

Patient Empowerment and New Citizen Roles through Telehealth Technologies

The Early Stage

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Abstract - The aim of the present article is to explore the potential for citizens to gain new empowered roles through the use of health technology. The authors propose the distinction between citizen roles on two levels: the role of the citizen as patient actively involved in his own treatment and then an 'extended citizen role'. Findings are based on a literature review combined with lessons learned from two telehealth projects currently running in Denmark. The authors find that the empowerment happens through information-sharing; offering the patients a visual overview of their course of treatment, letting the patients take their own measurements, and letting them provide verbal and written inputs. Finally, perspectives on communities of shared care and 'ambient assisted living' are discussed.

Keywords - telehealth; patient involvement; telemedicine; home monitoring; citizen roles

I. INTRODUCTION

When studying recent literature on the delivery of health services it becomes clear that health sectors all around the world are overburdened and under severe pressure. The demographic challenges faced by the aging nations of the developed world as well as the developing nations with a new, growing middle class, combined with the increasing need for treating chronic illnesses, imply that the relationship between citizens and their health sector is bound to change. The use of information and communications technology (ICT) in telehealth programs is a part of future health care, but in order to significantly reduce the burden of health sectors, citizens must know how to help themselves – and each other.

The present article reflects upon experiences and potentials in terms of patient involvement from two telehealth projects carried out in Denmark, both of which rely partially on self-management, and discusses these experiences in relation to findings from the literature. The focus of the present article is telehealth technologies that are related to the ideal of 'ambient assisted living' as described later. The projects included are Tele Ulcer Care and DREAMING (eDeRly-friEndly Alarm handling and MonitorING).

Tele Ulcer Care demonstrates the use of ICT in the treatment of patients with diabetic foot ulcers. The project started as a research project in which video conferencing was

used, i.e., synchronous treatment [1,2]. After the research phase, the project entered a development phase in which transferring images and notes via mobile phones and a web-based ulcer record was introduced, i.e., asynchronous treatment involving the patient, the visiting nurse, and the ulcer specialist. During the development phase, a mini-Health Technology Assessment (HTA) was produced [3] in which the benefits for the patient were established; reduced time spent on waiting and commuting, faster diagnosis and treatment, and fewer hospitalizations and visits to the outpatient clinic. The mini-HTA also states that the web-based ulcer record allows for patient involvement in own treatment, which is discussed later. Currently, the project is demonstrating the asynchronous system at various sites in Denmark and is aiming for national implementation.

DREAMING is a research project under the auspices of the European Union, which tests a range of welfare technology services in real life pilots in cooperation with public authorities under a randomized control trial. The project tests elderly-friendly alarm and monitoring technology in the citizens' home. The technology consists of medical measuring equipment, environmental monitors, and video conferencing. The citizens included must be at least 65 years old and suffer from diabetes, heart failure, or COPD (Chronic Obstructive Pulmonary Disease). The citizens take their own measurements, which are transmitted wirelessly to a portal accessible for the visiting nurses. The project is currently trialed at pilot sites in six European countries: Denmark, Sweden, Germany, Estonia, Italy, and Spain.

The two projects are at different stages in their life cycles: Tele Ulcer Care has been through its research and development phases and is currently demonstrating the technology as the final step before national implementation, while the DREAMING project is currently collecting its initial research results. Note also that the projects are primarily relying on tele-monitoring and are not examples of self-management in its full form. Despite these factors both projects present relevant experiences and elements of patient empowerment and self-care, and the authors believe that the projects teach us some important lessons in terms of technology and patient roles, that are relevant for future self-management projects. Finally, the projects differ in the degree to which they are currently relying on patient empowerment. This will be discussed later.

In terms of citizen roles, this article suggests distinguishing between two levels: the first level is the

citizen as a patient actively involved in his own treatment, the second level is the citizen as actively involved in the general delivery of health care services to the social environment, e.g., a senior community or a virtual network, in which the citizen lives. This level is what we call 'the extended citizen role'. The first level is very present and widely discussed in published literature, while the second level is a somewhat novel, undocumented idea, but nonetheless an important perspective that can help us imagine how the future of health care might look like.

The aim of this article is to explore the potential for citizens to gain new empowered roles through the use of telehealth technology. The following section is based on a literature review in which these questions are attempted answered: How does telehealth technology influence the way health care services are delivered in terms of the patient's role? What barriers and issues are important to keep in mind when attempting to empower the patient?

Section II outlines research on telehealth and patient involvement. Section III describes the methods used in the research of the present article. Section IV presents results from the two projects Tele Ulcer Care and DREAMING and Section V discusses these results in relation with the findings of Section II. Section VI draws conclusions from this discussion, and finally, in Section VII, perspectives beyond the scope of the present article are presented.

II. BACKGROUND

Telehealth, including telemedicine, programs are feasible for the education and involvement of patients in their own illness and for motivating them to engage in self-monitoring [4-7]. ICT in general allows for a more interactive patient-provider relationship based on information-sharing [8]. For instance in ulcer care, appropriate information about options, benefits, and risks, helps the patient make better decisions in daily, or even acute, self-treatment [9,10]. Note however, that others have documented that telemedicine does not necessarily facilitate self-care [11].

Studies have shown that patient education has the potential to improve the quality of care, including improving patient satisfaction with the treatment [9,12,13] and enhancing the patient's access to information [13,14], sense of control [5,14] and quality of life [15]. Other studies have documented improved patient-provider relationship (despite a decrease in the amount of personal contact) [5,6] and reductions in the number of readmissions [15] as well as in the duration of face-to-face consultations [9] due to patients' better understanding of their illness.

Particularly synchronous telehealth, i.e., tele-consultation using video-communication, allows for a dialogue between e.g., patient, visiting nurse, and expert, through which the patient becomes empowered and more actively involved in the planning of his or her care [10,16]. Asynchronous telehealth (e.g., utilizing and transferring digital images in ulcer care), on the other hand, results in easily accessible visual data that allow patients to follow the progress of their treatment, which gives a significant psychological boost [17]. Involving the patient is beneficial for the providing organization as well; including the patient's perspectives in

the telehealth program improves the implementation of such programs, since it allows for continuous adjustments [14].

Certain barriers to patient involvement have been identified: the need for training and getting used to communicating via e.g., video, which lacks the natural flow of face-to-face communication [16], hesitation towards self-care due to unfamiliarity with the technology [18], inadequate video quality and internet connections [7], and finally, impairments of vision, hearing, psychomotor skills, and cognitive skills, esp. with elderly patients [15].

Although some studies document patients' enthusiasm about the new technology [4,14], patient involvement is crucial in overcoming potential opposition towards the technology, and studies show that the longer patients have been involved in a telehealth project, the more likely they are to accept the technology [10,12]. Note that it is crucial to identify the personal characteristics of the target patient, e.g., urban/rural, young/old, since these will give an indication of potential patient-barriers to unfamiliar technology [19]. Since the target group of many telehealth programs is the elderly population who often have special needs when it comes to home care, it is especially important that these citizens and their daily lives are involved in the planning of care. Generally, it should be recognized that when care takes place in the patient's home, it must be carried out on the patient's terms [20]. In one study, it is stated that patients are of the opinion that home hospitalization results in an easier and quicker return to everyday life both physically and mentally [21].

There are a number of ethical issues to consider in telehealth programs, some of which are related to the empowerment of the patient: privacy of information, informed consent, the accessibility and usability of the technology, and the danger of making patients too dependent on technological support instead of making them more autonomous [22].

The project MethoTelemed has published the manual Model for ASsessment of Telemedicine (MAST) [23] in which issues and perspectives relevant for the evaluation of telemedicine programs are outlined. The MAST manual considers patient empowerment a sub-topic to 'patient perspectives', which mainly focuses on patient satisfaction and perception. In general, the manual only briefly discusses the concept of patient empowerment and focuses mainly on the *delivery* of health care services, instead of the patient's *active involvement* in these services. Further, a gap in the literature on this topic is also revealed. The MAST manual does however include aspects that are central to the present article: The patient's relatives' perceptions of telemedicine, changes in the patient's role in social life, and changes in the way responsibility is allocated.

The present article focuses on the potential of patient empowerment in order to contribute to the debate on the future of health care and the role of the individual citizen.

III. METHODS

The present article applies findings from the literature to the experience and lessons learned from two telehealth projects, Tele Ulcer Care and DREAMING. The emerging

perspectives are then analyzed in relation to the theme of the 'two levels of citizen involvement'.

The literature used was found in the databases ACM Digital Library, Cochrane Library, CSA Illumina, Ovid Medline, and PubMed. We used the following search strategy: (telemedic* OR telehealth OR telecare) AND ("self care" OR "self treatment" OR "patient involvement" OR "patient empowerment"), and ended up with approx. 30 articles of significant relevance.

IV. RESULTS

Tele Ulcer Care is founded on the research of [1,2,24] who used participatory design methods, field observations, semi structured interviews, focus groups, and qualitative analysis of transcriptions of telemedical consultations to investigate experiences with telemedical treatment. The authors propose a joint treatment between the expert, the visiting nurse, and the patient, and they find that telemedicine improves the specialist's basis for decision, and enhances the confidence and the satisfaction for both the patients and the visiting nurses.

As mentioned above, we distinguish between two levels of patient involvement: 1) involvement in own treatment and 2) the extended citizen role. In terms of patient involvement on the first level, Tele Ulcer Care has experience which sheds light on this aspect: Firstly, the joint care between patient, visiting nurse, and expert, whether it is through video conference, transfer of digital images, or communication via an electronic record, allows for the patient to learn more about his own illness and which precautions to take without physically having to seek expert advice. Secondly, the patients perceive, to a great extent, the applied technology (a web browser and a mobile phone or video conference equipment) to be simple and familiar, which is essential in patient involvement. Finally, since foot ulcers can cause social stigma, the patient is likely to be interested in being in charge of his own life as much as possible and to reduce the extent to which he is perceived as being 'ill'. In terms of the extended citizen role, Tele Ulcer Care has no experience yet, but there is a potential as discussed in the next section.

In the DREAMING project, the citizens are involved at both of the two before mentioned levels. At the first level, involvement in the citizen's own treatment takes place from the moment he enters the project. In terms of the second level, the technology included in the project opens up for the possibility of creating an 'ambient assisted living' (AAL) society like the one described in the next section.

Lessons learned in the project so far have shown that when introducing the technology to elderly citizens, appropriate training and involvement in the process promotes a positive attitude towards the technology. This experience has also been described in [25] along with challenges and lessons learned in other areas within the project. Thus, the DREAMING project has acquired important knowledge about how to successfully bring together the elderly and the technology. After having become involved in the project, the citizens see how the project will benefit them and want to be empowered through the technology. Furthermore, they do

not find the technology intrusive, but clearly feel safer with the technology in their home than without.

At an early stage of the project, the first Danish citizen included in DREAMING had the technology installed in her home on a small, isolated island. Despite her previous occupation as the head of the island's post and ferry office, this particular citizen had never used a computer in her life and always wrote down everything using pen and paper. However, after instructions from the project team, she had no difficulty using the equipment and was happy to avoid some of the time consuming trips to her doctor on the mainland [26].

V. DISCUSSION

One way to realize the concept of patient empowerment, i.e., allowing the citizen to undertake some of the visiting nurse's former tasks, is to create ambient assisted living-spaces where self-care technologies are integrated in the citizen's daily life in a non-intrusive way. Self-care is made easier if the technology utilized is already familiar to the citizen and even easier still if the technology is integrated into other familiar, non-technological objects. An AAL-space could be the citizen's home, or it could be a senior community, or even village, where the inhabitants all have social roles to fulfill and are empowered in such a way that they are capable of helping each other in their respective management of care. In an AAL-environment, the citizen is autonomous, but never isolated.

In Tele Ulcer Care, the visiting nurse is currently responsible for treating the patients' ulcers, taking pictures of the ulcers with her mobile phone, and uploading the pictures along with any additional notes to a web-based ulcer record accessible to the ulcer specialists at the hospital and to the general practitioners (GP). The ulcer record works as a platform of communication between the patients and the health professionals, and the patient himself and his relatives can also gain access to the patient's personal data in the ulcer record and this is where the project includes elements of patient empowerment: The patient can keep track of his treatment and the healing (or deterioration) of the ulcers. It is then interesting to note that although findings from the literature supports the idea that telehealth motivates the patients to be actively involved, Tele Ulcer Care's mini-HTA states that the patients' request for gaining access to their personal data in the ulcer record was not as present as expected. A possible explanation might be that we as patients have yet to get used to the idea that we have the authority to be more than just passive receivers of health care services. Another explanation for the degree of patient motivation might be whether the telehealth technologies are perceived by the patient as being user friendly. Note however that since 2009, as can be seen in Fig. 1, the number of notes uploaded to the electronic ulcer record by the patients has increased gradually. This might indicate that appropriate training and enough time to get familiarized with the technology can facilitate patient involvement.

The research on which Tele Ulcer Care is based found that telemedicine has the potential to bridge the gap between the medical experts (i.e., doctors and/or nurses at the

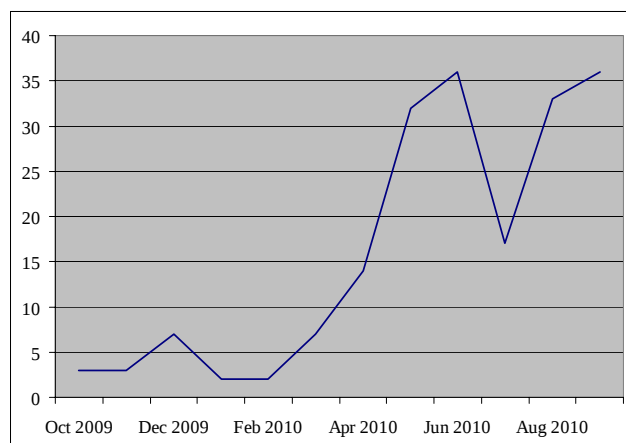


Figure 1. Development in the number of patient notes uploaded.
Source: Dansk Telemedicin.

hospitals) and the visiting nurses treating the patients in the sense that the triangle of patient, visiting nurse, and medical expert is completed (Fig. 2). This might be perceived as leaving the patient out of discussions on his treatment but it has quite the opposite effect: Instead of having to act as the intermediary between expert and visiting nurse, i.e., having to answer questions about the treatment, which the patient might feel insecure about, the completed triangle ensures that he no longer has to worry about the communication between expert and visiting nurse. Instead, he can assume the role of the patient that is actively involved in a three-way dialogue, knowing that his inputs are valuable in the course of treatment and that they are received by both the expert and the visiting nurse. The asynchronous telemedicine system of transferring images and notes, currently demonstrated in the project, has the potential of further enhancing the level of patient empowerment: instead of having to be present at the same time as the visiting nurse and medical expert as with video conferencing in synchronous treatment, the patient can access his data in the ulcer record whenever he has the time, and he can even write notes in his own record for the health care professionals.

Note that although the work of [24] takes a patient-involvement approach, it still focuses mainly on the patient as a receiver rather than an active user. However, an important perspective can be drawn from the research: the patients' feelings of satisfaction, security, and confidence with this new kind of treatment might be an indication of the patients being ready for health care services in which they are more actively involved.

The technology of telemedical ulcer treatment is very simple; the phone is an off-the-shelf mobile phone with camera and the electronic ulcer record is a user friendly browser, hence patients are likely to easily familiarize themselves with the technology and not to have significant resistance towards using it.

The simplicity of the technology and its non-intrusive, mobile nature combined with the potential for this kind of

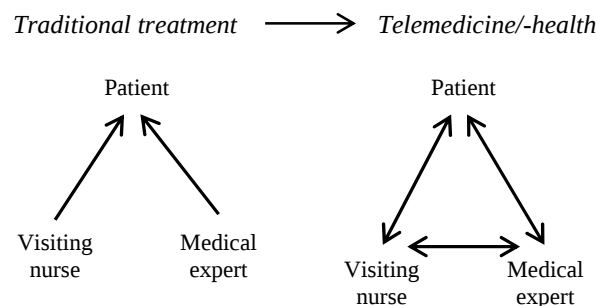


Figure 2. The new joint triangle of care

treatment to reduce some of the social stigma related to foot ulcers shows that telemedical ulcer treatment can live up to the ideal of ambient assisted living. Future perspectives on citizen involvement in ulcer treatment are presented in section VII.

In DREAMING, the citizens assume a new role as patients from the very beginning in that they manage a number of tasks previously handled by the visiting nurses. By taking their own measurements and communicating with the nurses via video conference, the citizens become involved in their own course of treatment in a way that is radically different from traditional patient roles. In fact, they take over some of the central nursing tasks and are thereby largely in charge of their own treatment. Thus, the treatment of chronically ill elderly citizens takes on a new aspect of self-management and moves away from the traditional treatment methods concerning this demographic group living in their own homes. By having the necessary measuring equipment at home, the citizens are not only more independent, but also safer as they can take measurements if they feel unwell and because they know that their daily measurements are evaluated continuously by the nurses who used to actually take the measurements. This assertion is supported by statements from one citizen who says: "I like the fact that we are closely monitored" and continues by agreeing with a statement made by the project nurse: "It gives a sense of freedom to be able to handle your own treatment, while knowing that you are still being looked after. That's really an advantage." Another citizen states: "It is so simple" and continues "Technology really is genius" [27].

Video conference technology opens up for a more active dialogue between the citizens and the visiting nurses, and for citizens to take their measurements on their own and thereby to gain a better understanding of their particular condition.

Earlier studies of a similar nature have reported positive effects on patients' health and quality of life as well as cost-effectiveness and structural aspects [28-37], and it is anticipated that the solutions applied in DREAMING can improve health care services dramatically.

The technology applied in DREAMING also allows for the citizens to take on an extended role in the larger perspective of society. AAL technologies offer a new freedom for chronically ill elderly citizens and allow for them to be actively involved in society for longer. In

DREAMING, this is particularly pertinent to the video conference component. This system is connected to and runs via the citizen's own TV and therefore constitutes a familiar interface for the citizen. The system brings society into the citizen's own living room, so to speak, by offering the possibility of face-to-face contact with nurses, GPs, family, and friends, including other elderly citizens experiencing similar health problems.

In the abovementioned MAST manual, potentials of patient empowerment is not listed as one of the preceding considerations deemed necessary when evaluating telemedicine programs. It might be beneficial to include this aspect in the preceding considerations since the opportunities that patient empowerment allows for, are likely to significantly influence the assessment of telemedicine.

VI. CONCLUSIONS

The present article has shown how, in research projects, citizens' role as patients in health care has already been influenced by telehealth technology. Examples have been presented that show telehealth technologies can empower patients in such a way that they are actively involved in a new triangle of care. The empowerment happens through information-sharing; offering the patients a visual overview of their course of treatment, letting the patients take their own measurements, and letting them provide verbal and written inputs. Further, the idea has been presented that the technology can pave the way for citizens to take care of each other. Also, both projects show that old age is not necessarily a barrier in the use of ICT.

Of the two projects presented, DREAMING relies on patient empowerment the most due to these factors: The patients themselves are already taking their own measurements and the flexible video conferencing system makes it easy to establish contact with health professionals.

In order to fully realize the second level of citizen involvement, the extended citizen role, in telehealth projects, it is crucial that it is made clear to the patients, relatives, etc. that their inputs are valuable and that the health professionals have an interest in empowering the patients since this improves the basis for decision and ultimately the quality of the treatment.

The success of telehealth programs rely heavily on patient inclusion in the planning and development processes as well as the technology being non-intrusive and user-friendly, even elderly-friendly; potential factors such as co-morbidities and reduced cognitive and psycho-motor skills have to be taken into consideration. Both projects have experienced how appropriate training and patient inclusion have lowered potential resistance to the technologies.

VII. PERSPECTIVES

In its fullest form, patient empowerment through telehealth technology allows for direct communication between the patient and the medical expert. Note however, that this does not mean that visiting nurses become redundant, but it does imply that as patients will become

more competent in their own care, the visiting nurse's professional role is likely to change. Training the patients in self-management does not, of course, entirely substitute the competences of the visiting nurses but it does have the potential of reducing their burden of tasks. More research on how telehealth technology will affect the roles of health professionals would be valuable.

The next step in terms of citizen involvement in ulcer treatment would be letting the patients take the pictures themselves and to upload both the pictures and comments on the state of their ulcers to the electronic record. In DREAMING, this is already taking place as the citizens are taking their own measurements instead of leaving the task for the visiting nurses. The second level of citizen involvement, the extended citizen role, in telemedical ulcer treatment as well as treatment for diabetes, heart failure, and COPD would be letting citizens perform this kind of treatment on each other and/or educating the relatives in performing it. In other words, to extend the above-mentioned triangle of care to include patients' relatives, neighbors, or other persons from the patients' social network as well. In this connection, the video conference component opens up for the possibility of a new network comprising not only medical specialists and relatives, but also new acquaintances in terms of other citizens in a similar situation. This would allow for the citizens to exchange experience and help each other. This is a valuable feature as other patients are often a better source of advice for how to live with a chronic illness than medical specialists who are primarily concerned with treatment of the illness.

An important lesson from the DREAMING project is that the more encompassing telehealth technologies are the better. For instance, since a diabetes patient is likely to suffer from several co-morbidities it would make good sense to provide this patient with a technology that is able to measure and/or monitor e.g., both his glucose levels and his foot ulcers.

To help relieve the strained health care sectors it might be necessary to let health professionals focus more on the actual treatment and then empower patients and their relatives to deal with the more care-related tasks. This might be realized through the use of AAL-communities in which non-intrusive technology, telehealth technology being only one kind, empowers citizens to be involved in their own care and the care of their fellow citizens. Ideally, the design of such AAL-spaces will be based on continuous user feedback. Self-care programs require patient involvement at every stage, as well as user-driven innovation, sharing of knowledge between providers and patients, and education about preventive care and treatment that the patient himself can be in charge of.

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