

Self-Care Technologies in HCI: Trends, Tensions, and Opportunities

FRANCISCO NUNES, Vienna University of Technology

NERVO VERDEZOTO, Aarhus University

GERALDINE FITZPATRICK, Vienna University of Technology

MORTEN KYNG, Aarhus University and The Alexandra Institute

ERIK GRÖNVALL, IT University of Copenhagen

CRISTIANO STORNI, University of Limerick

Many studies show that self-care technologies can support patients with chronic conditions and their carers in understanding the ill body and increasing control of their condition. However, many of these studies have largely privileged a medical perspective and thus overlooked how patients and carers integrate self-care into their daily lives and mediate their conditions through technology. In this review, we focus on how patients and carers use and experience self-care technology through a Human-Computer Interaction (HCI) lens. We analyse studies of self-care published in key HCI journals and conferences using the Grounded Theory Literature Review (GTLR) method and identify research trends and design tensions. We then draw out opportunities for advancing HCI research in self-care, namely, focusing further on patients' everyday life experience, considering existing collaborations in self-care, and increasing the influence on medical research and practice around self-care technology.

CCS Concepts: • **Applied computing** → **Consumer health**; • **Human-centered computing** → **Interaction design process and methods**; **HCI theory, concepts and models**;

Additional Key Words and Phrases: Chronic conditions, chronic diseases, home monitoring, home care, pervasive health, self-care, self-care design, self-care technology, self-management, telecare, telehealth, literature review

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1. INTRODUCTION

Current generations enjoy living longer lives than ever before due to advancements in medicine, technology, and social structures that occurred in the last decades. Although

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Authors' addresses: F. Nunes (corresponding author) and G. Fitzpatrick, Institute for Design and Assessment of Technology, Vienna University of Technology (TU Wien), Argentinierstrasse 8, 2. Stock, 1040 Vienna, Austria; email: francisco.nunes@igw.tuwien.ac.at; N. Verdezoto, Department of Computer Science, Aarhus University, Aabogade 34 D, 8200 Aarhus N, Denmark; M. Kyng, Department of Computer Science, Aarhus University and The Alexandra Institute, Aabogade 34 D, 8200 Aarhus N, Denmark; E. Grönvall, IT University of Copenhagen, Rued Langgaards Vej 7, 2300 Copenhagen S, Denmark; C. Storni, Interaction Design Centre, Computer Science Building CS2-032, Department of Computer Science and Information Systems, University of Limerick, Limerick, Ireland.

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the increase in life expectancy is a great achievement of our time, it is also related to a greater prevalence of chronic conditions [Ben-Shlomo and Kuh 2002; IHME 2013]. A chronic condition, or chronic disease, is a long-lasting disorder that, although maybe controllable with care interventions, cannot be cured. Thus, the goal of chronic disease care is to promote independence and quality of life for as long as possible [Holman and Lorig 2000]. Chronic conditions are likely to affect the lives of patients¹ [Wagner et al. 2001], challenging them to deal with symptoms, face some sort of disability, deal with the emotional impact, cope with complex medication schemes, perform radical lifestyle changes, and obtain useful medical advice from clinicians. These elements of living with a chronic condition largely require patients to manage their disease by themselves—through self-care. Self-care refers to the ability of individuals to manage symptoms, treatment, emotions, and lifestyle changes as part of living with a chronic condition [Barlow et al. 2002]. The goal of self-care is not to learn facts about a condition but to influence its course through practical everyday actions, maintaining a satisfactory quality of life for as long as possible [Clark et al. 1991; Barlow et al. 2002]. But, self-care does not imply that patients manage their conditions in isolation, as they are likely to collaborate with informal carers in their day-to-day self-care activities. Clinicians are also likely to collaborate with patients' self-care by, for example, providing advice during consultations.

In addition, technology can greatly support patients in their self-care management. A common self-care device is, for instance, the blood glucose meter that enables people with diabetes to monitor their glucose level and thus potentially control their condition. Self-care technologies are not restricted to medical devices and can materialise as online communities for discussion of issues related to living with a condition [Mo and Coulson 2010], web applications for obtaining feedback from clinicians [Mamykina et al. 2008], or smartphone applications for monitoring disease symptoms [Bardram et al. 2013]. Despite this widespread interest in self-care technology, no review in HCI has focused on the use of self-care technologies for chronic disease management.

Previous work in medical informatics has reviewed technology for chronic condition management (e.g., Paré et al. [2007] and El-Gayar et al. [2013]). These reviews provided an understanding of the existing technological solutions in medical informatics, together with an analysis of their health impact. In many cases, though, the reviews disregarded the evaluation of technologies from the perspective of the everyday life of patients [Koch 2006]. In HCI, reviews are not very common, but some prior work has reviewed technology for chronic conditions (e.g., Tentori et al. [2012] and Kientz et al. [2013]), taking a different perspective than the ones from medical informatics. In these reviews, the main goal was to describe the functionalities and interaction patterns promoted by the technology. In Computer-Supported Cooperative Work (CSCW) literature, Fitzpatrick and Ellingsen [2013] conducted a large review of healthcare research articles, pointing to the growth in self-care technologies, and argued for the need to further research in the area.

On the anniversary of 30 years of the CHI (Human Factors in Computing Systems) conference (1983–2013), we reviewed HCI research on technologies for self-care, as documented in its key journals and conferences. We focused on papers that discuss the use of technology, targeted at chronic care, for patients and informal carers. And we followed the Grounded Theory Literature Review (GTLR) method [Wolfswinkel et al. 2013] to map the landscape and identify directions for future research. The

¹In this article, we define patients as people that have at least one chronic condition. We recognise that having the chronic condition does not define a person. Being a patient is just one of the many roles (mother, teacher, etc.) a person with a chronic condition encounters in her or his everyday life. However, for clarity, we use the word patient in the text.

technologies that appear in the review are organised according to the categories that emerged from the analysis of the identified papers, namely opportunities explored, the technical systems employed, the different configurations of users and roles supported, and methods used as part of their research.

In addition, six tensions emerged from the analysis, namely: six tensions emerged, namely: autonomy, appropriation, choosing strategy, choosing devices, game-based approaches, and visualising chronic condition data. These tensions foreground critical issues of designing for the self-care setting and are presented as a tool “to think with,” especially useful for young practitioners. Based on the insights from the review, we suggest key opportunities to advance HCI research in self-care technologies, namely, focus further on patients’ everyday life experience, consider the existing collaborations in self-care, and increase the impact of more medical self-care technology.

The aim of this review is not to show a complete² picture of the work done on self-care technologies but to complement the existing body of work. As the number of patients using self-care technologies is growing, it becomes increasingly relevant to study how technologies shape the ways they manage their conditions. With this in mind, we focused on HCI studies that discuss the influence and role of technology in managing chronic care. Our work should be useful for researchers, designers, and practitioners who are involved in the conceptualisation, design, and evaluation of self-care technologies by providing them with an overview of the related work in HCI, implications for design, and current challenges. This review represents an additional step towards achieving a more complete picture of research in self-care technologies. As reviews from medical informatics and HCI are becoming available, future work may move towards a more complete meta-review spanning work in the different areas.

In the following sections, we provide details of the methodology of the review (Section 2) and an overview of the papers included in the review (Section 3). Then, we describe trends identified in the reviewed papers (Section 4) and present a number of design tensions to consider in the design of self-care technology (Section 5). We discuss and reflect on the overall methodological approach and conclude by presenting a set of unexplored opportunities for future work (Section 6).

2. METHODS

Our review followed the GTLR method [Wolfswinkel et al. 2013]. This method adopts a Grounded Theory [Glaser and Strauss 1967] approach to add rigour to the process of searching, selecting, and analysing studies in a review. GTLR uses the content from the papers as empirical material that is coded and constantly compared, thus grounding the insights of the review. This method is composed of five orienting stages, namely, (i) defining the scope of the review (inclusion and exclusion criteria, sources of information, search terms); (ii) search for the potential papers; (iii) selection of the papers for the review (filtering, refine sample based on title and abstract); (iv) in-depth analysis of the papers (through different coding levels); and (v) present the emerging categories from the papers. This method is not “prescriptive,” but rather informative, providing suggestions on how to conduct the different phases of a review to ensure it is grounded in the selected papers.

In this section, we describe the setup of our literature review, specifically the focus, index databases and search keywords used, the filtering and selection process, and the analysis process. We also position our own stance towards self-care technologies and our epistemological stance.

²Obtaining a complete picture is never possible with a review, as choices always constrain and direct the research in specific ways [Wolfswinkel et al. 2013].

2.1. Focus of the Review

We defined the focus of the review as the literature that discussed the use of a specific technology, targeted at the care of chronic conditions, by patients and informal carers. This focus enabled us to concentrate on how technologies are used for self-care, but also meant that a number of potentially related studies were deemed out of scope. In this regard, we make three notes.

First, the review was concerned with the *use of technology* in self-care practices. This excluded a number of papers that would otherwise be featured in the review, such as those contextualising the design space of caring for a chronic condition (e.g., Barnes et al. [2013]), those suggesting design concepts without evaluating them (e.g., Lee et al. [2010]), and those describing algorithms or software architectures to solve specific self-care problems (e.g., Schaeffer-Filho et al. [2009]). These types of studies are very relevant, but they were not about technology in use and, therefore, were excluded from the review. By drawing on the insights from the use of technology, we hope to uncover experienced-based design opportunities, tensions, and consequences.

Second, the focus was on the self-care of *chronic conditions*. This excluded self-management technologies focusing on ageing in place (e.g., Grönvall and Verdezoto [2013b]), wellness (e.g., Grimes et al. [2010]), or quantifying habits for health (e.g., Consolvo et al. [2008]). Therapy was only included if it was performed in the context of living with a chronic condition, but not when it was focused on recovering functionality (e.g., as in poststroke rehabilitation [Balaam et al. 2011]). By keeping the focus on chronic conditions, the motivation for using the technology was to perform care, and not pursuing personal interest, leisure, general well-being, or recovery of function, which would likely bring different principles for design and use.

Third, the focus was on *self-care*, active role of patients living with chronic conditions and their (potential) informal carers. This excluded a number of technologies for clinical settings in which patients have a (more) passive role (e.g., Bardram et al. [2005]). Excluding these studies enabled us to focus on the lived experience rather than the medical view of self-care.

2.2. Sources of Information—Index Databases

The papers in the review were collated in October 2013, primarily using the HCI Bibliography search engine.³ HCI Bibliography was selected for its broad coverage of literature in HCI, including the key conferences and journals, according to the Microsoft Academic Ranking.⁴ This includes, for example, CHI, CSCW, Ubicomp, and ECSCW conferences,⁵ as well as IJHCS, TOCHI, JCSCW journals.⁶ The IEEE Xplore⁷ was also used for accessing the Pervasive Health conference proceedings. The Pervasive Health proceedings were included due to its specific focus on technologies for health-care, including technologies for chronic care, and because of its close relationship to HCI/technology design concerns as indicated by the number of HCI/CSCW researchers who also publish in this venue and its IEEE affiliation (the first edition was also sponsored by ACM/SIGCHI). Not including this conference would provide a narrower view

³HCI Bibliography is a search engine for publications in the area of Human-Computer Interaction and related fields. The service is available at <http://hcbib.org>.

⁴Microsoft Academic top conferences and journals: <http://academic.research.microsoft.com/RankList?entitytype=4&topDomainID=2&subDomainID=12> and <http://academic.research.microsoft.com/RankList?entitytype=3&topDomainID=2&subDomainID=12>.

⁵Refer to footnote 17 for the meaning of the different conference acronyms.

⁶Complete journal names: IJHCS—*International Journal of Human-Computer Studies*; TOCHI—*ACM Transactions on Computer-Human Interaction*; JCSCW—*Computer Supported Cooperative Work*.

⁷IEEE Xplore is a search engine for publications of the IEEE association. The service is available at <http://ieeexplore.ieee.org/>.

Table I. Number of Papers Retrieved with the Different Keywords
Total 1,022 entries, reduced to 795 after removing duplications (see Table II).

chronic disease management	37	self-care	28	telehealth	31
home care	296	self-manage*	68	telecare	31
home monitoring	226	self-monitor*	47	telemonitoring	8
patient-cent*	27	self-reflection	30	pervasive health ¹¹	193

Table II. Papers in the Search Set, Preselection, and Fitting the Selection Criteria

	HCI bibliography	Pervasive healthcare	Total
Search set (unique and filtered)	638	157	795
Included for preselection	64	20	84
Fitting the selection criteria	25	4	29

of the research that is done in the HCI community. We had also considered including other conferences or journals (e.g., ICHI,⁸ JAMIA⁹), and other index databases (e.g., PubMed). However, for this review, we wanted to keep the focus on how the HCI community is engaging with the theme of self-care technologies.¹⁰

The earlier-mentioned sources returned results based on title and abstract search.

2.3. Search Terms

Through multiple sessions among the authors, who have all worked with healthcare IT for years, we selected 12 keywords (see Table I) that we considered most relevant to identify papers of interest, based on studies we were familiar with. As our set of keywords evolved, we made sure they followed three main criteria. The first one was to ensure that both recent (e.g., self-care) and older studies (e.g., home care) were included by using keywords that were popular in different periods. The second was that more medically oriented work would also be included (e.g., using the terminology of “patient” in patient-cent*). And the third was that more technically oriented work would be accounted for (e.g., pervasive health*). Some of the keywords include an asterisk to obtain all possible results that start with a specific search keyword entered (e.g., self-manage*, self-manage, self-management). The search results were transformed to a spreadsheet for analysis. Using the current keywords and the earlier-mentioned index databases, we obtained papers in different areas of self-care that capture a range of conditions (see Table VI).

2.4. Selection Criteria

Each entry in the spreadsheet included the title, abstract, DOI or URL, publication year, publication venue, and keywords that retrieved it. Using this information, the first two authors preselected the papers to be considered for the review¹² (see Table II).

The first step was to clean the dataset. In this process, we removed entries concerning workshop, panel, or talk abstracts, as well as proceedings index and title pages that only contained keywords and outlines. We also joined repeated entries of the same

⁸ICHI stands for the IEEE International Conference on Healthcare Informatics.

⁹JAMIA stands for the *Journal of the American Medical Informatics Association*.

¹⁰We recognise that many HCI researchers are increasingly choosing to publish in both HCI and medical informatics forums, which we applaud but scope the review here to the HCI venues.

¹¹The keyword *pervasive health* was only searched in HCI Bibliography database, as it would be too present in papers of Pervasive Health conference.

¹²In the auxiliary materials of this article, the reader can find a spreadsheet with the papers that were collated, preselected for reading, and selected to be part of the review.

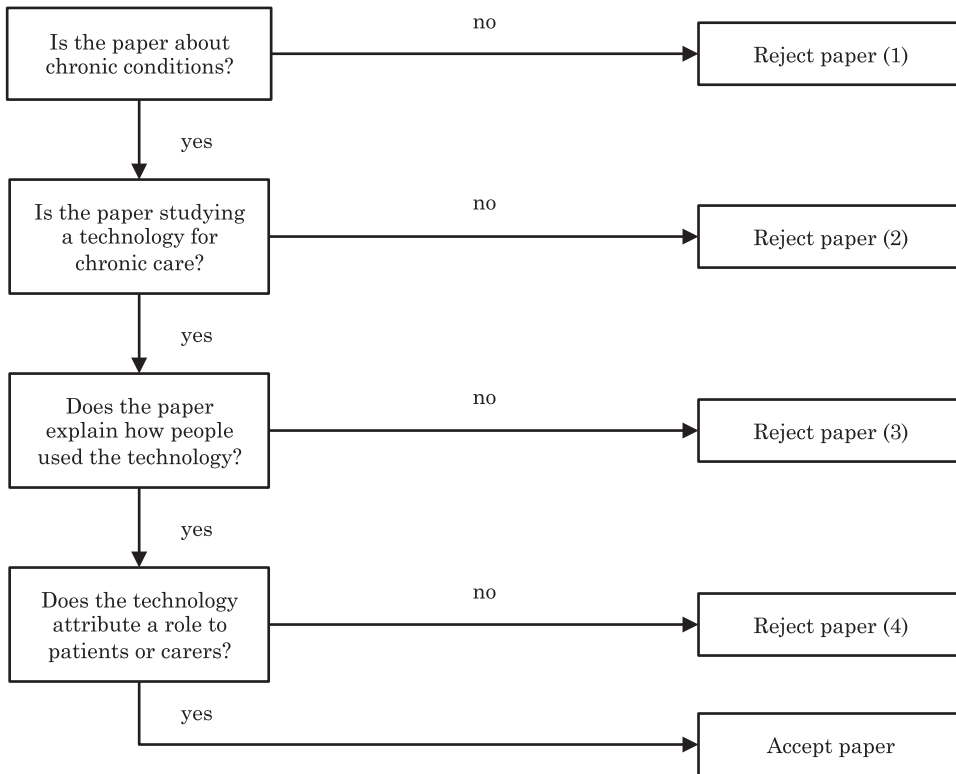


Fig. 1. Rules for screening search results.

article obtained using different search keywords, which reduced the number of entries from 1,022 to 795 unique paper entries.

The next step was to decide whether the article would be included in the preselection list. This was done by each of the two researchers (as mentioned earlier) independently working through the list, using the set of rules illustrated in Figure 1. Specifically, the two reviewers gave each paper their decision, and where the decision was to exclude, they also annotated the entry with at least one reason for excluding the paper from the initial selection. In case of doubt, the researcher skimmed (or read) the paper to support their individual decision and even consulted a general practitioner to obtain information about the specific conditions mentioned in the papers. Following the individual classification of the papers, the researchers combined their considerations, discussed each paper in turn, and agreed on the final decision to include or exclude papers from the preselection list.

In summary, 795 unique paper entries were analysed for inclusion in the preselection review pool¹³ (see Table II). From this set, 84 papers were selected that appeared to fulfil the selection criteria of the review. These were carefully read and analysed. In this process, several papers were excluded because they did not fit the selection criteria. In the end, the final review list was composed of 29 papers.

The GTLR method suggests also that the references from the papers could be followed; however, this fell outside of the scope of the review as previously mentioned.

¹³Refer to footnote 12.

2.5. Analysis

The set of papers in the final review were read again by the first and second authors and iteratively coded for themes. As new papers were added, new codes were created, renamed, removed, or rearranged to match the categories suggested by all studies included until that moment. Papers were read multiple times in order to ensure newer codes included all studies in the review. Comparative analysis was a driving principle in our analysis, forcing us to categorise the different studies, and leading us to reflect on what the data was telling us. Parallel to coding, memos were also written. The coding process was supported by Scrivener¹⁴ and was performed individually by the first two authors. The coding trees were joined at different moments to increase the range of the coding of the analysis. As themes became clearer, they were iteratively discussed among all the authors of the paper. The analysis was only complete as the final version of this article was ready for submission, since themes were further refined in the writing.

2.6. Positioning towards Self-Care Technologies

Our positioning towards self-care technologies is not neutral. All the authors have been working with self-care technologies and believe that technology can, in some way, and in some situations, improve the care and management of chronic conditions. The reason why we engaged in this review was the belief that the different studies have dealt with common issues and challenges and that an overview can be beneficial for designers, practitioners, and researchers working with self-care technology.

2.7. Epistemological Stance

We approach this review from a constructivist perspective. The selection criteria were drafted in the beginning, and iterated as the review process advanced. For example, self-care technology concepts informed by patients (e.g., Blondon and Klasnja [2013]) seemed adequate to include in the early stages of the review. However, these were later excluded because, without observing real use, these studies could only speculate rather than report on actual technology use in real situations.

Undoubtedly, the papers in the review grounded our analysis. However, further literature, previous research experience, and personal contact with patients were also important in sensitising us to important problems, helping us make sense of the issues across the diverse studies.

Last, we recognise that the papers are a subset of the self-care literature and that they cannot be used to make general claims about the complete literature of self-care technologies. However, the analysis of the different cases contributes to an informed account of self-care technologies from an HCI perspective that might sensitise or inform the readers to relevant issues in the area related to their work and also inform subsequent literature reviews across different disciplines.

3. CHARACTERISING THE PAPERS OF THE REVIEW

The final pool of papers in the review is composed of 29 studies (see an overview in Table IX). Although the initial list of collated papers covered more than 30 years of research (since 1981), the earliest article included in the review was published in 2006¹⁵ [Mamykina et al. 2006]. This initial paper was influential in seven subsequent studies present in the review.¹⁶ Since 2006, the HCI community has been publishing actively

¹⁴Scrivener is a writing software, available at <http://www.literatureandlatte.com/scrivener.php>.

¹⁵Further details on papers published before 2006 appear in Section 3.3.

¹⁶The influence of the paper (Mamykina et al. [2006]) was also manifest to other studies. Google Scholar, for example, reports 81 citations for the paper on December 14, 2013.

Table III. Keyword Frequency in the Papers of the Review

self-care	11	pervasive health*	7	self-reflection	0
home care	9	self-monitor*	4	patient-cent*	0
self-manage*	8	home monitoring	4	telehealth	0
chronic disease management	7	telemonitoring	1	telecare	0

Table IV. Papers in the Review by Conference and Year of Publication

	2006	2007	2008	2009	2010	2011	2012	2013	Total
AH	—	—	—	—	—	—	—	1	1
CHB	—	1	—	—	1	—	—	—	2
CHI	1	—	1	—	2	—	1	1	6
DIS	—	—	—	—	2	—	—	—	2
ECSCW	—	—	—	1	—	—	—	—	1
HCII	—	—	—	1	—	—	—	1	2
ICCHP	—	—	1	—	—	—	—	—	1
IJHCI	—	—	—	—	1	—	—	—	1
MOBHCI	—	—	1	—	—	—	—	—	1
PHEALTH	—	—	—	—	2	1	—	1	4
PNJ	—	—	—	—	—	1	—	—	1
PT	—	—	—	—	—	—	1	—	1
UBICOMP	—	—	—	—	1	—	—	3	4
UMUAI	—	—	—	—	—	1	—	—	1
VINCI	—	—	—	—	—	1	—	—	1
Total	1	1	3	2	9	4	2	7	29

on self-care technologies every year, although at different paces. The year represented with most publications in the final pool of papers is 2010, with nine, 2013 comes next with seven, but in 2012, there were only two papers. It was also curious to see that the use of self-care technologies in HCI becomes prominent only in 2006, especially considering the amount of research that has been conducted in healthcare scenarios, dating back to 1988 (e.g., Engestrom et al. [1988], see Fitzpatrick and Ellingsen [2013]).

The search keywords, shown in Table III, yielded varying results. The most common keywords were self-care with 11 appearances, home care with nine, and self-manage* with eight. There were also keywords that did not capture any paper in the final list of papers for the review, such as self-reflection, patient-cent*, telehealth, and telecare.

The papers are published in a number of different venues (see Table IV).¹⁷ In total, there are 24 conference publications and five journal contributions. The most common venue for publication was CHI with six papers, followed by UbiComp and Pervasive Health with four each. The remaining conferences and journals provided one or two studies. There are also some unexpected absences. For example, the CSCW community represented by JCSCW, CSCW, ECSCW, and GROUP has only one paper in the review (at ECSCW). This absence is probably explained by our selection criteria, which requires a specific technology to be used by patients or informal caregivers.

¹⁷Complete conference names: AH—Augmented Human International Conference; CHB—*Computers in Human Behaviour* (journal); CHI—ACM Conference on Human Factors in Computing Systems; DIS—ACM Conference on Designing Interactive Systems; ECSCW—European Conference on Computer-Supported Cooperative Work; HCII—International Conference on Human-Computer Interaction (includes Universal Access in HCI); ICCHP—International Conference on Computers Helping People with Special Needs; IJHCI—*International Journal of Human-Computer Interaction*; MOBHCI—International Conference on Human-Computer Interaction with Mobile Devices and Services; PHEALTH—International Conference on Pervasive Computing Technologies for Healthcare; PNJ—*PsychNology Journal*; PT—International Conference on Persuasive Technology; UBICOMP—ACM International Joint Conference on Pervasive and Ubiquitous Computing (includes Pervasive); UMUAI—*User Modeling and User-Adapted Interaction* (journal); VINCI—International Symposium on Visual Information Communication and Interaction.

Table V. Location of the Studies from the Review Papers (in Which a Single Country Could Be Identified)

Denmark	7	UK	2	India	1
USA	7	Austria	1	Netherlands	1
Japan	2	Germany	1	Switzerland	1

Table VI. Papers by Chronic Condition and Year of Publication

	2006	2007	2008	2009	2010	2011	2012	2013	Total
AIDS/HIV	—	—	—	—	1	—	—	—	1
Asthma	—	—	—	—	1	—	—	1	2
Bipolar disease	—	—	—	—	—	—	—	2	2
Cerebral palsy	—	—	—	—	—	—	—	1	1
CKD	—	—	—	—	1	1	—	—	2
COPD	—	—	—	—	—	1	—	1	2
Dementia	—	—	—	1	—	—	—	—	1
Diabetes	1	—	3	1	6	1	2	—	14
Fibromyalgia	—	—	—	—	—	1	—	—	1
Heart disease	—	—	—	—	1	—	—	2	3
Unipolar depression	—	1	—	—	—	—	—	—	1
Total	1	1	3	2	10	4	2	8	30 ¹⁹

It is also interesting to analyse the locations in which the studies took place. For this analysis, we considered the papers in which the location of the study was explicit and restricted to one country. Denmark and the United States are the countries with most conducted studies (seven) (see Table V). The other countries only present one or two studies. Looking through an even more general perspective, Europe is the continent with the most studies (13), America comes next with seven, then Asia with three, and Africa and Oceania have no paper represented in the review.

3.1. Chronic Conditions Approached

The papers in this review cover a broad set of chronic conditions (see Table VI). Diabetes is the condition that appears most (14 studies),¹⁸ while the other conditions are covered by one or two articles. We can also observe that diabetes has been a research interest since the beginning and that, in recent years, the conditions investigated have become more diverse.

Most conditions appearing in the review are considered “Major and Chronic Diseases” [Commission 2013], impacting at least 50 per 100,000 people in the European Union. The two conditions that are not included in this group are HIV/AIDS and cerebral palsy. HIV/AIDS has been excluded from the European Commission report because it is a communicable disease, but since it has no cure, it can thus be considered a (prevalent) chronic condition [WHO 2008]. Cerebral palsy also did not fit the Commission’s definition of chronic condition, but because it is a noncurable long-term disability affecting 2 in 1,000 births [Johnson 2002], it is considered, by our definition, a chronic condition. More important than the numbers is the impact that these diseases can have on the life of patients. For instance, inhibiting specific activities or forcing self-care tasks in patients’ everyday lives was commonly mentioned in the studies.

¹⁸It is curious that diabetes is so well represented in the review. This could be attributed to the pervasiveness of the disease, burden for patients and healthcare systems, influence of patient associations, the key role of self-care in the disease management, or even because these patients already use technologies such as the glucose meter. Either way, such prevalence seems to show a well-researched area.

¹⁹Some papers in the review refer to more than one chronic condition. Therefore, the total number of papers is greater than 29.

Table VII. Three Main Motivations Described in the Papers of the Review

Self-care is difficult to manage	Technology is the way to reduce costs	Explore technology and better understand self-care
[Mamykina et al. 2008; Yasuda et al. 2009; Glasemann et al. 2010; Mamykina et al. 2010; Mo and Coulson 2010; Nachman et al. 2010; O'Murchu and Sigfridsson 2010; Storni 2010; Camerini et al. 2011; Sota et al. 2011; Storni 2011; Taylor et al. 2011; Toscos et al. 2012; Bardram et al. 2013; Gldenpfennig and Fitzpatrick 2013; Kusk et al. 2013; Spina et al. 2013]	[Aarhus et al. 2009; Aarhus and Ballegaard 2010; Mamykina et al. 2006; Chatterjee et al. 2012]	[Farzanfar et al. 2007; Pinsker et al. 2008; Preuvneers and Berbers 2008; Kilbourn 2010; Yun et al. 2010; Craven et al. 2013; Grnvall and Verdezoto 2013a; Frost et al. 2013]
Underlying assumption: technology can play a key role in self-care.		

3.2. Perspective

As the papers in the review take different perspectives, we analysed how the papers define self-care and describe their motivation, methodological approaches, and theoretical framing.

3.2.1. Definitions of Self-Care. All of the papers say they are concerned with self-care technologies, but they rarely define what they mean by “self-care.” It is as if the term was common sense and shared among all. There are some exceptions though. Some papers point to general characteristics of self-care, such as being difficult to achieve [Chatterjee et al. 2012] or requiring support [Camerini et al. 2011]. Others mention that self-care has a practical nature that requires patients to take care of their health [Storni 2010] by observing signs, managing symptoms, and performing lifestyle decisions [Mamykina et al. 2006; Aarhus et al. 2009] to avoid further problems [Glasemann et al. 2010]. Only in one paper is an attempt made to formally define self-care; Aarhus and Ballegaard define self-care as “the tasks a person has been requested to do outside a clinical setting by healthcare providers” [Aarhus and Ballegaard 2010]. However, this definition does not fit all studies in the review because it expects clinicians²⁰ to request patients to perform care tasks.²¹ A broader definition that seems to cover all studies in the review²² is given by Barlow et al. [2002] who point to the ability to manage symptoms, treatment, emotions, and lifestyle changes as part of living with a chronic condition.

3.2.2. Motivation of the Studies. Authors position their papers according to varied motivations, but all of them recognise that technology can play a key role in the care of patients with chronic conditions. The different motivations tend to situate themselves according to at least one of the following three viewpoints (see Table VII).

- (1) Technology can help in the self-management of a chronic condition that is especially difficult to manage due to its characteristics and treatment (17 studies).

²⁰In this article, we use the word *clinicians* to refer to the whole team that is concerned with providing care to the patient including doctors, nurses, and other medical staff.

²¹In many cases, patients will be interested to explore their bodies, in ways that are not useful for their clinicians. As an example, we can refer to the patient that wanted to measure the effect of traveling by car in her blood glucose level (see Storni [2011]). While this information was not useful for the clinician to adjust treatment at the consultation, it was very handy for the person that lives with diabetes, and it aims to control the glucose level on an everyday basis.

²²We are aware that some authors define self-care more broadly, including healthy people performing activities to prevent health issues. In this article, however, these definitions are out of scope, due to our focus on self-care technologies for chronic care patients.

Table VIII. Design Approaches the Review Papers State They Adhere To

User-Centred Design	[Mamykina et al. 2008; Bardram et al. 2013; Frost et al. 2013; Guldenpfennig and Fitzpatrick 2013]
Participatory Design	[Glasemann et al. 2010; Kusk et al. 2013]
Ethnographically Inspired	[Mamykina et al. 2006, 2008; Aarhus and Ballegaard 2010; Kilbourn 2010; Storni 2010, 2011; Grönvall and Verdezoto 2013a]

- (2) Chronic conditions represent a large cost for healthcare systems, and these may be reduced through the introduction of technology (four studies).
- (3) Introducing technology is seen as an opportunity to explore technology and understand self-care (eight studies).

3.2.3. Methodological Approach and Theoretical Framing. In general, the papers in the review do not make explicit their methodological approach or theoretical framing.

For example, although a number of different papers are about designing technology, only four make explicit that they used User-Centered Design, and two others that they employed a Participatory Design approach (see Table VIII). The remaining papers do not explain whether they adopted a particular methodological approach in their design process. Regarding specific parts of their work, seven papers describe their work as ethnography or ethnography-inspired work, but most do not do so.

The theoretical framing is also mostly missing in the papers of the review. For example, the epistemological framing is not made explicit in any study of the review, even though most papers seem to align with interpretivist or constructivist perspectives. The same applies to theories of behaviour change. While most studies encouraged some sort of behaviour change, only five articles included the expression “behaviour change” in the text (ADMS, CHAP, Jog Falls, PersuasiveSens, MAHI-1). From this small set, only Jog Falls and PersuasiveSens explicitly stated that they adhered to Fogg’s persuasive technology framework [Fogg 1998, 2009]. On the contrary, MAHI-1 took an alternative approach to behaviour change, by adhering to the sense making framework [Weick et al. 2005]. The remaining studies did not make any explicit attempt to describe their theoretical framing of behaviour change.

3.3. Literature before 2006

The timeline of the selected papers in the review was somehow surprising. While the first HCI study concerning health dates back to the early 80s, the first paper to fulfil the selection criteria was published in 2006. The year of 2006 appears as an important year (see Figure 2). The number of retrieved papers in 2006 doubled the ones from 2005 and continued growing in the following years. While our keywords became more common after 2005, it does not explain why none of the 90 papers retrieved between 1981 and 2005, according to the selection criteria, did not make it into the final set of papers. To understand this gap, we returned back to the initial list of papers and reflected on our analysis.

The 90 papers retrieved before 2006 were excluded for different reasons that fell into five groups. The first group consists of a large number of papers (i.e., 31) that were excluded because they targeted a *different topic*. Although captured by our search keywords, the papers represented a different kind/domain of studies, such as education, that was not relevant for our review (e.g., Cothran et al. [2001]).

A different group of papers was excluded because they only targeted *care in clinical or institutionalised settings* (i.e., 29). This literature documented, for example, the interactions between clinicians (e.g., Fitzpatrick et al. [1998]), or more technical

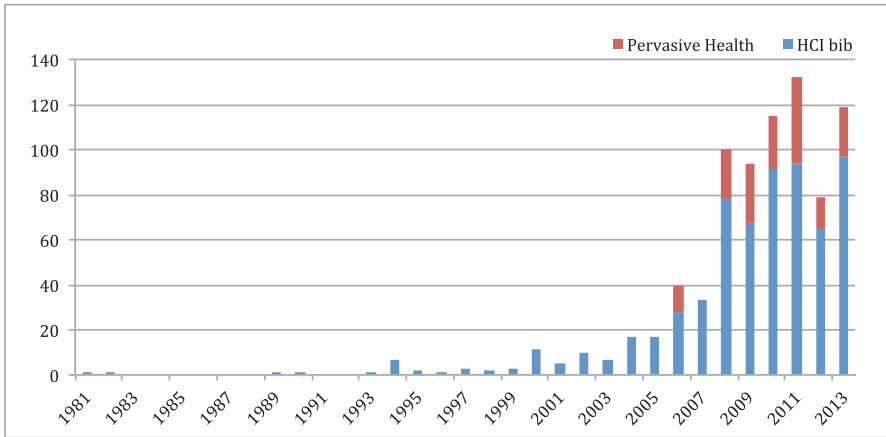


Fig. 2. Retrieved papers by year from the total search dataset (n = 795).

contributions such as the usability of leaflets in general (e.g., Morrow et al. [2003]), or the accuracy of medical devices (e.g., Surabattula et al. [2005]).

Another group of excluded papers focused on *older adults and ageing in place* (i.e., 14 papers). Probably some of the participants of the studies had chronic conditions. However, the technologies used did not focus on helping patients manage their chronic conditions, but rather support daily living activities (e.g., Blythe et al. [2005]).

Some technological support for patients was also excluded because they were *not meant for chronic care* (i.e., six papers). Among these papers, the focus was on acute conditions or in the area of detection/prevention of health issues (e.g., Riley et al. [2005]).

The last group of papers excluded from the review was related with technology that was *not used by patients* (i.e., 10 papers). These papers included theoretical accounts on self-care technologies, methodological contributions, or concepts for novel technologies (e.g., de Haan et al. [2005]).

4. TRENDS IN DESIGNING TECHNOLOGIES FOR SELF-CARE

Based on the initial characterisation of the analysed papers, we outline the main trends emerging from our analysis. First, we describe the technology-enabled opportunities that have been documented in the papers of the review. Then, we elaborate on the configurations that have been promoted by the technologies, and finally look at methods that have been used in the research.

4.1. Opportunities Created by Self-Care Technologies in the Review

Self-care technologies in the review provided numerous opportunities to patients, carers, and clinicians. In particular, five (nonexclusive) categories emerged from our analysis, namely, (i) fostering reflection by making health and contextual information available, (ii) suggesting care activities or treatment adjustments, (iii) sharing care activities with informal carers, (iv) enhancing the collaboration with the care team, and (v) sharing self-care activities and learning from others with the same chronic condition. These opportunities are described in the next sections together with examples of technologies that promoted them. The different technologies are referred after their system or project names (see the first column in Table IX).

Table IX. Overview of the 29 Papers Included in the Review, Ordered by Name of the System (Asterisk on the Ones We Named)

Name	Study	Condition	Type of study	d	#	Technology
ADMS	Toscos et al. [2012]	Diabetes T1	Interviews with seven families using self-monitoring technology. A 12-month RCT was held with 48 families (24 in intervention, 24 with normal treatment) measuring glycemic control four times. Semistructured interviews and questionnaires were conducted at 6-month intervals.	365	48	Children use blood glucose meter that sends measurements to the web and can be checked by their parents.
AssistingInsulin*	Preuveneers and Berbers [2008]	Diabetes T1	The system was piloted with 26 participants (11 with diabetes) who measured blood glucose four times a day for three weeks.	21	26	Patients use a smartphone app that recommends insulin dosages based on predictions of the user's activity.
AsthmaProbes*	Yun et al. [2010]	Asthma	The probes were piloted for 4 to 6 weeks in three families. Interviews and questionnaires were held pre-/postintervention.	42	6	Patients and caregivers use the Salut! system, desktop widget, peak flow meter, and indoor air quality sensor.
BoundaryWork*	Aarhus and Ballegaard [2010]	Diabetes or cardiovascular	4 years of participation in different projects, doing observation, interviews, and short tours in 50 homes of people using self-care technologies.	–	–	Patients use common blood glucometers, blood-pressure monitors, and INR meters.
BP@Home	Kusk et al. [2013]	Hypertension	Interviews with one patient (monitoring condition) and 15 clinicians. A focus group with five patients. 6-day pilot with four patients.	6	4	Patients use a tablet and blood-pressure monitor (with noise and movement sensors) that sends measurements to the patient record.
CHAP	Mamykina et al. [2006]	Diabetes	Interviews with 15 patients and observations on diabetes education centre for 6 months. Technology probe was piloted for 2 weeks in two houses, complemented with daily interviews.	14	2	Patients wore a watch that regularly measures blood glucose. They also reported activities, meals, and emotions with a desktop app.

(Continued)

Table IX. Continued

Name	Study	Condition	Type of study	d	#	Technology
CKDManagement*	Sota et al. [2011]	Chronic kidney disease	The pilot was conducted for 1 month with five patients. To evaluate the intervention, participants completed questionnaires.	30	5	Patients use smartphone app to visualise their blood tests and self-report symptoms.
COPD-Therapy*	Taylor et al. [2011]	COPD	Two feasibility studies. First, four patients used the system twice a week for 8 weeks. Second, three patients used the system with transmission of vital signs to the therapist. Evaluation included pre/postinterviews and questionnaires.	16	7	Patients attend physiotherapy sessions with a TV, set-top box, and webcam. Clinicians use a desktop interface to broadcast instructions and accompany the patients' exercise.
COPDTrainer	Spina et al. [2013]	COPD	The evaluation pilot was conducted with four patients with supervision from physiotherapist.	1	4	Patients exercise while wearing a smartphone for example, on their wrist to get feedback.
DailyAppropriation*	Storni [2010]	Diabetes, Hypertension	Interviews with eight patients using monitoring technology, seven community pharmacists, and two clinicians. Full-day observations of pharmacies were also held.	–	–	Patients used common blood-pressure monitor or glucose meters.
DialysisMachine*	Kilbourn [2010]	Chronic kidney disease	Using a design anthropology approach patients were observed using dialysis machines at home and in the hospital.	–	–	Patients use common dialysis machine.
eDiary	Aarhus et al. [2009]	Diabetes T1	10 home interviews with patients using glucometers. 100 hours of observations at outpatient clinic. eDiary was used for 1 month by three patients, interviewed (with partners) after study.	30	3	Patients use web app and the smartphone to monitor condition. Clinicians use the web app.
Food Quiz	Glasemann et al. [2010]	Diabetes T1	Two summer camps. In the first, interviews, observation, and design workshops were held with 24 participants. In the second, a prototype was piloted with 34 children in three lessons. Participants were observed and interviewed.	3	34	Patients play a smartphone game to learn counting carbohydrates.

(Continued)

Table IX. Continued

Name	Study	Condition	Type of study	d	#	Technology
HeartPatients*	Grönvall and Verdezoto [2013a]	Atherosclerosis, Hypertension	Seven patients were interviewed and observed during monitoring tasks, and 83 answered a survey. Two workshops with clinicians were also held.	–	–	Patients use scales, blood-pressure monitors, pulse oximeters, and ECG.
HIVForum*	Mo and Coulson [2010]	HIV/AIDS	340 patients answered a survey about their use of their online support group.	–	–	Patients used an online support group to share their health and life concerns.
ICT-BTMS	Pinsker et al. [2008]	Diabetes	Two pilot studies. First, 10 patients used the system for 3 months, answering postsurveys. Second, an RCT was held with seven patients for 3 months. Control and treatment groups used the system, but treatment had automatic-feedback.	180	17	Patients enter measurements on smartphone app which uploads them to the web. Clinicians use this data for analysis of evolution.
Jog Falls	Nachman et al. [2010]	Diabetes T2	A pilot study with 15 participants (three with diabetes) for 63 days. Evaluation was based on pre/postinterviews.	63	15	Patients use a smartphone app to track activities and food intake. Clinicians monitor evolution in web app.
MAHI-1	Mamykina et al. [2008]	Diabetes	4-week trial with 49 patients (intervention = 25; control = 24). Evaluation included interviews, pre/postintervention surveys, and log analysis.	28	49	Patients use glucometer, connected to a smartphone, to upload measurements to a web app, shared with educator.
MAHI-2	Mamykina et al. [2010]	Diabetes	12-week pilot with eight patients from a support group. Participants were interviewed and filled questionnaires pre/postintervention.	84	8	See MAHI-1.
MONARCA v1	Bardram et al. [2013]	Bipolar Disease	14-week within-subject design with 12 patients, using paper-based assessment and MONARCA. Postinterviews and questionnaires were held.	98	12	Patients monitor condition with a smartphone or web app. Clinicians track evolution and emergencies on web app.
MONARCA v2	Frost et al. [2013]	Bipolar Disease	Design workshops with nine MONARCA v1 users (six patients). Version 2 was piloted for 6 months with six patients. Users interviewed during pilot.	180	6	See MONARCA v1.

(Continued)

Table IX. Continued

Name	Study	Condition	Type of study	d	#	Technology
ONESELF	Camerini et al. [2011]	Fibromyalgia	157 people used the system once and reported perceived usefulness in a questionnaire.	1	157	Patients use web app for mimicking exercises.
PersuasiveSens*	Chatterjee et al. [2012]	Diabetes T2	One participant within-subject design, with 2 weeks' activity monitoring as baseline, and 4–5 weeks intervention. Pre/postexperiment surveys were conducted.	35	1	Home sensors (e.g., doors), and wearable sensors send data to central server. The patient receives weekly SMS and emails with recommendations.
RemoteLogCam	Güldenpfennig and Fitzpatrick [2013]	Cerebral palsy	First prototype was piloted for 2 weeks with one participant. The second version was used for 6 months by the same participant.	180	1	Patient wears glove that detects spasms, providing haptic feedback and taking a picture with the smartphone for later reflection.
RemoteReminiscence*	Yasuda et al. [2009]	Dementia	3-week pilot with four patients. In the first week, carers reported psychological stability and reminded daily activities. In the last weeks, patients engaged with the system in reminiscence sessions and in receiving scheduling reminders.	14	4	Patients attend reminiscence sessions, and receive reminders, from a desktop app. Caregivers provide content for sessions.
Report-Asthma*	Craven et al. [2013]	Asthma	2-week pilot with 11 participants that perform physiological measurements and complete a questionnaire every weekday.	14	11	Patients use a smartphone with sensors (oximeter, respiration flow, pulse) to report the disease state.
TiY-1	O'Murchu and Sigfridsson [2010]	Diabetes T1	Interviews with 10 patients, and observations of support group and design sessions. During one session participants tested the prototype.	–	–	Patients use a smartphone app to track their blood glucose and look for patterns.
TiY-2	Storni [2011]	Diabetes T1	Observation of a support group for 10 months, interviews with 14 patients and 13 clinicians, focus group with four patients. The pilot was evaluated with five participants for 2 months.	60	5	See TiY-1
TLC-Depression	Farzanfar et al. [2007]	Unipolar depression	4-week pilot with 15 participants, interviewed weekly	28	15	Patients report symptoms to telephony system, and use pillbox that monitors intake. Clinicians receive alerting e-mails.

Table X. Technologies in the Review for Making Health or Contextual Information Available

Health information	ADMS, AssistingInsulin, AsthmaProbes, BoundaryWork, BP@Home, CKDManagement, DailyAppropriation, eDiary, MONARCA, RemoteLogCam, Report-Asthma, TiY, TLC-Depression
Contextual information	AsthmaProbes, CHAP, Jog Falls, MAHI, MONARCA, PersuasiveSens, TiY

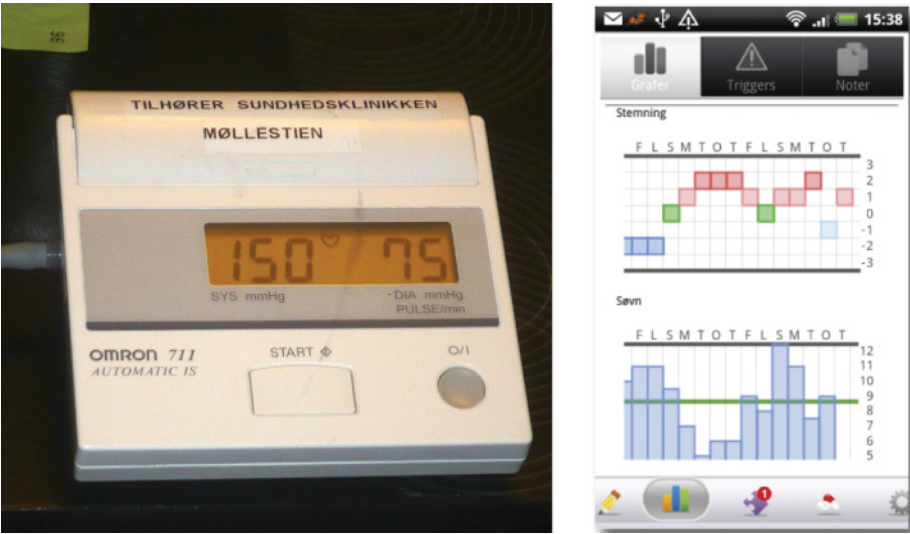


Fig. 3. Two interfaces providing health information are displayed. On the left, a blood pressure monitor displaying blood pressure values. On the right, an overview of mood and sleep levels over a period of time from MONARCA [Bardram et al. 2013], ©ACM.

4.1.1. *Fostering Reflection by Making Health and Contextual Information Available.* Knowing one’s body is essential to achieve control of a chronic condition. However, some changes and trends may be hard to notice in everyday life. Self-care technologies have been used to make health and contextual information available to patients and carers. These two groups of technologies are presented later and summarised in Table X.

Technologies providing *health information* have been used to document signs and symptoms.²³ Documenting patients’ symptoms has been achieved using self-report questionnaires for mental conditions, focusing on mood, quality of sleep, or suicidal considerations (MONARCA, TLC-Depression). Collecting signs has been achieved with technology that captures blood glucose levels (e.g., eDiary), difficulties of breathing (e.g., AsthmaProbes), the occurrence of spasms (RemoteLogCam), and blood test indicators (CKDManagement). The chosen user interfaces for visualising signs and symptoms varied, spanning from medical devices that could output a single value (e.g., blood pressure monitor), to more elaborate visualisations that could plot multiple values (see Figure 3). Technologies that collect and visualise health information provided patients with data about their disease state as well as feedback regarding their self-management; this data and feedback was essential in enabling them to change and adjust self-care practices.

²³The definitions of signs and symptoms are sometimes confused. While signs are characteristics that can be perceived and measured by others, symptoms refer to characteristics only felt by the patient.

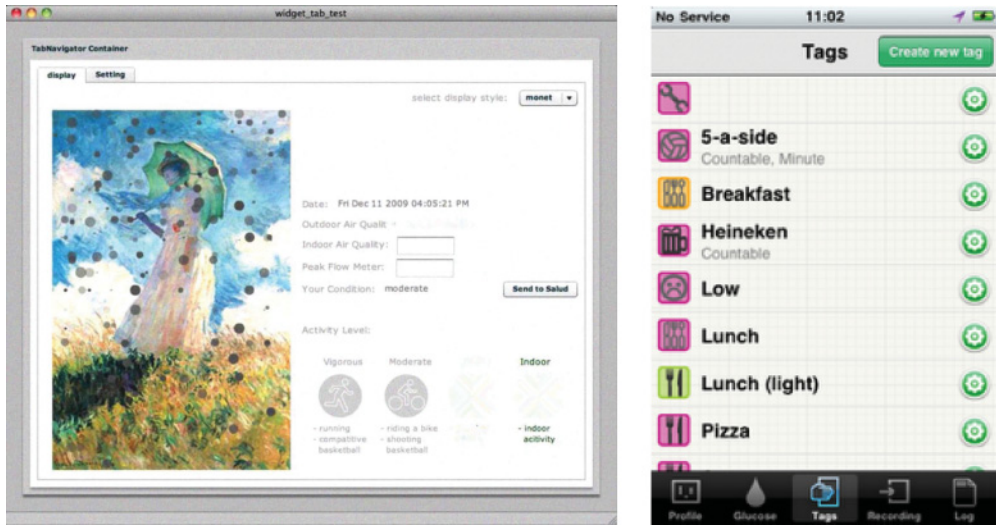


Fig. 4. Two interfaces for making contextual information available are displayed. On the left, AsthmaProbes [Yun et al. 2010] represents air quality by drawing bubbles on a Claude Monet painting, ©Rosa Arriaga. On the right, TiY [Storni 2011] shows examples of tags that could be used to assign to a blood glucose measurement, ©Cristiano Storni.

Technologies that make *contextual information* available helped patients understand their habits and the characteristics of their environment that contribute to their care and overall health status (see Figure 4). For example, data has been captured about what patients have eaten (e.g., MAHI), how much they have exercised (e.g., Jog Falls), how socially active they have been (e.g., MONARCA), as well as the air quality around them (e.g., AsthmaProbes). The contextual information was collected either manually and/or using sensors. This information was then displayed using different strategies such as avatars (e.g., Jog Falls), text and picture logs (e.g., MAHI), or more abstract visualisations such as using a Claude Monet painting with overlaid bubbles representing air quality in AsthmaProbes (see Figure 4). In general, technologies restricted the information conveyed to the user through explicit design choices, but there were exceptions²⁴ (e.g., TiY, AsthmaProbes). In TiY, for example, people with diabetes measured or tagged any occurrence, event, or activity without restriction. TiY has a number of data templates for common diet, exercise, and medication tracking, but any other data field could be created by the patient to track events of their personal interest. Using this information, patients could get a glimpse of their habits and contextual conditions, which enabled them to form small theories about the relationship of symptoms and context, or to act on their conditions in more informed ways.

While the technologies presented in this section varied substantially, they still each strove to make patients more aware of their health and their context. The influence of these technologies has been evident: the simple act of taking measurements for example improved the understanding of the health condition in HeartPatients. The ability to control the condition made patients feel more confident about their disease management (AsthmaProbes, ADMS). Furthermore, this ability also led to treatment adjustments in, for example, how much insulin to inject (eDiary) or how often to measure asthma symptoms (AsthmaProbes). Other studies reported behaviour changes, such as: losing weight (Jog Falls), knowing when to open the windows to avoid asthma

²⁴See more details in Section 5.2 on appropriation.

complications (AsthmaProbes), and being able to control spasms when they appeared (RemoteLogCam). Another positive result of an increased awareness was that it made (more-experienced) patients reflect on their identity as patients and their ability to manage their chronic condition (MAHI-2). While it is clear that technologies for making health and contextual information available brought benefits to patients, the benefits were dependent on the patients' ability to understand the status of the chronic condition through the technology. There were also some negative effects reported in the studies. For example, in Report-Asthma, one patient reported that thinking about coughing, motivated by the regular assessments, could make one cough more. In Daily-Appropriation, a patient had to be hospitalised for anxiety, which was caused by being overly aware of her blood pressure values. This particular patient had recently been prescribed the blood pressure monitor; however, she could not understand what the measurements meant. She started measuring repeatedly and her values kept increasing from measurement to measurement. This overmeasuring made her constantly think about the possibility of having a stroke at any minute and thus triggered her quick hospitalisation. Awareness in these two cases was more harmful than helpful. The important message to take here is that awareness may be positive or detrimental to the health and that different people can experience awareness in different ways; therefore, it is crucial to carefully consider the different cases and the context in which an awareness may be raised through technology.

4.1.2. Suggesting Care Activities or Treatment Adjustments. Self-care technologies have been used to make suggestions for care activities or adjustments to treatment based on available information. The goal of this feedback has been to improve self-management, either through starting or adjusting a specific care practice. This type of feedback may be especially important when learning about the condition to get proficient in managing it, or in everyday life to delegate care practices to the self-care technology and concentrate on other everyday activities.

Regarding the papers of the review, the *suggestions of care activities* spanned from reminders to other sorts of functionalities triggered when specific conditions occurred (see Figure 5). Reminders have been used, for example, to help people with dementia to take their medication (RemoteReminiscence) as well as to encourage individuals with mental conditions or diabetes to report their symptoms (MONARCA, TLC-Depression, ICT-BTMS). Other suggestions and functionalities were triggered by specific disease states. For instance in MONARCA, when the smartphone application detected high mania symptoms from individuals with bipolar disorder, a screen with coping strategies was displayed on the smartphone of the patient. A similar strategy was used by PersuasiveSens, in which a low level of physical activity triggered an SMS to motivate further activity in patients with type 2 diabetes. In TLC-Depression, the technology provided explanations about self-care practices each time a patient reported not performing the care activities at the recommended level.

Furthermore, technology suggested *treatment adjustments* taking into consideration the current state of the condition and self-management. In AssistingInsulin, the technology suggested insulin dosages based on previous measurements and expected activity level. In ONESELF, exercises were suggested based on the type of pain in muscles, ligaments, and tendons a patient experienced, as well as on the existing tools available at hand. In COPDTrainer, auditory feedback was given to patients to adjust incorrect exercise postures captured by wearable sensors.

In summary, the technologies presented in this section looked at improving care tasks or adjusting current treatments while suggesting specific changes to the patient. The results of using these technologies seemed to be mostly positive for patients. The reminders, for example, led to a more regular assessment of bipolar condition in

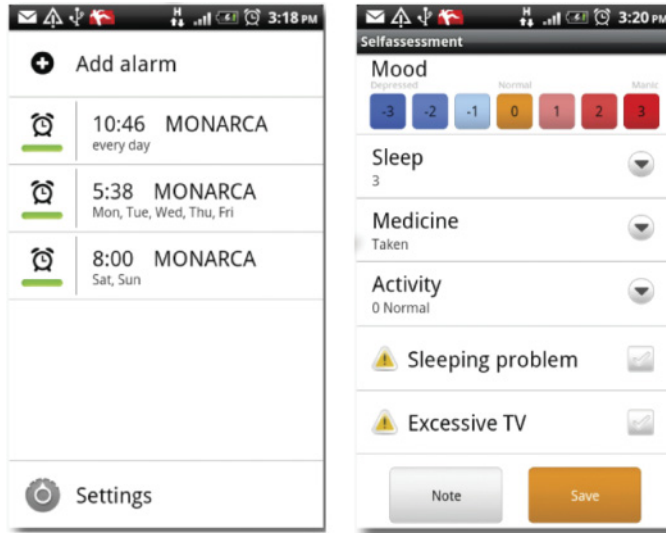


Fig. 5. MONARCA [Bardram et al. 2013] suggests patients to complete a self-assessment of their condition at regular times, ©ACM.

MONARCA and to an increased physical activity in PersuasiveSens. The functionalities triggered by specific disease states not only enabled patients to understand how to circumvent negative situations in MONARCA but also how to adapt the prescribed exercise plan to the current disease state in ONESELF. The feedback on care practices enabled patients to correct their exercises while performing it in COPDTrainer. On a less positive note, patients reported that the insulin dosage recommendations of AssistingInsulin were too similar to their care plan and that, though correct, were not useful for their management. There were also some negative aspects reported, such as patients not understanding or acting on reminders for medication in Remote-Reminiscence. While this specific failure to act on reminders was not thoroughly discussed in the article, it could plausibly relate either to characteristics of dementia or to the system's design. There were also negative comments from a participant reporting that the persuasive messages in PersuasiveSens were not particularly motivating and that they would become dull in the long term.

4.1.3. Sharing Care Activities with Informal Carers. Self-care is likely to happen in a context with one or more informal caregivers participating in both care decisions and activities, even when the patient is not dependent on external support [Aarhus and Ballegaard 2010]. The involvement of informal caregivers varies from case to case, depending on the chronic condition, its current stage, and the personalities, values, and routines of both patients and caregivers. Some of the technologies in the review have acknowledged the role of informal caregivers by designing technology that was shared with them. These technologies can be divided into two groups: (1) technologies for sharing information between patients and their respective carers and (2) technologies for supporting carers in their informal care activities.

Technology has been used as a vehicle for *sharing information between patients and their respective carers*. The most common example in the review was sharing information between children and parents. In both AsthmaProbes and ADMS, parents used a web application to monitor their children's condition. Using this information, parents were able to instruct (or advise) their children regarding which actions to take. However, there were also other examples of information beyond just children

and parents. In eDiary, for example, pregnant women with diabetes shared monitoring data and videos from medical consultations with their partners. Despite sharing data with different people, the advantages of such information-sharing technologies are the same and include improving the overall understanding of the chronic condition for both patients and carers, increasing the ability of caregivers to participate in self-care, and enabling shared responsibility through technology.

Technology has also *supported caregivers* by helping them care for the patient, especially when patients stopped being able to participate as much in their own care. In RemoteReminiscence, for example, caregivers received support in self-care. The system reminded patients to take medication, by recording and then playing an auditory/video reminder, thus relieving carers from this task. DailyAppropriation reported on an individual with diabetes helping a relative with the same condition to follow a treatment plan and instructing on how to eat. The technology, a blood glucose monitor in this case, made visible the required information to enable the caregiver to act.

In general, the studies in this section presented positive outcomes for caregivers; patients reported feeling less anxious and more in control of the condition when receiving caregiving support (see, e.g., eDiary and ADMS). Technology enabled caregivers to engage in richer discussions and participate in care decisions. However, surprisingly, not many studies accounted for the role of caregivers in self-care.

4.1.4. Enhancing the Collaboration with the Care Team. Although patients largely manage their own care autonomously, they are also likely to visit their clinicians regularly, to analyse their condition state, update treatment, and discuss other issues they face. Self-care technologies enhanced the collaborations with clinicians by enabling patients to collect rich materials to discuss during the consultations, or by creating new opportunities for getting information from clinicians.

The technologies in the review have explored ways of collecting *rich materials* to discuss during medical consultations, although with different levels of autonomy for the patient.²⁵ In the least autonomous case (TLC-Depression, ICT-BTMS, BoundaryWork, Jog Falls, and HeartPatients), patients self-reported their health data to a central system that summarised, filtered, and displayed it to their clinician. While being useful for self-care, these technologies were designed for clinicians to reflect by themselves, and later to provide advice to patients. There were also technologies that expected a more active role from the patients. In those cases (eDiary, TiY, PersuasiveSens, MONARCA), patients collected their data and reflected on it before a medical consultation, being able to bring questions and hypotheses to the appointment (see Figure 6).

Self-care technologies have also created new opportunities for patients to *get information from their clinicians* (see Figure 7). We divide these technologies into three types of tools. The first consisted of remote consultations and therapy using video-conference tools (eDiary, COPD-Therapy, RemoteReminiscence). The second was about forum-like platforms for enabling patients to discuss with their clinicians in a question-and-answer format (MAHI). And the third type consisted of recording consultations and making them available for patients to watch at a later time (eDiary). These platforms enabled patients to coordinate care with their clinicians without attending regular colocated meetings.

The technologies presented earlier shared the common goal of enhancing the collaboration between patients and their clinicians. The outcomes of using these technologies were mostly positive in supporting self-care management. For instance, we have seen

²⁵Further engagement and control from the patient might not be always adequate. Patients will have different characteristics and may be able (or not) to become more active in their care. See Section 5.1 for further details.

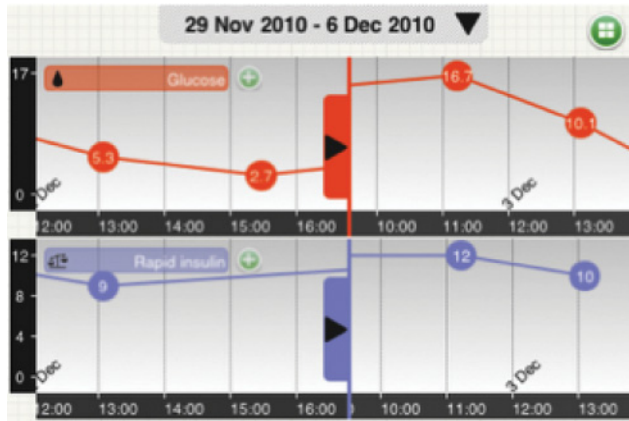


Fig. 6. Using TiY [Storni 2011], patients were able to reflect about their condition in different ways, which enabled them actively to prepare for their clinical appointments, ©Cristiano Storni.

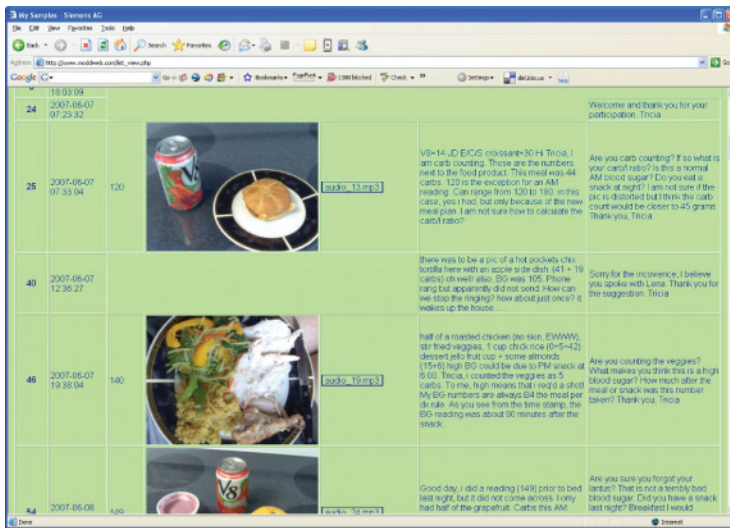


Fig. 7. MAHI [Mamykina et al. 2008] enabled an alternative way of communicating with clinicians, which provides regular feedback, ©ACM.

how collecting richer health data and reporting it back to clinicians enabled patients to obtain further information on their self-management from their clinician (see, e.g., Jog Falls, Heartpatients). When patients reflected on their own health data prior to consultations with clinicians, they were able to generate hypotheses to discuss or test (see, e.g., eDiary, TiY). The introduction of technology also changed the dynamics of (medical) consultations. In eDiary, patients were more active in their appointments when they controlled the technology than when clinicians were controlling the system from their own desktop computer. Indeed, remote consultations and therapy using video-conference tools enabled patients to receive care without leaving their homes, improving the organisation of their daily life or their ability to receive care (see Heart-Patients and COPD-Therapy). MAHI enabled patients to gain a better control of their chronic condition due to a very regular feedback on their condition, necessary when patients' start to self-manage. Besides the positive outcomes, there were also some

inconveniences and restrictions caused by these technologies. COPD-Therapy, for example, was considered restrictive to some degree, because therapists did not have a way to communicate individually with each patient using the video-conference system and had to call individual patients by phone. Systems that supported the collection of rich information (eDiary, TiY) were useful for patients, but this was not always carried through to the consultation room, in which clinicians expected the collaboration to be structured under their guidance and terms, not the patient's, thus hindering the patient from discussing issues as an equal with the clinician. Video-conference tools such as RemoteReminiscence were also difficult to use for some patients with dementia who became confused by the remote conversation, partly because of their chronic condition, but possibly also influenced by the technology.

Even though the outcomes of the studies were largely positive, it is not possible to fully assess the possibilities and impact that these systems could have in the longer term. One of the main reasons is that the findings from most papers are based on pilot or feasibility studies (see Section 4.4), which were too short to be able to develop or enhance patient's abilities and competencies over time regarding their self-care management.

4.1.5. Sharing Self-Care Activities and Learning from Others with the Same Chronic Condition.

Patients often connect with other people living with the same chronic condition. They use these interactions to understand how to live with their condition, to validate their theories about their body and self-care, and to obtain emotional support [Pols 2012]. The interactions among patients with the same condition have often been mediated by technologies (e.g., Preece [1999] and Newman et al. [2011]). In this section, we present technologies from the review that facilitated sharing or learning from other patients, through exchanging information, enhancing social support, or performing care activities together.

The first type of system was concerned with *exchanging information and social support*. In particular, one study followed this direction. HIVForum documented how online forums supported the interactions between people with HIV/AIDS. These online groups enabled less-experienced members to get to know the issues they may face in the future and discover how others have managed them in relation to their own experience with the condition. The forums were used for sharing diverse types of information and emotional support.

Other systems enabled patients to *perform care activities together* (see Figure 8). This was the case of the COPD-Therapy, which enabled patients to meet in a group during physiotherapy sessions. Interacting with each other made patients feel safe and that they belonged to a group—which was perceived as something positive. There were also other technologies promoting the interactions among patients, but unlike COPD-Therapy, these were not purposefully designed. In FoodQuiz, for example, children gathered in pairs to play an (individual) game for learning how to count carbohydrates. A common theme among these technologies is that they were able to gather peers to discuss aspects of their care, improving their self-management.

The results of using these two types of technologies were mostly positive. Obtaining information about the disease proved to be useful for the patients. All patients recognised the value of the HIVForum, in obtaining and providing information and support through the forum. The more active members were the ones reporting greater social support, showing that the technology can enable those seeking support to obtain it. Furthermore, performing self-care activities together (like exercise) also had positive results, enabling patients to feel like a group when performing physiotherapy sessions (COPDTrainer) or children with diabetes to have fun with others while learning to manage diabetes (FoodQuiz). Overall, technology played an important role in enabling patients to share and learn from others with the same disease, either through planned



Fig. 8. COPD-Therapy [Taylor et al. 2011] enabled patients to attend group physiotherapy sessions, ©Andrea Taylor.

Table XI. Papers under Different Configurations

Autonomous use	AssistingInsulin, BP@Home, CHAP, CKDManagement, DailyAppropriation, DialysisMachine, FoodQuiz, ONESELF, PersuasiveSens, RemoteLogCam, TiY
Together with other patients	COPD-Therapy, HIVForum
Together with caregivers	ADMS, RemoteReminiscence
Together with clinicians	COPD-Therapy, COPDTrainer, eDiary, HeartPatients, ICT-BTMS, Jog Falls, MAHI, MONARCA, Remote-Reminiscence, TLC-Depression

interactions or consequences of the intended design and their system appropriation by patients.

4.2. Configurations of Technology: Users, Roles, and Relationships

Technology shapes self-care in a number of ways, including the individuals who use the technology, the roles attributed to them, and the relationships anticipated. In this section, we look at four different configurations that were evident in the papers (see Table XI).

- (1) *Patients used the self-care technology autonomously.* This does not mean that patients acted in isolation, but rather that the relationships with caregivers, clinicians, or other patients were not mediated by technology. Under this configuration, patients monitored symptoms and signs, e.g., measure blood pressure (DailyAppropriation). The patients performed self-care activities previously agreed with their clinicians, such as physiotherapy exercises (ONESELF), or they learned about their condition, for example, regarding how to calculate meals to keep diabetes under control (FoodQuiz).
- (2) *Patients met with others who live with the same condition, mediated by technology.* For instance, online forums enabled patients to talk about their life experiences

Table XII. Technology Artefacts Patients Interacted within the Studies of the Review

Medical devices	ADMS, Assisting-Insulin, AsthmaProbes, BoundaryWork, BP@Home, CHAP, COPD-Therapy, DailyAppropriation, DialysisMachine, HeartPatients, ICT-BTMS, MAHI, Report-Asthma
Smartphone app	AssistingInsulin, CKDManagement, COPDTrainer, eDiary, FoodQuiz, ICT-BTMS, Jog Falls, MONARCA, Remote-LogCam, Report-Asthma, TiY
Feature phones	eDiary, PersuasiveSens, TLC-Depression
Tablet app	BP@Home
Web app	COPD-Therapy, eDiary, HIVForum, MAHI, MONARCA, ONESELF
Desktop app	AsthmaProbes, CHAP, RemoteReminiscence
TV app	COPD-Therapy
Sensors	Jog Falls, PersuasiveSens, Remote-LogCam, TLC-Depression

and concerns, as in the case of HIVForum. Patients also performed care activities together, for example, through remotely shared physiotherapy sessions in COPD-Therapy.

- (3) *Patients and their informal caregivers collaborated in self-care using technology.* In this configuration, patients were supported by caregivers in their activities, as in the case of parents remotely checking blood glucose measurements made by children in ADMS. Patients could also use a technology that was enabled by their caregivers, as in the case of remote-reminiscence sessions in RemoteReminiscence.
- (4) *Patients and clinicians interacted using technology.* In some cases, patients have had their conditions monitored by clinicians through, for example, self-reporting mental health symptoms (TLC-Depression). Alternatively, patients received remote feedback and advice from clinicians regarding how to manage their mania symptoms (MONARCA). Or patients attended remote consultations for monitoring the condition (see eDiary). A number of different clinicians were mentioned across the papers—the most common were doctors, either the patients’ usual care providers or other doctors responsible for monitoring the technology. Physiotherapists and diabetes educators were also mentioned.

4.3. Technologies Employed

Most technologies in the review were systems with multiple components, including devices for patients, clinicians, and communication structures. In this section, we focus on the technology artefacts with which patients interacted (see Table XII). Of these, 13 were medical devices. Medical devices included blood monitors, blood glucometers, ECG, peak flow meter, pulse oximeter, and dialysis machines. Mobile devices were also frequently used in the reported studies. There were 11 smartphone applications, while feature phones were used in three studies for sending SMS or making phone calls. Only one tablet application was reported. Web applications were present in eight cases, desktop applications in three, and (smart) televisions in one study. Last, different activity or wearable sensors were used in four studies.

Most technologies used by participants were prototypes ($n = 23$), purposefully developed or adapted for the study. Only six studies involved final products, or commercially available technology (CHAP, BoundaryWork, DailyAppropriation, HeartPatients, HIV-Forum, DialysisMachine).

4.4. Methods Used in the Research

Across the papers, we observed a range of methods that we divided into categories of preparatory research, design creation, and evaluation (see details in the overview Table IX).

4.4.1. Preparatory Research. Preparatory research²⁶ is a stage used to gain a better understanding of the study context. This research phase is likely to contribute to the design process by providing ideas and uncovering problems or issues that the design could tackle. Under preparatory research, we found interviews, observations, workshops, and literature reviews. The interviews ($n = 8$) involved mostly a small number of participants (up to 10) and focused on gathering information from patients, healthcare professionals, or both. Observations ($n = 6$) spanned through several weeks or months and focused on everyday life aspects and activities specific to patients that took place during support groups, or visits to the doctor. Workshops ($n = 7$) were conducted also with a small number of participants, mainly for getting early feedback and discussing design ideas and concepts to be developed. Literature reviews were also reported in two studies, to get an understanding of the recommended self-management activities documented by prior work.

4.4.2. Design Creation. Design creation²⁷ includes techniques that aim at creating specific designs. These could be a new iteration of an existing technology or a part of a new interface for a new system in development. In this regard, the papers presented workshops and contextual interviews as design techniques. The workshops ($n = 7$) were useful for discussing and testing a prototype or for giving participants the opportunity to help design the technology by themselves. Furthermore, contextual interviews ($n = 2$) were conducted with patients and carers to obtain feedback on a specific prototype.

4.4.3. Evaluation. The main goal of the evaluation phase is to assess the value of the technology. As the review papers were concerned with how patients used the technology to support their self-management, the evaluation was typically oriented towards understanding the participants' experience with the self-care technology in real settings. Several strategies seemed to be in play, including (i) formal evaluations (i.e., interrupted time series or randomised control trials) ($n = 4$), (ii) interviews at the end of the pilot ($n = 4$), (iii) pre- and postintervention interviews and measurements ($n = 5$), (iv) regular interviews or logging participant's actions ($n = 4$), and (v) ethnographically inspired studies or other approaches to observe daily technology use ($n = 4$). There were both short- and long-term evaluation phases in the studies of the review (see Figure 9). In the short-term evaluation ($n = 7$), a small number of participants (typically up to 10)²⁸ used a technology for a limited number of times or days. Short-term evaluation usually focused on the usability and/or the feasibility of a technology. In contrast, long-term evaluations spanned from a few weeks to few months and were more common ($n = 22$). The main focus of long-term evaluation was not on usability but on understanding how people used the system in their everyday life as well as the effect of the technology on people's health.

Since most studies were explorative, evaluation rarely aimed at assessing the impact on actual medical outputs. In a small number of cases, though, studies offered physiological measures of the impact on health such as weight (Jog Falls, PersuasiveSens), HbA1c²⁹ (ADMS, PersuasiveSens), as well as blood oxygen and breathing difficulties acquired through self-reported questionnaires (COPD-Therapy). Another approach used

²⁶It is relevant to note that some studies in the review did not include preparatory research or design creation, being only concerned with how a group of people used a specific technology either through its trial or through their involvement with participants who already used it in their everyday life.

²⁷See footnote 26.

²⁸Exception to the reduced number of participants in short-term evaluation is ONESELF, which included 157 participants.

²⁹HbA1c stands for glycated haemoglobin and can give a sense of how controlled blood glucose values have been over a period of time.

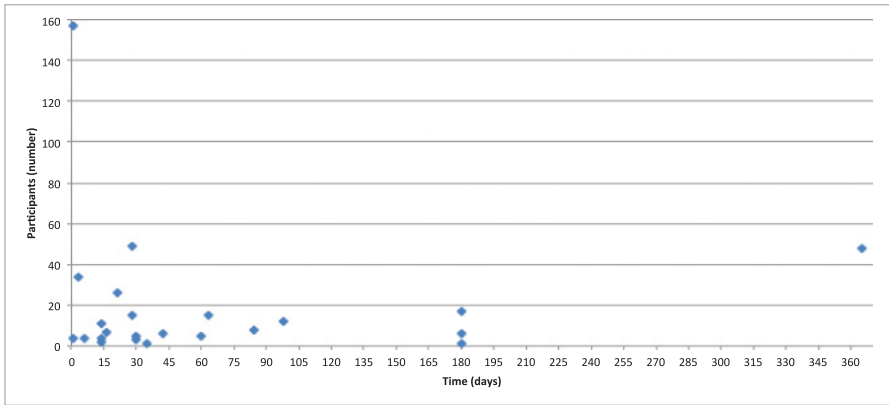


Fig. 9. Overview of the duration and number of participants in the evaluation phase of the studies.³⁰

within the studies was to measure self-reported effects in psychological parameters, such as ability to manage the condition (MAHI, ADMS), anxiety, and depression level (COPD-Therapy), and the perceived quality of life (MAHI). Besides health and psychological outcomes, studies also relied on analysing behavioural outcomes, such as changes in diet (MAHI), level of exercise (PersuasiveSens), and adherence to using the technology (eDiary, ONESELF, MONARCA, Report-Asthma).

Some of the work, though, raised issues regarding traditional metrics of impact. The argument was that these metrics, often derived from acute disease models, were overlooking the perspective of patients. For example, TiY showed that patients valued a range of outcomes that might go beyond the mere measurement of physiological values and that, for this reason, might be difficult to accept for the clinicians. A trade-off seems to emerge due to the different perspectives in play in self-care. On the one hand, clinicians expect to assess the impact of self-care technology in terms of how they influence health physiological measurement (DailyAppropriation, eDiary). On the other hand, patients highly value their lifestyle and daily habits, which are probably difficult to measure as health outcomes (TiY). While being very relevant for the patients, these characteristics can be seen as idiosyncratic or of secondary importance for clinicians.

5. REFLECTING ON THE DESIGN OF SELF-CARE TECHNOLOGIES: TENSIONS, IMPLICATIONS, AND QUESTIONS FOR CONSIDERATION

In this section, we reflect on the papers of the review with a focus on designing self-care technologies. In particular, we discuss six design-related tensions that emerged from our analysis, namely, (i) autonomy of the patient or control of chronic condition by clinicians, (ii) designing for appropriation or closing technology to changes, (iii) choosing strategy for proving or improving care, (iv) choosing devices for chronic condition support or daily life orientation, (v) game-based approaches or reducing the chronic condition to a game, and (vi) visualising chronic condition data for providing an overview or displaying contextualised values. Each design tension uses examples from the review to document the issues, derives implications for the design of self-care technology, and provides questions for reflection when designing self-care technologies.

³⁰The plot represents all the studies that provided concrete numbers of the duration regarding the evaluation phase and the number of participants. Short-term evaluations that lasted from one to three times appear in the plot as 1 to 3 days for simplifying the presentation.

We aim to provide a tool “to think with,” especially for young designers, to understand critical issues of designing for this setting.

5.1. Autonomy of the Patient or Control of Chronic Condition by Clinicians

The traditional model of care was organised to treat acute illness as the primary reason for medical care [Holman and Lorig 2000]. In this model, conditions were expected to be severe, but treatable after some days or weeks. After the medical treatment, the (mostly passive) patients would return to their homes with restored health. This model has been well suited for acute illnesses, however, applying it to chronic care fails because conditions are very different and people do not achieve cure [Holman and Lorig 2000]. Chronic care requires a collaborative endeavour³¹ between patients and clinicians to set goals and choose the adequate treatments [Bodenheimer et al. 2002]. Patients are expected to actively engage in their treatments, performing care activities and adapting their lifestyle, because their quality of life depends on that [Glasgow and Anderson 1999]. As patients live longer with the condition, they start gaining a better understanding about its characteristics and management, so they start taking on further responsibilities and control from their clinicians.³² Over time, clinicians can become advisers who explain and discuss different care alternatives, their benefits, and their consequences [Bodenheimer et al. 2002]. In some cases, patients will become completely autonomous from their clinicians; in others, they will still refer to them regularly for support (see DailyAppropriation). Technology can influence the autonomy of the patient by defining roles and processes in the system. The papers in the review point out solutions on opposing sides of this spectrum. In some cases, technology puts patients in a rather passive role and provides clinicians with the responsibility to coordinate monitoring, reflection, and action in the system (e.g., Jog Falls, ICT-BTMS). In contrast, in other cases, technology enables patients to take an active role (e.g., eDiary, CHAP, TiY), increasing their participation in self-care activities.

There does not seem to be an ideal solution, but rather different approaches with distinct requirements and outcomes. Understanding these two, sometimes opposite, poles of a spectrum has important implications for design. Therefore, in the rest of the section, we discuss four points that can help reaching an agreement on whether to design to provide more autonomy for patients or more control for clinicians (recognising this as a spectrum):

- (1) *Autonomy and control of the chronic condition are highly dependent on the disease and patient's current health status.* It is not possible to make assumptions about all chronic conditions as patients have very different experiences, even for the same condition (see DailyAppropriation). It is, therefore, important to reflect about these two perspectives for the different states of the chronic condition when designing, as well as on the personality of the patient when advising its usage.
- (2) *Different treatment decisions have distinct autonomy levels.* Patients perform care decisions on an everyday basis, but not all of them entail the same implications or risks. When designing, it is important to reflect on which decisions should be more or less supported by clinicians and in which ones patients can take a more active and/or autonomous role (e.g., compare use of eDiary in daily self-management vs. consultation).

³¹Self-care requires changes in the traditional roles of patient and clinician; however, not all practitioners accept or motivate these changes. Contributing to this might be routines, established practices, or views on care provision.

³²This can be seen, for example, in DialysisMachine, in which patients would perform more care activities as they became acquainted with the machine to perform dialysis.

- (3) The *focus can be on providing the most autonomy possible* to the patients rather than overmonitoring or overcontrolling the patient's behaviours. Patients are in charge of their chronic condition for most of the time; therefore, they should take as many care tasks as they can handle to manage at their best. Again, this will not apply to every patient and should be reflected on for each different case.
- (4) Technology can improve chronic care in a variety of ways, but *not all technologies can be used in complete autonomy*. In some cases, the complexity of the chronic condition, the diversity of variables to consider, or the expertise required to apply or adjust the treatment or technology may require feedback from clinicians (e.g., MONARCA, COPDTrainer).

Based on our analysis, the following questions seem to be relevant to discuss with patients, carers, and clinicians when considering autonomy in design:

- Which self-care decisions are patients making? Do these vary for different stages of the chronic condition? What about different patients?
- Which self-care decisions are safe for patients to do autonomously? Do these vary for different stages of the chronic condition? And for different patients?
- Which self-care decisions should be monitored by or performed together with clinicians?
- What are the consequences of wrong self-care decisions?
- What are the consequences of not making self-care decisions?
- What tools do patients use currently to make self-care decisions?
- How can technology further inform patients to make self-care decisions?
- How can technology support the “negotiation” of autonomy between patients and clinicians?

5.2. Designing for Appropriation or Closing Technology to Changes

Appropriation is a concept derived from anthropology that is related to making something one's own. In HCI, this concept appears to name the phenomenon by which users adapt and adopt technology to the specificities of the situations they have at hand [Dourish 2003]. User adaptations may occur within the expected usage of the system, but at times, users will operate technology in ways that were not anticipated or even intended by its designers. Appropriation is usually seen as an inevitable consequence of using technology [Dix 2007]. However, when the notion travels to healthcare, it becomes controversial due to the very real concerns of using self-care technologies in unintended ways [Storni 2010]. There seems to be a difficult trade-off in play when looking through the lens of appropriation. On the one hand, chronic care might become so personal and idiosyncratic to defy any one-size-fits-all approach. In this sense, self-care technology needs to allow a certain level of appropriation, enabling the personalisation of use to fit unique and often unpredictable contexts of use. On the other hand, safety concerns are very real and require designers to constrain technology to safe use conditions only. This issue links to the concerns about appropriate metrics to evaluate design interventions in this field and it remains a concerning open question.

Addressing the issue of appropriation has important implications for design of self-care technologies. Therefore, we summarise four points to discuss when designing that can promote appropriation in the designs.

- (1) Providing *visibility of how the system works* may enable patients to use the system more safely. The lack of visibility of how the technology works may lead to unintended situations such as overtesting in DailyAppropriation, contributing to poor management and understanding of the chronic condition. To avoid such situations,

designers should provide visibility and support patients in their interpretations, thus facilitating the appropriate use of technology in useful and safe ways.

- (2) Providing *flexibility is necessary to address a number of different cases* of the same chronic condition. People's lives are likely to be very different, even for patients who have the same condition. Their needs, characteristics, or even the way they adopt technology is probably different (e.g., the different reactions of patients using eDiary). Being so, it is likely that the designers will not take into account the complete variability, making it hard for them to predict every possible case. Being flexible is, therefore, an appropriate way to approach a variety of cases. This flexibility can be supported by enabling patients to add their own details, measuring categories, or performing other configurations, as in eDiary or TiY, or increasing the visibility of the system in terms of effects of actions that go beyond providing only the system status [Dix 2007].
- (3) Designers can adjust technologies to patients' lives by developing their products in *multiple iterations*. Designers will not be able to predict the way in which patients are going to use a system before it is developed (e.g., inability of MONARCA to track the number of cigarettes smoked by a heavier smoker). However, designers can and should observe how patients use their technology, to better fit it to their self-care practices. For this purpose, long-term evaluations will provide further feedback to system design regarding unexpected or more rare situations. Accounting for the dynamic process of appropriation will enable designers to discover patient's experiences using self-care technologies.
- (4) *Sharing adaptations that users do to technology*. We have seen that patients are required to fit the technology to their particular situations. The knowledge that they gain can be useful for others that experience the same challenges. Patients frequently share their solutions with other patients,³³ but technologies often do not encourage sharing these appropriation scenarios (see Dix [2007]). One way to improve the appropriation of technology would be to motivate this sharing in a way that it became more visible to others together with the explanations of how and why to use the technology in such way.

Based on our analysis, the following questions seem to be relevant to discuss with patients, carers, and clinicians when designing self-care technology:

- How does the design process enable designers to familiarise themselves with different appropriation cases? How flexible is the system to adapt to these?
- What are possible dangers of using the system in unpredicted ways? How can this be tackled while still enabling patients to manage the particularities of their chronic condition or settings?
- How clear is the visibility of how the system works?
- How is the development of new forms of use being supported?
- Can patients share their appropriation scenarios with others?

5.3. Choosing Strategy: Proving or Improving

One of the basic choices to make when planning a study around a self-care technology is to choose between proving or improving strategies [Mol 2006]. The first strategy is related with proving the effectiveness of a care practice, while the second is concerned with understanding the different effects of a specific intervention. In this section, we use these two concepts to investigate the impact of HCI self-care technologies in society.

³³Sometimes patients share innovations on the web. A good example is Patient Innovation (<https://patient-innovation.com>), a social network created solely with this purpose in mind.

The *proving* strategy appeared years ago when many medications started appearing on the market. Governments needed to ensure medications were safe for patients, so before approving them, they requested laboratories to show the benefits of their intervention, typically with a large randomised control trial. This strategy eventually expanded to other areas of healthcare research and practice. The *improving* strategy aims to improve care, rather than trying to prove it. This strategy was inspired by previous research in sociology that showed that treatment was not restricted to the physical nature of the body, but that the lived experience also affected the treatment. As a consequence, inquiry was not concerned with the effectiveness of one treatment over another (as is the case in a clinical trial), but rather with understanding the different effects of a specific intervention.

In the papers of the review, the most common approach was improving care (see Section 4.4). These papers focused on understanding multiple effects on patients' lives and clinical practices. Improving care approaches used techniques that inform about the current situation (e.g., through workshops, interviews, and observation)³⁴ and worked with localised settings. Improving care strategies is important for achieving better care practices, but sometimes technologies also need to be proved. Clinical trials are at times necessary for ensuring patients will receive a beneficial treatment. In the review, trials are quite rare,³⁵ which, while perhaps an artefact of being written for HCI rather than medical audiences, might be reducing the number of systems in research that end up being offered to patients.

To choose an overall strategy, it is important to consider a number of issues. Here, we present five points.

- (1) *Ensuring an adequate involvement of designers with the context* to the intended goal. Limited involvement can provide valuable insights; nonetheless further involvement is likely to reveal, or make more obvious, other dimensions of how the technology influences the life of the patients. If the interest is to understand or evaluate the feasibility of a new technology, a short involvement might be sufficient (e.g., eDiary) to influence future care. However, a longer involvement is more likely to make stronger claims on the adequacy of care (e.g., MONARCA).
- (2) *Stability of the technology*. In early phases, technology will undergo regular changes and adaptations. However, as time passes, it will become more stable. During regular changes, it is probably useful to proceed with an improving strategy. This will allow the system to be adapted to the particularities of the setting, complexities of the tasks, and the culture of the organisation, almost in a trial and error way [Pilemalm and Timpka 2008]. In case technology has been previously shaped, adapted, and is currently stable, conducting a more structured trial might provide additional insights.
- (3) *Methodology*. The two strategies try to observe different aspects of the intervention. An improving strategy will concentrate on understanding how a specific technology is used and, at the same time, adapt to the existing practices not yet supported. The proving strategy, in contrast, will concentrate on specific care outcomes planned in advance and avoid deviating from the initial plan [Craig et al. 2008].
- (4) *Validation*. Introducing a self-care technology in the market may require some sort of medical validation to “prove” the potential benefit of the technology [Commission 2014; FDA 2015], in particular, when a specific effect, such as

³⁴One can argue that a limited involvement, restricted to a couple of days or weeks of use, is not enough to understand self-management and thus unable to improve care. However, the principle of looking at use from a broad perspective would place these limited-scope studies under improving care.

³⁵This situation is quite different if we consider the medical informatics community. In their specific case, clinical trials are quite common and could be even considered the norm.

improving the condition state, is argued. It can happen that the technology being designed does not offer risks for health and, therefore, does not need such a structured validation process (e.g., RemoteLogCam). However, unless a self-care technology is announced as promoting healthy lifestyle behaviour, it is likely to require such validation [FDA 2015].

- (5) *Funding*. Contrary to the general healthcare field, research in HCI is mostly funded by public organisations and not by private funding of laboratories. Therefore, it might be difficult for an HCI research group to acquire the means for conducting large trials, unless they are financed by private institutions planning to introduce the technology on the market.

Based on our analysis, the following questions seem to be relevant to discuss when planning a study:

- What is the objective of the study to prove or improve a specific technology? Are the chosen methods aligned with this objective?
- Are the methods providing a broad perspective of care?
- Are the resulting claims appropriately stated to fit the objective, with limitations and/or future work clearly noted to achieve the broader perspective?
- Who are the research insights targeted to? Do the research insights benefit people in their daily lives?
- How long can the funding sustain proper evaluation?

5.4. Choosing Devices: Chronic Condition or Daily Life Orientation

Traditionally, self-care technologies have been medically oriented prioritising medical measurements and ignoring the lived experience of patients [Fitzpatrick 2011; [Storni and Bannon 2012](#)]. More recently, designers of self-care technologies also started to prioritise the lived experience of patients and tried to better integrate the design of technologies in everyday life. Each technology or prototype embeds different meanings and values. Therefore, we now discuss some of the issues one should consider when choosing a device.

- (1) *Stigmatisation caused by the design*. In some cases, it will be possible to perform self-care activities at home (e.g., HeartPatients); in others, patients may have to bring self-care technologies with them (e.g., MONARCA). When the technology is used at home, its appearance can be more “medical,” but even in those cases, patients may want to hide it from for example visitors (e.g., BoundaryWork). If technology needs to be carried around during the day and used potentially close to others, it should have an appearance that does not resemble sickness, not to stigmatise patients. One way to circumvent this stigmatising situation is to use personal devices that do not carry meanings of sickness. For instance, smartphones have been a popular choice used in the papers of the review (e.g., MONARCA, FoodQuiz, RemoteLogCam). Other studies also point out to this choice [[Tentori et al. 2012](#); [Klasnja and Pratt 2014](#)], probably because smartphones are familiar devices, can be carried around by the patient everywhere and retain data connection, and do not specifically stigmatise because of their ubiquity, all of which may help in integrating it with everyday routines.
- (2) *Reliability of the technology*. It may be hard to ensure reliable functioning in personal devices, like smartphones, in which a number of different applications are competing for the same resources. There are the risks of short battery life (e.g., Jog Falls), erroneous feedback due to poor sensor data recordings (e.g., COPDTrainer), connection problems (e.g., Report-Asthma, COPD-Therapy), and so on. Therefore,

when choosing a device, it is important to reflect on the reliability it can offer, so as not to put the patient's safety at risk.

Based on our analysis, the following questions seem to be relevant to discuss with patients, carers, and clinicians when designing or choosing devices:

- Does the self-care technology integrate well with the activities, routines, and settings of patients' everyday life?
- Can the self-care technology stigmatise the patient that uses it?
- Do patients attribute a meaning to that device that will not be detrimental to their health or care?
- Is the chosen device adequate for the specific case of use? Can it reliably and safely perform its function?

5.5. Game-Based Approaches or Reducing the Chronic Condition to a Game

Self-care technology often uses game-based approaches to engage patients in treatment. Game-based approaches can usually be categorised into two types: serious games and gamification [Deterding et al. 2011]. Serious games consist of full game systems for nonentertainment purposes, while “gamification” supposes the application of game design elements into the design of a system or an existing activity³⁶ [Deterding et al. 2011; McCallum 2012]. The goal of game-based approaches is usually to make self-care activities and treatments more enjoyable, motivating, and engaging. However, having an overemphasis on the “fun factor” [Monk 2002] may be detrimental to self-care.

The papers in the review present both positive and negative examples of using game-based approaches. We can find two studies showing positive results. The first, FoodQuiz, used several gaming aspects, such as levels, feedback, avatars, score, score list, and minigames, to motivate children to count carbohydrates. In the second example, ADMS, researchers reported that parents gamified a common blood glucose monitor, by making their children compete for the highest or lowest blood glucose value. This social element made the self-monitoring activity funnier and enabled children to understand that others shared the same chronic condition and monitoring activities. However, not all game-based approaches had positive results. MONARCA v1, for example, reported a failed attempt to use game design elements during their design process. Inspired by Consolvo et al. [2008], the researchers suggested a “scale, an equaliser, a river, a volcano, a dart board, and a radar” as a visualisation, which caused disparate opinions, with participants feeling their chronic condition was being reduced to a game. The mixed results of the studies show that game-based approaches should be used thoughtfully. We highlight four points that can help to decide how or when to use game-based approaches.

- (1) *The focus of technology should be on the treatment.* Technology should keep a focus on treatment goals, even when using gaming approaches, to avoid the wrong perception of reducing the condition to a game (see MONARCA v1). When patients use the system, they should understand it as a potential benefit. This means that if a user has a game for learning to manage diabetes, it should be clear to her or him that this experience can be positive for their management.
- (2) *Consider the danger of overengagement.* Competition (e.g., against the game) induces a high level of engagement. This can increase the motivation for self-care, but it can also hinder the thinking that has to be part of the blood glucose measurement (see FoodQuiz). For this reason, when considering game-based approaches,

³⁶Gamification is not necessarily restricted to the designed artefact, or planned *a priori*. It is also possible to observe gamification phenomena being created by the users [Deterding et al. 2011].

the possibility for overengagement should be weighed and balanced according to the situation at hand.

- (3) *Consider individual differences in perspectives of games.* We have seen how individual differences play an important role in the design of technology and how different game-based approaches can provoke different intended or unintended results. Therefore, all stakeholders should be involved in a careful assessment of users' needs to identify the most beneficial approach using gaming or not.
- (4) *Consider different motivating strategies.* The application of game-based approaches can increase people's motivation to perform self-care activities, especially when there is a lack of engagement in self-care (see RemoteReminiscence). However, there may be other alternatives for motivating people to their care, such as sharing and learning from peers, or others. Getting a deep understanding of the self-care activities will help designers to account for the different alternatives.

Based on our analysis, the following questions seem to be relevant to discuss when designing:

- Which gaming elements can be positive for the system?
- What is the motivation for using those gaming elements?
- Is there a risk that the chosen gaming elements reduce the chronic condition to a game? Are there any ways to reduce that risk?
- How does the design promote people's intrinsic motivation to self-care over external motivators caused by game-based approaches?
- Does the design promote a high user engagement that may remove the focus from the care practice?
- How are the health benefits of using game-based approaches in self-care perceived by the patients?

5.6. Visualising Chronic Condition Data: Providing an Overview or Displaying Contextualised Values

Traditionally, self-care technologies have used very simple interfaces. The blood glucose monitor, for instance, offers a single value with no further analysis support. However, more and more self-care technologies are providing alternative visualisations³⁷ of numeric values to enable patients to engage in self-discovery, decision making, and to gain insights from their health data [Fekete et al. 2008]. We discuss two types of visualisations centred around overviews, and contextualised values.

Overview visualisations give a retrospective view of health data (see Figure 3, on the right). By stripping values from their larger context, it is possible to represent health data according to a specific parameter, such as time. This perspective enables people to compare different values, to become aware about their health status, and to even find patterns to test and adjust their self-management. For example, when seeing a slightly higher blood pressure value in a plot, the patient could try to remember what was unusual about that day that could cause such an increment. Examples of overview interfaces include plots (e.g., AssistingInsulin, TiY, BP@Home), colour-encoded spreadsheets (e.g., ADMS), and the use of avatars (i.e., a turtle in Jog Falls).

Visualising contextualised values is another strategy for representing values of health parameters (see Figure 7). Instead of stripping values from their context, this visualisation type enriches them to foster reflection. Contextualised values can trigger reflection about a specific moment in the past. For example, in MAHI v1, patients

³⁷A *visualisation* is defined as “the use of computer-supported, interactive visual representations of data to amplify cognition” [Card et al. 1999, p. 7]. The objective is not to create good-looking plots but to facilitate the acquisition of new insights.

reported to have only noticed how they were eating when they saw the pictures that were attached to their glucose values. Furthermore, the documentation of values may enable patients to reflect on their actions at the moment they document them. In some cases, health parameters are enriched manually, using pictures (e.g., Jog Falls), audio (e.g., MAHI), or textual notes (e.g., eDiary). There is also the possibility of enriching the values automatically, using for example weather information (e.g., AsthmaProbes) or phone activity (e.g., MONARCA).

The visualisation strategy chosen for a specific interface has implications on how patients understand and manage their chronic condition. Here, we analyse and discuss five points for choosing a strategy to use.

- (1) *Level of understanding of health data.* When patients are starting to learn about the chronic condition, the overview visualisations are probably more useful, because they presents data in perspective, with different values that can be compared, and subtle clues to analyse the data (e.g., AssistingInsulin, MONARCA, BP@Home). When a patient is more knowledgeable about the condition, visualising contextualised values might be more beneficial, as it can enable reflection on multiple dimensions for the same value (e.g., MAHI).
- (2) *Amount of data to analyse.* The visualisation of contextualised values enables one to focus on a specific value and its context, however, it is dependent on the fact that the patient knows which value to investigate. If data is not easily filtered, it may be better to use an overview visualisation to start with.
- (3) *Over-simplification of health data.* The overview visualisation focuses on the evolution of values and not on their context of occurrence, which can contribute to a false sense of causality. Therefore, it is important to provide additional cues for avoiding a superficial interpretation. In case cues are not enough, it might be better to opt for showing a contextualised value, because it does not suffer from the same issue.
- (4) *Possibility to enrich a value.* In some cases, values can be enriched with contextual information, for example, adding a picture of a meal to a blood glucose value (e.g., MAHI). In other cases, there might not be easy ways to capture useful data that can complement a value. In these cases, it does not make sense to display contextualised values visualisations, as they do not add any meaning to the interpretation.
- (5) *Complementary visualisation strategies.* Our presentation of the different strategies may give an idea that designers should choose one strategy over the other. However, it might be beneficial to combine both strategies. For example, it might be possible to observe the same health data using different levels of aggregation (e.g., TiY) and so support the exploration, browsing, and self-discovery of health information.
- (6) *Multiple visualisation perspectives for different types of users.* Self-care technology can, for example, provide different interfaces for patients, carers, and clinicians (see different visualisations in eDiary). Using different visualisations can enable a collaborative sense-making [Fitzpatrick 2011], bridging the gap between clinical and nonclinical settings. Each visualisation strategy should be tailored to the specific interests of the different stakeholders, as well as integrate into their everyday lives and work routines.

Based on our analysis, the following questions seem to be relevant to discuss with patients, carers, and clinicians when designing self-care technology:

- Is the type of visualisation adapted to the characteristics of different patients and the health data they want to reflect on? If not, can patients configure it to their needs?
- Is the visualisation suited for different levels of understanding of the health data (e.g., stages of the condition)?

- Does the visualisation strategy take a possible information overload into account?
- Does the visualisation oversimplify the interpretation of health data from important characteristics?
- Does the contextual information attach meaning to the measured values?
- Does the self-care technology support self-discovering and self-reflection to different types of users with different perspectives (e.g., patients, clinicians)?

6. CONCLUSIONS AND FUTURE WORK

This study concentrated on understanding the body of work in HCI on the theme of self-care technologies for chronic conditions, focusing on the everyday experiences of patients using those technologies. We have reviewed studies from key journals and conferences in HCI that reported on the use of self-care technology by patients and carers. Using the GTLR method, we were able to derive trends, tensions, and opportunities for using self-care technology. In particular, we analysed the opportunities that have been created by technology, the different use configurations that were promoted, the technological components employed in the systems, and the methods used by HCI researchers. While reflecting on these trends, a number of design tensions emerged, highlighting the complexity of designing for this particular domain. We have articulated these design tensions along with questions “to think with” so that they can fuel discussions when designing a new self-care technology.

Previous work has reviewed technologies for self-care (e.g., Koch [2006], Paré et al. [2007], and El-Gayar et al. [2013]). However, these studies often promoted a medical perspective and inadvertently disregarded the perspective of patients and the mediating role of technology in self-care. This article adds to existing literature by unpacking how patients and carers use and experience self-care technology. Our work also complements existing reviews from related fields (e.g., medical informatics) by providing an overview of the work that has been published in HCI venues.

We conclude this article by outlining the characteristics of an HCI lens in studying self-care technologies and then discuss opportunities for future work.

6.1. The HCI Lens in Working with Self-Care Technologies

In the beginning of the article, we mentioned that self-care technologies span multiple disciplinary areas, each with its own lens. In this section, we characterise the perspective an HCI lens brings when working with self-care technologies, making use of the papers in the review.

Researchers using an HCI lens seem to pursue two broad *goals* with self-care technology. The first, more theoretical goal, is to understand how technology can support and influence activities, in this case self-management. We observe this goal when papers in the review try to understand how technology supports patients, how it changes their activities, and how it shapes their everyday lives (the improving strategy). The second goal, driven by action, is to provide better tools for managing their condition. Formal assessment of care outcomes in general is not sought, as in medical or biomedical informatics (the proving strategy), but health outcomes are rather arrived at as a consequence of providing better tools for patients and informal carers. The HCI lens does not promote the introduction of technology at all cost, nor is it interested in designing the best technology to measure parameter x ; instead, the strength of an HCI lens is in understanding everyday self-care practices and in trying to improve the quality of life of patients through the use of technology.

Using an HCI lens in self-care also entails engaging with *complex contexts* and relationships, for example, with multiple actors (e.g., patients, carers, clinicians), different settings (e.g., the home, the hospital), and resources (e.g., self-care technology). Furthermore, no two patients are the same, which creates different ways of appropriating

self-care technology. It is a great challenge to know what “needs” to be designed when so many stakeholders are involved and when the individual perspectives are so varied. A strength of the HCI lens is its ability to embrace this complexity, for example, through the use of qualitative methods, as seen across most studies in this review.

In dealing with these contexts, and being concerned with the more exploratory end of the technology lifecycle, the *approach* of an HCI lens consists mostly of design-oriented studies and, later, small-scale feasibility studies. Following some grounded preparatory phases, researchers select or create a technology to fit the needs of a localised group and then pilot it with a small group of people. As the goal is not to “prove” the clinical effectiveness of a specific technology, short and unstructured evaluations are the norm, drawing on qualitative or mixed methods to study the multiple effects of technology. Interestingly, researchers tend not to make their theoretical groundings explicit. This is evidenced by the omission of a self-care definition, the lack of reference to design approaches (e.g., participatory design), and the absence of details regarding theoretical framings (e.g., behaviour change theories) that, in some cases, influenced the development of the technology. The absence of theoretical groundings, though common in HCI [Hekler et al. 2013], should be a source of reflection for the community, as there is the risk of disregarding relevant previous work from other disciplines and promoting a fictional naïve perspective.

The *outcomes* of research using an HCI lens tend to be knowledge about how people self-manage their conditions using technology, crystallised in prototypes, or in theoretical accounts. The technology itself is not a “black box”, or an “intervention” that researchers put on trial. Technology consists rather of a set of decisions, taken before, as part of the design process, or after the pilot that provides suggestions to be taken into account in the future, the so-called implications for design emerging from studying the use of technology.

6.2. Opportunities for Future Research

The HCI lens described earlier has a number of strengths, including its ability to embrace complex settings and provide better tools to patients. In this section, we suggest how to expand the research in self-care technology, taking into consideration the strengths of an HCI lens and the good work that has already been done.

6.2.1. Focus Further on Patients’ Everyday Life Experience. Traditionally, self-care technology has been concerned with supporting the medical aspects of living with a chronic condition [Fitzpatrick 2011; Storni and Bannon 2012]. The goal of self-care technologies has been to quantify, to track, and to keep the condition under control. This overemphasis on the medical aspects of the chronic condition provided a partial picture of what self-care is. The users were *patients*, motivated to perform self-care, interested in collaborating with clinicians, and ready to put tight control in front of their interests and everyday lives. The truth, however, is that this objectified picture is somewhat detached from reality. In everyday life, we meet *people* that have different interests, hobbies, values, roles, and that, by chance, happen to have a chronic condition that sometimes requires time and concern [Aarhus and Ballegaard 2010; Storni 2010].

We argue that an HCI lens on self-care can contribute with developing and studying self-care technology that is not solely concerned with medical aspects of the condition. Although these technologies may be less interesting from a clinical outcome perspective, the studies in the review show how technology can be crucial in helping patients to adapt to their health situation in everyday life. Let us look at one example of self-care focused on the lived experience from the review. In TiY, a patient used the system to keep track of the effect of a car ride on her blood glucose level. It is hard to imagine that these insights would be relevant for adjusting the patient’s overall treatment at

the clinician's office. However, this piece of information enabled this patient to drive more safely without, for example, experiencing a hypoglycemic episode. Moving the research focus away from only considering the medical concerns to also consider the lived experience with the condition can have a great impact in the quality of life of patients. Instead of being limited to clinical objectives, such as keeping a symptom under x or y value, self-care also becomes focused on the mundane decisions and activities people living with a chronic condition engage with in their daily lives, negotiating these among the various other concerns of daily life.

In some way, researchers have started to investigate how to better integrate the lived experience of patients into self-care technologies. Evidence of such effort can be seen in the investigation of the daily practices of self-care before designing a specific technology solution (see Section 4.4) or in the use of personal devices, such as smartphones (see Section 5.4), which embed or fit better into people's routines, habits, and could, therefore, contribute to a self-care that is more grounded in the lived experience.

Taking an everyday life focus is challenging, requiring a great involvement with patients from early phases of design, to understand their needs, challenges, and concerns. Everyday practices are entangled with every other aspect of life, so understanding patients' actions requires one to investigate the routines and activities that make patient's lives. In understanding everyday life with the condition, literature from related areas, such as sociology of health or nursing, will be important to take into account, as these communities have also long been concerned with investigating the perspective of patients.

As self-care researchers in HCI move the focus away from an objectified view of health to a more holistic view centred on everyday life, they are likely to have a great impact on the lives of patients. This impact will be even greater as the remaining related areas developing technology, such as medical or biomedical informatics, are less likely to be concerned with technology that is not clinically oriented.

6.2.2. Consider the Existing Collaborations in Self-Care. Self-care involves a number of different collaborations [Strauss et al. 1985]. As previously mentioned, informal and formal carers are likely to influence or play a role in the self-care of the patient. However, these collaborations were sometimes neglected in the self-care technologies reported in the review.

Informal carers, in particular, were not attributed the role of users in most self-care technologies in the review (see Section 4.2), even though the HCI lens promotes the involvement of informal carers as part of understanding the context of self-care. By removing carers from self-care technologies, designers have created a self-care that seems to be individually performed by the patient, which might not match the everyday practices that are in place. By considering the role of informal caregivers in the design of self-care technologies, the developed systems will better integrate into the everyday practices and complement the individual self-care that the technologies already enabled.

Formal carers are well represented in the review; nonetheless, their participation was mostly restricted to doctors (see Section 4.2). It seems like a paradox that one doctor assures all interactions regarding self-care, when there are many actors involved, such as nurses, therapists, and others. Expanding the representation of other clinicians in technology design will provide technology that is more suitable for the context in which it inhabits. There is also the possibility of improving the quality of care, as different specialities can provide their contribution and expertise.

6.2.3. Increase Influence in Medical Research and Practice. HCI research has the potential to point to new design directions for self-care technologies that improve medical

research and practice.³⁸ However, at the moment, its influence is limited because most studies investigate the feasibility of prototypes, not reaching clinical trials, which are the basis for evidence within the medical community. If HCI research in self-care technologies is to achieve a greater impact in medical research and practice, it needs to consider how to shape its methods and argue for its contributions within this broader healthcare research and practice, and how to bridge from feasibility studies to clinical trials.

Bringing an HCI lens to medical research is critical for ensuring technologies are designed and evaluated with a deep understanding of everyday practices and so have the potential for greater effectiveness and impact. Technologies need to scale, from small prototypes to entire care structures. This requires a number of different pilot studies exploring different functionalities or perspectives. Furthermore, there is a need for ensuring the safety of technology. This might require the engagement of researchers with long-term studies integrating, in some cases, randomised control trials to show the possibility of new care practices over existing ones. Embracing such study methods will enable HCI researchers to attract healthcare funds, or raise the interest of medical device producers and laboratories, that can ensure the funding for conducting such pilot studies.

Studying all phases of use is also necessary for designers to understand how people use self-care technology in their daily lives. It is not enough to study early prototypes or the first months of use. To have an impact on the lives of patients, self-care technology studies should include longitudinal work spanning years, from initial stages of self-management to more advanced ones, and until disposal.

It can also be useful to expand research to a range of unexplored chronic conditions, with the purpose of bringing new insights that can help rethink or redesign existing self-care technologies. The current knowledge about self-care in HCI has largely been developed from a couple of key conditions, most prominently diabetes. While many chronic conditions share characteristics, they are also many differences, for example, in regarding the progression and fluctuations of the disease state. Expanding the types of chronic condition we engage with will provide a better understanding of the commonalities and diversities among conditions, enabling a better design of technological support across conditions.

6.3. Opportunities for Extending This Review

We suggest that the opportunities and issues presented earlier can inspire others to investigate self-care technologies and practices. We also see two main ways of building on this review.

The first consists of *creating a review of self-care technology involving different disciplinary research areas*. In this work, we have reviewed self-care technologies published in HCI venues. This was a necessary step because such review did not exist yet. However, self-care technologies span over different research areas, so it is not possible to have a comprehensive picture of self-care technologies unless one reviews work from different areas. In the introduction, we briefly mentioned the work of medical informatics, but there are also important contributions published in, for example, biomedical informatics, sociology of health and illness, and science and technology studies. Using our review and similar ones from related research areas (e.g., Paré et al. [2007]), it is now possible to create a meta-review that embraces work in different areas and, therefore, provide a more comprehensive picture of self-care technology.

³⁸Previous work has pointed to the need for further communication between HCI and medical and biomedical informatics areas [Pratt et al. 2004; Chiasson et al. 2007], for technologies for the clinical setting. In this section, we refer to the advantages an HCI lens can bring to self-care technologies particularly.

The second way is to *complement our review of (chronic) self-care technologies with systems for wellness and disease prevention*. There is a growing body of literature in HCI on using self-care technologies for promoting healthier lifestyles, some of which under the umbrella of personal informatics. This has not been the focus of our review, as the users of such technology have not yet developed a chronic condition. However, future work may focus on expanding our review by reviewing self-care technologies for well-being. Comparing such work with this review will provide insights that can be useful for both communities.

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