Breast cancer stories on the internet : improving search facilities to help patients find stories of similar others

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CHAPTER 4

Illness stories on the Internet: what do breast cancer patients want at the end of treatment?

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Abstract

The study aims to elicit user requirements for internet-based applications disclosing fellow patients' illness stories for the benefit of breast cancer patients. Twenty-six breast cancer patients, recruited via the Dutch Patient Organization for Breast Cancer, were interviewed about their preferences with regards to content, appearance, and search options concerning fellow patients' illness stories online. The interviews were analysed quantitatively (SPSS) and qualitatively (NVivo). Participants were mainly interested in fellow patients' experiences about how to cope with emotions, the impact of cancer in daily life, and physical discomforts. Most participants preferred a section of an illness story in text format about a specific topic; some of them wanted to be able to click on to the corresponding complete story, comprising of text alone or supported by voice or video clip. A majority of participants wanted to be able to select illness stories on the basis of several authors' features, i.e. treatment underwent, age, presence of metastases, time since diagnosis, and whether or not caring for children. Participants gave arguments for their preferences. The findings of this study will be used for designing an online trial with breast cancer patients aiming at refining the user requirements.

Keywords: Internet; breast cancer; illness stories; user requirements; patients' needs

1 Introduction

> You have received all necessary treatments. It has to be OK. And the world around you says: 'Well, come on, now we are facing normal life again, it's over!' But for yourself, it is not at all over... There is a life before [cancer], and a life after. (39-year-old breast cancer patient)

Cancer has an enormous impact on a patient's physical, psychological and social functioning. After treatments problems often last. Many patients experience long-lasting tiredness, pain, fear of recurrence, uncertainty about the future, difficulties in relationships with others, and problems with work rehabilitation [1]. Having cancer changes a person's activities and thoughts, and the way others treat and view him/her [2].

The life story, which every person constructs by weaving together the variety of events and experiences that make up life into a balanced entity, is disrupted by cancer. It can be repaired by constructing an illness story [3,4], which helps patients to (p. 16) '(a) make sense of health and disease, (b) assert control in the midst of physical and psychological losses, (c) transform their identities and social roles as a result of altered health and disease, and (d) make decisions about their health' [5]. Writing about personally upsetting experiences -like having cancer- can lead to significant health improvements [6,7]. Illness stories are not only beneficial for writers, we think, but also for readers who are in the same situation, fellow patients. They can use writers' illness stories as examples for repairing the life story.

A vast amount of illness stories can be found on the Internet. These stories can anonymously be read when and where readers want [8]. However, having studied features of websites disclosing breast cancer patients' illness stories in the Dutch language, we found neither search facilities based on the content of stories nor on personal features of authors [9]. This complicates both finding stories compiling of relevant topics and finding stories written by comparable fellow patients. Yet, we argue that stories that meet these two criteria are most useful in repairing one's own life story.

In order to develop websites that match patients' needs, the topics breast cancer patients want to read about in fellow patients' stories online and the way they want the stories to be presented to them should be known. To our knowledge no studies have been conducted that address this issue. Studies that have examined breast cancer patients' needs tend to focus on medical information needs [10,11] rather than on the needs concerning fellow patients' illness stories. Moreover, studies that have examined breast cancer patients' listservs [12,13] focused primarily on the topics participants write about and not on the topics they want to read.

Website developers should also be familiar with the personal features breast cancer patients want to know from authors of illness stories in order to identify with them. Bennenbroek [14] studied 'upward' and 'downward' comparison among cancer patients (i.e. comparing with others who are doing better, respectively, worse), but focused not on features such as fellow patient's age or treatment underwent. Rozmovits and Ziebland [15] found that is was positively viewed by their participants to be able to select fellow patients of a particular age, stage of illness, long-term survivors, or someone having opted for similar treatment, when looking for experiences of others. Yet, they did not investigate this further.

The study aim was to elicit user requirements for internet applications that disclose breast cancer patients' illness stories, using individual interviews. We focused on content and appearance of stories, and search options for authors' features.

2 Methods

2.1 Participant recruitment

The Dutch Patient Organization for Breast Cancer [16] published a recruitment advert in their magazine. To recruit a diverse group of participants no limitations were imposed on age, treatment underwent or phase of the breast cancer. When a woman decided to participate an interview appointment was made, her address was asked in order to send written information, and age, time since diagnosis and treatment underwent were noted.

In response to the advert 38 women called, the last seven were noted as reserve participants. Three of the first 31 callers appeared to be not interested in participation, and two women cancelled their appointment due to medical reasons. A number of 26 participants was seen as sufficient for exploring the user requirements.

2.2 Interview questionnaire

The first part of the self-developed questionnaire aimed at letting participants get used to the interview setting and at introducing the main theme by asking about the advantages and disadvantages of several ways to hear about fellow patients' experiences. Parts two to four focused on participants' preferences regarding illness stories' content, appearance, and authors. Part five comprised participants' demographic and health characteristics.

Card-ranking was used to elicit preferred content. This method was selected after test interviews demonstrated that ticking off topics one wants to read about from a list of topics was not useful due to the 'ceiling effect' [17] and that paired comparisons of Thurstone [18] were not applicable due to one's difficulty with choosing and its dullness as a result of the great number of pairs. In the final questionnaire, participants were asked to rank eight cards describing important topics in the scope of coping with breast cancer (identified in [19]) according to the degree they want to read about these in fellow patients' stories. While ranking the cards, participants were asked to think aloud, and to think back to the period they returned home after completion of treatments in hospital. We think that illness stories disclosing internet applications are most beneficial in this period during which many breast cancer patients struggle (e.g. [20]). Participants were also asked whether they want to read about other topics than the eight card topics.

Preferred appearance was also elicited using card-ranking. Participants were asked to rank six cards describing every possible combination of the following two aspects (inspired by [21]): (1) section of an illness story about a specific topic or a complete story about the whole course of illness, and (2) only text, text supported by voice, or text supported by video clip.

In the questions about preferred search options for authors' features clear examples were given to ensure that participants could imagine these accurately. We decided to do this after test interviews demonstrated that questions of the format 'Do you want to know the author's religion?' appeared to be difficult with chance on social desirable answers. In the final questionnaire we therefore used the format: 'We can divide fellow patients' illness stories on the website according to the authors' religion. We can make several buttons, for example: (1) stories of religious women, and (2) stories of women without a religion. Do you want this search option for author's religion?'. Participants were asked for an explanation. After 12 search options were asked for in this way, participants were asked to which three they gave priority and whether they wanted any other author search options.

2.3 Interview procedure

The first author conducted the interviews. An interview started when the interviewee had given permission for audio taping, had signed a consent form, and had no further questions. Interviews took place in booked rooms where interviewer and interviewee could talk without being disturbed in Leiden (LUMC) or in Utrecht (at the patient organization or a colleague's home) and lasted one to one and half hours.

Table 1 Participant characteristics (n=25)[a]

Characteristics		n (%)
Interview age	≤40 yrs	5 (20)
	41-50 yrs	6 (24)
	51-60 yrs	9 (36)
	>60 yrs	5 (20)
Marital status	Single	4 (16)
	Married/ partnered	21 (84)
Education level[b]	Low	2 (8)
	Moderate	9 (36)
	High	12 (48)
Employment at diagnosis	Employed	17 (68)
	Economically inactive	8 (32)
Time since diagnosis	0-24 months	6 (24)
	25-48 months	12 (48)
	>48 months	7 (28)
Diagnosis age (estimated)	≤40 yrs	5 (20)
	41-50 yrs	10 (40)
	51-60 yrs	8 (32)
	>60 yrs	2 (8)

Table 1 (continued)

Characteristics		n (%)
Treatment underwent[c]	Mastectomy	21 (84)
	Breast conserving therapy	10 (40)
	Chemotherapy	17 (68)
	Radiotherapy	12 (48)
	Hormone therapy	14 (56)
Treatment at interview	Chemotherapy and/or radiotherapy	0 (0)
	Hormone therapy and/or check up	25 (100)
Ways to hear about fellow patients' experiences[c]	Face-to-face support groups	17 (68)
	Telephone helplines	14 (56)
	Books and magazines	23 (92)
	Television programmes	22 (88)
	CD-ROMs	3 (12)
	E-mail messages	4 (16)
	Listservs/chat rooms	2 (8)
	Websites with illness stories	18 (72)

[a] One participant was excluded from the analyses due to not being a breast cancer patient, but a preventatively treated BRCA-carrier.
[b] Two missing values.
[c] Does not count till n=25 or 100%, because participants underwent more than one treatment, respectively, used more than one way to hear about fellow patients' experiences.

2.4 Data analysis

The audiotape recordings were transcribed. Quantitative data were analysed in SPSS [22] and qualitative data in NVivo [23]. The data analysis was carried out by the first author, who regularly consulted with the co-authors.

3 Results

3.1 Participant characteristics

One participant was excluded from the analyses due to not being a breast cancer patient, but a preventatively treated BRCA-carrier. The youngest participant was 36 years of age, the oldest 67 (mean= 51; SD= 9.6). Most women were married or living together, higher professional or university educated, and working at the time of diagnosis (Table 1). Time since diagnosis ranged from 7 to 144 months (mean= 41; SD= 28.0). The diagnosis age varied from 32 to 63 years (mean= 48; SD= 9.1) and was estimated by rounding the number of months since diagnosed into years, and subsequently subtracting it from the interview age.

All 25 participants underwent surgery: 15 women (60%) underwent mastectomy; four women (16%) underwent breast conserving therapy; and six women (24%) underwent both. Four women (16%) did not receive any kind of adjuvant therapy, some women received one (n= 8; 32%) or two (n= 4; 16%) kinds. Nine women (36%) received chemotherapy as well as radiotherapy and hormone therapy. None of the women received chemotherapy or radiotherapy at the time of the interview.

All participants were accustomed to hearing about fellow patients' experiences, but they used different ways (Table 1). The mentioned advantages and disadvantages pointed out that participants appreciate: (1) content that is relevant to them (i.e. stories about topics that interest them without extensive elaborations); (2) fellow patients who are comparable regarding treatments underwent; and (3) being able to select stories on the basis of (a) the ending, and/or (b) the writing style.

3.2 Content requirements

Figure 1 shows the results of the card-rank task about preferred content. The topic *coping with emotions* was the most frequently placed high in the order of rank (median= 3; inter-quartile range= 1–3), meaning that the majority of the participants wanted to read about this in fellow patients' stories online when being home again. The topics *impact on daily life* (median= 4; inter-quartile range= 2–4) and *physical discomforts* (median= 4; inter-quartile range= 2–5) were also often placed high. The topic *dealing with physicians* was the most frequently placed low in the order of rank (median= 7; inter-quartile range= 6–8), meaning that there was little need to read about this topic in fellow patients' stories.

The inter-quartile ranges in combination with the highest and lowest place on which a topic was placed indicate the degree of discord between the participants. Participants agreed most about the topics *coping with emotions* and *dealing with physicians*: both topics have an inter-quartile range of only three places (1–3 respectively 6–8) that coincides with an extreme place (1 respectively 8). Most disagreement was about the topic *accepting breast cancer*: the topic was placed on place 1 and 8, and the inter-quartile range comprises exactly the middle of the order of rank (i.e. 3–6).

The think-aloud part pointed out that ranking of the topics was influenced by participants' own experiences and thoughts. They placed a topic high in the order of rank when they had been:

- experiencing long-lasting problems regarding a topic (e.g. long-lasting tiredness or arm lymphedema);
- thinking about a topic over and over (e.g. the question 'Why me?');
- experiencing a topic negatively (e.g. *dealing with physicians*).

Participants placed a topic low in the order of rank when:

- they had not been experiencing a topic at all (e.g. participants who experienced no physical discomforts) or any problems regarding a topic (e.g. participants who dealt very well with physicians);
- they had not been thinking about a topic or already had finished thinking about it (e.g. the question 'Why me?');
- they found a topic only relevant during treatments (e.g. *dealing with physicians*);
- they thought that fellow patients could not give useful comment on a topic (e.g. *the why of cancer*).

Three new topics emerged when participants were asked for any additional topics they wanted to read about in fellow patients' stories:

1. Practical information (e.g. prostheses, wigs, swimming suits, lingerie)
2. Work rehabilitation (returning to profession: how, why, when, etc.).
3. Medical information (treatment and reconstruction options, side effects, heredity).

3.3 Appearance requirements

Due to the combination of two aspects on the appearance cards, seven participants (28%) could not rank them properly. Therefore, instead of analysing the ranking we summarized participants' preferences for the two aspects separately.

As depicted in Figure 2, 15 participants (60%) preferred sections about specific topics, six participants (24%) preferred complete stories, and four participants' preferences (16%) varied. Arguments for preferring sections were: being interested in specific topics; the inconvenience to read long texts on a computer screen; the difficulty to be patient and concentrated when reading complete stories; and, the fact that complete stories deal too much and too long about one particular fellow patient. Eight of the 15 participants who preferred a section wanted to click on to the corresponding complete stories when they got interested. Approaching fellow patients' stories in this way prevents feeling overwhelmed, some participants explained.

Participants who preferred complete stories about the whole course of illness explained wanting to know all in order to gain an accurate view of a fellow patient's situation and to enhance the chance of getting answers to their questions. Participants whose preferences varied explained wanting complete stories just after the diagnosis to read about all the things one has to face, and when gone through all the things (i.e. after treatments) wanting sections to read about specific topics. One participant explained also wanting complete stories when feeling sad to find consolation, but otherwise wanting to read sections.

Figure 3 shows that 13 participants (52%) preferred text only, four participants (16%) preferred text supported by voice, three (12%) preferred text supported by video clip, and five participants' preferences (20%) varied. Arguments for preferring text only were that voice and video clip distract one's attention, do not offer additional value, delay reading, and make it too personal and emotional. Text is least penetrating and quite impersonal and thus appropriate for becoming acquainted with fellow patients' stories, according to some participants. Three of the 13 participants who preferred text wanted to click on to voice or video clip when feeling comfortable with the text.

Participants who preferred text supported by voice explained that voice is easy to take up, gives the idea of really having contact with others, and since it is quite penetrating one cannot deny being a cancer patient. They mentioned turning off the sound when not wanting to hear a fellow patient's voice anymore. Participants who preferred text supported by video clip argued that stories become more human when seeing the author and her facial expressions, and that assessing a fellow patient's personality/type is easier.

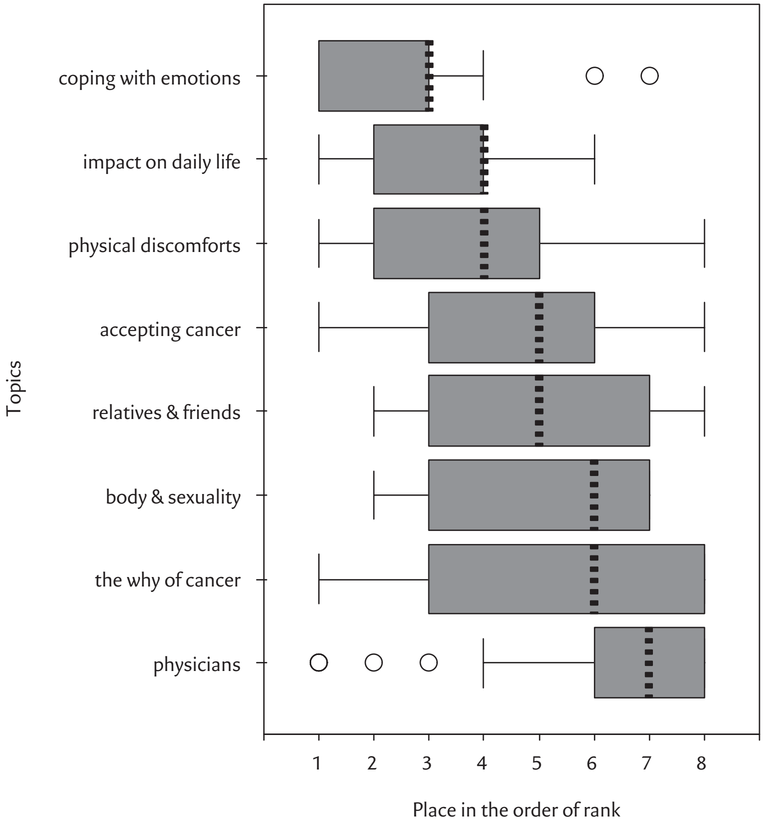

Figure 1 Boxplot of the results of ranking eight topic cards by 25 participants. Place 1= most need, ranging to place 8= least need to read in fellow patients' stories. Per topic is presented: the highest (├) and lowest place (┤) on which the topic is laid, any extreme values (circles), the median (dotted lines), and the middle 50% of observations (i.e. the inter-quartile range; grey rectangles). One participant laid two topics highest in the ranking, to these two the mean of 1.5 is assigned (=(1+2)/2).

Participants with varying preferences explained that their preferences depend on their own emotions, the author's emotions, and the story's length and writing style. When being self very sad or when an author is very emotional reading is preferred above watching video clip. Secondly, video clip during a fragment of a story is fine, but will be too intense during a complete story. Finally, when a story is an enumerative description of all the things an author went through video clip instead of text only is preferred.

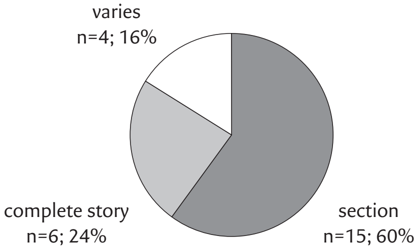

Figure 2 Participants' preferences regarding length and specification of online illness stories. Eight participants who preferred a section wanted to be able to click on to the complete stories.

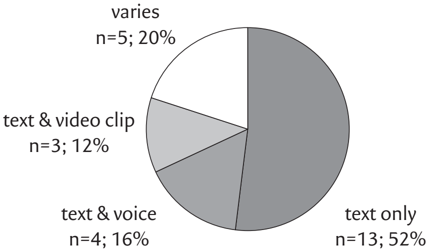

Figure 3 Participants' preferences regarding multimedia support of online illness stories. Three participants who preferred text only wanted to be able to click on to video clip.

3.4 Author requirements

Figure 4 shows participants' preferences concerning search options for authors' features. One search option that was asked for, i.e. future treatments (yes/no), was excluded from the analyses due to being ambiguous: no future treatments can mean both that one has cured from the cancer or that one's cancer has become incurable. The most wanted search options were those for authors' treatment underwent (n= 25; 100%), age (n= 24; 96%), presence of metastases (n= 24; 96%), time since diagnosis (n= 18; 72%), caring for children (n= 17; 68%), and time since last treatment (n= 15; 60%). Less than half of the participants wanted the other five author search options: hobby (n= 12; 48%), marital status (n= 11; 44%), profession (n= 10; 40%), religion (n= 8; 32%), and education level (n= 4; 16%).

Three main reasons emerged for wanting an author search option. Firstly, being able to search for one's own situation and find recognition in the case that different values of a particular feature lead to considerably different stories. For example, participants wanted the age search option because they noted that younger and older patients differ regarding problems in daily life and medical nature of their cancer. Secondly, being able to select or to exclude certain stories. For example, some participants wanted the search option for time since diagnosis to select stories of long-term survivors that can serve as encouraging examples, and some wanted the presence of metastases search option to exclude stories of women with metastatic breast cancer when not wanting that confrontation. Thirdly, being interested in a topic connected to a personal feature. For example, some participants wanted the search option for treatment underwent to read about why some women chose for breast conserving therapy and others for amputation.

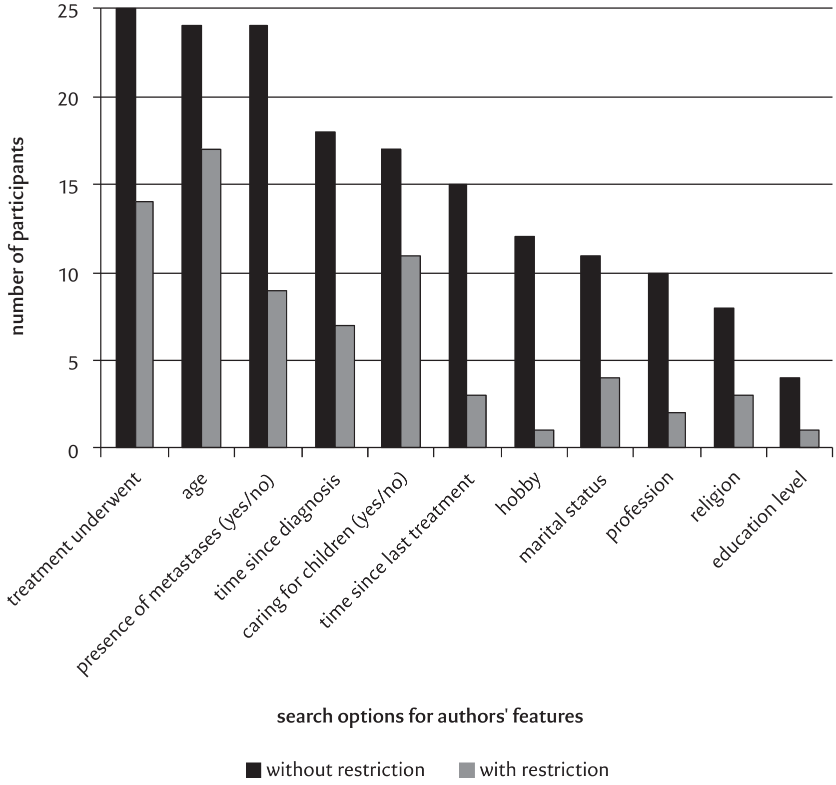

Figure 4 Histogram of preferred search options for authors' features, asked without restriction ('Do you want search option x?') or with restriction ('Which three search options do you give priority?')

Different reasons emerged for not wanting an author search option. When participants thought that different values of a particular feature did not lead to different stories (e.g. hobby), or when according to the participants being ill and having experiences with breast cancer was far more important than the feature (e.g. education level). Some participants did not want a search option because they themselves had a particular value of the feature. For example, some participants who were not religious and therefore not interested in religion did not want the religion search option. Yet, it could be argued that they actually want the search option to exclude stories of religious women (see Discussion). Thirdly, according to some participants separating on certain features is 'unfriendly' (e.g. age), and therefore they did not want these search options.

In addition, one participant expressed her concern about the last treatment search option, because patients do not know whether a last treatment is really the last one. Besides, participants saw a strong relation between the search options for time since diagnosis and time since last treatment, and also, although a weaker one, between the search options for age and caring for children.

When participants were asked which three author search options they gave priority, two were prominent: age (n= 17; 68%) and treatment underwent (n= 14; 56%). These were followed by authors' caring for children (n= 11; 44%), presence of metastases (n= 9; 36%), and time since diagnosis (n= 7; 28%). The necessity of the other search options is limited, ranging from n= 4 (16%; marital status) to n= 1 (4%; hobby and educational level). No other author features emerged when participants were asked for any additional search options they want to have at their disposal.

4 Discussion

This study's purpose was to elicit user requirements for internet-based applications that disclose fellow patients' illness stories for breast cancer patients. Our motivation to this stems from the enormous impact of breast cancer on patients [1,2], the usefulness of hearing and constructing illness stories [3–6], the current lack of search facilities concerning illness stories on the Internet [9], and the fact that applications that match with patients' needs maximize the chance that patients will use the applications and benefit from their use (e.g. [24]).

Recruitment via the Dutch Patient Organization for Breast Cancer [16] may have resulted in a relatively active group of participants. After all, members have put effort in applying for membership and are probably active information seekers. Therefore, the requirements found reflect above all the preferences of active information seekers. Yet, in our opinion, it is precisely this group that uses internet applications most often. Single, lower educated, and economically inactive breast cancer patients were underrepresented and should therefore be involved in future examinations of user requirements. Although the number of participants was limited, we have gained valuable insights from the detailed explanations participants gave for their preferences.

In general, participants wanted to read in fellow patients' illness stories about topics they are themselves suffering from, thinking about, or experiencing as negatively. Thus, participants seemed to take their own story as starting point when searching for fellow patients' stories. This finding supports our thought that patients use fellow patients' stories to further develop and construct their own story into a balanced entity. However, this may not be applicable to all topics. Participants did not want to read about topics of which they thought that fellow patients could not give useful comment on. Since patients' own experiences and thoughts influence what they want to read in fellow patients' stories, we cannot compile an universal list of content requirements. In addition, the fact that *practical information* was often mentioned as additional topic indicates that patients also want to try to make their life more comfortable by following fellow patients' advices.

Since many participants were interested in particular topics and saw text as sufficient, story sections in text format were most preferred. A substantial part of the participants wanted to click on to the corresponding complete story when the section interested them. These findings point out that internet applications that disclose illness stories should: (1) offer a search option using content keywords; and (2) present search results as story sections in text format with the possibility to click on to the complete stories. We realize that not all users will be satisfied with this, since some participants preferred complete stories, voice or video clip, or had varying preferences. However, we think that implementing these two requirements will enable most patients to find quickly and easily what they are looking for, which will be a great improvement compared to the current situation [9].

Most participants wanted the search options for author's treatment underwent and author's age, predominantly to search for their own situation. This finding seems to indicate that patients need these two features in order to be able to identify themselves with a fellow patient. Furthermore, many participants wanted the author search options for presence of metastases and time since diagnosis, among other reasons to search for their possible future situation. This finding suggests that patients are also thinking about their future. These four most wanted search options are in line with the findings of Rozmovits and Ziebland [15], except maybe the slight difference between their 'stage of illness' and our 'presence of metastases'.

The most wanted author search option regarding demographic characteristics -with the exception of age- is caring for children. All other demographic characteristics that were asked for (hobby, marital status, profession, religion, and education level) were only wanted by a few participants as author search options. This finding indicates that patients give priority to authors' health characteristics when searching for fellow patients' illness stories. Furthermore, the question 'Do you want to know the author's feature x?' differs slightly from the final question 'Do you want to search for an author's feature x?', since wanting to know feature x without wanting a search option is possible. Because of this we may have found fewer author requirements, but not incorrect ones, since wanting to search for an author's feature x inherently means wanting to know the author's value for that feature.

The mentioned advantages and disadvantages of several ways to hear about fellow patients' experiences -in the first part of the interview- pointed out that participants liked to hear relevant content from fellow patients who underwent similar treatments as they did. These two wishes were also found in the remainder of the interview as user requirements for internet applications. In theory it will also be possible to implement participants' other wish in an internet application, i.e. being able to select illness stories on the basis of the ending and/or writing style. However, in that case users may only select stories with a positive ending, with the consequence that they will not get a fully representative overview. Moreover, since the writing style of a story is rather subjective, it might in practice be difficult to group stories on the basis of their style.

We would like to make a few comments on our interview questionnaire and on choosing interviewing as method. Firstly, the card-rank task for content consisted of a limited number of topics (eight), which overlapped slightly. For example, *coping with emotions* can influence one's relationship with *relatives and friends*. The card-rank task for appearance was rather difficult, because a combination of two aspects was described on each card. Yet, in our opinion we did overcome these problems by asking also open-ended questions about content and by asking participants to think aloud. Secondly, the explanation of participants with a varying preference for length of a story (i.e. wanting complete stories just after the diagnosis and wanting sections a few years later) indicates that thinking back to the period of returning home after completion of treatments in hospital was difficult. However, in our opinion one cannot interview patients on that emotionally hard moment. Besides, we do not think that we found biased requirements, since we repeatedly reminded participants to think back to that period during the interview. Thirdly, in spite of changing the abstract questions about authors' features into more concrete questions with clear examples, some participants said not wanting particular search options, while their explanation suggested the opposite. Yet, the only feature where this might have led to a bias is author's religion, since for this feature the answers of seven participants seemed not to fit with their explanations. These inconsequent answers may not have occurred, if we had elicited the requirements with the help of a prototype instead of with interviewing. But, with a prototype participants would have been restricted to a particular framework leading them in a particular direction. On a whole, we think that our questionnaire and our choice for interviewing as method were very suitable for a first exploration of user requirements.

This study's findings will be used for designing an online randomized controlled trial aiming at refining the user requirements.

5 Conclusion

Internet applications that disclose fellow patients' illness stories for breast cancer patients should:

- offer search options for stories' content, authors' age and treatment underwent, and authors' presence of metastases and time since diagnosis (or at least mention the authors' values for these features);
- present search results as story sections about the topic that was searched for with the possibility to click on to the corresponding complete stories, both in text format.

This list of universal user requirements we found is rather short, since preferences differed between participants, and sometimes even differed for one and the same participant. In order to make applications valuable to all users, one possible solution would be to offer users an appropriate dialogue manager through which they can make their preferences explicit. Yet, developing such a dialogue manager requires new technical insights and is time-consuming. Meanwhile, applying our list of user requirements will be a big step forward, because applications will then match more with patients' needs which enhance the chance that patients use them and benefit from their use.

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