of existing ‘illness work’</td>
</tr>
<tr>
<td>Moral imperative to accept a technology</td>
<td></td>
</tr>
<tr>
<td>Process of comprehension as to how technology will impact upon illness identity.</td>
<td></td>
</tr>
<tr>
<td>Technology perceived as a signifier of illness</td>
<td></td>
</tr>
<tr>
<td>Presumption that others will make inaccurate assumptions about the individual.</td>
<td></td>
</tr>
<tr>
<td>Reconstruction of identity that retains a part of pre-illness identity</td>
<td></td>
</tr>
<tr>
<td><strong>The struggle to remain autonomous while allowing dependence</strong></td>
<td></td>
</tr>
<tr>
<td>Technology helped maintain some level of independence</td>
<td></td>
</tr>
<tr>
<td>Devices permitted a greater sense of self-regulation</td>
<td></td>
</tr>
<tr>
<td>Human qualities attached to the technology that aided engagement</td>
<td></td>
</tr>
<tr>
<td>A new autonomy brought dependence on the technology and others</td>
<td></td>
</tr>
<tr>
<td>Changes to relationships with health professionals experienced</td>
<td></td>
</tr>
<tr>
<td>Health professional’s views perceived to dominate</td>
<td></td>
</tr>
<tr>
<td><strong>Coming to terms with living a technology-assisted life</strong></td>
<td></td>
</tr>
<tr>
<td>Integration involved a process of normalization</td>
<td></td>
</tr>
<tr>
<td>New values and norms incorporated following the introduction of a technology</td>
<td></td>
</tr>
<tr>
<td>Balance needed between illness regimen and daily life</td>
<td></td>
</tr>
<tr>
<td>Alterations made to minimize intrusion</td>
<td></td>
</tr>
<tr>
<td><strong>Usability of devices</strong></td>
<td></td>
</tr>
<tr>
<td>Acceptance linked to user competency and user friendliness of the device</td>
<td></td>
</tr>
<tr>
<td>Usability linked to perceived simplicity, convenience and hygiene of the technology</td>
<td></td>
</tr>
</tbody>
</table>
Ring and Danielson’s interviews with patients who were dependent on oxygen therapy revealed similar feelings of uncertainty about the future. Respondents described a constant awareness of an inevitable worsening in their situation, with many expressing anxieties about becoming long-term hospital patients.

Interviews with recipients of recently introduced transvenous ICD implants found a constant awareness of death to be a daily possibility. Although the technology had allowed people to ‘choose life’, like those in the study of Lindahl et al., respondents lived with the uncertainty of the device failing or the possibility that the technology would eventually ‘wear out’. Participants described creating a reliable ‘backup’ by modifying existing resources and support networks to ensure survival for when the ‘inevitable failure’ happened. In addition, participants sought assurances for their long-term survival falling under the remit of technological advancement and being kept informed of any advances that may have a potential impact on their particular situation.

Lehoux’s study of users of four technologies (antibiotic intravenous therapy, parenteral nutrition, peritoneal dialysis, and oxygen therapy) did not make reference to uncertainty in terms of future mortality, but did find uncertainty and increased anxieties related to predicted technological failure. In the case of the intravenous therapy and parenteral nutrition, patients were anxious that their catheter would become dislodged. Wilde found similar anxieties among long-term users of urinary catheters. Peel et al. found that anxiety among diabetics using a self-blood glucose monitoring device (SBGM) was increased if readings were counter-intuitive and participants were unsure about how to respond to these results. Conversely, other participants felt that the readings provided a level of reassurance and reinforcement that they were managing their condition correctly.

The Reconstruction of Identity

Respondents in many studies perceived an imperative to accept home health technologies to allow the continuation of normal activities. However, societal reaction (e.g. stigma) threatened the ability to reconstruct a sense of normalized identity. Manderson conducted interviews with individuals who had stoma surgery and needed to have a colostomy bag fitted permanently; she found that some respondents saw the bag as an intruder. Lindahl et al. found that respondents preferred to receive oxygen through a mask than a tracheotomy, as the latter was perceived to be physically over-intrusive. In other studies, respondents found that the use of or need for a device made the condition more tangible and more visible. Lawton et al. conducted interviews with newly diagnosed diabetics, comparing urine testing and SBGM, and found that SBGM devices were viewed as being more sophisticated. This was interpreted by some respondents as an indicator of the seriousness of their condition.

Ingadottir and Jonsdottir explored patients’ and families’ experience of long-term home treatment with non-invasive ventilation, and observed that respondents wanted to retain the sense of being considered a healthy person and capable of having a normal life in spite of their illness. The loss of control over the body and the visibility of their illness affected their ability to do this. Curtin et al. observed that respondents wanted to be seen as having a ‘self’ separate from their illness, and that they still retained a part of their pre-illness identity that was unchanged by their condition, still valuable and worth preserving. The relative visibility or acceptability of a device, its potential for stigma, embarrassment, shame, and loss of dignity, impacted on identity, and acted as a signifier of illness, marking people out as ‘different’. This prevented the individual from presenting a preferred ‘normalized’ self, because interaction with a health technology textures a person’s selfhood and therefore their presentation of self to others.
To combat the chance of people misconstruing their identity, respondents described strategies that they used to minimize its impact. For example, Wilde and Manderson found that respondents would attempt to keep the device secret, and sought to conceal or disguise it to avoid the social consequences of being discovered. Lindahl et al. observed that people would have their ventilator built into a cupboard so as to make it less visible.

**The Struggle to Remain Autonomous While Allowing Dependence**

In a number of studies, the health technology being used helped individuals to maintain a level of independence that would not have otherwise been possible. However, with this autonomy came dependence on the health technology itself and on others, and many had a sense of gratitude towards it, as it had improved aspects of their quality of life or prolonged life. However, the technology was also viewed as a mixed blessing. Respondents in the study of Curtin et al. described having a ‘love–hate relationship’ with the dialysis machine. The interviewees of Ingadottir and Jonsdottir had difficulty in adjusting to the treatment and found that they had to force themselves to take an optimistic stance, with some doubting its efficacy. Although people felt uncomfortable about being reliant on a health technology, they believed that they were able to accept the advantages that it gave them. Respondents described needing to accept, and adjust to, the fact that they needed it and had to trust it. As one participant from the study of Ingadottir and Jonsdottir said, ‘I wouldn’t be alive if I had not got this treatment’, and so individuals were observed as ‘putting up’ with the technology in order to live. Conversely, Manderson found individuals to be unable to balance the disadvantages with the advantages, and the colostomy bag was always seen as an intruder that had to be constantly surveyed.

Wilde found that the language that respondents used to describe their health technology revealed their ability to integrate and normalize the device into their everyday life. Respondents used metaphors to reflect how they had integrated the use of a catheter into their lives. One respondent called a catheter ‘her necklace’ when taking a bath, which the authors of the paper took to mean that she viewed the device as ‘clean’ and as something positive. Some individuals were described as being able to integrate a particular technology into their lives and bodies so that it was no longer viewed as a foreign object but had become a part of the individual. Lindahl et al. also observed that individuals went through a process of internalization, accepting mechanical ventilation as an extension of their body. Strategies such as the use of humour were described as helping to ‘normalize’ and dilute feelings of shame and embarrassment. Some of the studies found that respondents attached human qualities to the technology as part of a process of engagement, integration and social support. Respondents used descriptors such as ‘protector,’ ‘pet’ or ‘rescuer’, while others described overcoming their negative relationship with their device, accepting their reliance upon it by becoming its ‘friend.’

The need for assistive technology was seen to amplify the importance of social support, particularly having a relationship with a significant other. Certain types of technology where the user needed assistance from others (e.g. in those studies that focused on dialysis, oxygen therapy and stoma) generated a greater need for investing trust in others. As Lindahl et al. observed, this increased the fear of becoming a burden. The introduction of a technology can, in some instances, contradict the internalized idea of the autonomous adult. A respondent in the study of Curtin et al. described dialysis as placing them in a dependent situation where they are constantly re-enacting child-like relationships. Similar references to reverting to a child-like state were evident in
respondents’ accounts in Manderson’s study of the use of a permanent colostomy bag. Dependence on others contradicted notions of adulthood and adult social relations, e.g. in the event of loss of bowel control. Manderson also acknowledged the blurring of role boundaries that can happen when the roles of ‘lover/partner’ and ‘carer’ become conflated. Respondents in the studies of Polaschek, Wilde and Manderson all reported having difficulty in sustaining intimate relationships, although only Manderson’s paper looked at the impact of the technology on sexual relationships in an explicit way.

The enduring nature of chronic conditions, together with the need to use a technology, suggested that relationships with health professionals changed over time. Individuals in some studies reported a perceived lack of involvement in decision-making. Professionals’ views were thought to dominate, and patients did not feel that their preferences were explored, which influenced successful utilization and integration. For example, in Polaschek’s study, the patients felt that the professionals were overly optimistic about the outcome of dialysis, which led individuals to feel misled, so that they in turn altered their regimen without consulting the professional. Some of the respondents of Lawton et al. were suspicious that the provision of urine testing equipment over SGBM was a form of rationing, and in the study of Ingadottir and Jonsdottir, respondents felt that non-invasive oxygen therapy dominated their lives. In contrast to other studies, the respondents of Peel et al. found that diabetic monitoring devices allowed them a new level of independence from health services, as the technology permitted a greater sense of self-regulation.

Coming to Terms with Living a Technology-assisted Life

Burke described the integration of the ICD as touching all aspects of her participants’ lives: their actions, thoughts, and beliefs. As well as having to get used to the sensation of the ICD inside their bodies, respondents employed a combination of other strategies. This included making comparisons of their previous abilities with those that they hoped for in the future. All but two of the respondents sought out others who had an ICD fitted, which allowed them to evaluate their own experiences and abilities against others. Respondents were observed as expanding their own definition of ‘normal’ to incorporate new values and norms. During this process, people resumed valued activities and relationships while discarding others that no longer fitted their new expanded definition of ‘normal’. The idea of returning to ‘normal’ was echoed in the study of Curtin et al., who described the integration of dialysis as a journey of transformation. Respondents worked hard to prevent it becoming the central focus of their lives and to re-establish a sense of balance by making an effort to fit in with ‘normal’ activities. Wilde observed that people covered their urine bags in order to present themselves as ‘normal’.

Respondents described having to find a fit between the use of technology and their lifestyle — finding a balance between the sustained work needed to maintain treatment and their daily life, so as to prevent it from becoming the central focus in their life. The technology needed to be usable and convenient, and in some instances treatment regimens needed to be altered in order to minimize intrusion while maximizing quality of life. If acceptable adaptations to lifestyles could not be made, the technology was viewed as problematic. The length of time taken to manage some technologies was the most difficult element for many to adjust to. The individuals in Polaschek’s study expounded the need for negotiation of the regimen into their weekly schedule, as treatment could last for up to 8h. Although respondents emphasized general compliance with what was required, they also indicated the need to make alterations to minimize intrusion.
For example, without consulting their health professional, some would periodically reduce treatment hours or the frequency of treatment without ill-effect.

Intrusiveness within the home setting also needed to be considered. In a number of studies, adjustments to the way in which people lived in their home were required. For example, in the study of Ingadottir and Jonsdottir, one respondent described having to put the oxygen machine outside the bedroom to minimize noise, while another’s partner slept in a different room for a period to catch up on sleep, due to the noise from the machine. A respondent receiving oxygen therapy in Lehoux’s paper also described the heat and noise generated by the machine when in operation, while the peritoneal dialysis patients spoke of the bedroom resembling a hospital room. However, home was perceived to be the place where patients had the most control over the technology, and additional consideration was needed if it had to be used outside of the home. Travel opportunities became diminished or necessitated careful planning. Social activities were also limited or curtailed due to the cumbersome or visible nature of the technology. Reluctance to venture into the outside world was observed, leading to some becoming socially isolated. For example, individuals who were receiving oxygen therapy did not like to be seen with their nasal tubes, and so did not invite friends over as much and ate out infrequently. A number of respondents in Manderson’s paper spoke about the planning needed if they were venturing outside, which included identifying where the toilets were and making sure that they carried enough supplies with them (i.e. changes of clothes). Once outside, they described their discomfort at the perceived visibility of the bag.

**Usability of Device**

Only three papers considered the notion of usability. Lehoux found that acceptance was closely linked to user competency. Manual dexterity was needed for all four of the technologies examined in the study. Lehoux observed patients having problems if their eyesight was poor, and found that people relied on their memory or made an informed guess if they were unable to read messages on digital screens, due to poor eyesight, limited English, or literacy problems. In addition, she found that older patients felt uncomfortable with computerized components. Peel et al. found that the degree of instruction or the way in which respondents had obtained their device did not impact on individuals’ views of equipment. They did, however, observe a gender difference within their sample, with male respondents responding more positively to the technical sophistication of the SGBM. Lawton et al. found that, when comparing two different monitoring devices that measured glucose levels, usability was linked with perceived simplicity, convenience and hygiene. Respondents found these latter aspects to be better for the SGBM than for urine testing. The perceived level of sophistication of the device (i.e. blood glucose over urine testing) impacted on respondents’ interpretation of the results of tests. A negative result from a urine test resulted in a loss of trust in the device or a belief that they no longer had the condition, whereas a similar result for respondents using the blood glucose testing device was perceived to indicate that they had successfully kept control over their condition. The papers concurred that acceptance of a device was linked to user friendliness.

**LOA SYNTHESIS**

The aim of this synthesis was to develop a LOA, which is developed here by considering each theme and its interpretations, and drawing together the disparate aspects of the lived experience of users of a technology into a unified, more useful whole. An overarching and unifying theme of the review is
that adaptation, accommodation and integration is an extension of identifying and living life with a chronic condition. Technological integration is both transformative of and continuous with this experience. Being diagnosed with a chronic illness involves disruption of the normal life course, changes to self-perception, adaptation to the social world, the redefinition of people’s competence as social actors, and the protection of self-identity from the threat of stigma. Self-management is represented by the mobilization of resources and the maintenance of normal activities and relationships (family, friends and occupations) in the face of an altered situation while responding to the disruption of chronic illness, and (‘coping’) refers to a sense of coherence and preservation of a semblance of normality to the outside world that individuals are able to maintain in the face of their condition. The notion of ‘strategy’ and ‘style’ captures the practical steps taken in order to mobilize resources and minimize problems in everyday life, and denotes the symbolic ways in which people respond to, present and contextualize their illness, both to themselves and others.

Extending Existing Illness Work

The synthesis indicated that the integration of a technology or device into the user’s lifeworld involved adjustment on a range of different dimensions that can be viewed as an extension of existing ‘illness work’. The adaptation to and management of illness has been articulated as various forms of work that are particularly relevant for our focus on patient normalization. Corbin and Strauss identified three types of illness work undertaken by those with chronic illness: illness work (concerned with symptom management); everyday life work (concerned with the practical tasks such as housework, caring, and paid employment); and biographical work (concerned with the reconstruction of the ill person’s biography). The individuals in the included studies, irrespective of the technology, made adjustments to their existing domestic and personal regimens in order to incorporate new tasks into their day. In many cases, integration required an extension of illness identity, and in some cases, a reconstruction of illness identity (biographical work). ‘Biographical disruption’, originally conceptualized by Bury, describes how illness undermines the ‘taken-for-granted’ structures of everyday life associated with the recognition of pain, suffering and, possibly, death. A series of permutations, such as ‘biographical re-enforcement’, ‘biographical continuity’ and more recently ‘biographical flow’ have evolved in documenting alternative experiences of specific groups and conditions. This literature highlights the ways in which people draw upon their social resources in the day-to-day (self) management of illness, and how these might be transposed, integrated or clash with self-management interventions designed to change both attitudes and health behaviours. The synthesis also indicated that the introduction of a technology imposed a new temporality on the individual (an external clock) that must be adhered to, suggesting that a precondition of successful integration is establishing a balance between the demands of the technology, the illness and a range of different life dimensions.

The Personalization of Technology: ‘For Better or Worse — Till Death us Do Part’

Technology in peoples’ lives is extended through a process of personal identification and transformation. Through narrative expression, technology takes on the status of a personified ‘other’ around which a set of personal and relational attributions are constructed. We suggest that this active anthropomorphic and relational re-casting of devices in biographical narratives permits a necessary cognitive closure, bringing a sense of permanency and objectification that deals with the uncertainties and biographical disruption that individuals are faced with. It makes sense of and brings finality into the incorporative process of the intrusion of technology, and deals more permanently
with questions of certainty and reliability of technology after a period of initiation. The anthromorphization of technology represents technology having become a permanent fixture, a taken-for-granted part of everyday life as well as an essential life saving prop.

CONCLUSION

Research on chronic illness and how people experience and manage illness beyond the realms of professional healthcare provides a number of ideas for understanding the workability and integration of technologies. The literature on the experience of chronic illness describes the way in which people adapt, change and develop strategies for managing chronic illness as a naturalistic response to having been diagnosed with a chronic illness. The synthesis of concepts in this review points to the way in which the previous literature acts as a reference point and continuum for what happens to peoples’ management of their condition when new methods designed to change illness behaviour or improve knowledge are introduced. The introduction and process of incorporation of new devices can be viewed as initially disruptive, followed by the renegotiation of a new personal and social equilibrium and re-drawing or modification of existing coping mechanisms, strategies and styles of adjustment.

The review has provided a reference point and guide for identifying what it is relevant to explore further — particularly how people experience, understand and negotiate the transfer of technologies into their homes, and how they view the virtual extension of the medical gaze into their lives. Important, too, is the way in which such technologies become routinely embedded in everyday life-worlds, and our meta-synthesis lends support to exploration of the organization of the work of managing technologies in domestic settings. In this respect, the notions of anthropomorphic and relational re-casting of devices in biographical narratives and continuity with patients’ existing illness work both resonate with notions of workability and integration of new technologies as a means of understanding the likely markers of successful integration in patients’ domestic settings.

REFERENCES


