

How Can Health Information Technologies Contribute to Improve Health Care Services for High-Need Patients?

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Abstract This paper discusses how health information technologies like tele-care, tele-health and tele-medicine can improve the condition for high-need patients, specifically in relation to access. The paper addresses specifically the values of timeliness and equity and how tele technological solutions can support and enhance these values. The paper introduces to the concept of scaffolding, which constitutes the framework for dynamic, appropriate, caring and embracing approaches for engaging and involving high-need patients that are vulnerable and exposed. A number of specific considerations for designing tele-technologies for high-need patients are derived, and the paper concludes that ethical and epistemological criterions for design are needed in order to meet the needs and requirements of the weak and exposed.

Keywords. Telemedicine, Health equity, Timeliness

Introduction

A recent study by Osborne et al. compare the citizen's assessment of health care access, quality and affordability in eleven countries. It is shown how many countries face difficulties in ensuring access to health care. Canadian, French, German, New Zealand, Norwegian, Swedish, Swiss, British and US adults were not able to get an appointment the same or next day and 20-29% in Canada, Germany, Norway, Sweden and the United States waited six or more days to get an appointment [1]. Between 40 percent and 64 percent of adults in all the countries in the study struggled to find care in the evenings and weekends without going to a hospital emergency department (except in the Netherlands at 25%).

Furthermore, it is shown that “patients with multiple chronic conditions and complex needs – particularly those who also experience poverty and material hardship – add stress to the health care system, are challenging to manage well and are costly” [1]. In the United States, it is known that patients with clinically complex conditions, cognitive and physical limitations, or behavioral health problems use a disproportionate amount of health care services [2]. Furthermore 66% of the health care expenditure in the U.S. were accounted for by 10% of the population [3].

Another recent study from the Commonwealth Fund showed how health care systems are failing to meet the complex requirements of high-need patients [4]. High-need patients were defined as adults with two or more major chronic conditions like heart

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failure, stroke, or diabetes requiring insulin. This group reported problems with access to care given that 44% reported delaying care in the past year because of lack of transportation, limited office hours, or an ability to get an appointment quick enough. In the control group, only 21% reported similar problems.

These present circumstances documented in the United States can with small variations be found in many other countries, and it points to the need to identify all the contributors to poor health including socio economic disadvantages.

1. New models for access to care

A number of recent studies show how investment in social services or integrated models of health care and social service has a positive impact on health outcome and spending [5].

In many of the same countries we have seen national patient portals being implemented to improve access to health care services [6]. In this study a wide variety was seen in the functionalities offered to the citizens and these variations are intimately related to the history and structure of health care service delivery in each of the individual countries. Moreover, the data revealed a difference in how each country varies in the embedded concepts on the expected and desired roles for the citizens in the management of their own health.

Giardina et al. reviewed the literature to determine the effect of providing patients access to their medical records on health care quality [7]. Their study included 27 studies of which 20 were RCT. The analysis of the studies addressed three of the quality domains defined in the IOM report "Crossing The Quality Chasm: A new health system for the 21st century" [8]: effectiveness, patient centeredness and efficiency. Outcomes were equivocal in terms of aspects of effectiveness and patient-centeredness. Efficiency parameters such as frequency of in-person or telephone encounters showed a mixed relation to patient access. However, the review found no current evidence to substantiate any negative patient outcomes resulting from access to health information, and the authors state that effects on patient safety, timeliness, and equity has been absent.

It seems that improving access alone to patient's record does not significantly improve health outcome, and it is uncertain whether improved access will have any influence on equity, and thereby enable high-need patients to improve the management of their own health.

2. New technology in patient provider relationship

Health IT systems has been widely used to improve access to health information, and now initiatives using various telecommunication technologies have been applied to intervene directly in the relation between a provider and the patient. Supporting chronically ill people living at home by caring at a distance has experienced a huge increase recently. Care providers have been using new communication technologies such as e-mail, webcams, electronic measuring instruments, and websites to monitor, transmit data, and communicate to provide instructions. These technologies have had a massive focus - in a small country with 5.6 million inhabitants like Denmark alone a national mapping has shown that 273 projects to provide telehealth services exist – the majority as pilot projects [9]. This myriad of health related tele-technology projects has given rise

to some confusion upon terminology around the concept of telecommunication technologies.

Stanton Newman [10] operates with three main definitions of health informatics performed at a distance (tele).

- Tele-care
- Tele-health
- Tele-medicine

Tele-care is available in several generations and is characterized by relatively mechanical, automated and passive processes. Here technology detects the patient and the spatial context through alarms, sensors, etc. and transmit the data to the health care professional who can then react accordingly.

In *tele-health* systems, the user is active in relation to the technology. It can be the patient, the caregiver or an informal carer who measures body conditions and sends the data to a professional in the health care system. In some cases, this can also be a computer that monitors and analyses the data. This may have significant implications for the behavior of the user in relation to the technology.

Tele-medicine is defined as technology supporting communication between health care professionals. It means that the patient, citizen, etc. is an object for diagnosis and decision-making within the organizational framework of the health care institution.

The general scope of telehealth may include *tele-medicine*, such as remote doctor-patient consultations, and *tele-care*, referring to the remote monitoring of vital signs and other health condition metrics, and patient assessment. Common telehealth technologies include videoconferencing, the internet, store-and-forward imaging, streaming media, and terrestrial and wireless communications [11].

3. The hybridity of tele-technologies

Tele means distance and the various technological devices that survey, measure, send, support and facilitate are mostly trying to bridge the temporal and spatial gap in between humans and non-humans in the ‘circuit’. The Dutch STS researcher Jeanette Pols talks about the widespread assumption and fear that tele technology will enhance and emphasize social segregation and exclusion, hence affecting those most in need. “The fear is that those already deprived of social contact will lose even more when technology takes over the tasks done by humans” [10]. It is obvious that this calls for a change of attitude and approach as we try to think humans and technologies in these types of ‘circuits’. Pols suggests that health care professionals collapse ethical and epistemological stances, meaning that the citizen/patient is met with empathy and involvement in a holistic perspective, and that they, at the same time, are detached like the scientist in objectifying the citizen/patient, because needed in order to interfere and evaluate. [10] The hybridity of such a stance is needed in order to embrace the multiplicity of issues that often characterize the complex social and bodily condition(s) of high-need patients/citizens. *Tele* technologies are not necessarily cold and human hands warm in this state of hybridity and roles in between humans and non-humans can switch in the process, meaning that *tele* technologies can support and help the weak and vulnerable, i.e. high-need patients, in their struggle toward better health; and at the same time release means and forces in the health care system so that more efforts can be addressed towards appropriate, timely and equitarian care of the weak and vulnerable.

Tele technologies in health care are meant for producing better health, better care at lower cost (Triple Aim). As we have mentioned these outcomes are uncertain and there is no evidence for this to be the case [5, 6, 7]. There has been a focus on effectiveness, efficiency and efficacy, hence instrumental and mechanical evidence, in implementation of tele technology in health care systems. We suggest that *tele* technological solutions are evaluated through different lenses and with different criteria for design and implementation. In order to embrace high-need patients/citizens that are often socially marginalized, we have to re-contextualize technology in relation to the reality of high-need patients/citizens.

On this occasion we introduce to the concept of scaffolding (*Gestell*), which originally was conceptualized by the German philosopher Martin Heidegger [12] and further developed by the French anthropologist/philosopher Bruno Latour [13]. Heidegger points at the fact that scaffolding or enframing is both a technical and mechanical construct and at the same time human activity. Latour takes it further as he states that we should always erect scaffolds, and asks: "How long will it be before the word is heard not as a war cry to take hammers and arms, but as an appeal for the extension of *care and caution*, a request to raise the question: How can I be built *better*?" [12]. Scaffolding is an enterprise that has the specific purpose of maintaining and supporting fragile structures, and furthermore to facilitate different processes of construction. Scaffolds are in this sense themselves dynamic and malleable constructions that meet and embrace the reality of what is scaffolded, in this case the high-need patients/citizens. Scaffolds mediate cure and care of the physical and psychological entity of the exposed patient/citizen.

4. Tele-technologies for the frail

The metaphor of the scaffold is also introduced in order to make us understand that even though we might not be able to measure evidence of effectiveness, efficiency and efficacy, then *tele* technologies could have different qualities if they are tailored/built in order to embrace the exigencies and needs of the marginalized and the frail.

In relation to the quality domains of the IOM report [8] we are specifically aiming at timeliness and equity as the main target areas of new tele-technologies. *Timeliness* means that waits are reduced to avoid harmful delays for both those who receive and those who give care. *Equity* means that the care provided does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socio-economic status. However, if these two domains shall contribute optimally to the triple aim in a health care system that is challenged by an increase in chronic conditions and changing demographics they should be reinterpreted in the light of our knowledge about socio-economic bias in the prevalence of high-need patients.

What is time? And on that note what is timeliness? We are generally used to time is something measurable in seconds, minutes, hours, days and so forth. But that not is the essence of time in the various tele-technological solutions.

If we take the tele-care solution then there is a need for time to be instant and chronological, which means that when things are measured there's somebody or something that reacts immediately. I fall on a floor, somebody/something reads and reacts.

Timeliness in a tele-health context is different. It means that the patient, care giver/taker is timely. This is about interpretation of when and why to give/take

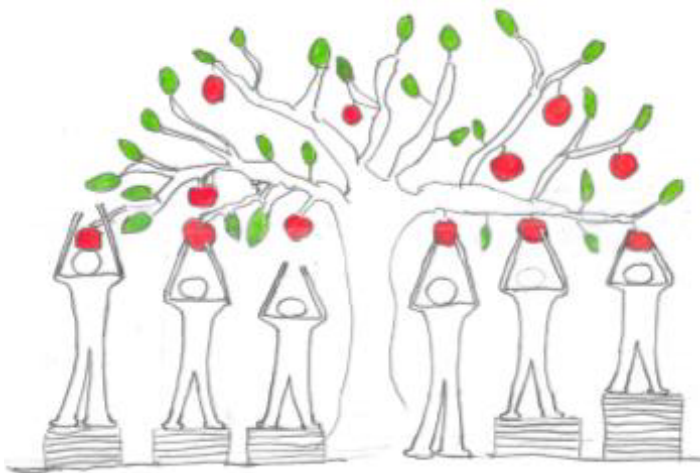
information. It is by no means chronological or stretched in relation to the body/sickness of the patient. It is a negotiation of what are at hand, data experiences, feelings and immediate reactions.

Tele-medicine is somehow in between, It is highly dependent on standardized communication in between professionals, but on the other hand it need to be alert on what is in between, i.e. the patient. The notion of time changes in these various settings. Time can be instant (tele-care), or interpretative (tele-health) or even something in between (tele-medicine). Timeliness is hence not something definite or stable. It highly depends on the technological solution, and at the same time high-need patients have very different perceptions of time.

What is equity? We are taught that we are all born equal, but this is not the case, especially in relation to access to and use of health care services. We might be prevented or reluctant, but nevertheless new tele-technologies have a high potential of creating democratic equity solutions if we focus on criterions that transcends economy and efficiency. Equity is mainly about creating the same conditions for maintaining and supporting health, independent of the outset, might that be socio-economical and/or sociotechnical. Equity in the health care system in relation to implementation of tele-technologies is about redistribution of means, where the strong and literate patient is 'left' with lesser support from the health care system, because capable of managing herself through tele care and tele health solutions. This means that financial means and human forces are released in the health care system and can be addressed to the frail high-need patient. In this way, we actually deliver better health, better care at lower cost.

Sometimes equity is confused with equality. Making personal health data available to individuals via Internet technologies provides everybody with the same options. In countries where the use of Internet hooked up computers, tablets, smartphones is possessed by almost everybody the access to personal health data will be possible for everyone with one of these devices. This denotes a high degree of equality. However, if you cannot read and understand the data to a degree that enables you to act upon them they are of limited value. (See figure 1)

Figure 1. Equality on the left side of the tree where everybody gets the same support to access the apples. Equity on the right side where the frailest are scaffolded to reach the apple.



Value sensitive design (VSD) is a design methodology that gives indications on how to integrate values in design processes. It consists of three elements or steps: values, norms and design requirements [14]. We have identified timeliness and equity as core values in order to support Triple Aim in relation to high-need patients. On the normative level, we point exactly in the direction of the weak and fragile, where we ask for design requirements that focus on the exposed body of the underprivileged. VSD is in this sense the scaffold that we erect in order to care, cure and cuddle patients that are in high-need for exactly this, i.e. we ask the question: “How can it be built *better?*” [12].

To meet the challenges of high-need patients the care provided should vary according to socio-economic status as their needs and their potential of benefitting from standard care are different. Timeliness is about avoiding delay in necessary actions of prevention, diagnosis, and treatment. Actions to avoid delays for high-need patients are more demanding as there are more tough challenges to overcome.

Table 1. Considerations for designing tele-technologies for health care

	Tele-care	Tele-health	Tele-medicine
Timeliness	One-to-one relation between what happens and the action needed. Data are present and need to be noted	Interpretive situation. What is timely and appropriate to say, do, or measure.	Improve professional access, availability and appearance. To be there on time.
Equity	The one-to-one relation filtered and adapted to demands of high-need patients.	Functionalities and user interfaces addressing specifically high-need patient groups.	Make the appropriate level of professional assistance available to the right situation.

5. Design considerations for tele- technologies

New tele-technologies have a unique potential to reach out to the high-need groups given that they are designed and implemented to meet these specific needs. We suggest the framework in table 1 to guide the design considerations in the three areas of tele-technologies in health care.

The common design principles for the timeliness applications to tele-care, tele-health, and tele-medicine are that it concerns building of basic infrastructure. Infrastructure we define as: *the technological system that facilitates the material and institutional exchange and transaction processes, which connects the socially divided labor processes* [14, p38]. The infrastructure of health technology has a technical aspect that comprise the suitable hardware and software, but also the adequate standards for exchanging data and categorize health and medical terminology and knowledge. But infrastructure also has a social aspect – the users must possess sufficient and adequate knowledge of how to operate the technology and apply the results. To build infrastructure to reach the high-need patients that satisfy both technical and social infrastructure demands calls for involving the users – not just as an information source, but an active participant in the design process [16].

The common principles for designing tele-technologies that will improve equity directed towards high-need patients is, especially in the initial phases where patient requirements are elicited, focused around user involving approaches like participatory design [17]. In later phases usability issues become very important. The usability of any system can be broken down into two major categories of human factors: basic interface

design (HF 1.0) and cognitive support of the user to complete specific tasks (HF 2.0). The basic interface design should follow principles to ensure clear and readable information, adequate font size, color and contrasts between foreground and background. The cognitive support of the user entails greater detail and a deep understanding of the cognitive needs of the user and the tasks to be completed.

Designing for the high need patients also has important consequences for evaluation and measurements of e.g. return of investment (ROI). As Kidholm et al. mentioned there has been several attempts to evaluate the impact from tele-technologies [18], however only very few has been able to show significant changes on traditional parameters such as clinical benefits and outcomes, or monetary return of investment. When evaluating tele-technologies that has been designed to overcome specific problems of high-need patients means that we have to ask how the technological solution mediates *empathy, inclusion and involvement* (ethics) as well as *knowledge, results and behavior* (epistemology).

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