

Chapter 21

Supporting the Development of Personalized E–Health: An Insight into the E–Patient Context

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ABSTRACT

The area of E-health development for patient-healthcare interaction has lately received significant attention by the health informatics community. Increasingly healthcare and information technology (IT) developers are proposed to take seriously the needs and preferences of the patients. This chapter explores the multifaceted E-patient context, in an effort to contribute to an increased patient-centeredness of this form of technology development. Patient-centeredness is captured in terms of personalization as an attempt to depart from patients' specific context to contribute to technology design and use. Using a qualitative approach, the chapter reports from 25 in-depth interviews performed with Swedish patients and representatives of patient associations. Six themes of the E-patient context derive from the findings (diagnosis, demographics, access, preferences, coping, and patient role). The results present a fine-grained picture of the E-patient context adding to previous approaches of personalization. The introductory discussion reflects on the themes in relation to their tentative implications for the development of patient-centered personalized E-health for patient-healthcare interaction.

INTRODUCTION

This chapter explores the multifaceted context of E-patients. The aim is to contribute to the ongoing discussion about patient-centered approaches in E-health development. In particular, the text concerns E-health solutions for online patient-healthcare

interaction. This form of E-health involves a wide range of technological arrangements including online support for patients to learn about health and illness (Murero & Rice, 2006), or to get informed about the healthcare system and to make choices in healthcare (Ranerup, 2008). Other arrangements are E-health applications for contact with treating clinic (Leimeister & Krcmar, 2006), remote disease management and care assistance (Torp et al., 2008),

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or systems to manage online bookings (McCarthy et al., 2007), etc.

Increasingly the discussion about E-health for patient-healthcare interaction proposes healthcare providers and information technology (IT) developers to take seriously the needs and preferences of the patients (Demiris, 2006; Johnson & Ambrose, 2006; Murero & Rice, 2006). Patient-centeredness considering the wider picture of the patient situation is promoted contrasting previous organization-centered approaches. However, taking the patient perspective seriously requires a detailed picture of the patient context moving beyond general ideas of patients or narrow biomedical perspectives. Therefore, it is here proposed that patients' experiences of illness, their varying needs and preferences should become central components (see Lewin et al., 2001). More specifically, patient-centeredness is here discussed in terms of *personalization*. This involves an intention to depart from patients' specific context to guide technology design and use.

Regarding the emerging forms of E-health for patient-healthcare interaction, two main dimensions characterize personalization. The first dimension departs from individual activities online like patients' seeking of medical information (Adams et al., 2006; Kivits, 2006; Josefsson, 2006; Morahan-Martin, 2004) or seeking of social support (Barnett & Hwang, 2006; Johnson & Ambrose, 2006; Wright & Bell, 2003). In its simplest form, this means personalization when patients (on their own) by means of different sources bring together a personal set of information according to their preferences and needs. This form of personalization is recognized by patients being considered a homogeneous group sometimes grouped together using general terms such as "health seekers" or "healthcare consumers", etc. suggesting that patients have the same or similar needs and preferences.

The second dimension of personalization departs from healthcare providers' information needs in the care process. Here personalization generally refers to E-health applications collecting personal biomedical data for disease management and follow-ups. Often these systems are organization-centered taking a medical and/or a technical interest to gather data. As an example, Benaroya et al. (2007) developed an interactive system (accessed in the waiting room) for patients to enter medical history data prior to appointments. Other examples involve patients' home-based access to the EPR (Electronic Patient Record) (Bergmann et al., 2007; Schabetsberger et al., 2006). Lately a development of this form of personalization has been noticed taking an increased interest in the wider patient situation (Burkow et al., 2008; Leimeister & Krcmar, 2006; Rahimpoura et al., 2008).

Both dimensions of personalization are important to the E-health development in the patient-healthcare relationship. However, to take patient-centeredness seriously and to open up for the Internet to become a more effectively utilized healthcare resource, there is a need for complementing approaches of personalization focusing on the fine-grained picture of the E-patient context. Further, thoroughly considering the E-patient context is here believed to make an important step towards new forms of E-health solutions where patients can contribute as the valuable healthcare resource they truly are (Demiris, 2006; Johnson & Ambrose, 2006).

The following text focuses on chronically ill patients suffering from long-term health conditions such as MS (multiple sclerosis), diabetes, or cancer. This choice is motivated by chronic illnesses being conditions that often develop over time, involve complex information needs, and require recurrent contacts with healthcare providers and professionals (Maes et al., 1996). This makes chronically ill patients important to focus on as potential long-time users of different

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