CLINICAL PRACTICE

Patient empowerment and involvement in telemedicine

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ABSTRACT

Objective: Telemedicine is a rapidly expanding area, and this article discusses the implications of patient empowerment and user involvement in relation to frail patients. Our aim is to critique the mechanical way telemedicine is being implemented in the health sector.

Methods: We present the basic ideas of empowerment and user involvement behind telemedicine, exemplifying them with a case of user resistance to telemedicine. Four logics of empowerment are employed to identify the underlying rationale in specific cases of telemedicine. The case comes from a large evaluation of new welfare technology products. The data consist mainly of written documents and an interview.

Results: Telemedicine is often considered a way to increase empowerment and user involvement in healthcare. The majority of the geriatric patients in the described case refused to engage in telemedicine, preferring instead to be hospitalized. The case appeared to be driven primarily by a professional logic of empowerment. User involvement and empowerment are discussed in terms of their demands and implication for users, such as 1) intrusion on the private sphere, i.e., the home and 2) the question of the responsibility for treatment and 3) the expectation, that the capabilities and resources of patients and relatives may increase.

Conclusions: Although telemedicine is acknowledged as relevant, a mechanical approach too often hampers empowerment for the patient. Some patient groups may not feel safe using telemedicine, in which case user involvement and empowerment are not possible.

Key Words: Telemedicine, Patient empowerment, User involvement, Healthcare, Geriatric

1. INTRODUCTION

Healthcare providers across Europe are looking for technological products to support the healthcare of nonhospitalized patients. One major tool is telemedicine, which is believed to improve communication between providers and patients, reduce the use of healthcare facilities, and increase the quality of life and empowerment of patients.[1–5] Such technologies may help establish ways of living with and managing a disease, but can also create problems.[6]

Recent developments in healthcare—such as the expected 30% reduction in hospital beds in Denmark with an associated increase in the treatment of patients at home—calls for improvement in existing technologies and the development of new technologies to support nonhospitalized patients.[7] It has been alleged that the ongoing user-driven development of technologies will support users in taking responsibility for their own health and treatment.[8]

This article explores the appropriateness of user involvement and empowerment in healthcare, with a particular focus on frail patients. It examines how user involvement and empowerment are conceptualized in the literature, as well as the way in which the two concepts are related. A further aim is to query mechanical understandings of telemedicine and empowerment or user involvement.

2. THEORETICAL BACKGROUND AND METHODS

The concepts of user involvement and empowerment are explored in relation to expectations, limitations, and strengths. The specific elements of users' involvement are characterized using a model of four underlying logics of empowerment and illustrated by a project employing telemedicine with geriatric patients. The project data were gleaned from a questionnaire concerning the development and aims of a telemedicine product, other written material from the project, and an interview with a project team member.

3. RESULTS

The concept of empowerment is rooted in workplace sociology and educational research from the 1960s. With Paulo Freire's work as an early influence,[9] Lemire points out the ambiguity of the concept and its many interpretations, calling it "a complex learning and action process that takes different forms or meanings as a function of the stakeholder, the context and time".[10]

A prominent feature of empowerment in healthcare is the idea of patients playing an active role in their own treatment.[11] Empowerment is often defined as a process of behavioural change in which patients become more knowledgeable and take control over their own body, disease, and treatment.[12] The goal is an independent, active, authorized patient.[13] Empowerment has also been described as an exercise of power in which an individual (here, a patient) wishes to change his or her conduct in certain ways—a process leading to what is often called personal development with increased personal responsibility, moving the focus away from living conditions and structural dimensions as causes of (continued) ill health.[13] Patient empowerment is thus seen to enable patients to control and take responsibility for their own lives, making their own decisions as to whether they want others to influence their lives, and how they should act in case of treatment.[7]

Four different logics of empowerment can be identified in our framework, which draws on Lemire, and they may co-exist within the same configuration of information and communication technology. Lemire distinguishes between the "professional logic", which is concerned with the behaviour of patients according to what has been prescribed by experts; the "technocratic logic", dealing with behaviour in terms of organizational or institutional goals; the "consumerist logic", which calls on the personal judgment of the stakeholder; and the "community logic", concerned with mutual assistance through citizenship.[10] In line with Lemire's distinction, we explore which logics are at play and their effects on the development of empowerment in this project.

Attention to user involvement has increased within healthcare in recent years. While patients were in general previously considered as the passive recipients of healthcare, the increased focus has had important implications for the distribution of power. In Denmark, for example, patients' right to a free choice of hospital has been incorporated into the legal framework of healthcare provision, while the focus on patients' obligations in self-care has also increased.[14] The emphasis on patients' involvement as active and responsible in relation to their own disease and treatment corresponds well to the strengthened interest in patient empowerment.

Healthcare in general appears to be moving away from viewing the patient as a purely biological body to a concept of an embodied subject experiencing and living with health problems in interaction with the surrounding environment. Telemedicine is believed to provide patients with the potential to become responsible and self-managing.[15] At the same time, this implies increasing individualization and privatization of the responsibility for good health. Telemedicine is seen also as a means to meet challenges faced by the welfare state in relation to increases in the elderly population and chronic disease patients. Using video communication and data from measurements performed by patients themselves, telemedicine allows the professionals to follow the health status of patients at home, making it possible to diagnose, treat, and advise on disease and treatment.[16] Ideally, patients will be able to follow their own health status and master their condition, lightening the burden on hospitals and day-care clinics. Patients are thus expected to take on some of the work that traditionally has been undertaken by healthcare professionals.[17] With patients becoming more responsible for their own treatment, healthcare professionals gain a new role as supporting and facilitative partners.[18] A key issue in relation to power and responsibility is the different kinds of knowledge possessed by patients and healthcare professionals: Where the patient's responsibility for the prevention is related to the individual home context, personal values and practical everyday life, the health care professionals' responsibility is related to the clinical context with set parameters they can measure and evaluate the effect of.[18]

The Danish Knowledge Center for User Involvement in Health Care (ViBIS) suggests that user involvement in healthcare involves engaging patients and their families in treatment and the sharing of knowledge between users and professionals with the aim of clarifying the preferences, needs, and knowledge of the patients.[19]

Patient empowerment is stated to be one of the main focuses of contemporary healthcare. Information and knowledge

management in general, and telemedicine in particular, are often driving issues for user involvement in the care and treatment of sick people. The provision of the appropriate tools (including software) to the home is expected to enhance the economic and clinical efficacy of healthcare while improving patients' ability to take responsibility for their own health and treatment. It seems to be a widespread idea in healthcare practice that being responsible for own illness and being able to stay at home lie at the core of patient empowerment.[20]

A case example

A project on telemedicine for geriatric patients suffering from multiple diseases provides a good illustration of user involvement and empowerment. The overall goal of the project was to develop a telemedicine product to support home-based treatment of geriatric patients. The product was developed and tested by a geriatric surgeon and an external steering group, with a prime focus on solutions to fit the logic and needs of the hospital. A technocratic logic of empowerment (cf. Lemire's four kinds of logic) was thus central. The feasibility of the technology has subsequently been tested in several workshops that included patients, so in the sense that they were engaged during product development, the users were involved.

The computer-aided communication tool was supplemented by intelligent sensors for the surveillance of the patient's home. The sensors registered the comings and goings and behaviour that might compromise safety, for example if the patient left his or her bed or fell. The hospital was alerted in case of acute emergency, or when the patient's activities indicated disease or shortage of fluids, and similar. Four sensors were used simultaneously, 1) one that reported opening of the front door, and which coordinated the communication between the other sensors; 2) one that monitored the kitchen—for example, whether the stove was being used correctly; in case of danger it would be turned off; 3) a sensor in the bedroom to monitor whether the patient was in bed, sitting up, or had left the bed; this sensor could also turn on the room lighting. Finally, 4) a bathroom sensor monitored whether the patient was in that room, and could message to the hospital in case of a fall or prolonged presence in the bathroom. These surveillance sensors were meant to create safety and security for the patient at home, and to support patients in living at home with their illness. Overall, while the technology was predicated on the belief that patients' independence and functionality are better preserved by staying in the home, where they can retain control and empowerment, the surveillance system was governed by a professional logic (cf. Lemire), as it aimed to monitor whether the patients were involved and engaged in their own healthcare, and if they were acting in accordance with professional ideas of correct behaviour.

The surveillance was also intended to provide a feeling of increased security for relatives of (say) patients with dementia, as well as to save visits by professionals and prevent hospitalization. The community logic of empowerment is at play, as the product was intended to provide mutual assistance for patients, relatives, and professionals in caring and providing security for the patient. The professional logic was at play in informing professionals about activities in the home that might be signs of the patient's worsened health, while technocratic logic was involved in so far as the technology aimed at saving professionals' time.

Even though the development of the technology met with several challenges, the most serious obstacle turned out to be the target group itself: few patients opted to stay at home and test the product. Thus, only seven out of thirty invited patients volunteered for this, with the rest feeling so sick and fragile that they preferred to be hospitalized.

4. DISCUSSION

This case demonstrates the importance of considering the user perspective and realistic potentials for empowerment in planning and developing telemedicine solutions. The majority of potential users of this product simply did not wish to use it, even though it seemed relevant and valuable from professional, technocratic and community perspectives.

Telemedicine is presumed to be able to improve cooperation between healthcare professionals and chronic patients and thus improve patients' quality of life.[1, 21] Yet telemedicine also transfers responsibility from healthcare personnel to patients. It may be a challenge for practitioners, patients, and families when responsibility and treatment are transferred from the clinic to the home, and expectations of what is to be done at home by the patient and family may collide with the patients' abilities, as well as hopes for the future. Patients and their families are thus enrolled into the healthcare system and their contributions managed by healthcare professionals.[22]

Pointing out that a move from hospital to home involves complex problems for professionals, patients, and families alike, Grøn et al. discuss how patients experience and cope with the dilemmas that emerge in the new hospital–home division of work and responsibility. Of prime importance is the time and social dimensions involved when patients and relatives engage in telemedicine projects. With formal healthcare as an expert-driven venture, the professionals become essential actors in the homes of the patients.[22] This mix of home and professional expertise raises a complex of social dilem-

mas between social life and healthcare, blurring the border between the two. With the surveillance involved in many telemedicine products, the tension between social life and healthcare potentially incorporates a community logic, insofar as life at home is no longer private, but becomes a joint venture for patients, relatives, and healthcare professionals.

Complexities involved in the successful implementation of telemedicine are many; a literature review of telemedicine thus identified a number of barriers, which included technically challenged staff (11%), resistance to change (8%), cost (8%), reimbursement (5%), patient age (5%), and patient level of education (5%).[3] For implementation to succeed, dialogue and involvement, negotiation, and flexible and adjustable solutions are required.[23]

The case examined in this paper showed that, although the development process did involve users as collaborators, the majority of the end users rejected the product, finding it neither relevant nor attractive. The involvement and empowerment of the patients thus appears to be viewed as rather mechanical process. Lemire's conceptualization of professional logic[10] seems to permeate an approach in which users are involved in the development of the interface of a telemedicine device, but not in the discussion of its relevance and appropriateness. Although patients' active participation in treating and monitoring their illness is sought, their contributions are expected to be in accordance with health expertise and knowledge. This points to empowerment as an issue related not only to the individual, but one that needs to be seen in a relational perspective.

People's resources are decisive for their active involvement in telemedicine, and thus for their empowerment.[24] In the case discussed here, the elderly and frail patients neither wanted to use telemedicine nor to be hospitalized in their homes. They had no wish to take a position of responsibility for their own care—an issue also emphasized by Andreassen and Trondsen, who state that "Not all patients want to take on responsibility for their own health; there are situations in which patients want doctors or others to be in charge... and hence do not want to be empowered either".[9] In a modern welfare state, the elderly may consider it a human right to be hospitalized when sick, and to be able to rely on traditional doctor–patient roles.[9] The concept of empowerment was developed along the lines of the relationship between a pupil and teacher, but fundamentally different issues may be at stake here. The patient's weakness may imply physical experience of bodily pain, the fear of pain, or even the fear of death,[9] and seeing a doctor in itself implies a transfer of responsibility. Further, Clemensen et al.[2] point to the importance of identifying the personal characteristics of the target patients of telemedicine projects—e.g., are they urban, rural, young, old, etc.? Telemedicine patients are typically elderly people requiring homecare, making it necessary to recognize "that when care takes place in the patient's home, it must be carried out on the patient's terms".[2] The patients' experience of their illness must be acknowledged, as well as their need for security and self-determination; successful empowerment occurs when patients come to terms with their threatened security and identity—not only with their treatment.[12]

5. CONCLUSION

The last decade has given prominence to user involvement and empowerment in the healthcare sector and in health policy. This article discussed these two concepts and argued that, although telemedicine is relevant, it is often approached in a mechanical fashion that impedes the empowerment of the patient. Some patient groups may not feel safe using telemedicine, and user involvement and empowerment will not be possible. Although telemedicine may be very attractive to healthcare professionals, as it saves time and other resources, to the frail patient it may be a rather unsuitable technology, creating insecurity and increasing responsibility for patients and relatives alike.

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CONFLICTS OF INTEREST DISCLOSURE

The authors declare that there is no conflict of interest.

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