Quality of Life through Quality of Information
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Improving quality of life through eHealth – the patient perspective

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Abstract. Patients have moved away from being passive recipients of care. They require access to their own health data, shared decision making and control over their care pathways. eHealth offers the tools to meet these requirements and to support both patients and care providers. However, opinions diverge in how far a patient-provider partnership should be supported or full consumer autonomy be provided and there is still not enough evidence on how to design and implement effective eHealth solutions that create patient benefits. In this keynote paper different perspectives on the patient empowerment process, outcome measurement and eHealth development will be discussed as well as ongoing developments in the field of e-citizen services be presented.

Keywords: Consumer informatics, eHealth, patient empowerment, patient benefit, personal health informatics, quality of life

Introduction

eHealth is an increasing field of interest with the potential to revolutionize the way health care and prevention is provided, shifting the balance of power and responsibility from health care professionals to patients and citizens [1]. Many agree with Charles Safran's quote "… [When patients] participate more actively in the process of medical care, we can create a new healthcare system with higher quality services, better outcomes, lower costs, fewer medical mistakes, and happier, healthier patients [2]. In this regard, patient empowerment is often used as a buzz word to describe the changing role of patients from passive recipients of care into active participants of their own care process. This leads to intensive discussions on the patient-provider relationship, on the patient's role and responsibility, as well as on the ownership of data. Institutions, providers, and informaticians now encourage healthcare consumers to take greater control of their own healthcare needs through improved health and wellness activities, internet-based education and support groups, and personal health records (PHRs) [3]. Some PHR developers are strong proponents of systems that are not in any way controlled by or linked to institutionalized systems in order to provide full consumer autonomy, whereas others claim that linkage to clinical systems is mandatory to achieve safe and high quality care [4-7].

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In this keynote, I will elaborate on these different perspectives in relation to patient empowerment and how eHealth may impact on the patient empowerment process and its outcome.

1. Patient empowerment process

The empowerment concept is emphasized by the World Health Organization (WHO) through the definition of health promotion as a "process of enabling people to increase control over and to improve their own health" [8] and may be defined as a complex experience of personal change [9]. An analysis of fifty-five research articles on the topic of patient empowerment showed that the process of patient empowerment can be seen from two perspectives adopting either the view of the patient-provider interaction or the point of view of the patient alone [9]. Whereas the former perspective is characterized by a collaborative process based on communication and education where knowledge, values and power are shared, the latter perspective is based on a process of personal transformation. Although those processes differ, both are based on an educational component and the outcome is expected to be the same, i.e. “to gain more power over one’s life” [9]. Irrespectively of the process, mandatory steps are “access to information”, “building knowledge” and “transforming knowledge into action”.

2. Measuring outcomes

According to Aujoulat et al. [9], outcomes of the patient empowerment process may be measured according to the following dimensions: (i) disease and treatment-related indicators, such as e.g. clinical outcomes; (ii) provider–patient interaction-related indicators, such as e.g. the patients’ satisfaction regarding consultation or intervention; (iii) psychosocial and life-related indicators, such as e.g. the patients’ quality of life. For patients in general and chronic or elderly patients specifically, three goals were further identified as particularly important; independence, continuity and participation [10]. Self-management, shared decision making and participation were considered important outcomes if resulting from a process of self-determination [9]. This is especially enlighten by findings where patients opt to delegate responsibility for decision-making on clinical issues to care providers. As a result of their empowerment process patients expressed a better feeling of understanding of their disease and a more positive attitude towards life [11]. As an outcome of the patient empowerment process, patients further reported that they were confident and actively involved in negotiating the goals of their care plan, that they had redefined health, revitalised their sense of self and the desire to live for themselves, and that they had gained more strength to help others [12].

Apart from disease-specific scales, different validated, more general scales for outcome measurement of patient perception do exist such as WHOQOL, the WHO scale for Quality of Life [13], or EQ-5D [14], the European standard instrument to measure health outcome. Such scales are used in medical, nursing and care sciences research and are usually based on pre-defined items from a professional perspective. Other authors report on novel approaches to measure disease-specific patient benefit based on patient-defined indicators [15] or on measuring quality of care based on patient-defined indicators [16] taking into account different perceptions regarding health outcome of patients vs. care providers.

3. Types of eHealth services supporting patient empowerment

The fields of Consumer Informatics and Personal Health Informatics study the information use of patients and citizens to support self-care, prevention and lifestyle management. Personal health records, patient portals and social networks but also sensor-based health-enabling technologies and personal health systems have been researched in this regard [4]. To support patient empowerment, eHealth services need to support the three steps of "accessing information", "building knowledge" and "transforming knowledge into action". All steps need to be set in relation to personal goals to be able to attain outcomes that are personally and clinically meaningful.

To access information numerous eHealth services do exist providing access to own health data via PHRs or health enabling technologies, or access to general health data and administrative services through patient portals, social networks and the like.

To build knowledge, validating the information is necessary. In an environment where the amount of information is growing and more easily available than ever before, sharing information with significant others is essential to be able to validate the information. Not least to be able to set it into a context of what is clinically meaningful, information sharing with clinical professionals is mandatory but will be complemented by e.g. e-patient networks.

Transforming knowledge into action is needed for informed decision making and eHealth services in form of context specific decision aids will be the future technology to support that.

4. Patients' perceived benefits and barriers

Studies focusing on the use of portals and social networks to deliver virtual services often report high satisfaction rates among patients who have followed a form of "virtual treatment" and report an impact on the patient-health professional relationship [4]. Also improved quality of life, less in-person consultations, greater knowledge, and better self-management are mentioned as driving forces of patients' satisfaction with portal- and social network-based applications [17].

Even with increasing availability of PHRs and a documented consumer interest, the actual adoption of PHR systems is however not that high. Besides the problem of interoperability and access to the clinical base data, patients' worriedness about data protection, security, privacy and confidentiality are stated as main reasons behind this low adoption rate [4].

5. Discussion

In all three areas described above; patient empowerment process, outcome measurement and eHealth development, we can see two flip sides of the same coin. All three areas include a patient side and a care provider side and the author is convinced that both sides need to be intertwined to achieve the benefits in form of quality of life that patients expect. To make this happen however certain preconditions will need to be in place. Such as the patients' role has changed, the care providers' role will need to change from a pure expert role into the role of a facilitator. Patient empowerment will thus be guided by the principle of self-determination and facilitated by healthcare providers that adopt a patient-centred approach of care which acknowledges the patients' experience, priorities and fears [9]. Outcome measurement will need to be complemented by patient-defined indicators and eHealth development needs to discuss the shared information space in more detail.

One of the bottlenecks of eHealth development is the access to and interaction with health data in an environment where patients are increasingly receiving care from different care providers and where more and more health-related data is getting public and, in addition, a huge market for health-related mobile applications has emerged. Some care providers provide patients with a tethered PHR, national patient portals allow for appointment booking and other administrative services and promoters of full patient autonomy claim to be able to collect all health data and have it controlled by the patient. But few solutions have really been designed as decision support tools for patients. PHRs mostly represent a snapshot of the provider's EHR without redesign!

So, how to provide effective eHealth services that create patient benefits? As stated above, patients are increasingly receiving care from several care providers, thus information needs to be presented as a patient-centered, continuous, inter-organizational care process. In the context of a specific situation, patients need to be able to follow their pathway in different phases, and have access to information to make informed decisions, be able to document specific events either for their own use or to communicate to care providers. Care-related services are a part that needs to be tackled in a shared or coordinated way between patients and providers. A greater spectrum of health-related services such as lifestyle management applications can be handled purely by the patient but nevertheless information exchange is necessary.

One project that aims to create new mobile citizen e-services that allow patients to follow, own and manage their care process related information is the Swedish research project ”My Care Pathways”[18]. The project is based on a secure national integration platform where individual health data will be made available and templates for patient-provider communication do exist. Patients can request their health data from any care provider and gather it in different context according to characteristics of their pathways that vary over time. As patients now own their data they can also provide it to third party applications but will define themselves which information to share with whom and for how long in a secure way. Patients' process related information needs have been analyzed and reported elsewhere [19]. One further important aim is the implementation of a Software Developer Kit (SDK) with online services for software developers to be able to design applications that are interoperable with current health information systems through the platform [20].

6. Conclusions

Whereas other parts of health-related data such as lifestyle management information will be controlled and managed purely by the citizen, care-related information will be handled in partnership and different parts of the care-related data will be controlled by different actors and patient empowerment achieved in a collaborative process based on communication and education. Future eHealth services need to be adaptable to and guide the patient through the care process which must thus be combinable with e-services outside the care sector.

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