

Reducing Errors through a Web-Based Self-Management Support System

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Abstract. Web-based self-management support systems SMSS, can successfully assist a wide range of patients with information and self-management support. Or as a stand-alone service, are e-messages. This study describes how one component of a multi component SMSS, an e-message service, in which patients with breast cancer could direct questions to nurses, physicians or social workers at the hospital where they were being treated, had an influence on safety and continuity of care. Ninety-one dialogues consisting of 284 messages were analysed. The communications between patients and the healthcare team revealed that the e-messages service served as a means for quality assurance of information, for double-checking and for coordination of care. We give examples of how an e-mail service may improve patients' knowledge in a process of taking control over their own care – increasingly important in a time of growing complexity and specialization in healthcare. It remains to be tested whether an e-message service can improve continuity of care and prevent or mitigate medical mishaps.

Keywords. Continuity of care, Patient safety, Secure e-message service, Self-management.

Introduction

Healthcare systems worldwide face huge challenges in the coming decades as a consequence of a growing and ageing population and new groups of patients with chronic and complex disorders. Decentralization (i.e moving care into patients home) is intended to increase the patient's quality of life but it may also generate new risks [1]. In a Canadian study 19% of patients suffered from adverse events after discharge from hospital, 70% of which were either preventable or ameliorable [2]. Patients' role has changed from being passive recipients of care, to becoming active participants of their own care process. In some cases patients themselves take responsibility to ensure that information is transferred across institutional boundaries [3].

As care becomes more and more complex, communication and organizational aspects become increasingly important. Improved information to patients and shared decision making has been proposed as a way of improving safety [1, 4]. When patients participate more actively in the process of care, it is claimed that the healthcare system will be characterized by services of higher quality, better outcomes, lower costs, fewer

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medical mistakes, and happier, healthier patients. Studies shows that web-based self-management support systems, SMSS, can successfully assist a wide range of patients with information and self-management support and improve communication and shared engagement in care planning [5, 6]. One component often offered as a part of multi component systems, or as a stand-alone service, are e-messages. Use of a secure e-mail communication between physicians and patients has been associated with a decrease in office visits, an increase in measurable quality outcomes (in primary care), and excellent patient satisfaction [6]. We found that an e-message service between patients and nurses was used to address unmet communication needs [7] and raise concerns related to uncertainty in everyday life [8]. Less is known, however, whether an e-message service would improve patient safety and continuity of care. This study aimed to explore if and how an e-message service, a single component of practice-integrated SMSS affect the continuity of care and safety of patients with breast cancer.

1. Method and material

This study is part of a larger project aimed to investigate the effects of a practice-integrated SMSS for breast cancer patients and of a single component of the system: an e-message service. In this ongoing study (ClinicalTrials.gov NCT00710658), 200 patients were included and randomized into: (1) a control group, (2) a group given access to either an e-message service (EMS), or (3) a multi-component SMSS, called WebChoice (figure 1), further described in [5, 9]. To be eligible for inclusion the breast cancer patients had to be over 18 years old, be within their first year after diagnosis, have access to Internet at home and have a personal e-key solution for secure log-on to the system. WebChoice consists of self-monitoring; choice of self-management options; information resources; a forum and a blog for discussion with other patients; a diary, and an EMS allowing communication with the hospital where the patient was treated.

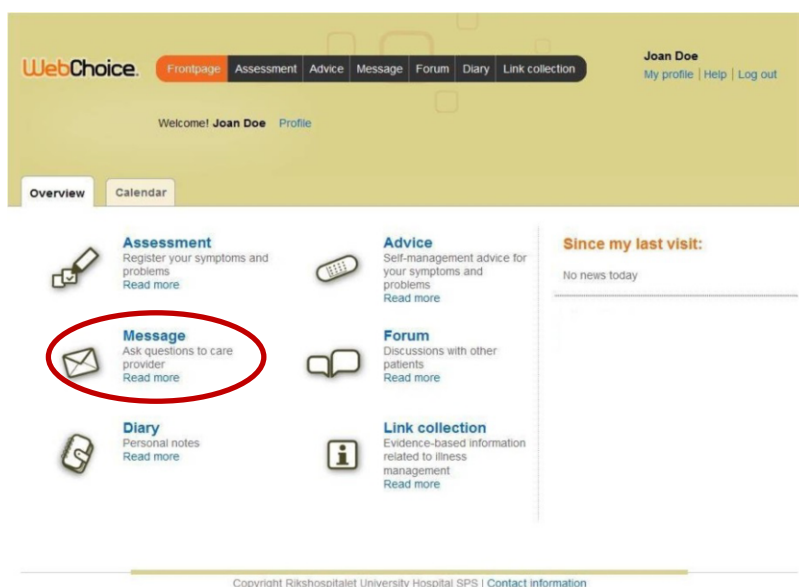


Figure 1 Screenshot of the WebChoice overview page

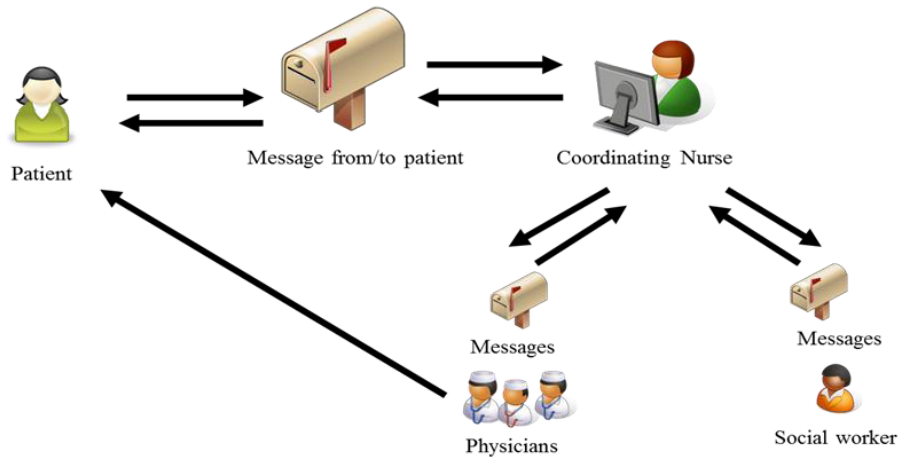


Figure 2 The message flow between patients and healthcare providers

The current study examined the content of a subsample of e-messages sent among those who had access to WebChoice for one year. The e-message service made it possible for patients to direct questions to nurses at the hospital where they were treated (Figure 2). If needed, the nurses could forward messages to physicians or social workers.

The e-messages were written between June 2010 and November 2012. The material consists of 91 dialogues comprising a total of 283 messages between nurses, physicians and 30 different patients, written after the patient's discharge or between hospital stays. We had access to complete strings of messages, which meant that if more than one message was sent between patient and nurse on a specific issue, we could see the entire correspondence.

Patients randomized to WebChoice were offered access to the service for 12 months. Expert nurses and physicians in cancer care at the department where the patient received treatment answered the patients' questions and concerns within 48 hours (weekdays). The e-mail service is primarily run by nurses in the sense that a team of expert nurses working in the actual clinical setting administer the service. They have access to the patients' medical records, and are expected to answer most of the questions themselves. The physicians and social care worker could answer directly to the patients or send comments back to the expert nurses who then answered the patients (Figure 2). The patients in this study were between 37 and 69 years old, and median time since diagnosis was one month (range 0-9). Six nurses and two physicians answered the e-messages. Their age ranged between 36 and 60 years, and they had from 7 to 33 years' working experience. No messages were forwarded to social care workers.

1.1 Ethical considerations

This study was planned and performed in compliance with the principles outlined in the Declaration of Helsinki and approved by the Norwegian Regional Research Ethics Committee. We had the full support of the Data Protection Official at the hospital involved. The Norwegian government demands a high level of security to allow patients to communicate personal health information on the Internet. Thus strong authentication was required, and data were sent via an encrypted connection.

1.2 Analysis

The analysis of the messages was informed by qualitative content analysis, as described by Graneheim and Lundman [10]. Three of the authors (ME; EB; IKS) analysed the 283 e-messages between breast cancer patients and health care professionals, written after the patient's discharge or between hospital stays. We followed the temporally organized sequences of conversation (the patient's questions as well as the healthcare professional's answers) and analysed how the first message was followed by an action/answer, and then another that systematically took the first message into account, and so on. As we analysed the string of conversations in series, we looked for signs that an e-mail service contributed towards improving safety and continuity of care. Both the manifest and latent content were of interest, which necessitated repeated reading of the messages, and going back and forth between studying each message and looking at the entire material. These procedures were continued until the themes were saturated and no new information emerged from the data. Consistent with established standards of rigor for qualitative research, extended data samples, the emerging codes, subthemes and themes were shared with the research team periodically during the analysis.

2. Results

Our analysis of each separate series of communications between patients and the healthcare team revealed two areas where e-mail service served as a means for quality improvement and safety; *quality assurance of information flow* and *double checking and coordination of care*. These themes are presented below and illustrated by quotes.

2.1 Quality assurance of information flow

The patients used e-mail for quality control of the information they had. The strings of conversation revealed that the patients had gleaned information from many different sources: through their own research on various web-based information sites, through anecdotes told by family members, friends and other patients; and through what they had "seen and heard" in newspapers and mass media. Even the credibility of information obtained from different healthcare providers during the patients' treatment journey, needed to be confirmed; sometimes further explanation was needed. This was used as an opportunity to adjust the patient's knowledge and understanding in relation to treatment and care, and to decrease both their worry and the risk of mistakes. By asking for specific advice in relation to their own diagnosis and treatment, the patient got tailored information, and mistakes and malpractice could be avoided.

I find that I'm getting different advice when it comes to omega 3/cod liver oil during chemotherapy. I was told to continue taking my multi-vitamin and omega 3 supplements. Now, the newspaper writes that this may prevent the chemo from working properly. Can you help me? Should I cut out the omega 3 or not? I want to do what is best for my body, so that treatment has a chance to work properly. This is quite disturbing. Regards xx' Answer from Nurse: *'Hi xx. Now I have talked to the oncologist who specializes in this. You can safely take omega 3: it does not affect the chemo. What you should be aware of is that you should not have anything that contains plant estrogen. Please contact us if there is anything I can help you with...'*

2.2 Double checking and coordinating of care

The patients also used the e-mail service to alert the healthcare team to symptoms and aspects of treatment and care that the patients perceived as risks. By being made aware of the patient's concerns, healthcare professionals could bridge gaps in the continuity of care and possibly avoid or mitigate mistakes. An example of such concerns was when a patient had found changes in the other breast and sent an e-message requesting an appointment for a check-up. An example of a case where e-mail service was used to prevent injury was when a central venous catheter had been left for several weeks after treatment and the patient experienced inconvenience and pain. The patient wrote:

'I called you last week about getting an appointment to remove the venous catheter that the doctors have forgotten several times. I would really really like to have it removed now, because it's uncomfortable having it there. After radiation it would be good if I could lie on my right side but I haven't been able to do that because of the catheter. I'll be staring the track season for shooting in a couple weeks, and the catheter is right in the spot where I hold the rifle butt. It would make me so happy if I could continue with my hobby.' The nurse's response shows how the message put the healthcare system into action: *'Hi, I've just spoken with the gastrosurgeon, who will call you shortly. They have an opening 11 May at 9 a.m. I hope this will solve your problem.'*

Other cases were when patients used the e-mail service to inform about intricacies and delays in treatment, in connection with change of hospital or transfer between different departments. In some cases, the messages ensured information transfer over organizational boundaries and between multiple professionals. A patient acting as a coordinator of her own care is illustrated in this excerpt from the dialogues:

Patient: 'Hi, Now I've started radiation therapy. All OK. I've been given an appointment for a check-up with a doctor at the surgical polyclinic (gives name, date and time). I mentioned this to Dr X at (name of cancer centre) and she thinks I should wait with this check-up until after radiation therapy because of soreness and so on. What is your opinion about this? Last radiation 19 October. Sincerely, (name)'

Doctor: 'Hi, I'm glad to hear things are going well. It's a good idea to wait with the check-up and mammography until about three weeks after the end of radiation. I'll make a new appointment and send you a letter. Thanks for letting us know.'

Patients also used the e-mail service to follow up on test results and double-check that their individual care plan was being followed. The healthcare team appreciated the patients' involvement, and encouraged them to actively prevent examinations and referrals from getting lost.

Patient: 'The examination on April 26 was also a CT of internal organs, (CT Thorax/abdomen). I just wonder if it wouldn't be possible to see a blood clot in that image. Shall I give them a call and try to book a screening? A copy of the referral letter was sent to me and my ordinary doctor. Or is this something that is handled by the hospital (named) and I'll be summoned?'

Nurse: 'I'll forward this to the doctor in charge.'

Doctor: 'It might have been possible to see this on the CT scan from 26 April. But we often make CT scans of lungs according to a "pulmonary embolism" protocol to make it even easier to see. You might ask them to go check this. We are usually the ones

who order this screening, so keep an eye on this and see if it's the same where you live. In other words, it will be handled by ... (hospital's name).'

3. Discussion

This study gives examples of how a secure e-message service, that enables communication between the patient and the healthcare team after discharge or between periods of treatment, improves continuity of care and prevents or mitigates adverse events and mistakes. The e-message service was also a tool for quality assurance in the information flow and may as such promote the patient's empowering process, enabling patients to increase their control over, and improve their own health. Moreover, the study emphasizes how such a tool increases predictability and helps reduce worries that are common among patients after discharge or between treatments [8].

Gaps in the delivery of care are identified as a major threat to patient safety [11]. Ultimately, patient safety is determined by what happens at the 'sharp end' of practice, i.e. at the point of contact between the patient and the medical system. In an earlier study we found that gaps often occur when personal contacts are brief or lacking as in transitions between different types of care [12]. The patient's role as coordinator in his or her own care, as this study gives example of, is becoming increasingly important in parallel with the increased complexity and specialization of healthcare. This study demonstrates how an informed, knowledgeable patient may be a buffer against medical mishaps and delays in treatment. In addition, our results show that in an environment where the amount of information is growing and is more readily available than ever before, it is essential to be able to validate that information. For patients to be able to set it into a clinically meaningful context, the information must be shared with clinical professionals. Thus, any support that facilitates patient participation and communication with the medical team is highly warranted.

The explorative design of this study does not allow us to draw conclusions about causality. In a dynamic and adaptive system, like health care, risks are continually identified, prevented or mitigated as part of the health care professionals' daily work, which makes controlled studies challenging. Recent research on safety in complex adaptive systems indicates that the introduction of new tools intended to make the system safer, may increase the complexity of interactions and thus also introduce new risks [13]. It remains to be tested whether an e-message service can contribute to patient safety and continuity of care.

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