Heart Patients' Experiences and Use of Social Media in Their Rehabilitation: A Qualitative Study

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Abstract

In the Teledi@log project, an interactive portal, ActiveHeart has been developed. The portal contains information for patients on how to make lifestyle changes presented in text, speech and video. The aim is to explore how heart patients experience and use social media as a part of their rehabilitation. The patients had access to the portal for three months. Qualitative interviews (n=7) were conducted and participant-observation was performed (n= 3.5 hours). A theoretical framework based upon eHealth Literacy, crisis psychology theory and learning theory has been used. The computer programme NVivo 10.0 was used to analyse the collected data. The results show that the patients were used to finding health related information on the Internet. The patients were affected emotionally to different degrees after having had a heart attack/ surgery. The patients had different competences in using new technology, and their skills in eHealth Literacy varied. The study concludes that the patients' emotional state may influence their ability to learn and reflect upon new information and social media can support the patients' eHealth Literacy.

Keywords: Heart patients; telerehabilitation; social media; eHealth Literacy

Introduction

Heart patients often experience loss of memory, increased fatigue, depression, anxiety and reduced quality of life following a heart attack or heart operation. Two international meta-analyses conclude that hearth rehabilitation is effective in lowering mortality and improving quality of life [1,2]. Today most health information is available on the Internet. The use of the Internet can improve patients' understanding of chronic disease, the treatment offered or help them understand other symptoms related to their disease [3]. To use the Internet as a health information resource, it is necessary to possess certain skills. These skills may be defined by the concept of eHealth Literacy. An individual's level of eHealth Literacy depends on whether they are used to using the Internet to seek and find information, and if they are capable of understanding the information obtained [4]. The literature shows [5] a focus on using the internet as a mean to manage rehabilitation. The purpose is to help patients make behavioural changes and to reduce symptoms. Simultaneously, using the internet to make interventions do help reduce several traditional barriers, such as shortage of qualified working capacity, prolonged communication waiting time, difficulties with treatment or unwillingness to seek treatment [5]. Using web portals enables the patient to receive care from the healthcare professionals because the patient is able to give and receive social support, acquire new knowledge and information, and feel they are a part of a community [6]. Therefore, the current study examines how heart patients experience and use the interactive portal, ActiveHeart as a part of their rehabilitation.

Teledi@log – a telerehabilitation program

Teledi@log, a Danish research project, has developed a telerehabilitation program for patients with the following diagnosis: patients suffering from angina or who have suffered from a cardiac attack, heart failure, or patients who have had bypass surgery or who have received a new heart valve. Heart patients participating in the telerehabilitation programme receive telehealth equipment so that they can monitor their weight, pulse, blood pressure and steps. The data are transmitted to an online patient record, to which both patient and healthcare professionals have access. The patients can view the data on a tablet device or on their personal computer. A part of the telerehabilitation programme is an interactive portal, named ActiveHeart, where heart patients can find information on how to make lifestyle changes. Information is presented in the form of text, speech and video. The hypothesis of the research is that using social media as part of the heart rehabilitation of the patient may help the patient to seek out, locate, understand and evaluate health information from electronic sources and apply the knowledge gained to addressing or solving their personal health problems. The information on the portal covers topics relevant to a heart patient, such as how to talk about one's condition in the workplace or how to be intimate with one's partner. The portal operates at three learning levels. In the short videos, heart patients and their relatives tell their story about living with

heart disease. The portal also has a forum for heart patients so that they may share their experience with other heart patients, ask and exchange advice. The portal has a nurse and a psychologist connected to it, enabling heart patients to obtain professional guidance. The ActiveHeart is developed using user driven innovation. Figure 1 shows a screen dump from ActiveHeart.

Figure 1 - Screen dump of patient's options after logging on to ActiveHeart. The five categories are: 'My Heart', 'My mood & my relatives', 'My disease course', 'My workout' and 'Health Advice' (call centre).
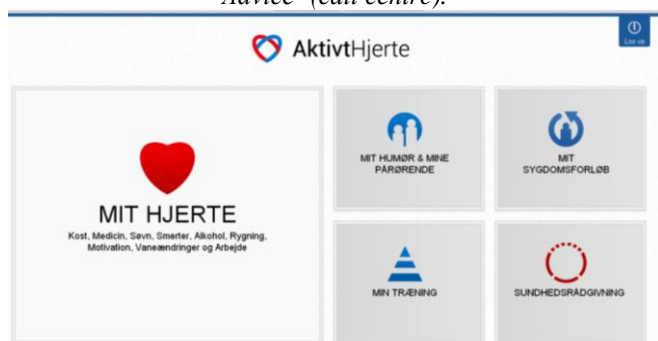
The Teledi@logs project has been approved by the local ethical committee (N-20120051) and was carried out according to the Helsinki Declaration. A qualitative study has been performed. The participants in this study were selected from the pilot phase of the Teledi@log project. The heart patients included in this study have used the ActiveHeart portal for 3 months. Semi-structured interviews were conducted with seven patients (5 men and 2 women) in their homes, and participant-observation was also performed (n= 3.5 hours). The aim of the observation was to clarify the patients' ability to navigate on the portal. Table 1 describes the characteristic of the participants in this study.

A theoretical framework, eHealth Literacy theory [4], has been used for analysing the data. eHealth Literacy theory provides a framework for accessing the patients skills in locating, understanding and using health information on the Internet.

Crisis psychology theory [7] was chosen in order to focus on the emotional situation of a patient following a heart attack or heart operation. Learning theory [8] was as applied in order to understand how patients learn and reflect upon using social media in a rehabilitation process. The theories support each other in understanding the mental situation of heart patients after eg a heart attack. Data from the interviews and notes from the participant-observation were audio recorded and transcribed. QSR NVivo 10 software was used to code the collected data. The analysis was done in collaboration with a research colleague.

Methods

Table 1 - Participant characteristics

Identification	Sex	Age	Diagnosis	Work	Computer/use of tablet
Patient A	Male	89	Heart attack	Retired engineer. Working as a freelance photographer and journalist	Experienced computer user – both at work and in spare time
Patient B	Male	51	Heart attack	Excavator driver	Experienced computer user in spare time
Patient C	Male	65	Bypass and new heart valve	Excavator driver	Not familiar with using a computer
Patient D	Male	66	Bypass	Early retirement. Active in different associations	Experienced computer user in spare time
Patient E	Female	68	Heart attack	Retired home helper	Experienced computer user – spare time
Patient F	Female	67	New heart valve	Retired librarian	Experienced computer and tablet user – work and spare time
Patient G	Male	56	New heart valve	Fisherman – unemployed	Experienced computer user – spare time

Results

The patients have used the ActiveHeart portal differently over the period. One patient had used it approximately once a week, five patients had used it during the first six weeks, and one had not used ActiveHeart at all. The following table shows themes and sub-themes found in the data analysis.

Table 2 - Results of patients' experiences and use of ActiveHeart

Themes	Sub-themes	Quotes
Emotional status	• Patients do not recognise their disease • Patients are moving on with their life • Patients are able to reflect on their progress in life	"I want to keep it in a completely different place. It's not me that it has happened to" (Patient C). "Yes it is properly because I have felt, 'What can I say, the development goes in a different direction where I have more and more energy'" (Patient F). "Well, there are so many aspects to it, I think, because in a sense you could say, 'I have at least got my life back'" (Patient D).
Competences to use the Internet for locating health information	• Poor at reading and writing • Competent in searching and using health information	I cannot get it down in writing. And I have never been able to" (Patient E). "I can use the computer to find different things" (Patient E).
Internet as a source for health information	• Patients are used to finding information on health issues on the Internet	"Well I do it on the Internet. I have used the Internet quite diligently (…) Actually, I have searched mostly on the Internet" (Patient F).
Use of social media	• Patients are used to commenting on pictures posted on Facebook • Patients are passive on Facebook	"But I like to comment and 'like' the photos they put in, it is kind of fun to follow them, too" (Patient E). "I use Facebook, but it's to see what others are doing" (Patient G).

Discussion

The purpose of this study was to examine how heart patients experienced and used social media in their rehabilitation. The sample of participants was limited due to the fact that they were participating in the pilot phase of the Teledi@log project. Even though the sample was limited, however, they still managed to provide a useful picture of how they experienced using the ActiveHeart portal.

The patients had different psychological reactions to their disease. Two patients stated that they had trouble recognizing that they had been sick; they did not want to be remembered by others as having had a disease. Analysis of data showed that they distanced themselves from the disease and their surroundings. Five of the patients found they were able to move on with their lives, returning to work, if they were still on the labour market, and participating in their everyday lives as they had done before.

The patients explained that when searching the Internet, they looked for information that was easy to read. The analysis point out the importance of having credible sources of health information on the Internet. If the patients automatically search for information that is easy to read, they might choose information of low quality because they find it easier to understand. This may lead to the patients making decisions that may have a negative influence on their health or quality of life. Ghaddar et al. found that it is important for patients to have access to a credible online source of health information,

and that it could be beneficial to introduce this source in a school health education curriculum to promote Health Literacy [9]. Two patients with poor reading and writing skills experienced trouble reading and sometimes understanding the health information they found on the internet. Reading and writing skills are essential for achieving Health Literacy and eHealth Literacy. In eHealth Literacy, the ability to read, write and speak a language is called 'traditional literacy' [4]. If a person does not possess these skills, they can experience problems with everyday tasks and have difficulties utilizing the health information they find. More than 65 percent of the health information available on the Internet is in English [4], which makes it even more important for these patients to know where to find a reliable source of health information.

Six of the seven patients all believe, that they are able to use the information they find on the ActiveHeart portal to obtain a lifestyle change. The patients showed two learning styles in assimilating new information. One group preferred to read it themselves, since they achieved a better understanding of the text and had the opportunity of absorption. The second group preferred to hear the information from someone else. One informant explained that it was good to be able to ask questions, when given oral information. This correlates with the existing knowledge that everyone has different learning styles. This testifies to the importance of presenting information in several different ways so as to ensure that everyone has an equal opportunity to learn new information. If the information is presented in only a single way, some people will have difficulty assimilating it.

The analysis showed that the patients were aware that the Internet may be used as a source of new health information. Six patients were used to finding health information on the Internet. They preferred using the Internet when having to find new information on disease and health. In the USA, the proportion of people using the Internet to find health-related information has increased significantly, from 53 percent in 2005 to 71 percent in 2008 [10]. The number and proportion of online health information users is expected to increase as more people obtain Internet access. Among the most searched topics on the Internet, are the leading causes of death: cancer and heart disease [6].

Five of the patients were familiar with the use of social media (Facebook) in their everyday life. They described the ability to keep in contact with especially children and grandchildren as their largest motivation. Three of them had posted information about themselves on their 'wall', but most used it to comment on others pictures and status updates. They did not believe themselves to be experts in using social media, describing themselves largely as beginners, even though more than one had used Facebook for a period of over three years. These comments resembled those made about the forum on ActiveHeart; forum members liked the idea of following what others wrote but did not want to take an active role.

Conclusion

Evaluation of the pilot phase in the Teledi@log project shows that emotional states of the patients may influence their ability to learn and reflect upon gaining new information on how to change their lifestyle. The results indicate that the interactive portal, ActiveHeart may support the patients' eHealth Literacy. Further studies are needed.

Acknowledgements

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