

Taking Health Information Behaviour into Account in the design of e-health services

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Abstract

The aim of this article is to bring forward the benefits of a better integration of a comprehensive understanding of individuals' information behaviour in the design and development of e-health services. This study is a descriptive review based on a non-exhaustive selection of literature that describes the state-of-the-art, problems and opportunities identified in e-health, health information behaviour and health information literacy research. By focusing on how to tailor the information provided and the technological devices to fit the information behaviour, the approach has also potential to uncover new insights into how to adequately implement and integrate ICTs into everyday life practices of other hard-to-reach groups in society. We presuppose that it will be possible to give practical recommendations based on a combined understanding of individual differences in health information behaviour and users' expectations and experiences, acquired through empirical studies focusing on older adults. Moreover, the usefulness of health information literacy as an indicator of the patterns and competences related to health information behaviour is highlighted.

Keywords: information seeking behavior, health literacy, consumer health information, telemedicine, technology

Introduction

Many e-health services and technologies have been unsuccessful in bringing sustainable innovations into health care practices [1]. E-health services and technologies often fail to acknowledge the interdependency of technology, socioeconomic environment, and the entire spectrum of citizens' health information behaviour [2-3]. The aim of this article is to bring forward the potential benefits of a better integration of a comprehensive understanding of individuals' information behaviour in the design and development of e-health services. Moreover, it outlines a preliminary agenda for a general line of e-health research that puts more emphasis on a better understanding of health information behaviour. As a part of this endeavour, the potential usefulness of health information literacy as an indicator of the patterns and competences related to health information behaviour in an e-health context is highlighted.

The discussion in the text is contextualised in the empirical objectives of the Academy of Finland funded (2015–2018) collaborative project Taking Health Information Behaviour into Account: Implications of a Neglected Element for Successful Implementation of Consumer Health Technologies on Older Adults (HIBA) to assist in developing comprehensible, manageable and, in particular, more meaningful and user friendly e-health services in the future. The project is hosted at the Faculty of Social Sciences, Business and Economics, Information Studies at Åbo Akademi University, Finland, and conducted in close collaboration with the Research Unit of Information and Communication Studies at the University of Oulu, Finland and the Department of Archives, Library & Information, Museum & Cultural Heritage Studies (ALM), Uppsala University, Sweden. Even if this specific project is used as a point of reference, we posit that the role and implications of health information behaviour are a broader issue that cannot be addressed in a single project and should be taken into account to a much larger extent in all e-health related research.

The major projected contribution of the approach discussed in this article is to provide a holistic point of view on e-health, the use and users of e-health services that acknowledges the interdependency of human

information behaviour, technology, and the social environment, as this has been lacking from previous research. The empirical studies conducted within HIBA will focus on older adults. An in-depth understanding of the relation between ageing, health information behaviour and technology use will give us a useful starting point for an effective tailoring of services for other age groups as well. The findings inform research in the field of health information behaviour and e-health, but also in related fields from medical informatics to human-computer interaction, public health, and computer science. The practical significance of the proposed line of research is in that by using an action research inspired approach it provides a basis for obtaining directly applicable information on user practices and the actual utility value of the studied e-health services that can be used in improving existing services and developing new ones.

Methods and material

Methodologically this article is a descriptive review of literature. Quite a few studies on this topic were already familiar to us. Additional relevant research was searched using Library and Information Science Abstracts (LISA) and PubMed with a focus on texts on "health information behaviour", "health information literacy", "e-health" (with all common spellings and synonyms). In addition, reference lists of known articles were searched for additional references. The analysis was based on close reading of the texts and was restricted to key texts describing the current state-of-the-art of research and future research needs together with a non-complete sample of individual studies on specific aspects of e-health, health information behaviour and health information literacy. A systematic review was not possible at this time.

There are obvious limitations with the chosen approach. The review is not systematic and the analysis is based on a non-exhaustive sample of all possibly relevant literature in the intersection of several large multidisciplinary research areas. For this specific reason it was also impossible to conduct a comprehensive meta-analysis of empirical findings. Therefore, the findings of

this study are based on conclusions of earlier research. All of this affects the reliability of the findings and conclusions of this study. However, considering the aims of this descriptive review to explore a general gap identified by the authors in the current literature and to propose an approach to bridge it, it is highly improbable that the chosen non-systematic review method would significantly bias the final conclusions of this study.

Background

Healthcare is in great transition. There have been considerable expectations that technology will have the capability to induce better outcomes, reduce costs and facilitate the on-going shift from treating conditions to patient and prevention-centred and -driven healthcare. Consumer health technologies have so far not been as successful as anticipated in bringing sustainable innovations into people's healthcare practices though [1]. E-health services are mostly too technology driven, and often fail to make it past the pilot version because they neglect to acknowledge the interdependency of technology, human (information) behaviour, and the social environment [4].

There are multiple definitions of e-health, for example, by Eysenbach [5] and Wyatt and Liu [6]. Here the notion is understood in a general sense as the use of information and communication technologies to improve health in general and the healthcare system in particular [7]. The state-of-the-art e-health research has underlined the need for a new, holistic approach to the development of technologies that addresses "the complexity of health care and the rituals and habits of patients and other stakeholders" [1].

In spite of the apparent potential of the Internet and e-services in healthcare and the dissemination of health information, the e-health visions of the late 1990s [e.g. 8-9] are still, after almost two decades far from being fulfilled. A lot of people, especially older adults in age categories 55+, do not seem to seek or obtain health information from the web at all [10-13], and the deployment of e-health services has been much slower than expected. In general, Internet use tends to be less

common in older age [14-16]. Especially seniors with poorer health more often belong to a group of non-Internet users [15]. A significant proportion of the increasing public expenditure on healthcare, health services, and currently wasted human lives could arguably be traced back to information and information management problems.

e-Health and barriers to its use

At present, healthcare systems around the world are facing a number of huge challenges. One crucial issue is the rapid growth in the number of older people which has resulted in an extensive rise in healthcare expenses, overstressed healthcare professionals, and a significantly increasing incidence of multiple chronic conditions. This coupled with substantial sociotechnical changes is challenging conventional healthcare delivery systems. Consumer health technologies have varying levels of quality and their use and content are not always easy to comprehend. Bridging the gap between access to information and information comprehension requires a deep understanding of the backgrounds, needs, and preferences of health information users, particularly because the profile of the e-health information consumer is changing [17-18].

The focus of health care has largely shifted away from the paternalistic model where an expert makes decisions on behalf of a patient, and towards a patient-centred approach [19-20]. Individuals are encouraged – and even expected – to be well-informed, to play an active role in managing their own health, and to participate in medical decision-making [19]. This approach has many benefits [19] but it also puts pressure on individuals to take more responsibility for their own health, including informed decision-making and self-management of chronic conditions [21]. The shifting focus from the treatment of conditions also highlights the importance of holistic well-being, prevention, early intervention, and support of functional capacity for the development of future services. User-focused health technologies are therefore deemed weighty catalysts for empowering consumers to be proactive in managing their health and related costs [22].

The question is how people could and could be encouraged to use existing technology more effectively to obtain information. Several barriers to Internet use have been identified, not the least among elderly persons. These include perceived lack of user skills [15,23-27], lack of interest for Internet use, lack of a computer or Internet access, perceived problems with usability [28], and feeling too old to use the Internet in the first place [24]. Furthermore, psychological barriers such as perceptions of usefulness and ease of use, familiarity, trust of the technology and privacy can influence Internet use [29-30]. The provided information itself might be problematic especially for less educated people, as health information on the Internet might require fairly advanced reading skills [e.g. 31-33]. Also knowledge about services is important as, for example, Harris, Wathen, and Fear [34] have stated that ignorance of the existence of health portals could be a reason for limited use (see also [29]). Yet another important factor is security. Nearly 40 per cent of the respondents in an American study indicated concerns about potential violations of privacy or confidentiality as barriers to use the Internet to obtain health information [35].

One of the key issues for motivating people to use existing information and services to obtain it is its quality. Quality of information can be assessed by factors related to authority, accuracy, bias, and currency [e.g. 36]. Worries about the trustworthiness of Internet-based health information can be a barrier to its use [e.g. 12,37-38]. Even if the trust in health information on the Internet sources has been increasing steadily, there are still a substantial number of individuals who are sceptical [e.g. 12,39-40]. Especially older adults over 65 years reported not trusting the Internet for health information as much as younger population in a nationally representative study in the United States [38].

Consequently, not everyone has the needed skills or motivation to succeed in receiving, processing, understanding, and acting on information disseminated by healthcare providers through online health services. Even the aims and frame of seeking and consulting health information vary between individuals to a considerable degree [41] and depend on multiple factors such as health condition, level of education, gender and

age to name just a few [e.g. 12,42-46]. In order to really be empowered people need to be able to master the information they obtain about health issues, that is, people need to be health information literate. This includes being able to recognise a need for health information, to know how and where to find this type of information, and how to evaluate, understand, and use it to make good health decisions [47].

As science advances and society develops, dependence on technology for health counselling, provision of care, and communication increases. We posit that the current crucial challenge for healthcare and medicine is not the lack of available treatments, but rather a deficit of patient involvement and consumer-focused provision of health information. People cannot truly participate in decision-making without having the right access to relevant health information at the right time. People who often go to the Internet for health information and have high expectations of the value and quality of online health information – particularly in terms of reliability, relevance/context, and interaction – have been shown to be those who are more likely to perceive the Internet as playing an important role in health and life decisions [48]. Unfortunately, healthcare providers and health information system developers may often implicitly make somewhat simplified assumptions that every single person has equal access and ability to receive and process technology-based health information. Information is perceived as an unambiguous message, not as a sign that is dependent on how it is interpreted and how individuals make different interpretations of same information [49].

Consumer health technologies have extensively been created assuming that presumptive users can identify their health needs and have the ability to receive, understand, prioritise, and access resources to meet them [50]. It has, however, become clear that a “one size fits all” approach has a limited impact [51-52]. In addition, sensory disorders (e.g. hearing impairments or visual disability) and various diseases can influence the ability to seek, understand, and act on health information [e.g. 25,53-54]. From these disabilities, which are far more frequent in an ageing population, arise very distinctive needs that are mostly left aside in the design, develop-

ment, and implementation of e-health services resulting in scarce adoption and success.

Previous research has pointed out that assimilation and usage of novel ICT devices among the ageing population are highly underutilized. Motivation for technology uptake among the ageing has been shown to rest on suitability, relevance, perceived usability, and anticipated benefits related to usage of the device [55]. The “user demand” perspective should strongly be taken into account in the development of technology for the elderly [56]. To have an impact and be cost-effective, consumer health technologies and their contents should therefore, at least, be tailored to the desire and needs of its users or target audience [57]. Tailoring (customisation, personalisation) health information makes the information more relevant and interesting to the individual. Furthermore, the e-health services can be tailored or targeted in many different specific and personalised ways for individuals and their needs [58]. The aim of providing tailored information content for the older adults is that the service content and use would feel more personal and satisfying. In spite of the positive outcomes of tailoring of health related messages to diverse groups of patients [e.g. 59], it has become apparent that an effective consumer focus would require much deeper consideration of information related behaviours than mere tailoring of messages and that there is a clear gap in the research on this matter [52,60].

Health information behaviour and health information literacy

Human information behaviour has been defined as “the totality of human behavior in relation to sources and channels of information, including both active and passive information-seeking, and information use” [61]. Attitudinal, cognitive, and medical problems might affect reception and understanding of provided information [25,54,62-63]. In our information rich society, health information (i.e. “information for staying well, preventing and managing disease and making other decisions related to health and health care” [64]) is

obtained from many different sources and angles and people have to try their best to master it [65].

Whereas health information behaviour refers to the totality of health information related human information behaviour, the notion of health information literacy pertains to health information related information competences and capabilities. The Medical Library Association [47] defines health information literacy as a “set of abilities needed to: recognize a health information need; identify likely information sources and use them to retrieve relevant information; assess the quality of the information and its applicability to a specific situation; and analyze, understand, and use the information to make good health decisions” and it can be seen as a combination of information literacy and health literacy [12,47]. In contrast to health information literacy, health literacy is typically understood in broader terms than health information literacy, namely as a capability to navigate through the health system in the context of everyday life; and in contrast to health information literacy, it is focused on individuals’ abilities to make decisions rather than to information processes and informational capabilities [12].

The aspects of information behaviour have been insufficiently examined in relation to ageing. However, the studies do indicate that the amount and quality of daily activities and health information relate to older adults’ wellbeing and health [66-68]. The ability to master health information, health information literacy, is weaker among older adults than in the rest of the population. Older adults, in particular those whose education level is lower, who are in poor health, or who are not interested in health information, are at risk of exclusion from access to information [12,43]. Those older adults who have a weaker level of understanding of health information, usually have also weaker computer and internet literacy skills [69]. The older adults of the future will be more used to computers and ICT, but even they are not a homogenous group of individuals. Better understanding of the information behaviour of the older adults of today and tomorrow is needed to form a basis for effective tailoring of technology-based consumer health information services for that particular group.

Similarities in age related patterns related to health information behaviour and technology use have been observed also in other age groups. For instance, Enwald, Hirvonen and their colleagues have studied the factors relating to the health information behaviour of young men [70-71] and Moreno et al. [72] adolescents access to online health services. Therefore, it is apparent that, in general, a better understanding of the relations between ageing, health information behaviour, and technology use can be expected to function as a useful starting point of effective tailoring of services for other age groups as well. Addressing this general question will advance our theoretical and practical understanding of the premises of delivering effective e-health services and in more general terms, provide answers to the previously scarcely researched question of how individuals' health information behaviour influences the effectiveness and impact of consumer health technologies.

Objectives and premises for future research

Various barriers may hinder the utilisation of existing consumer health technologies, including actual or perceived lack of technology skills, or doubts about the quality and/or relevance of the information [12,23-26,37,46,57]. Security issues form another possible barrier [35,37], as people might be afraid that sensitive information about their health is spread in an unintentional way. Secondly, on the basis of a previous systematic review [73], we hypothesise that e-health services have an impact, but the impact is not necessarily the same that was expected or desired. Finally, drawing from findings in human-computer interaction and information use research [3,50], we expect to identify such characteristics related to health and information practices that can be useful in tailoring and targeting e-health services for consumers/patients.

As a part of the broader line of research on health information behaviour in the context of e-health, the practical objective of the HIBA project is to interact with older adults (born 1946–1965, age categories according to [10-11]) to develop comprehensible, manageable and, in particular, more meaningful and user friendly

health information systems in the future. That is, which sociotechnical solutions have the potential for motivating, persuading, and empowering consumers to support and promote sustained utilisation of cost-effective health information systems in society. Based on both an extensive survey of earlier multidisciplinary research and analyses of new empirical data from a small number of targeted quantitative and qualitative case studies of older adults, the practical objective of the project is to assemble a set of health information behaviour related factors, which influence the perceived usefulness and the patterns of actual use of specific types of e-health services with a focus on such aspects of information behaviour that are usable in the tailoring of existing and development of new services. The project continues the work of the Health Information Mastering (HIM) Oulu & Åbo research group in the Academy of Finland funded projects "Health Information Practice and its Impact. The Context of Metabolic Syndrome and Obesity (HeIP)" 2008–2012 and "Information Mastering: a Health Promoting Tool (InfoMast)" 2009–2011. Both HeIP and InfoMast continued the research tradition set up by the project "Citizens, Health and the Changing Media Culture" funded by the Academy of Finland in 1999–2002 [74]. HIBA furthermore collaborates with three other ongoing multidisciplinary projects: PrevMetSyn research consortium (Improved Methods of Lifestyle Modification for Patients at High Risk for Metabolic Syndrome, funded by Academy of Finland 2012-2013), GASEL study (Gamified Services for Elderly, funded by the Finnish Funding Agency for Innovation 2014-2016) and the Swedish DOME consortium on the deployment of e-health services [75]. The empirical focus of the consortium represented by the authors is to analyse two types of e-health services: those that traditional health care institutions offer and, on the other hand, wellness coaching services that are tools of health promotion and means of enhancing health behaviour change, such as weight loss or increase in physical activity.

In addition to the specific studies conducted in the context of the HIBA collaboration, we posit that there is a need for a broader emphasis of health information behaviour and health information literacy in the context

of e-health. To raise the quality of collaborative e-health services and the standard of care by more efficient and cost-effective ICT healthcare systems, it seems to be needed to call in and unleash the consumers by putting their everyday health information behaviour under the loop. This provides a basis for testing and sharing efficient mechanisms for improving consumer health technologies. We propose that instead of focussing on the adoption vs. non-adoption of particular technologies, self-reported satisfaction, or mere clinical outcomes without a proper understanding of why services are used, why users are satisfied or dissatisfied, and how a service contributes to the clinical outcomes, it would be important to pursue for a comprehensive understanding of how a particular e-health service is linked to the general conduct of everyday life, information seeking and use of its users, and utilisation of, among others, other electronic/digital and health related services. This can be achieved by designing specific studies but also by revising current research instruments by adding interview and survey questions relating to the health information behaviour and, for instance, the health information literacy of the informants, and incorporating these issues as a part of ethnographic observation protocols.

From the scholarly perspective the proposed line of research is focussed on addressing an empirical knowledge gap in the current understanding of how individuals conceptualise and perceive various aspects of consumer health technologies, and how these technologies could be applied with respect to their everyday health information behaviour. We presume that it will be possible to give practical recommendations based on a combined understanding of individual differences in health information behaviour and users' expectations and experiences. A crucial and simultaneously non-trivial part of the proposed line of research is to identify factors that are capable of informing the development and tailoring of new and existing services whether they are general issues affecting all users of a particular type of e-health services or specific issues related to a particular segment of users. Finally, as a whole, the approach pushes further the current state-of-the-art in e-health and health information research by developing a

combined theoretical and empirical understanding of tailoring of consumer e-health services based on a holistic point of view on the multifaceted e-health conception that accounts for the interdependency of technology, human information behaviour, and social conditions that has widely been disregarded in earlier research.

Conclusions

We posit that a line of research that assumes a holistic approach to health information behaviour as a basis for development and tailoring of effective e-health services opens up major possibilities for substantial breakthroughs in the multidisciplinary field of consumer health technologies by putting the everyday health information behaviour and practices of the intended end consumer at the very centre of research. By focussing on how to tailor the information provided and the technological devices to fit the information behaviour of a hard-to-reach segment, i.e. an ageing population, the approach has also potential to uncover new insights into how to adequately implement and integrate ICTs in general into everyday life practices of other hard-to-reach groups in society. Furthermore, as a specific disciplinary impact, all the nuances and complexities involved in the multidisciplinary e-health and health care context provide a fruitful environment from which to develop novel models and theory as well as elaborate and extend existing theoretical concepts and models on human information behaviour in the field of information studies.

Conflicts of Interests

The authors are unaware of any financial and personal relationships that could inappropriately bias their contribution.

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