Chapter XIV
Incompatible Images:
Asthmatics' Non–Use of an E–Health System for Asthma Self–Management

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ABSTRACT

This chapter investigates asthmatics' reasons for not adopting an e-health system for asthma self-management. An understanding of these reasons is particularly relevant, because clinical evidence indicates that, if used, such systems lead to better asthma management. The investigated asthma system is, however, based on a taken-for-granted image of asthmatics as, per se, striving to be symptom-free. This image is incompatible with interviewed asthmatics' day-to-day performances of their asthma, and renders invisible (a) that their asthma performances emphasize an economy of good passages and of feeling capable, (b) that they achieve the objective of feeling capable in quite different ways, and (c) that feeling capable does not per se equal being symptom-free all the time. To attain long-term use of self-management systems and other patient-centred e-health systems, such systems must acknowledge and link into the manifold performances that comprise users' ways of living with their disease.

INTRODUCTION

Asthma, diabetes, and other chronic diseases cannot be cured. This positions these diseases at the periphery of common conceptions of diseases and their treatment. First, whereas healthcare professionals can diagnose chronic diseases and make plans for their treatment, the actual treatment, which is thus management, must to a large extent be performed by the patients themselves (Newman, Steed, & Mulligan, 2004). Second, many chronic diseases are in part caused by what

can broadly be termed patients' life styles, and the management of these diseases involves as a core element comprehensive changes or restrictions in patients' habits and day-to-day lives (Butler, Rollnick, & Stott, 1996; GINA, 2005). Third, even brief failures to comply with proper management of the diseases may lead to symptoms or an irreversible worsening of the patient's condition. For many chronic diseases, patient-centred e-health systems are therefore seen as a way of supporting patients' self-management of their disease, primarily by providing information not otherwise available and by extending the communication between patients and healthcare professionals beyond infrequent, face-to-face consultations (Ball & Lillis, 2001; Safran, 2003).

This chapter analyses an e-health system for asthmatics. For reasons of anonymity, the system will be referred to as AWeb, and the company developing it as ACorp. Though asthma is a condition asthmatics have to live with, the risks of symptoms can be minimized by taking the right amount of medication. It is, however, no simple task to determine the correct amount of medication, because this depends on various risk factors, which may change dynamically and be hard to foresee. To accommodate the difficulties with dosing medication, asthmatics' self-management of their medication is considered a cornerstone in asthma treatment (Gibson, Powell, Coughlan, Wilson, Abramson, Haywood, Bauman, Hensley, & Walters, 2002; GINA, 2005). AWeb provides tools for asthmatics to manage their asthma themselves. Nevertheless, in spite of the utility of AWeb and considerable marketing by ACorp the system never attained widespread use and was discontinued after five years. To inform other initiatives toward providing e-health support for self-management of chronic diseases, we provide two accounts of the relations between asthmatics and their asthma:

- *The system's image of the user*: How does AWeb set up a way for asthmatics to think about their asthma?
- *The self-image of asthmatics*: How do asthmatics perform their asthma on a day-to-day basis?

The aim of our analysis is to elaborate and contrast these two images. We do not take asthmatics' non-use of AWeb as a rejection of self-management initiatives, but rather seek to inform future initiatives by attempting to explain why AWeb was not taken up by the targeted users.

Previous work on e-health systems for self-management of asthma has suggested several reasons for asthmatics' low uptake of such systems (Anhøj & Nielsen, 2004; Nielsen, 2005). The suggested reasons include inexperience with the Internet and computers, a latency time between starting to use a system and realizing the benefits of using it, and unpredictable interactions between the system and asthmatics' everyday lives. A limitation of this previous work is, however, that reasons for non-use have been derived from studies of asthmatics that—admittedly, to varying extents—are users of e-health systems for self-management of asthma. In the present chapter, we extend previous work by turning to non-users for input to an understanding of what "went wrong" in the AWeb project. Such an understanding is particularly relevant because a clinical test shows that, if used, Web-based asthma monitoring leads to better asthma management (in terms of symptoms suffered, lung function, and so forth) compared to monitoring by asthma specialists or general practitioners (Rasmussen, Phanareth, Nolte, & Backer, 2005).

BACKGROUND

Asthma is a chronic inflammatory disorder of the airways (GINA, 2005). This inflammatory condition causes hypersensitivity to risk factors

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