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Cancer patients' experiences of using an Interactive Health Communication Application (IHCA)

GRO H. GRIMSBØ, Msc[1], GUNN H. ENGELSRUD, PhD[2],
CORNELIA M. RULAND, PhD[1], & ARNSTEIN FINSET, PhD[3]

[1]*Centre for Shared Decision Making and Collaborative Care, Oslo University Hospital, Rikshospitalet, Institute of Clinical Medicine, Faculty of Medicine, University of Oslo, Oslo, Norway,* [2]*Norwegian School of Sport Sciences, Oslo, Norway, and* [3]*Department of Behavioural Science, Institute of Basic Medical Sciences, Faculty of Medicine, University of Oslo, Oslo, Norway*

Abstract
Interactive Health Communication Applications (IHCAs) are increasingly used in health care. Studies document that IHCAs provide patients with knowledge and social support, enhance self- efficacy and can improve behavioural and clinical outcomes. However, research exploring patients' experiences of using IHCAs has been scarce. The aim of this study was to explore cancer patients' perspectives and experiences related to the use of an IHCA called WebChoice in their homes. Qualitative interviews were conducted with infrequent, medium and frequent IHCA users—six women and four men with breast and prostate cancer. The interviews were transcribed and analyzed inspired by interactionistic perspectives. We found that some patients' perceived WebChoice as a "friend," others as a "stranger." Access to WebChoice stimulated particularly high frequency users to position themselves as "information seeking agents," assuming an active patient role. However, to position oneself as an "active patient" was ambiguous and emotional. Feelings of "calmness", "normalization of symptoms", feelings of "being part of a community", feeling "upset" and "vulnerable", as well as "feeling supported" were identified. Interaction with WebChoice implied for some users an increased focus on illness. Our findings indicate that the interaction between patients and an IHCA such as WebChoice occurs in a variety of ways, some of which are ambivalent or conflicting. Particularly for frequent and medium frequency users, it offers support, but may at the same time reinforce an element of uncertainty in their life. Such insights should be taken into consideration in the future development of IHCAs in healthcare in general and in particular for implementation into patients' private sphere.

Key words: *Cancer, IHCA (Interactive Health Communication Applications), interactionism, the active patient's role*

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The role of the patient has changed dramatically over the last decades. Patients are no longer regarded as passive recipients of treatment, care and information, but rather as active and informed knowledge-seeking agents. Many patients gain an expertise in their illness, seeking to manage their illness by developing knowledge relevant to maintaining health and countering sickness (Fox, Ward, & O'Rourke 2005; Heldal & Tjora, 2009; Shaw & Baker, 2004; Tjora, 2008). The trend towards becoming active, expert patients is reinforced by healthcare reforms in many countries that encourage patients to be active communicators and participants in own care and treatment (Epstein, Fiscella, Lesser, & Stange,

2010; Pasientrettighetsloven, 2001; "Patients' Bill of Rights", 1998).

To offer patients secure ways of communicating and finding relevant information, a number of interactive health communication applications (IHCAs) have been developed (Murray, Burns, See Tai, Lai, & Nazareth, 2005). IHCAs have been defined as computer-based, usually web-based, packages for patients that intend to combine health information with elements of social support, decision support or behaviour or change support (Murray et al., 2005). The rationale behind offering IHCAs to patients is that these systems can assist patients in achieving a better understanding of their illness and in

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managing symptoms and problems, as well as providing patients with opportunities to communicate with health care providers and other patients from the privacy of their homes (Ruland et al., 2012). Several studies have indicated that IHCAs may have a positive impact on people with chronic diseases (Shea et al., 2009; Van der Meer et al., 2009; Moore, Brennan, O'Brien, Visovsk, & Bjornsdottir, 2001). A recent review from the Cochrane database on the effects of IHCAs concludes that "IHCAs appear to have largely positive effects on users; they tend to become more knowledgeable, feel better socially supported, and may have improved behavioural and clinical outcomes compared to non-users" (Murray et al., 2005, p. 2).

However, a search of the literature on Information and Communication Technology (ICT) in health care in general and on IHCAs in particular, suggests that there are few studies focusing on the patients' perspectives and experiences related to using and interacting with IHCAs during periods of illness and rehabilitation (Åkesson, Saveman, & Nilsson, 2007; Ziebland et al., 2004). The few studies that have been conducted have concluded that participants see the value and potential of IHCAs and that even those with modest previous computer experience could use them with little training (Kerr, Murray, Stevenson, Gore, & Nazareth, 2005). In Åkesson et al.'s (2007) review, the authors concluded that consumers (patients with hypertension, breast cancer, diabetes etc) felt more confident and empowered by the use of IHCAs; their knowledge increased and their health status improved due to the ICT resources. Lack of face to face meetings did not appear to be a problem.

Despite these studies, there is little research based knowledge on the interrelation between IHCA and the users of the technology in telemedicine projects. According to Berg, the ways ICT affects the social environment have "been painfully overlooked in telemedicine projects" (Berg, Aarts, & Van der Lei, 2003, p. 297). As information systems require interaction with people and thereby inevitably affect them, understanding information systems requires a focus on the *interrelation* between technology and its social environment, including users of these systems. In this article, the users of the technology are patients with cancer, who interact with an IHCA called WebChoice from the privacy of their homes. Drawing upon interactionistic perspectives (Goffmann, 1959; Latour, 1992; Mol, 2002; Mol, 2008) our interest is to investigate how patients experience is constituted in the interaction between humans or human or objects. As Annemarie Mol puts it: "The body, the patient, the disease [...] the technology: All of these are more than one. More

than singular. This begs the questions of how they are related," (Mol, 2002, p. 5).

In addition, Latour points out that scientific studies of humans and society should include the objects, or the "artefacts" as Latour calls them, since human action and experience are created in relation to materiality and objects (Latour, 1992). Objects are according to Latour dynamic and mutually constituting to human experience. We apply this perspective to our understanding of the WebChoice system. The perspective leads us to be specifically interested in the relationship between the patients with cancer and the WebChoice application, and what this relationship means. We ask how patients with severe illness interact with technology from the privacy of their homes, and what kind of relationships that are constituted through this interaction. Talking about the active patients' role in the beginning of the introduction, we also understand, in line with interactionistic perspectives, that using IHCAs can be a stage upon which the role of the "active patient" is performed and constructed (Goffmann, 1959; Tjora & Sandaunet, 2010) and takes part in the way people "stage their identities" (Mol, 2002). Since all patients that are served by IHCA systems today, more or less are bound to fulfil and perform the role of the active patient, we ask what this performance might *do* with the patients feelings and concerns about being ill and exposed to technology also in their private homes.

Description of WebChoice

WebChoice (www.communicaretools.org) is an Internet-based IHCA designed to support patients with breast and prostate cancer, living at home between treatments and during rehabilitation. WebChoice is comprised of a set of components designed to address patients' needs, perspectives, and experiences, to enable patients to self-manage their illness and to facilitate patient-provider communication. WebChoice allows patients to monitor their symptoms and health problems, currently and over time, in addition to self-management options that adapt to patients' self-reported problems. WebChoice also provides patients with information and support to manage their symptoms and illness-related problems. In addition, the system offers personal mail communication with expert nurses in cancer care and an e-forum for group discussion with other cancer patients (Andersen & Ruland, 2009; Hjelmeland Grimsbø, Ruland, & Finset, 2011; Ruland et al., 2007; Ruland et al., 2012). A randomized controlled trial (RCT) in which 325 breast- and prostate-cancer patients were randomized to the WebChoice or usual care control

group were conducted to test the effects of Web-Choice. Results showed significant group differences in global symptom distress. Also, patients in the WebChoice group had significant within-group improvements in depression over the study period while in the control group self-efficacy and Health Related Quality of Life (HRQoL) significantly deteriorated (Ruland et al., 2012).

Methodological approach

The study was approved by the Regional Committee for Research Ethics of Norway, Region South. All participants provided written informed consent.

Participants

To examine the interaction between patients and WebChoice, the first author contacted 10 patients from the intervention group in the RCT mentioned above[1]. The patients were contacted by telephone and invited to take part in an interview. All 10 of the patients who were asked decided to participate and share their perspectives on their use of WebChoice. All patients had have access to Web-Choice at least 3 months; however some were in the beginning months of participating in the RCT, some closer to the end. The patients were categorized as high, medium and low frequency users based upon the activity log from the WebChoice application. The activity log measured each patient's activity level in the program, which reflects all the activities that the patients took part in during their interaction with WebChoice, e.g., visiting websites, doing assessments, writing emails, reading emails etc. We decided to define high frequency users of the system as patients who had a mean of 16–30 activities, defined as the number of mouse clicks, per day up to the time of the interview. Patients who had 6–15 activities per day were medium frequency users, and those who had used WebChoice for five or fewer activities each day were low frequency users. According to the activity level categorization method we used, the participants of this study consists of

three high frequency users, five medium frequency users and two low frequency users. See Table I for further descriptions of the study participants.

Interviews

Individual in-depth interviews were conducted with all informants based on principles of qualitative methods (Denzin & Lincoln, 2003; Järvinen & Mik-Meyer, 2005; Kvale & Brinkmann, 2009). The interviews were dialogical, based on what Kvale and Brinkman describe as an "open narrative approach" (2009, p. 155). This approach is characterized by the researchers' interest in personal stories from the life world and experience of interview subjects (Bengtsson, 1999; Fontana & Frey, 2005). The first author conducted the interviews from November 2007 until February 2008[2]. Seven of the interviews were carried out in the homes of the informants. Three interviews were conducted outside the homes of the informants: one in the informant's own office at his/her workplace, one in the interviewer's office, and one as a telephone interview. The interview was semi-structured and based on an interview guide that covered the main topics of inquiry while being sensitive to the patient's inclinations allowing room for departure to pursue novel topics and experiences introduced by the participants (Kvale & Brinkmann, 2009). All the interviews started with open questions, about how the patients used WebChoice and what components of the program they mostly used and their reflection and reasoning regarding their use of the program. Following this track, the patients brought up experiences and stories that indicated what WebChoice did in interaction with them as well as what they did with WebChoice. During this process of the interview, the researcher asked follow-up questions such as: "Can you tell more about that?" Such questions encouraged the patients to clarify and expand upon their experiences, and it allowed nuanced reflections and insights to occur during the interview. At the end of the interview, the participants were invited into further reflections

Table I. Demographics of the study participants.

Gender	Time since diagnosis	Stage of disease	Activity level
Female	More than a year	First time diagnosis	Medium
Female	1 year or less	Metastasis and/or recurrence	High
Female	More than a year	First time diagnosis	Medium
Female	1 year or less	First time diagnosis	Medium
Female	More than a year	First time diagnosis	High
Female	More than a year	Metastasis and/or recurrence	High
Male	1 year or less	First time diagnosis	Medium
Male	1 year or less	First time diagnosis	Medium
Male	More than a year	First time diagnosis	Low
Male	1 year or less	First time diagnosis	Low

about the role of technology in their home and in healthcare more general. Statements could be asked such as: "Some people might say that the technology is going to take charge over the human care and communication in healthcare. What are your opinions about this statement?" This technique often brought nuanced insights into the conversation (Staunæs & Søndergaard, 2005) such as contradictory experiences according to earlier expressed experiences during the interview. During the interview, the first author was sensitive to the new topics being brought up by the participants, but also tried to follow the questions in the interview guide. While conducting the interviews, the first author observed that the use of WebChoice was often less important to the patients than their experiences with cancer and their relationships to health care and health personnel.

The precision of the patients' knowledge, the richness of their experiences, and their willingness to share those experiences indicated that the interview was satisfying some needs to express themselves to a researcher. Finally the patients were together with a person who had time to listen to their powerful illness narratives[3]. The interviews were tape recorded with the permission of the informants. Each interview lasted between 1 and 1.5 hours.

Analysis

Our analytical process was inspired by what Kvale and Brinkmann (2009) and Denzin and Lincoln (2003) call the "bricholage" approach. This is a way of analyzing subjective experiences in which the researcher as a "quilt maker" may use several different techniques and concepts as long as they are based on systematic readings of the material. Further our analytical process fits to what Denzin and Lincoln describe as the "interpretive bricholage" which is a pieced together set of representations that is fitted to the specifics of a complex situation as an "emergent construction" (Weinstein & Weinstein, 1991, p. 161). The construction changes and takes new forms as the bricoleur adds different tools, methods, and techniques of representation and interpretation to the puzzle (Denzin & Lincoln, 2003). In our analysis, the techniques were based upon different approaches to the research material and the context during the analytical process.

The first "patch of the quilt" began already during the interviews themselves (Fangen, 2010). It became apparent that several patients' experiences with WebChoice were ambivalent. As we shall see, this ambivalence became an important part of the study's findings.

After each interview, the interviewer wrote a context description with information on where the interview was carried out, impressions of the surroundings, and the researcher's experiences before, during and after the interview. The context description served as a "reminder patch" of the atmosphere of the interview, helping the first author to, in a sense, "rebuild" the interview situation during the later analytical process. Meeting cancer patients at home struck the first author as an emotionally strong situation and experience. The patients' vulnerability caused by their cancer, had a powerful affect. The patients, however, wanted the researcher's company and she was invited into a warm and friendly atmosphere in their homes. The patients sometimes gave the first author slippers to keep her feet warm; they served her coffee, mineral water, fruit, sandwiches and sweet pastry. Candles were sometimes lit and the fireplace was burning. The first author met some of the patients' children, spouses, friends and pets: dogs, cats and parrots. She looked at pictures and heard stories about kids and grandkids. Some of the patients seemed healthy and lived an active life despite metastases or pain and impressed the first author with their strength, energy and positivity. Other patients were severely ill; one of them could not even get up from the sofa, immobilized by respiratory problems. In this situation the respiratory problems could affect the first author's own breathing, something which indicated the strong intertwinedness between these bodily conditions. Her experience as a nurse came back to her and she felt compassion and a strong desire to help, to show care and empathy. These experiences also indicate that interaction between human beings hold an important position in health care, a point that we will come back to later.

When all 10 interviews were conducted; the first author started to listen to the taped recordings of them and wrote down her reflections in a notebook. She wrote what she heard and interpreted to be the main content in the interview, and also reflections about what she considered as important statements, striking expressions, possible analytical tracks to follow, and themes and stories that functioned to normalize the patient to their situation. For example, one patient used metaphors to describe being sick and being taken care of by the healthcare services as being "passed through a canal," and that she and other patients were being treated like "a bunch of cows." The first author wrote these expressions down in her notebook, and they helped her to remember the informants' ways of expressing themselves and the intuitive first impressions she had of them when she went back

and listened to the recordings of the interviews. Both the notebook and the context description already mentioned, functioned as a part of the bricholage and were used during the formal analytical phases of the research. The richness of the interviews is expressed in the patients' voices and bodily movements, their intentions and the general atmosphere in the rooms where the interviews took place. Together these reveal the subtext of the informants' statements.

After listening to the tapes, the process of verbatim word by word transcription began. The verbatim transcription of all the 10 interviews produced 130 single spaced pages of text (Kvale & Brinkmann, 2009).

After the first author read through the written transcripts several times as a whole material, but also only women, only men, only patients with metastases and only patients with a first time diagnosis, she assembled an overview of the data material and thereby got a broad picture of how the patients talked about their experiences and interactions with WebChoice. WebChoice was not only "a choice" they could use, but "a thing" that made a strong impression on them and affected them. Expressions such as "using WebChoice reminds me of cancer [….] I do not want to be stuck in this cancer thing," inspired us to further analyze patients' relationship to WebChoice, how patients' use WebChoice and WebChoice's "use of them". These decisions were made in the process of "making the quilt" in light of our data material and our interactionistic focus on the interrelation between the patients and WebChoice.

At this point, we began to analyze how the patients expressed their relationship with Web-Choice. When we read the material wearing our "relationship with WebChoice lenses", we identified that the patients talked about their interaction with WebChoice in quite different manners depending upon whether they found WebChoice "to be useful or not", as they expressed it. The way the patients interacted with WebChoice indicated they had different *agendas* for using the system. When we read the material looking for "agendas for using WebChoice," we discovered that the patients had clearly used the program for certain purposes and WebChoice directed the patients' actions. Simultaneously, we began analysis of the patients' expressions of emotions in their interaction with the system, which shed light upon what kind of affects that occurred between WebChoice and the patients. Nobody referred to WebChoice as a neutral support system, instead their interactions with the program created ambivalences. These ambivalent experiences were typical in the material.

Based on our interactionistic perspective, we systematically went through the material several times, letting theory, method, and our material with its selected citations work together in an "ongoing swirl" (Wadel, 1991). The voices and tones in the taped interviews as well as the written dialogue and citations reflected central themes from the experiences of the informant. The first level of analysis utilizes the patients' voices. Next, we interpreted beyond a restructuring of the patients' expression to a more critical interpretation of the interviews (Fangen, 2010). At this stage, the interpretation included our theoretical framework, which moved our analysis to a higher level of abstraction (Kvale & Brinkmann, 2009). We contextualized the WebChoice users' experiences using our theoretical framework as well as previous research in the field of Interactive Health Communication Applications. This process goes beyond what the informants have said directly in order to reveal the opinions and relationships that are not evident at first glance. Verbatim quotations have been used in the article to show what the interpretations are based upon.

Findings

During the analysis, three themes were constructed:

(1) WebChoice as a "friend" or a "stranger."
Theme one relates to the different relationships that evoked through the patients interaction with Web-Choice.

(2) Constituting oneself as an information-seeking "actor."
Theme two relates to how the patients with cancer got constituted as information seeking agents and active patients through access to WebChoice.

(3) Ambivalences in use of WebChoice.
Theme three and its subtopics relates to the ambivalent emotions that evoked through the patients interaction with WebChoice.

This third theme has seven subtopics:

- "Feeling calmed down"
- "Feeling upset"
- "Feeling normalized"
- "Feeling stuck with cancer"
- "Feeling like part of a community"
- "Feeling vulnerable"
- "Feeling supported"

The reason that this theme is broken down into subthemes is that the patients gave particularly rich descriptions of their experiences with ambivalence.

Theme one: WebChoice as a "friend" or as a "stranger"

The extent to which patients gave the WebChoice system a meaningful place in their homes varied between the high, medium and low frequency users. The high frequency users typically gave WebChoice a more prominent and central position in their private sphere. For example, one patient placed a computer with Webchoice on the coffee table in her living room, indicating the centrality of the computer in her life. She explained by saying, "when you are done with [treatment], then you are alone. But I didn't feel alone because I had WebChoice … I'm going to miss WebChoice when it's gone." According to the woman, Web-Choice gave her company and friendship. The woman clearly perceived WebChoice as an actor that helped her to feel less alone. WebChoice was a friend she could rely on when she needed support, and as a friend, WebChoice could also be missed when it was gone (after the study period.) Another high frequency user of WebChoice said, "I feel that WebChoice gives me what I need … [It is] one of the first things I check every day, and at night, when I can't go to sleep, I'm in there looking as well."

For informants in the medium and low frequency user categories, WebChoice's role as an active agent was weaker. These informants did not have Web-Choice on their computers on the coffee table; it was more typical for them to have WebChoice placed less centrally in the house. Medium and low frequency users often characterized WebChoice as a "supplement" to ordinary health services, but WebChoice alone was not sufficient to provide them with support. These patients expressed a need for "human contact" and people who were able to "look them in eyes" and give them "a pat on the back" when they "need comfort." As one patient put it, "a computer can never replace that. It can give you a lot of answers but you … I don't really think you can get a lot of comfort [from a computer program], if you need that."

Medium frequency users also expressed that if they had the option of choosing between communicating with technology or humans, they would prefer the human contact: "For me, this [prostate cancer] is very personal, and talking face to face will make it into a personal conversation … communication is much more than just words … [but an email] is just words."

Low frequency users' perspective was that they did not use the system because their needs were met by their hospital, family members or support groups in daily life. They felt "uncomfortable" spending a lot of time in front of the computer and they did not see themselves as "chatters." Some also interpreted the information in WebChoice as "too general" and not tailored to their own unique illness experience. One low frequency user said outright, "For me, WebChoice isn't something I can use for support." Low frequency users perceived their relationships to WebChoice as impersonal, for them the computer program was an actor that they were unable to trust and interact with.

The next section explores both patients' agendas for using WebChoice and how access to WebChoice influenced the information-seeking behaviour of the informants.

Theme two: Constituting oneself as an information-seeking "actor"

Because of their access to WebChoice, the high frequency users, as well as some of the medium frequency users, found themselves constantly situated in a "checking" and "searching" process, "keeping a lookout" for any new information of interest that they could "take advantage of" or that could "make their situation with cancer improve." One patient described the experience in this way:

> You can never really get enough information, you know … You're constantly looking for opportunities to get better, if there's anything to gain … it could be anything … food or alternative medicine, you just have to try and see if anything will help … that's how searching works…

Patients were "throwing themselves" into all the new information that they could find on the Web-Choice program, simply "eating it up," in their search for "opportunities to get better" and advice that was intended to improve their everyday life. They valued WebChoice's ability to lead them directly to the specific information they wanted, allowing them to avoid the waste of time and energy involved in finding the right information on a normal internet search engine.

When the patients talked about their use of the WebChoice program and how they sought information, they described it as a working activity that *flowed* naturally into their daily routine along with "house cleaning" and "paying bills". They incorporated their work with the technology as a familiar activity that they quickly began to take for granted as a basic part of their daily life with the illness. The "hunt" for information from home was, however, time consuming. One patient would get up at night when she couldn't sleep, and log on to the WebChoice system to "check" whether there was "anything new going on" and to have something to "work on." Often, this constant search

for new information was connected to patients' anxiety about whether the treatment they received was the "best treatment they could get" and their desire to seek out alternative treatments. One participant had several bad experiences that made her feel as though the health care system gave her little more than "a lick and a promise" for several years running. She said that she had "no time anymore for more mistakes" concerning treatment and medication. This sort of distrust of the health services was expressed by several participants. One result of this distrust is that it led some patients to try to gain control through WebChoice. Their desire to gain control and a measure of certainty over their own situations was a crucial factor in their use of WebChoice. Seeking information on WebChoice reinforced the patients' self-image of being as *active and informed* as possible. In this way, access to WebChoice stimulated them to take on the role of active patients. Being prepared for their scheduled meetings with their care providers seemed to be very significant to them. One woman said that she never went to the doctor's office without "knowing what [treatments] she concretely needed." By preparing herself with the proper agenda, she felt that she had positioned herself to have more control over her relationship with the doctors and increased the chance that she could help the doctors "to make the right decisions." WebChoice played an important role in this search for information and certainty about one's own situation with cancer.

When patients were seeking information on Web-Choice, they tended to hunt for an "exact answer" that would serve the function of prediction of the length of their life. Besides reading general information about cancer and statistics that inspired them to compare themselves with others, a common activity among users was also to search in the peer-to-peer communication for information from other patients in the forum who had "exactly the same diagnosis", "lab results" "tumour size and grading". Discovering these matches allowed patients to investigate "how is it going with him/her?" and what can I expect for my own future based on what I read? For these patients, comparing their own situation with that of others became an important indication of how their own life with cancer would progress. One women said, "I always seek an answer for how long I am going to live with the illness … If I have anything to gain from the other users of WebChoice … [it is] their experience."

The next section shows how interaction and information-seeking in WebChoice created ambivalent emotions. The section reflects experiences especially from high and medium frequency users of WebChoice, but some experiences from low frequency users are also included.

Theme three: Ambivalences in use of WebChoice

Feeling "calmed down". Patients' interaction with WebChoice produced feelings of "being in control" and being "calmed" during their ongoing struggle with cancer. Actively seeking information was rewarding as long as it increased the user's knowledge and feeling of control. One woman spoke about the way WebChoice helped her:

> I need to know [how] to stay in control … I actually lost that control … and it was really horrible… So that's why I always pop in [to WebChoice] and check … Then I need to see how others are doing who might have had it [cancer] longer than me … That's the way it is … that's what it's all about …

Reading about information and experiences that they could relate to their own created a feeling of control in the patients. Sometimes the information and the other patients' experiences were positive and uplifting, indicating a hopeful prognosis and good news for their own struggle with cancer. Reading positive, encouraging information therefore had a calming effect on the patients. Many patients also appreciated that, with WebChoice, they could decide for themselves when they were ready and open to new information.

Feeling "upset". The information seeking act in itself could be risky and dangerous. Patients said that some of the information within the system, especially other people's written descriptions of their experience with cancer, could be both "strong and painful," sometimes "too much" or even "absolutely terrible." The information could make them feel "sad," "moved," "confused," "downhearted," "scared," "shocked," "upset" and "angry."

> Yesterday I was reading an article [on WebChoice] about skeletal spread … and that's the first time I've really gotten into it, because I've always thought I could put it off … It said that it was a sign of a long developing illness … and then it said that the survival time was between 6 and 48 months … and then I thought … "Why do I have to read this? How stupid!"… to read it on WebChoice there, and then I thought that I should know what I'm heading into, and know what I'm reading about … I'm going to prepare myself by thinking that it's only statistics … and it's all history … and what is going to happen

going forward can be better for me … I shouldn't [believe] it word for word … because that might depress me.

Discovering unwanted statistical information about diagnosis, survival rates and prognosis "upset" and "worried" some of the cancer patients in our study. When they became worried, they also felt alone. It became apparent to them that they were only interacting with a computer program, and there was no one to calm them down, support them or offer comfort in that period of anxiety that the unwanted information from WebChoice had created.

Feeling normalized. Patients found that interacting with WebChoice created an increased focus on, and knowledge of, symptoms and symptom experiences. Patients used this knowledge to prepare themselves for their consultations with their healthcare providers, and to help them formulate questions about symptoms and treatments. Interacting with WebChoice also helped patients to understand their own symptom experiences and make them more visible by having them acknowledged within a medical context as valid, real and "normal" experiences. By collecting information and knowledge about symptoms from WebChoice, they could find a measure of reassurance that, for example, their own experience of being fatigued was a common side effect caused by the treatment. When such an experience was defined, it diminished the patient's worries about whether their symptoms were signs of relapse or sensations unrelated to the disease. Using WebChoice in order to define uncertain symptoms offered patients the relief of normalization in their daily life.

Feeling stuck with cancer. Patients were also conscious that their interaction with WebChoice could sometimes cause an unwanted and increased focus on symptoms, cancer and illness. The interaction with WebChoice could in some situations "create a fear of getting even more side effects or problems" or of recurrence. One patient remembers thinking, "I haven't got this [symptom] right now, but is it something I'll get, something that's up ahead?" In these situations, access to WebChoice constantly "reminded" the patients about cancer, made them feel even sicker; some felt that they were surrounded, encapsulated and trapped by the illness. One of the high frequency users of WebChoice expressed it this way:

I'm actually just sick of cancer. I've tried to put it behind me, and not be constantly reminded of [it] … Yeah, I don't really want to be a cancer patient. I've been declared healthy … I have, I'm suffering from some side effects, but I want to … try to put this behind me as much as I can, and then move on and start focusing on other things. Using WebChoice, constantly being on there and reading, it reminds you of your illness and … and it … I know that I've had cancer, and it's had significance to me. A lot [of significance] for a time. It still has a little, but I want to be done with it, as much as I can. I'm very conscious of that. I wish, in a way, not to be reminded of it all the time … I don't want to be stuck in this cancer thing.

A central point here is that in some phases along the illness trajectory, some patients reach a turning point where they do not want to focus on cancer anymore but desire instead to "move on and start focusing on other things." In these situations, WebChoice becomes a non-human actor that binds the patients closer to illness. This seems to be especially true for the patients who are nearly finished with treatment and are diagnosed as healthy.

Feeling like part of a community. Users of WebChoice placed a high value on meeting and connecting with other patients on WebChoice's e-forum. Learning about the "personal experiences" of others who suffered "the same fate" and "who know where the shoe hurts" created feelings of "commitment", "being in the same boat" and "belonging to a community" of shared experience. Reading and sharing similar stories with others in similar situations made the patients aware that they were "not alone in their struggle with cancer." Others suffered and lived through many of the same challenges, some even more so, and this could be a valuable source of comfort in itself. The patients stressed that it was not always necessary to write their own experiences, it could be more than enough to read other patients' forum messages in order to have one's own questions and worries "validated" or "rejected." The cancer patients' relationships with other WebChoice users were highly important and meaningful, even though these others were only internet friends. The patients felt a commitment and a sense of belonging to the community even though they could not see or know the other people posting on the forums personally.

Feeling vulnerable. The importance of the "invisible others" was also obvious when it came to the more

challenging aspects of writing messages in Web-Choice e-forum. Some patients described writing these forum messages as a vulnerable process, both because they felt uncertainty about *what* to write to invisible others and also because of feelings of "irritation" and "dissatisfaction" with one's own email messages sent through the system. The patients said that it was sometimes hard to write about their experiences because they did not know and could not see the invisible others' reactions to their forum messages and that they did not know how serious the others' situations were at that moment. One patient remembered writing a post and then thinking: "[Maybe] this was a little bit over the top for some, it is hard to know where others stand." Many WebChoice users described being afraid of hurting other patients' feelings with their own forum contributions and showed a high degree of respect and responsibility for the invisible others.

Feeling supported. Three patients' had actively used the possibilities for e-mail communication with the oncology nurses in WebChoice. These patients could describe the interaction with the nurses as "amazing", "useful" "exiting", "valuable" and that they felt "supported" and "followed up" by a professional. The nurses were able to "acknowledge" the patients symptom experiences and to validate or reject whether the symptom experience was something normal or abnormal. One patient even described receiving an e mail message from the nurse as a sort of "care". Others described feelings of happiness:

> I think it is really exiting … you become happy you know because you receive an answer so quickly … you feel followed up and that they [the oncology nurses] take you serious … it's really great … because it is not that easy to reach through otherwise [to the healthcare system].

Patients' valued the nurses' "quick answers" and their "pleasant", "friendly" and "humble" attitude. They also valued that the nurses signed their e-mail messages with their full names something which made the communication between them more personal. Some patients reflected upon that the value of e-mail messages was that they were able to write in the moment of a thought or a question, and that they knew that the nurses could give them an answer whenever appropriate in relation to their time and workload. To sit down, all by themselves, and formulate and edit their email messages was important, and helped them to "keep on track":

To give themselves time to reflect was supported in the e-mail communication with the nurses.

However, patients' also expressed that the e-mail messages from the nurses sometimes was "too general" and not enough tailored to their own unique illness experience and situation. They believed that this had to do with that the nurses did not know them as patients, and the nurses did not have access to their personal health record. Other patients reflected upon that the face to face interaction with the nurses was most important for them, and that they would have preferred this personal communication if they had to choose. Having cancer was experienced as something "very personal" and that to communicate face to face with the nurse was the most appropriate thing to do to constitute a personal interaction.

Discussion

WebChoice as a friend or a stranger

As already stated, WebChoice enjoyed high status as an integrated part of high-frequency users' daily life, and a friend that reduced their feelings of loneliness. WebChoice appeared to actually take the status of a *subject* from whom the patients sought support and information both night and day. This sort of relationship is discussed by Lupton (1995), who suggests that "humans think, feel and experience their computers and interact with them as subjects," and that computers can be invested with emotions and personal attributes such as "friend," "work companion" or even "lover." High frequency users' description of WebChoice as a friend that they would miss when it was gone indicates that WebChoice became an active agent in their lives, an important friend that supported them along their cancer trajectory. On the other hand, our results show that often for medium, and especially for low frequency users, WebChoice did not take a role as an actor in their lives, but rather, could be experienced as a "stranger." These patients longed for human relationships and comfort that the computer program was unable to give them. As with all friendships, if this one is not stimulated it dies—which is exactly what happened to those patients who did not find WebChoice to be a useful partner in their life. These results contradict Lupton's reflections and indicate that even if technological tools are regarded as subjects, they lack some of the central attributes of human bodily subjects. Technological tools do not listen, wipe your tears or give you a pat on the back if you need comfort. This became particularly visible when the first author visited the patients at home

and experienced their need for contact with living persons.

The theme; "WebChoice as a friend or a stranger" implicate that patients with cancer evolve different relationships to technological tools in healthcare. These tools are, no doubt, developed to support them in their "battle" with cancer. From the medical point of view the system can only be better and be developed to serve the patients need even better. Patients who welcome the technology and actively use and interact with the systems, adapt positive feelings regarding the program and see valuable sides about what the technology are able to give them of support and comfort. They perform a mutual positive constituting of each other. On the other hand, patients who have doubts and discomfort towards the technology do not interact, and the relationship between them fades away. In this study, we are unable to define patients with specific characteristics who benefit the most by the use of WebChoice, this was very individual from patient to patient. Our main implication here is that developers of the IHCA systems can not be able to develop systems that are within the "one size fit all" category. The programs start to act and affect the patients in multiple and ambivalent ways that cannot be predicted before the systems are in use by the patients. As Mol (2009) puts it: "Technologies are not only demanding, but also rarely do what is promised on the package. Instead, they do more, or less, or something entirely different." (p. 1757). By this reflection, we argue that technologies like e.g., WebChoice who are developed for certain intentions and scripts (Akrich, 1992) cannot have a fixed and given identity, but it gradually comes into being when the patients starts to interact with the system. Sometimes, WebChoice does more than the developers of the system intended to do, it becomes a friend for the patients. Sometimes it affects the patients less—the system becomes a stranger in the patients' life. In other situations, WebChoice creates something entirely different, like e.g., feelings of uncertainty, anger or happiness.

Constituting oneself as an information-seeing actor

Access to WebChoice stimulated and exaggerated especially high and medium users' information seeking activity and shaped them to fit into the role of active patient in relation to the healthcare system. Goffmann's (1959) concepts of "backstage" and "front stage," can help us gain a better understanding of how the patients fulfilled and moved between different roles in their interaction with WebChoice. At home with the computer and the WebChoice program, the patients were in a "backstage position"—reading, collecting, hunting and preparing for the "frontage position," which is the face-to-face encounter with healthcare professionals. By gathering as much information and knowledge as possible while in their safe sphere at home, the patients *created and constructed* themselves as active patients and knowledge-seeking actors, prepared to take responsibility for their own health and illness.

Findings showed that when the patients with cancer fulfilled the role of the active patient, they used WebChoice to keep themselves updated on medical news and information in order to ensure that they received good and appropriate treatment. Ziebland et al. (2004) found similar results in her study focusing on breast cancer patients' use of the internet. One of her conclusions was that the patients' search for specific knowledge and information may be the emergence of a "felt imperative to be (or to present oneself as) an expert and critical patient, able to question one's doctors and nurses and locate effective treatment for oneself" (Ziebland et al., 2004, p. 1792). Pitts' (2004) point of view is that the focus of medicine in our modern society is on survival and the cure of illnesses and that it is in this context that health-related internet use is performed. Her concern is that the internet might foster unrealistic expectations about how the illness is to be cured. Access to information seems to offer the patients not just a chance, but a *responsibility* to save themselves. For this reason, patients go on an endless and exhausting hunt for lifesaving treatment. Pitts' research is in accord with our results, which show that access to WebChoice, especially for the high frequency users of the system, turned patients into information seeking agents who were constantly hunting for "anything" that could help and support them. Our results also show that patients used WebChoice to find out how long they were going to live with cancer, a question that no one, including WebChoice, could answer. One patient reflected on this during the interview and said, "So no … I've mostly found answers to my questions [in WebChoice] … and the final question can't be answered by anyone anyway … [laughs] …" The woman's quotation, which also became the title of this article, confirms that despite her intense search for information that would allow a fruitful comparison of her situation with that of other patients, on some level she knew that all the information in the world and all the patients' experiences she could gain access to through WebChoice—or any other means—would never be enough to predict her future with cancer with 100% accuracy. In the end, she has to live with and manage the illness and the

uncertainty by herself. The quotation is an important existential reminder that, despite the patients' search for control and certainty, no one can control prognosis or life span—even with constant access to technology and information. These reflections can be supported by Mol who argues that: "Life may be doctored with, but it cannot be controlled" (Mol, 2009, p. 1757). No matter how objective the "evidence-based" knowledge within WebChoice is, there is always a subject and an individual patient with a unique illness history and prognosis in front of the screen whose questions cannot always be answered. The theme "Constitution oneself as an information seeking actor" implicates that, for some patients, access to WebChoice constructs them into the active patients role, and their needs to be "passive" patients disappears. By performing the role through WebChoice, the patients with cancer are sometimes thrown into an endless search for information and control and even to search for answers to existential questions that is not within human life to know.

Ambivalence in use

Our findings also indicate, as stated in the introduction, that patients today are expected (directly or indirectly) to fulfil the role of an active and informed patient through the interaction with technology. To interact with WebChoice is a challenging work for the patients and that it frequently is involved with ambivalent emotions. Some patients' expressions indicate that using WebChoice was interconnected with control, calmness and supportiveness that contributed positively in their "battles" with cancer. Similar results have been found in Sandaunet's (2008a) study. One could say that IHCAs such as WebChoice are able to support and empower patients so that they can better cope with their illness by increasing their confidence, as Åkesson et al., (2007) concluded in their study. However, there is always a risk of stumbling across biomedical and statistical information or experiences from other patients that contain negative, frightening or discouraging information. Such information might not lead to the improved coping or empowerment that the Åkesson et al. study refers to. On the contrary, such information might be experienced as an indication of a reduced life span, making patients even more conscious of the potentially deadly nature of their disease. This line of thought is more in keeping with Broom & Tovey (2008) who, among other things, found that the primary difficulty that cancer patients' experienced with the internet was "accessing (and if necessary, avoiding) biomedical, diagnostic and prognostic information." According

to Broom and Tovey, the internet may pose a significant threat to cancer patients' emotional well-being in terms of exposure to negative prognostic biomedical information about how little time they have left or how serious their condition is (Broom & Tovey, 2008). Similarly, Sandaunet (2008b) found that one of the reasons why women with breast cancer withdrew from online self-help groups was the need to avoid learning painful details about breast cancer. Women wanted proof that it was possible to get through the cancer, not the opposite. They wanted to keep believing that their prospects were good, which may be understood as a fundamental need to see a hope of recovery. By playing the role of active patient, WebChoice users run the risk of losing their hope for recovery, depending upon whether the information they find seems to indicate a positive or negative prognosis for their own situation.

WebChoice offered patients a forum in which their symptom experiences could be acknowledged, normalized and encapsulated within a medical context. This act of "self-screening" that the active patients performed in their interaction with WebChoice is one aspect of the extension of telemedicine and informatics to the general population (Cartwright, 2000; Crysanthou, 2002). In this way, WebChoice may be seen as a tool for *demedicalization* because it allows patients to be more actively involved in taking care of and resolving their problems and worries *on their own*, without being dependent on the ordinary health services. On the other hand, our results show that some patients also felt an increased—and undesirable—focus on illness and cancer. Interacting with WebChoice in their homes was a reminder of their serious situation and the risk of potential upcoming problems and deterioration caused by their disease. In this light, Webchoice must be seen as a part of a *medicalization*, as a technological tool that contributes to binding people into their role as sick patients, which might be counter-productive, especially when they are diagnosed as being cured and are trying to get on with their life.

Furthermore, integrating WebChoice into patient's homes might alter the atmosphere and feeling of privacy. Even if homes today are equipped with Internet and that technology is a part of life, a home is still seen as a private place where you can be yourself and decide who you invite in. During illness, a home, in contrast to the hospital, can be a safe zone, since pain and suffering are associated with cancer, the need to feel safe and sheltered is central. In line with Latour (1992) WebChoice can represent an extension or delegation of information and communication services that

healthcare traditionally has offered, into the patients' homes. In an institutional context, the WebChoice application can operate as "a stand-in" for the health services. One perspective is that integrating WebChoice into private homes allows "the medical gaze" to dominate—not only in the health service—but also in the patients' homes, with interruption of privacy as a consequence. In this way, WebChoice both opens new possibilities for contact with other patients and the oncology nurses. The contact is, however, not a lived and bodily felt relation. Left behind the screen can as well leave the patients in loneliness and isolation. These reflections are in line with Turkle (2011) who view the power of technological tools as potential creators of both isolation and connectivity. Our informants' ambivalent needs and experiences can shed light upon this dilemma.

The theme "Ambivalence in use" implicates that technological systems are active agents or forces that involve affects and emotions in both uplifting and depressing ways. The patients have to deal with the emotions that evokes in interaction with the technological systems and by performing the active patient's role they are given hopes for the future. However, findings also sheds light upon that hope are taken away from them.

Limitations

This study builds upon material gathered from 10 interview subjects who can be defined as active patients' since they took part in a research project. The results reflect the experiences of this small group of patients and not those of cancer patients in general. Among high frequency users, two out of three patients had metastasis. This life threatening stage of illness could have confounded some of the statements and perspectives being expressed by these specific patients. However, WebChoice was developed to be used by patients in all stages of the disease. One might also question how representative the patients in our study were for the whole group of patients with cancer. There are also differences between male and female both concerning experiences of their diagnosis but also their relationships to technological tools and in the length of time they had access to WebChoice. We have not taken these considerations into account when working with the analysis. When the transcriptions were done, and the initial themes were developed, we did not return the verbatim descriptions and the themes to the participants to see if they agreed with the analysis. All of these moments can be a limitation of the study.

Conclusion

Our analysis shows that the system created different meanings for each patient depending on usage. High frequency users of the system embraced WebChoice as a friend in their life, one that supported them through their battle with cancer. WebChoice became an integrated part of their life that they were able to trust and to seek support from. Medium and especially low frequency users often related to WebChoice more as a stranger, which in turn meant that their use of the system was more sporadic and that WebChoice did not play an important role in their life with cancer. This suggests that cancer patients have different needs, and that a technological tool like WebChoice is meaningful and suitable for some cancer patients, but not all.

High frequency users of WebChoice exhibited particularly intense information-seeking activity, searching for any insight that could improve their daily life with cancer. Access to WebChoice could also for some create an obsessive need to search for final answer to the question of how long they were going to live with cancer, an answer that no one was able to give them. By offering them a world in which to quest for information and knowledge, WebChoice cast the patients as active patients in their own care and treatment. However, fulfilling the role of active patient was difficult, challenging work, as they careered between hope and hopelessness and a wide spectrum of both uplifting and depressing emotions. Even though some of the research literature argues that an IHCA can contribute to a measurable positive outcome as long as the patients interact with and use the system (Åkesson et al., 2007; Moore et al., 2001; Murray et al., 2005; Ruland et al., 2012; Shea et al., 2009; Van der Meer et al., 2009), there are other issues at stake. Research-based knowledge that views the technology as well as the humans as active players in shaping social processes supports our findings (Berg et al., 2003; Bijker, Hughes, & Pinch, 1987; Mol, 2002; Mol, 2008; Latour, 1992).

This article contributes to an increased understanding of some of the unintended challenges that the implementation of an IHCA into the private sphere of severely ill patients can create. Patients are supposed to gain support, and they often do, but an IHCA can also increase suffering and uncertainty. By identifying these challenges, we hope to shed more light on the reasons that studies of IHCA use show that about 30% of patients with access to IHCAs do not use them (Gustafson et al., 2002; Patten et al., 2007; Ruland et al., 2007). Our conclusion is that the development

and implementation of IHCAs into the homes of patients suffering from cancer has benefits, but also limitations for some patients. In addition to giving the patients a sense of control and calmness, as well as feelings of commitment and being normalized, access to WebChoice also created increased uncertainty, worry and a compulsive need to search for answers to existential questions that are essentially insoluble. It is worth considering whether these unintended emotions and actions improve cancer patients' overall health, even though better health is the ultimate goal of IHCA tools. Our study also shows that technological tools need to be further questioned and discussed in relation to how it as a non-human actor is both different from but also similar to human actors and relations. All of these insights are important as a context for further development and implementation of IHCA into patients' private homes and lives.

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Notes

1. When the patients signed the informed consent for the RCT study, some patients marked on a questionnaire that they were interested in participating in an interview, discussing their use of, perspectives on and experiences with the WebChoice program. Before all the interviews in this study began, the FA also talked with the patients about the content of the informed consent, their ability to withdraw from the study, about transcription of the data material, use of citations in publications and confidentiality.
2. One interview was carried out as a pilot interview before the others.
3. The significance of conducting the interviews face-to-face led the first author to reflect that being in the patients' homes, actually seeing them and listening to their stories sheds light upon a limitation in WebChoice. WebChoice is present in their homes, but it is not a listening subject that is able to replace the human contact.

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