# CHAPTER 6

## Searching for breast cancer stories online: What topics and/or writer characteristics do patients search for?

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## Abstract

Online patient stories can provide other patients with support and information. This study explores breast cancer patients' information need from stories and use of social comparison at the level of writer characteristics. Log data of 122 patients who participated in an online randomized controlled experiment on search facilities for stories were analysed. Many participants searched for topics in the domains 'Treatment' and 'Living with it', and for the writer characteristics 'treatment received', 'age at diagnosis' and 'time since diagnosis'. Per search patients used more writer characteristics than topics. They preferred to search for others with similar characteristics as their own.

## 1 Introduction

Breast cancer has a major impact on physical, psychological and social functioning. On the Internet there are many stories of breast cancer patients in which they describe what happened to them -from the suspicion of cancer, the diagnosis, the treatments and onwards- and how they cope with cancer (e.g. [1,2]). These stories can provide other patients with support and information [3]. In the context of online patient stories it has been studied how giving and receiving social support is experienced [4] and what the effect is of online patient stories on health care participation [5] and making health care decisions [6].

Yet, to date, little is known about the specific information breast cancer patients actually search for in stories of other patients. In an earlier study we interviewed breast cancer patients and asked them what they wanted with respect to stories of others [7]. These interviews showed that they preferred to know a writer's age and treatment undergone and to read how other patients coped with emotions and physical discomforts and how having cancer impacted their daily life. To our knowledge, no other studies focused on the specific information need from stories. Yet, there are studies on general information need about breast cancer showing that younger patients are interested in information about physical and sexual attractiveness [8], breast conserving therapy and metastases [9], and recently diagnosed patients in topics such as likelihood of cure, the spread/stage of the disease and treatment options [10-12]. In one of these studies, patients actually selected information from a CD-ROM [9], the other studies used surveys to examine information need. Yet, patients' general information need may differ from their information need from stories, since the information in stories is from fellow patients who describe their real life experiences in everyday language.

In reading stories of other patients social comparison plays a role [13]: when someone is uncertain (especially when there is no objective information) about how to think, feel or behave, then thoughts and behaviours of other persons who are in a similar situation can be used as a source of information. Comparison with someone who is as close as possible to oneselves on several characteristics (age, treatment received and so on) is assumed to provide information with the most impact (parallel comparison). Bellizzi et al. [14] found, for example, that in autobiographical books cancer survivors used predominantly these parallel comparisons. However, patients can also choose to compare themselves with others who are worse off (downward comparison) in order to feel good about themselves, or with others who are doing better (upward comparison) to engender hope and optimism [15]. As far as we know, it is not known how patients who search online for stories of others apply social comparison at the level of writer characteristics: do they search for writers with similar characteristics as their own? Research from the group behind the healthtalkonline website (formerly Dipex) [3] showed that patients viewed it positively to have access to stories of others who had opted for similar treatment as they had opted. Yet, our interviews revealed that patients wanted a search facility for time since diagnosis to be able to select stories of long-term survivors that can serve as encouraging examples [7].

In an earlier study –an online randomized controlled experiment- we examined breast cancer patients' satisfaction and search success when using a story topics and/or a writer characteristic search facility to search for other patients' stories [16]. The experiment yielded log data of the actual searches of patients. The present article presents the results of an extensive analysis of these log data. Besides our interest in the information need from stories and in social comparison at the level of writer characteristics as described above, we were interested in the specificity of searches (i.e. the number of topics and the number of writer characteristics that is combined per search). To our knowledge no earlier studies were performed about specificity of searches in the domain of breast cancer stories. In the present article we have addressed the following three research questions:

1. Which topics and/or writer characteristics do breast cancer patients search for when they have a search facility for story topics and/or writer characteristics? (information need)
2. Do breast cancer patients search for writer characteristics that are similar to their own? (social comparison)
3. What is the specificity of the searches breast cancer patients perform (i.e. how many topics and how many writer characteristics do patients combine per search)?

## 2 Methods

### 2.1 Empirical material

We used log data of an earlier performed online randomised controlled experiment that examined breast cancer patients' satisfaction with the search process and the stories retrieved of four different search facilities for other patients' stories [16]. In this earlier experiment, Dutch-speaking women who were diagnosed with breast cancer and who gave informed consent were randomly assigned to one of four search facilities: 1) alphabetical listing by story writers nicknames (control group), 2) a search facility for story topics, 3) a search facility for writer characteristics, and 4) a combined search facility for story topics and writer characteristics. In the three latter groups participants could check the items they wanted to search for and then click the search button. By clicking on the search button, stories were retrieved and presented to the participants. Participants could search for stories of *De Amazones*, a group of young women with breast cancer who founded a website with stories and information in order to provide their peers with information and support [17]. After the participants searched for stories as long as they liked, they filled out a questionnaire including questions about demographic and disease characteristics. Log data (for example, the number of searches participants performed and the items they searched for in their searches) and questionnaire responses were automatically saved in a database. See [16] for more details. In the present study we analysed the log data of the participants who used the story topics and/or writer characteristics search facility. The group with the alphabetical list of stories is not considered in the present study.

### 2.2 Search facilities

Figure 1 shows a screenshot of the search page of the combined search facility. The search page of the story topics search facility consisted of only the left side of this screenshot and the search page of the writer characteristics search facility consisted of only the right side.

With the story topics search facility one could search for topics in four domains: I) Diagnosis, II) Treatment, III) Health care system, and IV) Living with it. The four domains contained a total of 17 main category topics, of which 9 were not divided in subcategory topics and 8 were divided in subcategory topics. In total, there were 27 subcategory topics (Table 1). In the remainder of this article we will use the general term 'topic' to refer to: a) a main category topic without subcategory topics, b) a main category topic with subcategory topics, or c) a subcategory topic. For each of the topics the search page contained a tick box (Figure 1). One could search for stories by checking as many tick boxes as preferred. When the tick box of a main category topic with subcategory topics was checked, all the subcategory topics were automatically included in the search.

With the writer characteristics search facility one could search for six writer characteristics: 1) age at diagnosis, 2) time since diagnosis, 3) children, 4) partner, 5) treatment received, and 6) phase in the course of disease (Table 2). 'Treatment received' was divided in eight treatments, each with a tick box (Figure 1). To search for a treatment the tick box of the treatment could be checked. The other five writer characteristics could be searched for by drop down menus: from each drop down menu one category could be selected in a search (Figure 1). For 'age at diagnosis' the drop down menu consisted of four categories: 20-30 years, 30-40 years, 40-50 years, and over 50 years. The drop down menu of 'time since diagnosis' consisted of five categories: less than half a year ago, ½-1 year ago, 1-2 years ago, 3-5 years ago, and more than 5 years ago. Both the drop down menu of 'children' and the drop down menu of 'partner' consisted of two categories: yes and no. For 'phase in the course of disease' the drop down menu consisted of five categories: in first treatment period, free of cancer, cancer for second time, metastasised cancer, and passed away (stories of deceased writers remained on the website with an obituary added by the moderators). All dropdown menus had a "neutral" option, which was the default setting. When a participant did not change the default setting, the concerning writer characteristic was not searched for.

With the combined search facility one could search for story topics only, for writer characteristics only, or for a combination of these two.

### 2.3 Data analysis

The statistical data analysis was performed with SPSS version 17.0. Log data of participants who completed the final questionnaire and who performed at least one search were analysed. These were the log data of 122 participants: 40 participants in the story topics search group, 43 participants in the writer characteristics search group and 39 participants in the combination search group. Descriptive analyses were performed to describe the participants' demographic and disease characteristics and their number of searches performed. A search was defined as clicking the search button after one had checked the tick boxes and/or selected the categories from the drop down menus of the items one wanted to search for.

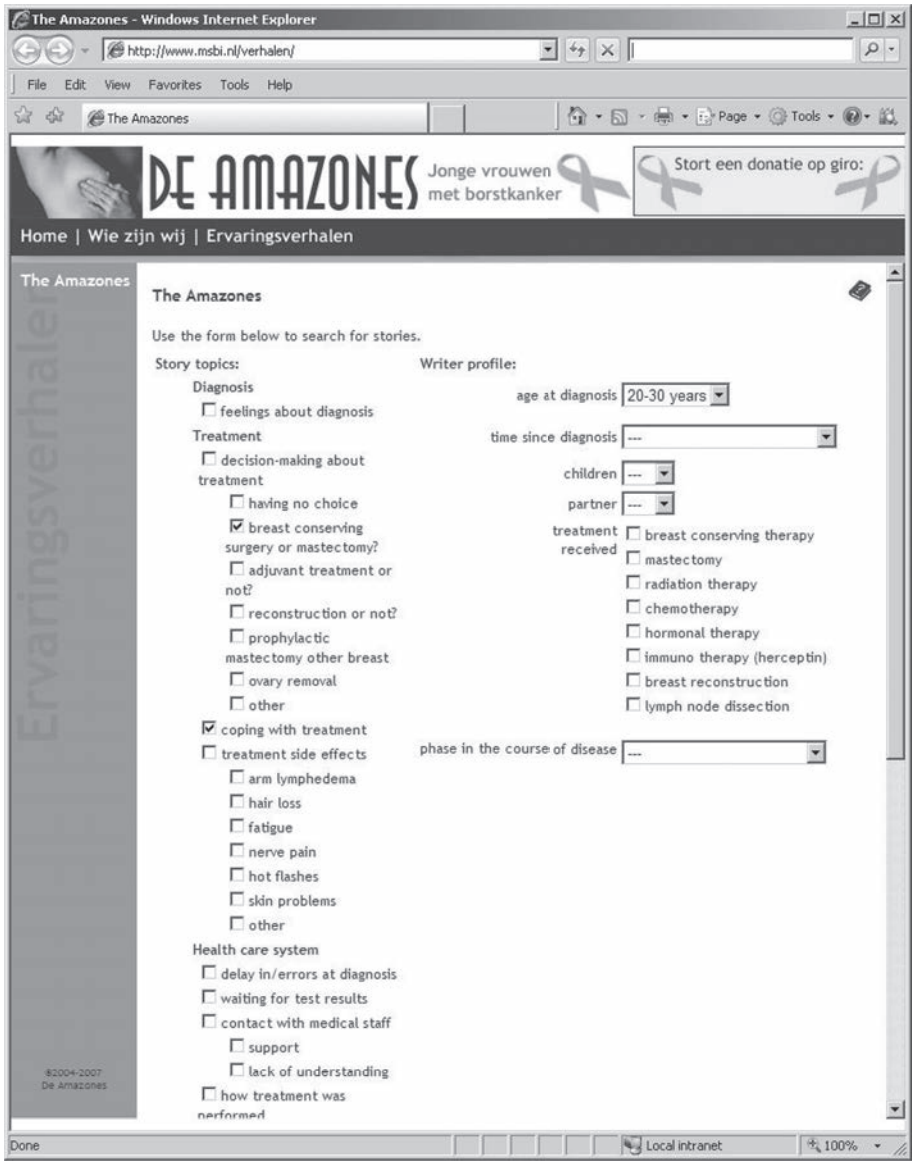


*Figure 1* Screenshot of the search page of the combination group.

*Table 1* Number of participants (n, %) who searched for the topic in at least one of their searches of those who could use the story topics search facility (n=79). When a participant searched for several subcategories of a main category, this participant is counted once in the main category.

| Domain | Topic[a] | n (%) |
|---|---|---|
| **I. Diagnosis** | **1. Feelings about diagnosis** | **17 (22%)** |
| **II. Treatment** | **1. Decision-making about treatments** | **42 (53%)** |
| | a. having no choice | 8 (10%) |
| | b. breast conserving surgery or mastectomy | 12 (15%) |
| | c. adjuvant treatment or not | 10 (13%) |
| | d. reconstruction or not | 18 (23%) |
| | e. prophylactic mastectomy of other breast | 10 (13%) |
| | f. ovary removal | 15 (19%) |
| | g. other | 10 (13%) |
| | **2. Coping with treatment** | **18 (23%)** |
| | **3. Treatment side effects** | **47 (60%)** |
| | a. arm lymphedema | 17 (22%) |
| | b. hair loss | 15 (19%) |
| | c. fatigue | 27 (34%) |
| | d. nerve pain | 18 (23%) |
| | e. hot flashes | 24 (30%) |
| | f. skin problems | 12 (15%) |
| | g. other | 14 (18%) |
| **III. Health care system** | **1. Delay in/errors at diagnosis** | **9 (11%)** |
| | **2. Waiting for test results** | **8 (10%)** |
| | **3. Contact with medical staff** | **9 (11%)** |
| | a. support | 9 (11%) |
| | b. lack of understanding | 7 (9%) |
| | **4. How treatment was performed** | **8 (10%)** |
| | a. satisfied | 8 (10%) |
| | b. dissatisfied | 5 (6%) |
| | **5. Second opinion** | **3 (4%)** |

*Table 1* (Continued)

| Domain | Topic | n (%) |
|---|---|---|
| **IV. Living with it** | **1. Work and insurances** | **12 (15%)** |
| | **2. Family and friends** | **24 (30%)** |
| | a. support | 13 (17%) |
| | b. lack of understanding | 16 (20%) |
| | c. talking with and worrying about | 19 (24%) |
| | **3. Body image and sexuality** | **23 (29%)** |
| | a. (partly) missing a breast | 20 (25%) |
| | b. partner's reaction | 14 (18%) |
| | **4. Pregnancy issues** | **4 (5%)** |
| | a. pregnant at diagnosis | 2 (3%) |
| | b. wanting to become pregnant after treatments | 3 (4%) |
| | **5. Coping with breast cancer** | **36 (46%)** |
| | a. thinking (emotional-focused coping) | 35 (44%) |
| | b. doing (problem-focused coping) | 29 (37%) |
| | **6. Practical advice** | **19 (24%)** |
| | **7. Concerns about heredity** | **13 (17%)** |
| | **8. Coping with metastasized breast cancer** | **27 (34%)** |

[a] Topics in bold are main categories; topics in non-bold subcategories.

To answer our first research question (patients' information need from stories), we analysed how many of the 79 (=40+39) participants who had the story topics search facility at their disposal searched for the different topics in at least one of their searches. When a participant searched for several subcategory topics of a main category topic, this participant is counted once in the main category topic. Furthermore, we analysed how many of the 82 (=43+39) participants who had the writer characteristics search facility at their disposal searched for the different writer characteristics in at least one of their searches. When a participant searched for several of the eight treatments, this participant is counted once in the overarching category 'treatment received'.

*Table 2* Number of participants (n, %) who searched for the writer characteristic in at least one of their searches of those who could use the writer characteristics search facility (n=82). When a participant searched for several of the eight treatments, this participant is counted once in the overarching category 'treatment received'.

| Writer characteristic | n (%) |
|---|---|
| **Age at diagnosis** | **59 (72%)** |
| **Time since diagnosis** | **57 (70%)** |
| **Children** | **54 (66%)** |
| **Partner** | **55 (67%)** |
| **Treatment received** | **70 (85%)**[a] |
| Breast conserving therapy | 23 (28%) |
| Mastectomy | 45 (55%) |
| Radiation therapy | 38 (46%) |
| Chemotherapy | 42 (51%) |
| Hormonal therapy | 35 (43%) |
| Immunotherapy (herceptin) | 12 (15%) |
| Breast reconstruction | 26 (32%) |
| Lymph node dissection | 30 (37%) |
| **Phase in the course of disease** | **55 (67%)** |

[a] The overarching category 'treatment received' could not be searched for directly; the percentage is calculated based on the checked tick boxes of the eight underlying treatments.

To test whether the associations found in previous studies between younger patients and general information need [8,9] and recently diagnosed patients and general information need [10-12] also hold for information need from stories, we examined associations between participants' time since diagnosis and searching for the topics 'decision-making about treatments', 'treatment side effects' and 'coping with breast cancer', and associations between participants' age at study participation and searching for the topic 'body image and sexuality' and the writer characteristics 'breast conserving therapy' and 'metastasised cancer' (category of 'phase in the course of disease'). Due to the relatively small numbers and some skewness of the variables time since diagnosis and age at study participation, the associations were tested with Mann-Whitney U-tests. P-values lower than or equal to .05 were considered significant.

To answer the second research question (social comparison at the level of writer characteristics), we analysed for the searches containing a particular writer characteristic how often the category that was searched for corresponded with the category of the participant. For example, all searches with 'children: yes' and 'children: no' were examined. The own category was searched for when a participant had children herself and searched for 'children: yes' or when a participant had no children and searched for 'children: no'. Percentages were calculated on the basis of the number of searches: participants who had multiple searches on 'children' counted multiple times. In searches in which the own

'time since diagnosis' was not searched for, we examined which category was searched for instead in order to get insight in whether patients search for long-time survivors as encouraging examples, as resulted from our earlier interviews [7].

To answer the third research question (specificity of searches), we analysed for each search containing topics how many topics were combined. We used the definition that one could search for 36 topics per search: 9 main category topics without subcategories and 27 subcategory topics. Thus, for the 8 main category topics with subcategories we counted the number of subcategories that was checked. In the case the main category was directly checked by the participant all subcategories were automatically checked and included in our count. In a similar way, we analysed for each search containing writer characteristics how many writer characteristics were combined. One could search for 13 writer characteristics per search : 8 tick boxes (treatments) and 5 drop-down menus.

## 3 Results

### 3.1 Participant characteristics

Table 3 presents participants' demographic and disease characteristics. The mean age of the participants was almost fifty years: the youngest participant was 25 years of age, the eldest 70 years of age. The mean time since diagnosis was over three years, but there was much variation in time since diagnosis. Over three quarters of the participants lived with partner and children. Two thirds of the participants had undergone chemotherapy and more than half had undergone mastectomy, lymph node dissection and radiation therapy. Most participants were cancer free at the time of the study.

The mean number of searches participants performed was 2.02 (SD=1.86). The number of searches per participant ranged from 1 to 11 searches. Of the 122 participants 75 participants performed one search, 22 participants two searches and 25 participants performed more than two searches.

*Table 3* Participants' demographic and disease characteristics (n=122).

| Characteristic | | (mean (SD); min-max) |
|---|---|---|
| **Age at study in years** | | 48.5 (9.0); 25-70 |
| **Age at diagnosis in years** [a] | | 45.1 (9.1); 24-68 |
| **Time since diagnosis in months** [a] | | 39.1 (41.8); 0-229 |
| Characteristic | Category | n (%) |
| **Family situation** | With partner | 95 (78%) |
| | With children | 95 (78%) |
| **Treatment received** | Breast conserving surgery | 53 (43%) |
| | Mastectomy | 71 (58%) |
| | Lymph node dissection | 68 (56%) |
| | Radiation therapy | 68 (56%) |
| | Chemotherapy | 80 (66%) |
| | Hormonal therapy | 57 (47%) |
| | Immunotherapy (herceptin) | 12 (10%) |
| | Breast reconstruction | 23 (19%) |
| **Phase in the course of disease** | Just before or in first treatment period | 17 (14%) |
| | Just after first treatment period | 12 (10%) |
| | Breast cancer for second time | 11 (9%) |
| | Metastases to other parts of the body | 15 (12%) |
| | Cancer free | 67 (55%) |

[a] Unknown n=2

### 3.2 Patients' information need from stories

Table 1 shows for the participants who used the story topics search facility (n=79) which topics they searched for in at least one of their searches. The two topics most participants searched for were from the domain 'Treatment': 'treatment side effects' (60%) and 'decision-making about treatments' (53%). The topic 'coping with breast cancer' from the domain 'Living with it' was searched for by almost half of the participants (46%) in their search session. Topics from the domain 'Health care system' were least often used by participants in their search session.

Table 2 shows for the participants who used the writer characteristics search facility (n=82) which writer characteristics they searched for in at least one of their searches. The

majority of participants (n=70; 85%) searched in their search session for one or more of the eight treatments. After 'treatment received' the writer characteristic 'age at diagnosis' was searched for in most of the search sessions (n=59; 72%). Each writer characteristic was searched for by at least two thirds of the participants in their search session.

Participants who searched for the topic 'treatment side effects' were more recently diagnosed than participants who did not search for this topic (mean time since diagnosis 26.7 versus 54.5 months; P=0.012). Participants' time since diagnosis was not associated with whether or not searching for the topic 'decision-making about treatments' (mean time since diagnosis 30.6 versus 45.8 months; P=0.330) and whether or not searching for the topic 'coping with breast cancer' (mean time since diagnosis 30.0 versus 46.6 months; P=0.092). Participants' age at study participation was not associated with whether or not searching for the topic 'body image and sexuality' (mean age at study 49.1 versus 48.1 years; P=0.553), nor was it associated with whether or not searching for the writer characteristics 'breast conserving therapy' (mean age at study 45.4 versus 47.9; P=0.519) and 'metastasised cancer' (mean age at study 50.4 versus 46.6; P=0.168).

### 3.3 Social comparison at the level of writer characteristics

Table 4 shows for the searches in which a particular writer characteristic was searched for how often the category that was searched for corresponded with the category of the participant. For almost all writer characteristics was found that in the majority of the searches the participant's own category was searched for.

In 100% of the searches for 'breast conserving therapy' the participant herself had undergone breast conserving therapy. Also the other treatments scored high in searching for the own category: the percentages ranged from 71-96% (table 4). An exception was 'breast reconstruction': in 34% of the searches in which breast reconstruction was searched for the participant herself had undergone breast reconstruction.

Furthermore, in the majority of searches the own children status (97%), the own partner status (96%) and the own age at diagnosis (79%) was searched for. In a smaller percentage of searches the own phase in the course of disease (62%) and the own time since diagnosis (65%; 64 of 99 searches) was searched for. Of the 35 searches in which the own time since diagnosis was not searched for, 20 searches were for writers with a shorter time since diagnosis and 15 searches for writers with a longer time since diagnosis. In 22 of the 35 searches a category of 'time since diagnosis' that was adjacent to the own category was searched for.

*Table 4* Number (%) of searches for writer characteristics that corresponded with participants' own category.

| Writer characteristic | | Number of searches (n) | Searches that correspond with own category of participant (n, %) |
|---|---|---|---|
| **Age at diagnosis** | | 108 | 85 (79%) |
| **Time since diagnosis** | | 99 | 64 (65%) |
| **Children** | | 95 | 92 (97%) |
| **Partner** | | 96 | 92 (96%) |
| **Treatment received** | Breast conserving therapy | 42 | 42 (100%) |
| | Mastectomy | 77 | 74 (96%) |
| | Radiation therapy | 74 | 63 (85%) |
| | Chemotherapy | 73 | 65 (89%) |
| | Hormonal therapy | 58 | 50 (86%) |
| | Immunotherapy (herceptin) | 21 | 15 (71%) |
| | Breast reconstruction | 38 | 13 (34%) |
| | Lymph node dissection | 53 | 46 (87%) |
| **Phase in the course of disease** | | 96 | 59 (62%) |

### 3.4 Specificity of searches

A total of 161 searches was performed in which one or more topics were searched for: 92 searches by the 40 participants in the story topics search facility group and 69 searches by 36 participants in the combination search facility group (three of the 39 participants in the latter group did not search for topics, only for writer characteristics). Per search a mean number of 4.22 topics was searched (SD=4.84; range 1-34). Figure 2 shows the distribution.

A total of 134 searches was performed in which one or more writer characteristics were searched for: 78 searches by 43 participants in the writer characteristics search facility group and 56 searches by 29 participants in the combination search facility group (ten of the 39 participants in the combination search facility group did not search for writer characteristics, only for topics). Per search a mean number of 6.94 writer characteristics was searched (SD=2.94; range 1-12). Figure 3 shows the distribution.

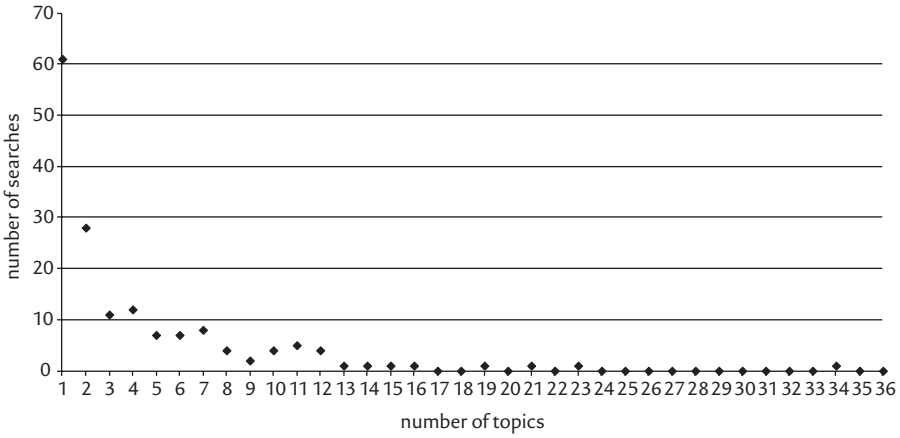


*Figure 2* The number of topics that was searched for in searches with topics (n=161). A maximum number of 36 topics could be searched for (9 main category topics without subcategories + 27 subcategory topics).

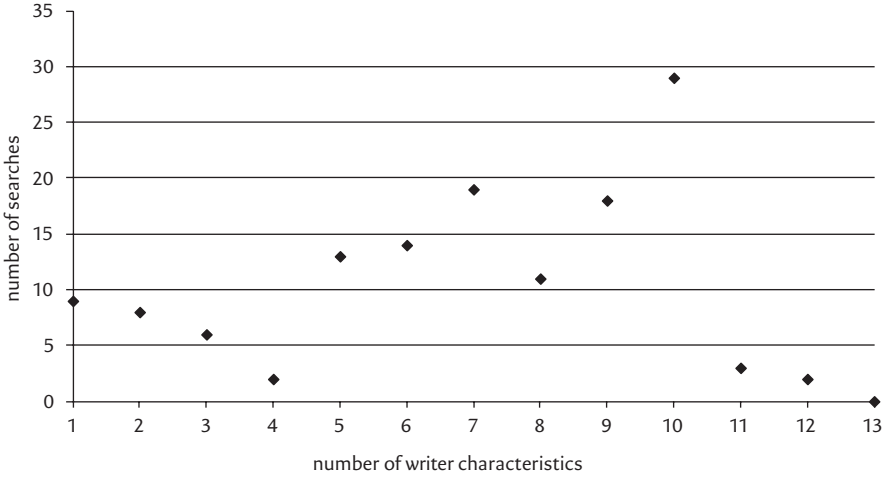


*Figure 3* The number of writer characteristics that was searched for in searches with writer characteristics (n=134). A maximum number of 13 writer characteristics could be searched for (8 tick boxes (treatments) + 5 drop-down menus).

## 4 Discussion

Stories of other patients can provide breast cancer patients with support and information. In this study we examined what kind of stories breast cancer patients searched for when they used a search facility for story topics and/or writer characteristics.

A clear result is that participants who could use the writer characteristics search facility made full use of this search facility. Each writer characteristic was searched for by at least two thirds of the participants in their search session. Participants searched predominantly for writers with similar characteristics as they themselves have. The result that the majority of participants searched for writers who had undergone similar treatments as they themselves had supports the finding of Rozmovits & Ziebland [3] that patients appreciate it to have access to stories of others who had opted for similar treatment as they had opted. The finding from our earlier interviews [7] that patients want to search for writers who received the diagnosis longer ago than they did and therefore can serve as encouraging examples, was not supported by the results: only in a minority of searches writers with a longer time since diagnosis were searched for.

For 'breast reconstruction' we found that only in a minority of searches the own category was searched for: stories of writers who had undergone a breast reconstruction were relatively often searched for by participants who themselves did not have had a breast reconstruction. An explanation for this finding is that these participants may consider undergoing a breast reconstruction and want to read others' experiences with it. In this context it is important to notice that undergoing a breast reconstruction differs from undergoing, for example, a mastectomy. A patient can take time to decide in advance whether or not she wants to undergo a breast reconstruction, whereas in undergoing a mastectomy in most cases the patient has no choice: it happens to her and she has to cope with it.

A striking result for specificity of searches was that the number of writer characteristics that was combined in searches was higher than the number of topics that was combined. Participants searched on average for 7 writer characteristics per search (of the maximum number of 13 writer characteristics). This indicates that patients are looking for stories of writers with a clearly defined profile. It seemed less important for participants that multiple topics were simultaneously present in a story: in the majority of the searches with topics only one or two topics were searched for per search (of the maximum number of 36 topics). The type of search facility might be an explanation for the result: mainly drop down menus for writer characteristics and tick boxes for topics. Participants may have thought that they had to choose a category from each drop down menu. Another explanation for the relatively low number of topics per search might be that there is some kind of natural limit to the number of items participants check when they can choose from a lot of items.

Many participants who had the disposal of the story topics search facility searched in their session for the topics 'treatment side effects' and 'coping with breast cancer'. These two topics are broadly consistent with the top three topics resulting from our interviews with breast cancer patients about favourite topics in stories of others: coping with emotions, impact on daily life and physical discomforts [7]. Furthermore, we found that participants who searched for the topic 'treatment side effects' were significantly more recently diagnosed than participants who did not search for this topic. This result is in line with the findings of earlier studies on general information need in breast cancer

patients [10-12]. However, we did not find any other associations between participants' time since diagnosis and searching for certain topics and between participants' age at study participation and searching for certain topics and writer characteristics. Yet, these associations may have been expected given the results from earlier studies on general information need [8-12]. An explanation for the result that these associations were not found in the present study on information from patient stories could be that patients prefer to receive information about certain topics from medical specialists and not from other patients. It may also be that other background variables that were not considered in the present study play a role.

### 4.1 Limitations

The present study was an analysis of the log data of a previous conducted experiment [16]. As a result, we were dependent on the research design of this earlier experiment.

In order to examine specificity of searches, searches from participants in the combination group were taken together with searches from participants in the story topics search group (to calculate number of topics per search) or with searches from participants in the writer characteristics search group (to calculate number of writer characteristics per search). Yet, in the combination group the number of topics searched for may be influenced by the fact that one could also search for writer characteristics, and vice versa.

The fact that eight main category topics were divided in subcategory topics may have led to some interpretation difficulties. Firstly, by checking the tick box of a main category topic with subcategory topics, all the subcategory topics were automatically included in the search and their number counted in the specificity of searches (while the participant checked only one tick box). Secondly, to determine information need participants who searched for at least one subcategory topic were counted in the main category topic. The latter was also true for the overarching category 'treatment received', with the difference that this overarching category could not be checked directly (no separate tick box).

Participants' reasons for participating in our study are unknown. In our call for participation we asked patients with interest in stories of others to participate in our study with the aim to improve the ways to search for stories on the Internet. Some patients may have participated not so much for their own information need, but rather to help us in testing the search facilities.

### 4.2 Conclusions

This study has shown with respect to information need from stories that there is no major discrepancy between what breast cancer patients want to read in stories of others and what they actually search for in stories when they have the disposal of a topics and/or a writer characteristics search facility. Patients use relatively more writer characteristics to search for stories, than topics. Herein they prefer to search for stories of patients with similar characteristics as they themselves have, probably because of their informational value. Given the variety of patients, stories provided on the Internet should reflect this diversity.

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## Conflicts of interest

The authors report no conflicts of interest.

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