Adaptive Information for Consumers of Healthcare

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Abstract. This chapter discusses the application of some of the technologies of the adaptive web to the problem of providing information for healthcare consumers. The particular issues relating to this application area are discussed, including the goals of the communication, typical content of a user model, and commonly used techniques. Two case studies are presented, and evaluation approaches considered.

15.1 Introduction

So far this book has looked at some of the techniques that have been developed for the adaptive web, focusing on how we model the user, and how we use that information in adapting the user’s experience. In this chapter we show how some of these ideas apply to one particular application area: the provision of information to consumers of health care.

In recent years the way in which people are involved in their own health care has changed dramatically [47]. While, in the past, the almost exclusive source of information was the medical staff directly concerned with the provision of care, nowadays the Internet and the World Wide Web have provided new opportunities for a new generation of users, the “health information consumers”. These have been defined by organisations like the American Medical Informatics Association as people who seek information on various aspects related to health and well being, like health promotion, disease prevention, management of long term conditions, and so on. Health information consumers are therefore not only patients, but also their family and friends, or simply people concerned about health.

An increasing number of people are now using the Internet to support their health care [58], and the amount of information available on the Web continues to grow. The information needs of healthcare consumers are different from those of the members of the healthcare team (see [59, 53, 28] for some examples of research in health information systems aimed at health care providers). For example, patient-oriented health information systems may include providing information to promote patient choice, informed consent, self-care and shared patient-doctor decision-making (e.g., [46]). Providing such health information via adaptive web-based systems offers new possibilities...
for pursuing public health objectives like providing knowledge and inducing behaviour change. Furthermore, recent studies have shown that web-based interventions (to provide knowledge and induce behavior change) can have more impact than non web-based interventions [73]. This includes increased knowledge about conditions and treatment, increased participation in health and more uptake of behaviour changes. In addition, sites that pointed readers to relevant, individually tailored material reported longer session times per web-visits and more visits.

There is also evidence that decontextualised, impersonal and generic health information, as typically found on the Internet, has less impact than health information tailored to the individual, at least in some situations (e.g., [3, 49, 18, 69, 70, 68]).

There has therefore been much interest in how we can design systems capable of tailoring information to the health care consumer, and exploiting the great potential to enhance health information and education through web delivery – applying ideas from adaptive web-based presentations and adaptive hypermedia to the problem of providing users with relevant, appropriate, understandable, and potentially persuasive information relating to their needs. There are particular issues in this area to be aware of, focusing now on patients as our main healthcare consumer.

First, we need to consider some of the goals of patient information and education. Patient information may be intended to inform, to enable decision-making or to persuade. We may, for example, want to: inform the user about their condition or about the side-effects of their treatment; give them enough information to enable them to take an active role in the decision-making concerning whether or not to have surgery; or persuade the patient to improve their diet. Persuading the user of a course of action may be part of encouraging patient compliance (or adherence) – we may want to encourage and motivate them to go along with the treatment regime proposed and take the necessary actions.

Whatever the objective of a healthcare communication, different patients have different individual needs. A good healthcare professional will recognise this and adjust the content and level of verbal information to the patient’s perceived needs (both informational and emotional) and their level of understanding. He or she may also ensure that the language employed is both understandable and appropriate for a specific patient, remembering that, first, most patients are not medical experts, and, second, they might already be under considerable cognitive load and stress due to the situation.

This contrasts with current written sources of information (e.g., leaflets and websites) which are normally targeted at the typical patient, not at the individual. Yet written information is also of vital importance in healthcare communication. Verbal messages are often forgotten, while written information is there for reference, and potentially provides a shared information source for patient, family and friends. Recognising this, for example, a genetic counselor will always provide patients or carers a one- to two-page letter summarising the information that was given to them verbally during the consultation [4].

Given the need for personalised or tailored information and the benefits of written sources, many researchers have explored how we can automatically adapt the content of healthcare messages to the patient (or more generally, to the user). Information may be delivered through printed leaflets, online via adaptive websites, or through phone/text