

This forum is dedicated to personal health in all its many facets: decision making, goal setting, celebration, discovery, reflection, and coordination, among others. We look at innovations in interactive technologies and how they help address current critical healthcare challenges. — Yunan Chen, Editor

From Medicalized to Mundane Self-Care Technologies

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Living with chronic conditions is extremely complex and demanding. Patients and carers often need to monitor symptoms, manage treatment, and deal with disability and other impacts, while accepting that they will continue having these issues throughout their lives. Care in these contexts happens mostly at home and in everyday life; it is traditionally called *self-care* to distinguish it from professional or medical care. Self-care technologies have the potential to support the self-care of patients and carers; however, these tools often embody a medicalized perspective and fail to support the mundane work of performing self-care. In this article, I suggest a reorientation of self-care technologies that gives primacy to people’s mundane activities, their values, and their quality of life, to better support patients and carers.

HIGH GROWTH BUT LOW UPTAKE OF SELF-CARE TECHNOLOGIES

The past few years have seen a boom in the number of technologies for supporting people with chronic conditions [1]. *Self-care technologies*, as I call them, take different forms, from apps to medical devices, and are engineered, for example, to remind people to take medications, to measure body signs, to monitor symptoms, or to enable rehabilitation at home.

The potential of self-care technologies is great, considering the daily challenges of patients and carers living with chronic conditions.

Nevertheless, the uptake of self-care technologies has remained low [2]. Studies investigating this low uptake point to issues related to regulation, incentives, evidence, and, perhaps more relevant to this community, design. In fact, research reports patients rejecting self-care technologies because tools were forcing incompatible practices into their self-care [3]. A similar reaction is observed in self-care technology pilots, where patients decline to participate due to the expectation of being required to change their self-care practices in a detrimental way [4].

It is normal to expect minor changes in self-care when adopting a technology, but for patients and carers, changing to accommodate the technology might negatively affect their self-care and their quality of life. This issue alone should motivate our community to reflect on how well technology is supporting patients and carers.

MEDICALIZED SELF-CARE TECHNOLOGIES

Many self-care technologies seem to embody a medicalized perspective

Insights

- Self-care technologies have often been medicalized, disregarding the practical work of achieving self-care successfully.
- Recognizing the mundane work of self-care opens new directions for design to support the everyday lives of patients and carers.
- HCI is especially well positioned to lead the change from medicalized to mundane self-care technologies.

that disregards the mundane work of engaging in self-care. Even though patients and carers engage in self-care activities by themselves, self-care technologies are designed to be used with clinicians within structured processes, often mimicking activities as they happen in medical institutions. These technologies tend to focus on activities where clinicians can potentially be involved, such as reminding patients of medication or tracking symptoms. Moreover, the features and ways of operating these technologies seem to promote constant oversight and guidance from clinicians, as if patients were hospitalized.

Medication reminders are good examples of medicalized self-care technologies, in the sense that they reproduce medication practices from hospitals. For example, they usually have a single schedule for weekdays, weekends, and holidays, even if many medications can have their intake schedules adjusted. Snoozing or delaying options are mostly absent from reminders, implying that patients need to take a medication once they see the reminder, similar to when a nurse comes to a patient’s bed at the hospital. Moreover, adherence plots are often part of these technologies, implying that missing intakes is always a sign of noncompliance from the patient.

Technologies for monitoring symptoms and signs also have characteristics that remind us of a medicalized perspective. Those that can be tracked are consistently the ones with clinical value, such as a symptom that can indicate exacerbation or trigger treatment adjustments.

	Medicalized self-care technologies	Mundane self-care technologies
Focus	Medical care processes	Medical care processes, mundane challenges, and mundane work to successfully achieve self-care
Purpose	Improve reference health outcomes	Improve quality of life in the terms defined by the people living with the condition, which also includes their health outcomes
End goal	Improve adherence	Improve health literacy and appropriate decision making in everyday life
Role of clinicians	Medical care and self-care coordinators	Medical care and self-care advisors
Role of patients/carers	Data providers and instruction followers	Coordinators of self-care and of the challenges and priorities in medical care

Table 1. Characteristics of medicalized and mundane self-care technologies.



Figure 1. A mundane medication reminder could enable people to delay their medication to better fit their activities.



Figure 2. A mundane rehabilitation tool could be designed to monitor informal exercise activities, which can be appropriate for the patient and have other purposes relevant to the person.

Measurements tend to be programmed according to the schedule with clinical meaning, and systems often do not enable patients to visualize or analyze the data they collect.

We can also observe elements of a medicalized perspective in rehabilitation tools. Even in the novel rehab tools that tend to draw on serious games or playful elements, the exercises performed are those with stronger clinical impact. The exercise routines that are adopted are also the ones with more clinical evidence, and there is little space for personalized approaches. Even though the exercises are performed at home, there isn't much difference from how they would be performed at a rehabilitation clinic.

MOVING TOWARD MUNDANE SELF-CARE TECHNOLOGIES

Although many self-care technologies have embodied a medicalized perspective, the self-care of chronic conditions is filled with mundane activities and challenges [5]. I use the term *mundane* in relation to self-care to highlight the practical, routine, or banal work that is part of performing self-care successfully in everyday life.

While studying the self-care of people living with Parkinson's disease, I saw, for example, relevant mundane work for taking medication. Patients and carers would place medication boxes on the kitchen table or their bedside table to provide visual reminders for taking medication during meals or before going to sleep. They set the alarm clocks of their mobile phones to ring at medication times, and they constantly checked clocks to avoid missing a pill. Some patients advanced

or delayed medication to better deal with commitments and activities. Since the effects of Parkinson's medications wear off after a few hours, patients experimented with intake times to improve control of their body during the times that were most important for them. When advancing or delaying a pill, patients had to adjust their subsequent medication intake times to maintain the appropriate distance between pills and avoid dyskinesia, a symptom that appears when a patient has too much medication in their body. If we consider the practice of remembering medication from a medicalized angle, it is simply about reminding them to take the pill. But there is important mundane work involved in successfully taking medication in everyday life.

Reorienting the focus of self-care technologies to focus on the mundane work of self-care will not be straightforward (Table 1). The solution does not seem to reside in simple usability corrections to interfaces, but rather will require us to consider the value frame that underlies our understanding of self-care and the role of self-care technologies within this frame. That does not mean there is nothing we can do, though.

For example, when designing a medication reminder, we can consider including multiple medication schedules and offer ways to advance, delay, and replan alarms (Figure 1) to enable people to weave their medication into their day-to-day activities, avoiding reminders at troubling times and reducing missed intakes.

When designing a technology for monitoring symptoms, we can enable

patients and carers to monitor clinically relevant symptoms, but also to measure the impact of experimentations and other activities for learning about the condition. The symptoms and signs don't need to be restricted to the relevant clinical features; they can be more holistic, encouraging people to learn about different symptoms and the ways in which their body responds and reacts. Moreover, visualizations can be made available to patients and carers, as they are the ones who can benefit most from them.

Rehabilitation tools can be engineered to detect informal kinds of exercise with potential to benefit patients (Figure 2), in addition to formal activities. The patients could be encouraged to find activities in their everyday life that include the exercises they need to perform, so that rather than following a plan, they would just be going about their activities. The repurposing of rehabilitation activities would better connect rehabilitation with everyday life, potentially increasing therapy engagement.

The following are some ideas that can be used to explore how to better adapt self-care technologies to the mundane work involved in self-care.

From structured care processes to the mundane work of self-care.

As described earlier, self-care technologies have had a tendency to enable structured medical care processes. This could be a result of having clinicians involved in the design of many technologies, or the great abundance of papers describing medical-care scenarios. However, we cannot restrict the design of self-care technologies to activities with clinicians. Apart from the minutes people spend with their clinician, they are responsible for everything that happens regarding their care. Focusing on the practical issues people face and the activities and strategies in which patients engage will provide material for designing self-care technologies that better support everyday life with a chronic condition. Observing practices that contribute to self-knowledge and decision making in everyday life will also be useful.

From reference health outcomes

to quality of life. Recognizing the mundane work of performing self-care also orients our gaze to the multiple priorities involved. Patients and carers in daily life are not solely trying to attend to their condition, but also trying to care for family members, work, be with friends, and have fun. Consequently, self-care technologies should adjust their focus away from simply focusing on promoting the reference health outcomes to enabling the flexibility for patients and carers to define what their goals are at each point. The technology does not need to abstain from encouraging healthy self-care behaviors, but it is up to patients and carers to define what is best for them at each point. Helping patients and carers understand the different advantages and inconveniences of their options can also be a relevant role for self-care technology to play.

From care coordinators to advisors.

The medical literature has long argued that clinicians are advisors in medical care. However, in many self-care technologies, clinicians are seen as care coordinators. Designing mundane self-care technologies requires a change of roles. For example, if patients and carers are in charge of their self-care, they need to be able to monitor all symptoms and signs that are relevant for them to learn about the condition or adjust their self-care. Patients and carers need to be able to visualize the data they collect and be able to structure the data presentation, for example, for discussing it with others living with the condition or with their multiple clinicians.

It might be relevant as well to question the pervasive role of clinicians in self-care technologies. Just because self-care technologies deal with chronic conditions does not mean that clinicians should always have a direct role in the system. Thinking about what patients and carers need that does not require a clinician could be an interesting way of uncovering mundane day-to-day challenges.

A PLEA FOR THE CHI COMMUNITY

My argument is that reorienting self-care technologies to focus on mundane

self-care work over medically oriented self-care will better equip researchers and designers to design for the practical work of patients and carers. The CHI community has played an important part in the development and understanding of self-care technologies, and since we know how to study the lives of patients and carers, and their use of technology, we are especially well equipped for driving the design of mundane self-care technologies. Thus, it is up to all of us to use our fieldwork insights and design skills to make a difference in the lives of patients and carers.

ENDNOTES

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