# Chapter 2
# On Challenges Designing the Home as a Place for Care

**Erik Grönvall and Stefan Lundberg**

## 2.1 Introduction

Demographic trends over the next 15–20 years show an increased percentage of people aged 65+ in western countries. This shift in the composition of the population is expected to put a great deal of pressure on societies' financial resources all over the industrialized world. This demographic change brought about the definition of an 'ageing-in-place' philosophy [1], which resulted in more nursing and personal care moving out of the hospitals and professional care institutions and into private peoples' homes [2, 3]. From time to time this relocation of care can turn private homes into wards or places for rehabilitation and care.

A number of studies have shown that home-based care has been positively perceived from both a patient and societal perspective (e.g. [4]). To sustain home-based care, the care receiver might have to be subject to both technological and human support. Hence, Information Communication Technology (ICT) has for some time now been regarded as an important tool in handling the growing number of older adults without reducing the quality of care. Technological support for home-based healthcare range from simple solutions such as pill boxes, personal social alarms and blood pressure measurement devices to more complicated technologies such as dialysis machines and oxygen flow/breathing apparatuses. Additionally, home care

E. Grönvall (✉)
IT University of Copenhagen, Rued Langgaards Vej 7, 2300 Copenhagen S, Denmark
e-mail: erig@itu.dk

S. Lundberg
KTH Royal Institute of Technology, Alfred Nobels Allé 10, 14152 Huddinge, Sweden
e-mail: slundb@kth.se

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workers and nurses may visit a home regularly, even many times a day, to support the 'patient at home'. The above mentioned home-based care assistance range from help to get dressed, personal hygiene to more specialist interventions such as providing injections or doing bio-measurements.

Much of the HCI research within home-based healthcare has focused on designing novel technological solutions or on ergonomics and usability concerns related, for example, to how older adults can be supported by technology and how they can handle the introduced technological aids. However, as the authors argue in this chapter, the consequences of implementing pervasive healthcare solutions in private homes may go beyond application specific considerations, such as the selection of the right bio-sensor or the development of a user friendly interface. The authors suggest that, in an extension of medical and usability demands (e.g. to be able to operate a device and interpret an interface), other challenges exists that should be addressed already at design-time. Home-based healthcare may not only be an issue for the patient (and the immediate family) and the day-to-day healthcare provider but may include and affect also the local community, regional, national, and in some cases even global concerns.

This chapter exemplifies non-functional-related aspects of home-based healthcare (i.e. aspects that are not directly related to the medical functionality of a device or how a person can interact with a medical device) and discusses their impact on the individual patients, their care providers and the society at large. The seven challenges discussed in this chapter are: (1) Appropriation, (2) Aspects of control in multi-site healthcare scenarios, (3) Societal concerns, (4) Heterogeneity of care providers, (5) Mobility, (6) Installation and maintenance, and (7) Training and learning. From the authors perspective have these challenges not been satisfactorily considered in most home-based healthcare designs despite the fact that they are indeed important when designing for holistic and sustainable home-based healthcare scenarios.

More specifically, this chapter aims to raise awareness about non-functional aspects of home-based healthcare, which can both inform and challenge large scale implementations of home-based healthcare technology. The focus of this chapter is to provide foremost HCI (Human Computer Interaction) designers, but also patients, healthcare professionals, policy-makers and politicians with an understanding of the issues that would be beneficial to address when designing home-based healthcare solutions. We also propose strategies on how to identify, address and work with the above-mentioned challenges in home-based healthcare design projects.

The rest of this chapter will be outlined as follows: The chapter will start with a description of Sect. 2.3 within home-based care and the Sect. 2.3.2. It is in that section where the above mentioned seven challenges are further described and their impacts on home-based healthcare designs is discussed. This will be followed by an examination of Sect. 2.4. Section 2.5 will then conclude this chapter.

## 2.2 Glossary

**Appropriation** How for example technology becomes part of people's everyday lives.

**Bio-value** A measured biological value, for example SpO2, pulse or body temperature.

**Bio-waste** Discarded medicines, cytotoxic drugs, infected tissues, solid waste tubes, catheters, intravenous set etc

**Care network** Constellation of formal and informal care providers.

**CSCW** Computer supported cooperative work

**FCC** US federal communication commission

**HBHC** Hospital-based home care

**HCI** Human computer interaction

**Home-based care** Professional care at the patient's home

**ICT** Information communication technology

**Informal care** Care provided by a relative, a friend or voluntaries

**In-patient** A patient in the hospital

**IP** Internet protocol

**Non-clinical settings** The patient's home, workplace or vacation resorts

**PD** Participatory design. Design together with current and future users and other stakeholders.

**QoS** Quality of service. A measurement of quality (e.g. up-time, mean time between failure (MTBF) and bandwidth).

**Self-monitoring** Monitoring of bio-values done by a person for his or her own needs.

**SIAT** Swedish institute of assistive technology

**Social alarm** A safety alarm system. Usually connected to the telephone system with an alarm-button worn by the user so s/he can call for help if needed.

**SCAIP** Social care alarm internet protocol (a Swedish standard for how social alarm communicates).

**Tele-monitoring** A collaborative service where a person at home send bio-values to a care professional.

**Tele-care** Collective term for diverse healthcare scenarios including a remote partner.

**User-centred design** Design with a specific (group of) users interests in mind.

**VoIP** Voice over IP. Voice communication over Internet rather than land-line or GSM telephones.

## 2.3 State-of-the-Art

Traditionally, there has been much attention on workplace studies and design for work within the HCI and CSCW (Computer Supported Cooperative Work) communities. Some years ago these research domains increased their interest in healthcare and professional healthcare settings. Since then, numerous research projects have investigated work-related activities within professional care settings such as hospitals. Research projects have for example studied handover between shifts [5] and how in-patient care can be supported through novel technologies [6]. These studies have to a large degree focused on designing care worker support, rather than patient support. More recently, attention has also been given to non-professional care settings such as patients' private homes [2, 7–10]. Indeed, as sensor technology becomes smaller, more stable and more economically attractive and infrastructures such as mobile 3G networks becomes ubiquitous available more and more Pervasive health and home-based care scenarios are explored [11]. As a consequence, a growing number of projects put attention on the patient and other non-professional actors at home.

Two growing application-domains for home-based care, both in research and commercial systems, are tele-monitoring of diverse bio-values and video consultations. However, not all tele-care initiatives have been designed with the end-users' needs in focus. For example is it important to consider how the ICT support is implemented in the users home [12]. Already in 2009 Chan et al. [13] pointed out that the technology development of home-care support was dominated by a technology-push rather than a demand-pull approach and a better understanding of human needs would help put attention on use demands rather than what is technologically possible. In recent years there has however been an increased interest in pervasive health applications and the end-users of healthcare technology, from both industry and the CSCW and HCI research communities [10, 14–19].

The interest in home-based healthcare emerges from a number of different reasons. The translocation of care from hospitals to the patients' private homes (i.e. hospital-based home care (HBHC) or home-based care) can enable a more sustainable and economic care solution from a societal perspective [20]. Patients also tend to prefer home-based care compared with being hospitalized [4]. However, the home (in contrast to the hospital) is not designed as a place for care. Indeed, moving healthcare activities, including treatments of severe diseases, to private homes' and other non-clinical settings (e.g. the patient's workplace or vacation resort) not prepared for these care activities challenge on different levels the patients, their care providers and society at large. Still, many home-based healthcare scenarios explored in research consider only the patient and the care provider (and their respective use settings) in isolation. However, these care initiatives are inserted into pre-existing, larger ecologies of actors, service providers, contexts and geographical locations. As exemplified in Fig. 2.1, the implementation of a home-based care regimen may influence (and be influenced by) other actors than the care provider and patient, for example the water and electricity service providers and the society at large. A home-based care scenario (e.g. enabled through the use of a specific technology) may require a number of services such as broadband internet connectivity, electricity or even water. Home-based treatments may also produce waste such as trash and liquids flushed away in the toilet. The handling of such bio-waste may be regulated in different laws and challenge local wastewater treatment plants and waste disposal services that may not be dimensioned to handle bio-waste at a larger scale [21]. Generated bio-waste (especially in non-clinical settings) may therefore affect the environment at large and hence become a national and international issue. Also, novel treatments and affiliated technology require education and training.

The effects and relationships exemplified in Fig. 2.1 may not be directly relevant to consider in any small-scale test or local implementation of a home-based care system. As an HCI researcher it may therefore be hard to identify a link between for example one's research project, national legislations and potential environmental effects a wide-spread use of a system may have. However, neither technology nor design is neutral and it may be fruitful to envision the effects of large-scale deployment of research projects and solutions. There is a risk that we fail to understand the full cost and effects of moving care out of the hospitals and into private homes if we neglect the societal effects of implementing diverse home-based care scenarios. Figure. 2.1 also illustrates the fact that we in our design work normally only consider the most obvious consequences such as education and installation to some degree, but not the environmental impact at all. The 'red' arrows (Initial action arrow + arrow going to Education and Support) represent the traditional focus and the 'blue' arrows (Initial action arrow + the following chain of arrows (Sawyer and Waste etc)) the new, extended focus discussed in this chapter.

We will now look at three scenarios illustrating possible effect-chains as a result from implementing care and treatments in private homes and everyday life.

Example 1: The move of advanced care from the hospital to private homes' is happening without any discussion about legal responsibilities and possible cooperation

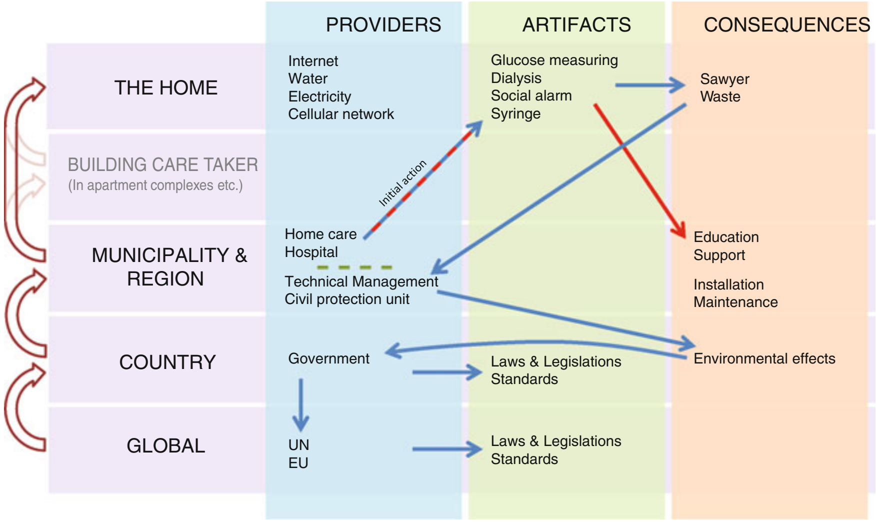


**Fig. 2.1** Example effect-chains and active relationships when inserting care in private homes

between the house inhabitant(s), house owner, infrastructure providers and the caregiver. The society should already be warned by the catastrophes with non-function social alarms due to a switch from analog to digital technology in the telephone system. For example in Sweden several lethal accidents have been reported related to a pre-sequel move from landline telephones to IP based communication systems and the social alarm providers today warn anyone from using analog alarms on digital tele-lines [22]. Since the consequences of a possible catastrophe scenario when medical care is moved to private homes have not yet been legally assessed, the responsibilities are unclear. Is the caregiver responsible if a critical function provided as an infrastructure to a household suddenly is lost with severe consequences for the patient, or is it the house owner, or someone else, that bares this responsibility?

Example 2: In a multi-storey building there is normally a caretaker running different maintenance activities, for example to turn off electricity or water for a couple of hours while maintenance work is performed. What information must the building caretaker have regarding ongoing medical care in the apartments and how would the possible sharing of such information interfere with the patients' privacy? One could hypothesize that in diverse breakdown scenarios, the patient should be (pro)-active which requires a resourceful person that can both mentally and physically act on the breakdown at hand. As home-based healthcare aim to treat ill people, it might not always be the case that the patient has such available resources.

Example 3: Another issue is how the caregiver should handle hazardous waste when treating someone in their own home. Examples of hazardous waste could be contaminated rags and bandages with blood and other body liquids, cannulas, medicine etc. Home care providers have special containers for such potentially hazardous materials that they place in a person's home or that they bring with them.

However, if not only professional home-based care increases in the future, but also self-management of one's health or family-provided care increases, there may be less control of correct management of bio waste generated in non-clinical settings such as the home. With increased home-based care, there will also be much more medication remains in the sewage as some of the administered medication's potent components passes through, and leaves the body, together with the urine (at the hospital, this is handled through for example filtering).

To investigate and develop healthcare solutions for sustainable and large-scale home-based deployment we must understand the above mentioned, and similar, issues. When moving healthcare out of the controlled hospital environments and into private homes there are both easily identified and harder to recognize effects, or effect chains, that may emerge. The example challenges discussed in this chapter should be understood and considered when developing healthcare prototypes and products for a future, realistic insertion into peoples' everyday lives. In this chapter the authors argue that in an extension of medical and usability demands (e.g. to be able to operate a specific device and interpret an interface), other challenges exists that should be addressed or at least considered at design-time. These challenges have not yet been satisfactorily taken into account in much homecare HCI research and design. Our chapter proposes that designers and HCI practitioners should be aware of, and reflect upon how these particularities can challenge the value, feasibility and a wider implementation of their homecare designs.

We will now continue this section with related work, followed by an investigation of the identified challenges.

### *2.3.1 Related Work*

A range of projects have examined how to support a patient in the transition from the hospital to the private home [23–26]. Also, a range of healthcare solutions exists to support patients once at home, for example different tele-medicine and monitoring solutions [20, 27, 28]. Much of the previously reported on homecare design work within research have been rather technology-driven [13], demonstrating for example technological requirements and possibilities with tele-care and tele-monitoring [29]. Homecare applications include for example vital signs monitoring (e.g. heart rate, ECG, and SpO2) [30], diabetes [31, 32] and asthma [33]. Mental health problems such as bipolar disorders [34] have also been investigated as possible candidates for home-based care. Pre-existing off-the-self technologies can also enable self-measurements (not necessarily in a tele-monitoring context) in unsupervised settings such as the home [35]. Two examples of such pre-existing self-monitoring technologies are the thermometer and the blood pressure measuring device.

The (re-)configuration of care challenges both the novel places for care and what it means to be a 'doctor' and 'patient' in such places [28, 36]. Challenges previously reported on in home-based care include (but is not limited to) the acceptance of technology in peoples' homes [37], to find a physical place for the technology within the home [17] and how care technologies can be successfully integrated in everyday life [23], without creating unwanted dependencies or foster social isolation [38]. Others have discussed the need to reflect on how the technology actually gets transported to, and installed in, a person's home [39]. Will for example a solution require broadband or other technical installations and can the required technology be carried home and put to use by the patient him/herself or is there a need of some special service person to perform such tasks [39]? As pointed out by Palen and Aaløkke [14] technology for the home must be extra robust and built to sustain activities also during technology breakdowns. Research projects have also investigated the possible negative effects healthcare technology can have once implemented in a private home (i.e. people can be "alienated by the technology" [40] and experience stigmatization [41]).

Lang et al. [2, 42, 43] have investigated safety concerns in homecare and reports that while risks exists in all healthcare settings, private homes lacks the uniformity of institutional care environments. Lang also mentions that homecare is superimposed on peoples' everyday lives. As described in the work of Palen and Aaløkke [14], people develop their own strategies to integrate for example medication administration into their everyday routines. However, people have also expressed a need to retain control over their lives when prescribed with care at home, something that can challenge adherence or a successful treatment or home-based monitoring [44] if not properly designed for.

User Centred Design and Participatory Design (PD) are common design approaches and these methods both have long track-records within HCI research and design [45, 46]. While PD has been used in diverse healthcare projects (e.g. [16, 23, 47, 48]), the use of PD have been challenged in diverse home-based healthcare scenarios [39, 40]. An important question in many HCI projects, and in particularly PD projects, is what stakeholders and interests should be included and safe-guarded in the design process. A natural minimum of stakeholders to be involved in a HCI and Participatory design project are normally the directly involved actors plus the design team. In home-based healthcare projects this usually intend, a part from the design team, some healthcare professionals directly involved in the project and the target patients [39]. Some projects have used mediators [49, 50] speaking on behalf of some specific user-group, rather than involving that particular group directly. The use of mediators may be applied for example when working with user groups that can be challenging to include as equal partners in a design process, for example due to difficulties to express one's needs and wishes or dementia such as Alzheimer. A mediator can for example be a close family member or care provider that talks on the behalf of the care receiver. The idea of mediators could however include other, also non-person entities, which could benefit from being represented in the design process. However, to consider including legal or environmental entities have not been previously reported on, something that could add novel input to home-based healthcare designs.

### *2.3.2 On Challenges Designing for the Home as a Place for Care*

As presented in the Introduction and Related work sections, much previous research has focused on technological challenges and possibilities when designing and implementing different home-based care scenarios, including self-monitoring, rehabilitation and treatment. These previous investigations has primarily been grounded in an engineering perspective (for example investigating how to construct better blood pressure monitoring devices [51]), a HCI perspective (such as designing for home-based stroke rehabilitation [16]) or a medical perspective (such as how to use game-consoles in rehabilitation and their clinical effects [52]).

The relevance of this previous research can be exemplified by projects like ACCENT (Advanced Component Control Enhancing Network Technologies) that allows effective management of a home care system [53]. Nevertheless, designers of home-based care solutions and services may be both challenged and inspired by more directly consider the effects a large-scale deployment of their home-based healthcare designs may have on for example patients, care providers, organizations, laws, legislations and the environment. A goal of this chapter is to help designers of future home-based healthcare systems to understand what roles their designs may take considering a larger context. To do so, this chapter will now present and discuss seven challenges that we argue can influence the design and realization of diverse home-based healthcare services, namely: (1) Appropriation, (2) Aspects of control in multi-site healthcare scenarios, (3) Societal concerns, (4) Heterogeneity of care providers, (5) Mobility, (6) Installation and maintenance, and (7) Training and Learning. The authors are not aware of HCI related research that actively have reported on, and incorporated, the wider set of challenges (exemplified by the challenges mentioned above) that may affect home-based healthcare designs to different degrees.

Another important aspect of implementing assistive support in people’s home is how this influences the relation between the care receiver, professional caregivers and possible informal caregivers. Ward-Griffin and MacKeever point out that the relationships between community nurses and family members caring for frail elders are complex, dynamic, and multifaceted [54]. A new device that is supposed to support independent living for someone in need for support might stress the formal caregiver by demands such as settings, checking batteries and other supportive actions not normally a part of the work. Bossen et al. [55] have also identified this need and developed a mobile, collaborative tool for professional and informal care providers. The above-mentioned works shows that it is important to understand how a design may decrease or increase the burden for the caregivers around a care receiver and users of healthcare technology.

In the following sections, we present and explore the above-mentioned seven challenges. We have selected these seven challenges as they represent a cluster of challenges that, at a glance, might not be considered relevant in a HCI research project. One reason that designers may not reflect on these (and other similar) challenges may be that normally research projects are not designed for long-term use, large-scale deployment and commercialization. However, the authors' perspective is that an active reflection and understanding of these challenges could both challenge and inform healthcare designs and provide the means for developing more sustainable home-care solutions in the future.

#### 2.3.2.1 Challenge 1: Appropriation

To become part of people's everyday lives, new technology must be interpreted and ascribed meaning. This is an on-going process called appropriation [56, 57] and it is through a dialogue between the user and a contextualized artifact that appropriation takes place. As healthcare technologies are introduced into peoples' pre-existing routines, homes and everyday lives they become, to different extent, appropriated. To design for appropriation can facilitate an acceptance and everyday use of healthcare technologies. Carrol et al. [58] even distinguish between technology-as-designed and technology-in-use. In home-based healthcare scenarios appropriation may be challenged for example due to how a technology is introduced into a person's everyday life. Indeed, in contrast to traditional consumer products, people normally do not select a specific healthcare technology out of interest or its aesthetical properties but rather out of a specific need identified by a healthcare professional.

Furthermore, when developing healthcare IT one must consider that all homes are different, and so are their inhabitants. After all, the only thing that might connect or be shared among a group of people with a specific diagnose may be their illness. Designers should be aware of how to design for a wide acceptance of a particular healthcare technology and allow for tailoring or other strategies to align healthcare technology to its intended users, their everyday lives and homes. Also, the appropriation process is far from mere physiological as it also involves issues like how a particular healthcare technology can be installed, powered and maintained in a person's home.

User's acceptance and appropriation of any system, including healthcare technologies, are important aspects to understand (especially over time) when evaluating any product or research prototype. As a consequence designer could benefit from understanding how to design, also in research projects, solutions that do not only fit a few lead-users but can be appropriated by a large variety of users in different contexts. As illustrated in the related work section (e.g. [39]), this issue has been previously highlighted but few research projects have actively disseminated work where HCI healthcare research projects' design-decisions have been inspired also by large-scale deployment requirements. In commercial products the large-scale implementation factor naturally is more common, but these products may embed other HCI design limitations that challenge the appropriation process.

Looking at the research field of HCI at large, two related (and during the last years widely researched) topics that affects the appropriation process are aesthetics and the aesthetics of interaction [59, 60]. Aesthetics of interaction explore both the expression of the designed object and the human experience in interacting with that object [34]. However, while these two HCI related domains have been studied

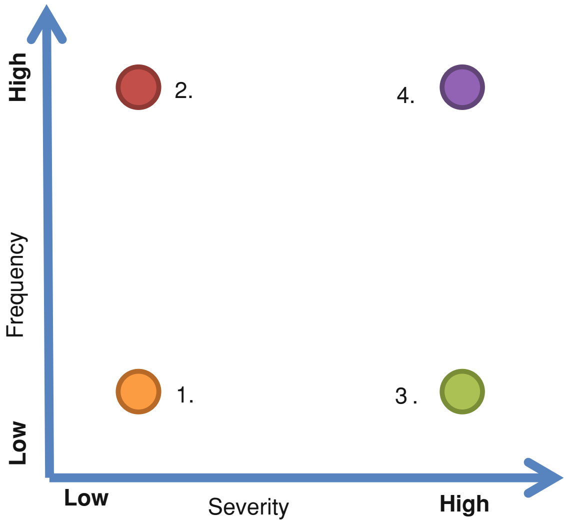


**Fig. 2.2** Example configurations of Frequency-Severity relationships in home-based care scenarios

at large, they have not been widely reported on regarding work on home-based healthcare designs.

To further discuss aspects of aesthetics we now present two use-related home-based care and healthcare technology concerns; frequency of use and intervention severity (see Fig. 2.2). The frequency of system use deals with how often a home-based care support system is needed and in use (i.e. low (e.g. once a day or less) or high (continuous support throughout the day)) and the severity of the intervention (i.e. ranging from preventive wellness to direct life-support). We identify four extreme-points where a home-based care scenario can be located in these two interlinked continuums.

To promote the appropriation of both healthcare technologies and prescribed treatments into a person's life, it could be argued that the further a person moves towards the left side (configuration 1 and 2, Fig. 2.2) and especially the lower-left corner (configuration 1, Fig. 2.2) the more important become the non-medical aspects of a home-based care technology. Similarly, in configuration 3 (Fig. 2.2), it's beneficial if the technology can remind the user about the needed intervention. In configuration 4 (Fig. 2.2) a high level of technology acceptances may be found, not out of the technology's aesthetics but out of required use, but there is still a wish to move towards a situation where the technology does not remind the user about one's illness or the hospital. In interviews with tele-monitored heart patients we have identified these aspects of aesthetics as these heart patients tend to accept the technology due to a strong perceived need. However, these heart patients still prefer technology that do not stigmatize them in their daily lives (an example of this could be to use a standard tablet device for hospital communication rather than a special-made tele-monitoring input and communication device) [44]. In a rehabilitation project [61], the project participants had a low acceptance rate inserting care technologies into their everyday lives as they did not perceive their illness to be so severe. Many home-based care interventions do not require constant use of an assistive technology (configuration 1 and 3, Fig. 2.2) throughout the day. Still, at times, when it's time for the intervention these technologies should 'come alive' and give clear cues to the user, and reminding him/her about the intervention. Hence, the technology should maybe not normally remind a home-based patient about his or her illness, but when needed become 'visible' and notify the user that it's time for a treatment. To be able to do so, the technology should be able to shift character rather than be hidden away when not in use. Also, if the frequency of use is high (configuration 2 and 4, Fig. 2.2), it's beneficial if the technology appearance do not stigmatize as the system may have to be used among others and acts as a daily reminder of one's illness.

An example of a wellness self-monitoring technology that is not so frequently used (max ones a day) and normally related to a low severity treatment is a common bathroom weight scale. The weight scale is rarely hidden and left visible in for example the bathroom also when guests are visiting. Indeed, a weight scale signals more wellbeing and that a person takes care about him/herself rather than illness and hospital treatments [44]. Indeed, a challenge seems to be how to design care technologies so they do not communicate illness in peoples' everyday lives as this can hinder the appropriation process. Previous work has discussed (especially in less frequent care technology use scenarios) what role the technology has when not in use (for providing care). If a home-based treatment that requires a purpose-made technology takes 15 min a day to perform, the treatment-specific technology remain 'useless' for the rest of the day (i.e. 23 h and 45 min). Can we design for a secondary usage of healthcare designs and by that lower stigmatization while promoting use? In a previous project, we explored scenarios of such secondary use where the care intervention was in the vicinity of configuration 1 (Fig. 2.2). In the project, a specific rehabilitation tool intended for home use was developed. One design aspect explored in that rehabilitation project was that the rehabilitation tool could act as a reading lamp when not used for the rehabilitation exercises [39]. In that way, the rehabilitation tool had a function also outside of the prescribed care intervention and hence did not 'occupy a lot of space'. As a lamp, the rehabilitation tool could remain visible and hence also be ready for rehabilitation use.

As designers of home-based care we should design for user acceptance, appropriation and everyday use. One popular way to design for user acceptance and motivation (for example in home-based rehabilitation) is to work with serious games and Gamification [62]. Another less discussed strategy could be to design also for non-medical or non-treatment scenarios. This could be especially relevant in care scenarios that do not require care activities to be performed more than ones a day.

#### 2.3.2.2 Challenge 2: Aspects of Control in Multi-site Healthcare Scenarios

In a care situation where the patient is hospitalized, the hospital in a way represents a setting with 'total' control of 'everything'. When a person is admitted to a hospital, the hospital takes over the day-to-day care of that person (a responsibility normally handled by the individual him/herself, or that is shared with actors in the person's Care

Network [63] (e.g. close family members and homecare workers). Indeed, different physical settings can embed different configurations of control. Also, how control is granted, taken, negotiated or given in any particular setting or configuration of people depends on a number of aspects; for example cultural, organizational or authority reasons. While a person is admitted to a hospital, that hospital controls the treatment including exercise, rehabilitation and medication. The hospital also controls what and when a patient eats, when people can visit, and where the patient should be at specific times (for example to make x-rays). In contrast to the hospital setting, one may assume that a person is in full control when at home; both over his/her own time and the home as such. However, this is not always the case. It is not uncommon that even an adult patient at home is subject to control-limiting factors in relation to how prescribed care activities and technologies are inserted into his or her everyday life, for example;

(1) The patient might live with other people such as a spouse and/or children. The lived space and the actual time for conducting treatments might therefore have to be negotiated among the household inhabitants. In households where more than one person undergoes treatments there may also be conflicting needs that have to be taken into consideration. It might for example be that two people in the household should both use the TV during the same morning hours to perform video-consultations with different wards at the hospital.
(2) To support home-based care, treatment-specific equipment and aids may be inserted into the home and hence into a person's everyday life. The need for such particular equipment (special beds, dialysis equipment, rehabilitation tools, pill dispensers, oxygen tubes, hygiene aids, and etc.) directly limits the level of control a person have over his or her own home. For example if a specific bed has to be used to assist the home-care workers in caring for a person at home, the care receiver can no longer choose to use his or her own bed. This in turn may imply that a couple no longer can share bed, or even bedroom. Also, that a person is 'ill' or 'weak' becomes obvious for anyone entering the home by just looking at the bed. Furthermore, at home the patient becomes a citizen with many other roles than being ill [64]. Hence, one has to negotiate (with oneself and possibly others) what role an illness will take in everyday life.
(3) The hospital may impose control outside the hospital, for example in a patient's home and everyday life, through video- and bio-monitoring and remote consultations. Still, the hospital's influence is diminished at home. However, someone (e.g. the patient, a family member, a home care worker) should carry out care activities in the home that otherwise may have been carried out together with a healthcare professional at the hospital. Indeed, healthcare technology in peoples' homes both enables and requires articulation work [65]. The technology inserted into a patient's everyday life introduces a division, and translocation, of labor among two or more actors. As a minimum this translocation includes the hospital and the patient (at home), but may expand to include also homecare workers, family members and friends (i.e. both professional and informal members of a patient's Care network) [55].

As presented in the related work, much research has worked with tele-monitoring and control from the healthcare professionals' perspective. However, as care is pushed out of the hospital, much work and responsibility is moved out of the professional hospital setting and into private peoples' homes and everyday lives. We argue that the citizen and his/her everyday life to a higher degree must be acknowledged in home-based care designs to raise the level of positive outcomes in home-based care. There seem to be a general assumption that 'just' because people may benefit from home-based healthcare technologies (for example since they might not have to visit the hospital as often) they will comply. This assumption may in some care situations be challenged. Also, when people do comply, other challenges may exist. Investigating a remote monitoring project [44] where pregnant women with preeclampsia (i.e. pregnancy poisoning) were tele-monitored from home instead of hospitalized, it became clear that these women performed their daily measurements as scheduled (this was also checked by the hospital midwife as the women's daily values were sent to the hospital). However, some of the women deliberately reported false values at times so the midwife would not have them come to the hospital for a more extensive test (something that could 'ruin the day') for the woman. This was for example done by a woman who had been called to the hospital as a result of her monitoring results. However, once at the hospital it was found out that the values was not alarming or did not need to be corrected in any way [44]. The example of the pregnant women illustrates the complexity of calling for action when not really needed but not knowing exactly if it is. For safety's sake the midwife will always want to call one time too much than missing any critical issue. This can only be solved by information and understanding that the alternative to self-monitoring is regular visits to the hospital and that this includes some visits of unnecessary sort.

A first step to design for the diverse, and possibly distributed, notions of control in home-based healthcare scenarios could simply be to acknowledge that for many people, (also prescribed) healthcare is not the highest life-priority [66] and neither is technology. Working with different projects we have observed that people can have problems integrating treatments and associated technology into their everyday lives and hence there is a risk of less successful treatment outcomes [44].

#### 2.3.2.3 Challenge 3: Societal Concerns

As previously mentioned, a hospital is explicitly designed to be a place for care. To sustain both critical and day-to-day care, the hospital has not only control over the patient, but also over the complete hospital-environment and required infrastructures. For instance may a hospital be equipped with backup electricity to be used in case of a power-failure, water cleaning facilities (e.g. filtering medication remains away from the waste water) and ventilation that do not spread airborne diseases. A hospital also has routines to handle bio- and toxic waste that can be the results of different interventions and treatments. As such, a hospital is built to answer to societal concerns and requirements regarding medical care.

In contrast to the hospital, a private home is seldom built to sustain diverse care scenarios and hence do normally not incorporate strategies to handle care-related societal concerns. Even in the case where a patient is his/her own house owner, the provision of water, (bio- and toxic) waste treatment, and electricity is handled by others (e.g. different service providers such as energy companies). A part from providing a specific service to a household or building complex, such as water or electricity, the interaction between a house owner and a service provider is sparse. If one or many of such services would be turned off (for example due to an invoice not being paid on time) or interrupted due to a system failure there are no backup systems that can guarantee the home-based care (at least for a longer period of time). Wireless and wired communication can also be interrupted due to for example interruptions in the provision of electricity. The effect on care situations that a loss of IP-connectivity can have has been publically discussed concerning emergency calls using Voice over IP (VoIP) to national emergency numbers such as 911/112. Government bodies such as the US Federal Communication Commission (FCC) have even published consumer guides to inform about the effect of VoIP-connectivity and care-critical services. The FCC guide state that VoIP consumers must be informed about the limitations with VoIP regarding emergency calls and that such calls may not work due to for example Internet Quality of Service (QoS) related problems [67]. However, IP connectivity issues and IP QoS and their impact on home-based care have not been brought to public attention at any larger scale.

Today more and more advanced medical care is provided in people's home and can involve both critical waste and complex equipment. The regulations that normally are applied to workplace contexts now have to be implemented in private home-environments. For example may storage space in the home need to be built to keep oxygen tubes or toxic waste in a safe way. According to the Swedish regulation AFS 1998:7 oxygen tubes and spare tubes should be placed close to the entrance, which is also the place where older adults may have their outdoor wheel walker or a chair they can use when they put their shoes on. Cancer treatment with cytostatic in the home is a wonderful development in medical care giving the patient a much better comfort in a complicated treatment and can help reduce some of a stress that can emerge from living with this condition. But the medical waste is dangerous for the care personnel involved in the treatment and for the personnel responsible to handle the waste. It takes careful packaging, sealing and handling of such material. This is applicable both in the home and during the transportation of waste from the home. While we can expect home nurses or other care personnel to follow rules and legislations, unsupervised care interventions done by the patient may result in for example bio-waste that is not satisfactorily handled from a society perspective. In a report from the central hospital in Linköping, Sweden, the risks and challenges that follows with more and more advanced home care of home based patients has been analysed [68]. One important result from the Linköping study is the fact that in the home there is not really any control of vital infrastructure such as water, electricity and communication. The report states that "Staying in a home without electricity or water is not reasonable for any longer times. We believe that a sick person needs to be moved to a secure accommodation within a half to a day" (ibid). The fact is that it is not only medical devices that need electricity; electric wheelchairs, beds and lifts may all need power to operate. So even if the medical device itself is powered by battery this will not necessary mean that the apartment is possible to use as a place for care during for example a power failure.

From both a national and local community perspective there are also other issues to consider. For example do parts of the medication we consume leave the body together with the urine (i.e. excretion). At the hospital medication waste and medication remains in the urine can be extracted through sewage filters, but that is seldom the case in our private homes where the water closet transmits these substances directly to the waste water treatment plant. As a direct consequence, medication remains are nowadays found in both the ground- and surface water [69].

We can expect several conflicts in the future between demands related to storage and handling of medical equipment and our perception of the home. Indeed, the transition of care from the hospital to the home must be done in a way that complies with both legislations and the private sphere.

#### 2.3.2.4 Challenge 4: Heterogeneity of Care Providers

The demographic change has led to a growing prevalence of informal or family-based care [70]. As a consequence of the increasing level of homecare in society, family-based care can be expected to continue to grow. Non-professional care at home have been regarded as a way for society to save money [9] while it also have shown to provide families with a much higher quality of life (ibid). Both formal and informal collaboration normally take place between for example family members of a referred older adult and municipality care workers. However, as stated by Bødker and Grönvall, on neither side of the family-municipality collaboration there is a simple and open relationship; families are complicated as are municipal bureaucracies [8]. Indeed, both possibilities and conflicts may arise as professional and informal care providers enter the care receiver's home with different stances, roles and time rhythms to collaborate around the care of a person [55].

At the hospital or other care institutions there are mainly one group of care providers; professional caregivers (such as physicians, nurses and physiotherapists). At home, these actors are supplemented by home care workers and home care nurses. Furthermore, at home there may also be a mix of both professional and informal care providers. Indeed, a part from the mentioned professional care workers, the home may also embrace informal care providers such as next of kin, close friends and neighbors. All these diverse actors have different relationships and roles in respect to the care receiver. While diverse actors' roles and the internal relationships between members of the care network have previously been discussed [55], it is evident that these actors have different temporal rhythms, stances and relationships to the care receiver and there is a de-facto division of labor between the diverse care actors [63]. For example, a home care worker may visit ten different clients a day and handle both cleaning, care and intimate hygiene while a close relative usually provide simpler household tasks such as shopping and cleaning. A close relative may act out of love or a perceived need to ‘pay back’ for care received during childhood while the professional care worker perform a paid labor [55, 71]. Potential conflicts do exists between these diverse care providers and their roles [63]. To safeguard one’s personal health, care workers often try to retain a professional stance, or distance, to the care receiver and the care receivers family [63]. Family members providing care of a loved one may care for just that one person. They act out of love rather than a professional stance and may hence lack proper care training and insight in the professional care workers routines, laws and possibilities. Similarly, the professional care worker is ‘trapped’ in a professional role with a tight schedule and the need to care for many people throughout a day. Designers of home-based healthcare should hence acknowledge both professional and informal care providers, their relations and needs in relation to the care receiver.

Another aspect to consider in home-based care designs is that both informal caregivers and the majority of frontline long-term care workers are women [72] and caring for someone (as a professional or informal care provider) is not always an easy burden to carry. Sequeira reports that caregivers of older people with dementia are more vulnerable due to their higher levels of burden, which are associated with higher levels of difficulties and reduced sources of satisfaction [73]. It has also been noted that informal caregivers experiences problems with mental health and social participation [74]. For example can informal caregivers of relatives with dementia experience depressive symptoms [75, 76]. To acknowledge and cater for diverse care providers and their needs could prove important in future healthcare designs. We must not only design to allow diverse care providers to deliver care in terms of using a specific care technology, but we should also consider designing for the care providers’ potential need of physiological support.

#### 2.3.2.5 Challenge 5: Mobility

When people are outside of the hospital they do other things than being ‘ill’. People go to work, visit friends and travel. For the person undergoing a treatment and society at large, it is important both from an economic and social perspective that the person can return to work as fast as possible. This is mere two reasons why it would be preferred if technology for treatments and cures could sustain care activities outside of the home. Indeed, many illnesses and rehabilitations do not require people ‘per se’ to remain at home or in another fixed location. If healthcare technologies were developed to allow a person to bring (also parts of) the required healthcare technology to work and diverse leisure activities, a higher freedom could be achieved while lowering stigmatization and isolation for the patient. One could argue that a continuous and active participation in different activities and in the society at large is a democratic perspective that should not be considered irrelevant when designing for non-institutionalized care.

To make care technology transportable is naturally a fundamental aspect to support mobility during treatments. There are many examples of current care solutions, for example within rehabilitation [77, 78] that are rather stationary in their setup.

However, there are other concerns that could be important to consider when designing for the integration of non-clinical treatments in a person's everyday life. A less thought of difficulty that could be handled in the design of healthcare technologies is that different countries have different protocols, standards (e.g. radio bandwidth) and legislations that challenge a 'lawful' roaming of care technologies between different locations. If healthcare technologies were designed to support different national standards and legislations, healthcare technology could more easily be brought along on business trips and vacations.

A current topic is social alarms and their transition from analogue to digital communication protocols. In Sweden the government has given the Swedish Institute of Assistive Technology (SIAT) the assignment to study the future of social alarms. The assignment was to "implement development and information activities to support municipalities in strengthening security in security alarm services in connection with the ongoing technology shift to Internet-based technologies (IP) in the telecommunications sector" [79]. The assignment lead to the development of a Swedish standard for how social alarm communicates called SCAIP, which is an abbreviation of Social Care Alarm Internet Protocol. This protocol will make it possible to select a social alarm system without having to check whether a specific call centre can receive the signals from the alarm terminal or not. With traditional social alarms today this cannot be done. When buying a new social alarm today, one must first know which call centre will receive the alarm, and then buy the proper alarm according to that call centre's specification. Furthermore, if the alarm operator is replaced by a new procurement it may be that the new call centre uses another protocol and consequently, all the alarms must be replaced or modified. Also, a user of social alarms can in most cases not use the alarm outdoors. The municipality social responsibility is limited to the apartment and does not cover an outside stay.

But today users are used to GSM and 3G telephones which can be brought to almost any country with full functionality. Some people also live a very mobile life that takes them both to other parts of the country and abroad. It is a natural step forward, for example within the EU, to allow social alarm users to also use their social alarms anywhere, at least in Europe. This is not blocked by technology at first but by local laws and regulations in diverse countries and practical arrangements how to handle these 'roaming' users of social alarms. But it has not yet promoted an EU standard protocol for social alarms. Still, this is also on the agenda and SIAT has an assignment versus the EU commission to present a standard protocol for social alarms [80].

Since the market for assistive devices is not expanding very fast, many small companies are trying to introduce systems based on proprietary protocols, which in itself will lead to difficulties for users to incorporate more than one system in the home. Accordingly, the only way to develop sustainable products within the field of homecare technologies is to look at the global market and more open standards and protocols.

#### 2.3.2.6 Challenge 6: Installation and Maintenance

A number of HCI research projects have investigated functionality, use and effect of diverse pervasive healthcare solutions targeting private homes (e.g. [19, 55, 61, 81]). However, few HCI design projects have reported on non-functional requirements such as how to install a solution in a private person's home (exceptions include for example: [39, 44]). While focusing on usability concerns like interface design, the HCI research field to a large extent has not reported on usability issues related to the installation and maintenance of home-based healthcare technologies.

The installation of consumer electronics and household appliances is by many people perceived as cumbersome. DVD players, stereos and computers are all examples of technologies that many people find complicated to install and configure. Many home-based healthcare technologies have a similar minimum complexity in setup and installation as these above-mentioned consumer products; they may require Internet connectivity, a connection to the TV or other existing technology and mains power or batteries to function properly.

We argue that it would be beneficial, also from a design research perspective, to extend the research-field of technology acceptance and usability to explicitly include also the installation and maintenance of everyday healthcare technologies. To challenge research-based healthcare designs by including also easy installation and maintenance requirements in the design work could allow researchers to evaluate, from a more holistic perspective and over time, the value of a particular healthcare design.

#### 2.3.2.7 Challenge 7: Training and Learning

Home care technology that exist in private peoples' homes range from simple devices such as blood sugar level (glucose) monitoring devices to systems to sustain for example complicated cancer treatments and blood dialysis. With a more wide-spread use of home-based treatments one cannot expect that either professional or informal care providers can keep up to pace with the technological development and the rather advanced technology that may enter into the home. At the hospital, a given number of people handle a specific kind of technology or perform certain activities (e.g. blood analysis or x-rays). This defined set of people hence work with a technology over time and it is predefined that they will handle a specific type of technology. As care move into private peoples' homes and the main responsibility of a patient, treatment and handling of advanced apparatus is transferred from the hospital to a municipality or general practitioners office, the number of people in need of training increases. When informal care providers, such as family and friends get involved in the day to day care—further people, also without a formal healthcare training, may have to operate advanced healthcare technologies. Economic drawbacks within the healthcare sector can also put less emphasis on dedicated training sessions, favouring situated learning, both for professional and informal care providers. Furthermore does homecare work represent a work domain with a high turn-around number of employees and where many people work extra to finance their studies etc. Short-term or time-limited work situations challenge how structured training for all care workers within a homecare organization can take place. Also new members of a care network, such as a vacation substitute care worker should be able to use and benefit from existing machinery when visiting a particular client. New healthcare designs for non-clinical settings may consider in-activity learning support for both professional and informal actors as a strategy to work-around the above mentioned issues while still provide training and ensure that people can operate assistive care systems distributed throughout a home.

Earlier non-healthcare projects have examined 'sandbox' use of technology, for example in private-municipality communication and collaboration [82]. A sandbox provides a 'safe space' for experimentation within a system-in-use. To be able to experiment with functionality and try out different use scenarios and be able to discover the answer to 'what if'-questions may not only demystify the care technology but also promote learning. How experimentation and learning during use can be done within a healthcare context still has to be investigated, but if possible from a patient safety and legislation perspective, one fruitful strategy could be to allow heterogeneous users with diverse background and formal training to use and interact meaningfully with healthcare technology.

## 2.4 Open Problems

This chapter has on a high level introduced and discussed a set of challenges that is important to consider and reflect upon when designing the home as a place for care. The presented seven challenges were: (1) Appropriation, (2) Aspects of control in multi-site healthcare scenarios, (3) Societal concerns, (4) Heterogeneity of care providers, (5) Mobility, (6) Installation and maintenance, and (7) Training and Learning. While not being directly related to a system's technological or medical functionality, these challenges should still be seen as aspects relevant to consider for developing future, sustainable home-based healthcare systems and services. One interesting point is how ICT-based care services influences the home environment and can transform it into a care institution [83]. It is therefore important to provide users with systems that support their perceived needs and that empower them [20].

The authors' perspective on Pervasive healthcare development is that it can be beneficial for researchers to know about, consider, and explore a wider set of 'non-functional-related' aspects of home-based care in their design work than currently is being done. The seven challenges discussed in this chapter represent examples of such 'non-functional-related' aspects. As the use of ICT is expected to increase in the future, there are additional aspects which need to be considered as new services are introduced insofar they challenge the traditional beacons of healthcare ethics and values [84, 85].

How we build homes, ranging from apartment buildings to single-family houses, also influence how care can enter into peoples' homes. A building is rarely built to function only for a few years. Rather, it is not uncommon that a building is used for 30–100 years. Therefore, and in combination with people's mobility (we change jobs, move to new locations, etc.) it is not uncommon that a building or apartment has many different people living in it, and at very different stages of their lives. At different levels, a building adapts to its current inhabitants and their needs [86, 87]. However, this adaptation is often limited, based on some technical constraints, existing building materials and the inhabitants' economy. It may however be difficult to foresee needs that may follow from illness or aging. Therefore it could be beneficial if (residential) buildings were designed with care in mind and those emerging needs that may follow from illness and aging (e.g. large door posts to allow a wheelchair to easily move from one room to another). Today it is not uncommon that people move from a house or apartment, where they have lived for many years and where they have their friends nearby, to another living location only because their original living location could not support some emergent needs and requirements as they age. Furthermore, the home as such is also just one node in a larger system of infrastructure- and service-providers such as water and electricity providers and municipalities. Additionally, there are also regional concerns, national laws, regulations and interests to consider.

One thing that has not been included in our discussion on design so far, but still is a most important problem, is how to keep the cost of assistive devices to be implemented in the home at a reasonable level. The total cost of installing much research-based solutions in a home-setting is often far too high and hence will never reach the beneficiaries. This aspect must be included in the design process and the cost effects of different design choices evaluated as a part of the research outcome.

As we design for home-based care, we should also reflect on the methodological stance we apply. Within for example the HCI community there is a long tradition of using different co-design approaches, lead-users and Participatory Design methods when developing novel technology. As this chapter has presented, the diverse set of challenges present when designing for the home as a place for care makes us question who should be part of a cooperative design process and whose interests must be safe-guarded. Instead of limiting the represented partners in the home-based healthcare design process, it might be beneficial to bring in the municipality as a partner, not (only) to have access to municipality home care workers or other care professionals but to understand and design for data-safety (legislations) and environmental laws. Lawyers with specific environmental expertise, city plan offices, architects and infrastructure service providers may represent other relevant design-partners when we design future, sustainable home-based care services. There is also an issue of how we test and evaluate the impact of home-based care services. Within HCI, there has been a move away from lab-testing towards testing 'in the wild' [88]. As a middle ground there are also so called 'living labs' where technologies can be tested in a 'close to real' context. It should be stressed that private homes as a setting for healthcare design is very heterogeneous and so is its inhabitants [44]. While living labs are purposefully built to function as labs, most private homes are not [87]. As a consequence, and to truly understand the large-scale impact of a home-based care design we must favor so called 'in the wild' testing. To understand the impact a specific service or technology have on society, to allow for appropriation and to see how use and behavioral change over time we should also initiate tests and evaluations over longer time periods. We further suggest that care providers, and house and apartment owners make mutual check lists on prerequisites needed to handle risks, logistics, infrastructures and backup systems to minimize failures or the impact of failures. Next step is to understand how different aspects relate to each and every-ones responsibility. All this must be anchored in legislations and laws.

The authors perspective on the issues presented in this chapter is that these issues represent ‘the next step’ when designing for, and conducting research within, the ever-growing field of home-based healthcare.

## 2.5 Future Outlook

It is clear that there are many possibilities with care at home and many possibilities for ICT to support such home-based care. However, as presented in this chapter there are numerous challenges in implementing care at home. Some challenges might be, at a first glance, easily overlooked by HCI researchers. Such challenges extend usability and fundamental technological issues like data resolution and data integrity when transferring data between the home and a hospital.

To better understand the challenges presented in this chapter, and to identify other relevant challenges in designing the home as a place for care, much more work and practical experience is needed. As noted in the Open Problems section above, architecture and how future homes will be designed and built represents only one area of future interest. Another example topic that would be relevant to investigate further is cloud-services and patient-integrity as data in theory can be located in different countries that have diverse privacy laws. Also, to investigate trans-national infrastructures to support safe and lawful translocation of patients and their care services is another field that deserves further research attention.

The authors will continue to work with projects examining how to design better home-based healthcare solutions and what impact and consequences healthcare ICT can have on patients, their private homes, care givers and society at large. The authors also like to develop more clear guidelines and strategies for designers to help them to limit the impact of the challenges discussed throughout this chapter. Finally, we see the education of researchers, healthcare professionals, patients, government bodies, policy-makers, politicians and IT developers as an important vehicle for change, and we hope to contribute to this area through further research and dissemination of our work.

Finally we would like to emphasize the novelty we introduce in in this chapter namely the connection between two of the most important societal challenges the world is facing right now: the demographic development and the environment. Here we try to show that they are linked through primarily the care moving from the hospital into the home, which also will be much more common in the future. The environmental consequences must be taken into consideration when designing the home as a place for care.

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