Chapter 52
From Idea to Use:
Lessons Learned From a Participatory ICT Healthcare Case Study

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ABSTRACT

The objective of the case study presented here was to develop and investigate the use of a novel e-health technology called the Memory Stone. This personal device was intended to be used for storing information and enabling communication with the healthcare information system. It would also serve as an intimate repository during the pregnancy, and as such, function as a learning tool during the course of a pregnancy. Using a participatory design approach, the work was performed in collaboration between a multidisciplinary research team, ten pregnant women, and eight healthcare professionals including midwives, general practitioners and medical specialists. In this chapter, some more or less problematic issues encountered during the case study will be discussed and put forward as topics to be considered in future research concerning e-health technology. This discussion includes areas such as initiative versus creativity, methodological issues, stakeholder interests, and other difficulties when introducing novel information technology in a healthcare context.

INTRODUCTION

During the last decade, the development of healthcare related information and communication technology (ICT) has shifted from wired and stand-alone systems such as centralized information management towards integrated wireless and embedded devices (Koch, 2005). This shift also has a foundation in the development of smaller handheld devices with increasing computational powers, biosensors, wearable technology and internet-based services. To some extent, the focus has changed from a primary technical one towards a more user centered design, making technology a tool for patients and relatives and not as previously merely a concern for professionals.

Many of these applications are part of the telemedicine paradigm and are often used by the individual patients to monitor their own medical condition at home (Wootton, 2001). This includes performing diagnostic procedures at home, relaying data to and from medical facilities from the home, and similar activities. Another area where patient-based applications are in focus are the many online forums, where information is exchanged, both between professionals and patients, and between different patients or individuals, such as pregnant women (Kouri et. al., 2006).

The case discussed in this chapter is primarily about providing tools for non-professional individuals to help them cope with a new and changing health condition, namely a pregnancy. The chapter draws on the knowledge gained from a larger participatory design research project and specifically from a case study within this project focusing on affective experiences and information handling during pregnancy and early maternity.

The purpose of this case was two-fold: firstly, it aimed at improving the communication between healthcare professionals in order to free time for patient care and personal interaction. Secondly, it aimed at making the nine months of pregnancy more enjoyable for the expectant mother and her spouse. The general idea was to provide the women with a personal digital device called the Memory Stone, a small handheld storage and communication tool holding text, images and other media.

The aim of this chapter is to discuss some general observations from this work and to point out a handful of issues, or lessons learned, which might be relevant to considered in future design research and development projects. The case study and the supportive technology developed are presented in more detail elsewhere (Enquist, 2008; Enquist & Tollmar, 2008; Vonge Corry et al., 2005). Here, the intention is to discuss ethical, practical, methodological as well as personal and affective aspects when researching and developing novel information technology in relation to present healthcare practice.

Current Practice of Information Handling

During a pregnancy, a woman is in contact with several healthcare professionals, and information is collected and stored for many different reasons; some for purely clinical purposes, while other is intended to be used by the pregnant woman herself. In the present work practices, information about the status of the fetus and the pregnant woman is kept in a number of different places, not only on various media, but also in different geographical locations. This scattering of information is partly due to the origin of the data, i.e. some are recorded by a midwife and stored on the local computer or paper file while other are stored elsewhere by the general practitioner. In addition, there is no means for the midwife to access the medical record of a patient kept by the doctor since the information systems are separated and in most cases not even compatible. Occasionally, the same information is provided and stored by different healthcare professionals, creating disturbing repetition and unnecessary redundancy, which in turn necessitates repetitive tasks of updating and cross-checking different medical records. This impinges on the efficiency of the consultations and also makes it cumbersome to correct errors in the distributed patient records.

Currently, there is no single place where all information is collected. The most comprehensive record is the pregnancy journal ("vandrejournal" in Danish), a paper folder kept by the pregnant woman (Figure 1). This increasingly thicker folder of notes and forms is brought to each consultation and updated by the midwife or general practitioner. It thus has a dual function: it is the only joint collection of health data during the pregnancy, and as such, it is the main means of communication between different groups of healthcare professionals.

The healthcare professionals use a wide range of clinical and technological tools to carry out their tasks. Some are common everyday devices,

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