Author: Overberg, Regina Ingrid
Title: Breast cancer stories on the internet : improving search facilities to help patients find stories of similar others
Issue Date: 2013-09-10

CHAPTER 2

Illness stories on the Internet: Features of websites disclosing breast cancer patients' illness stories in the Dutch language

Regina Overberg[1]
Pieter Toussaint[1]
Bertie Zwetsloot-Schonk[1]

[1] Clinical Informatics Group, Leiden University Medical Center, Leiden

Patient Education and Counseling 2006; 61: 435-442

Abstract

Objective To examine the way in which breast cancer patients' illness stories in the Dutch language are disclosed on the Internet.
Methods Websites containing Dutch illness stories written by breast cancer patients were selected using a search engine on the Internet. A checklist was developed based on a theoretical framework for analysing communication processes in order to examine the selected websites.
Results None of the websites implements search facilities based on either the content of an illness story, or the personal features of the author. A minority of the websites offers information about the illness stories, such as author's genuineness and editor's review.
Conclusion The Internet's opportunities are not fully utilized with respect to disclosing breast cancer patients' illness stories.
Practice implications In order to support a patient in finding appropriate illness stories in the diverse set of available stories, we are in the process of developing an application that combines symbolic and statistical natural language analysis techniques to facilitate content-based retrieval.

Keywords: Internet; Websites; Breast cancer; Illness stories

1 Introduction

Breast cancer incidence in The Netherlands is among the highest in the world. On the basis of the present incidence rates, about one in every eight to nine women in The Netherlands will develop breast cancer. Although, in general, cancer is most common among the elderly, almost half of the breast cancer diagnosis in the Netherlands in 2000 occurred in women between 20 and 59 years of age [1].

A breast cancer diagnosis and subsequent treatment commonly cause many psychological problems in patients such as distress, anxiety, depression, and fear [2,3]. Patients also experience social isolation [2], a disturbed body image [3], and difficulties with sexual functioning [2]. In some patients, these problems persist even years after diagnosis [2].

One of the ways to cope with these psychological consequences is to exchange illness experiences with fellow patients [4]. During illness experiences exchange patients share experiences that are related to their disease. In this way, they can exchange information, find recognition in each other's experiences, learn from each other how to accept and adapt to the disease, and express their feelings [5].

Illness experiences can be exchanged in different ways. One way is to take part in face-to-face conversations in waiting rooms or during support group meetings. Another possibility is reading books or magazines that compile illness experiences, or watch TV-programmes in which fellow patients tell their story. The Internet is a new but rapidly growing channel for exchanging illness experiences. There are forums, chat rooms and websites that enable patients to exchange illness experiences.

Several studies have examined the effects of face-to-face and web-based illness experience exchange between breast cancer patients. Face-to-face exchange of illness experiences increases breast cancer patients' quality of life [6] and self-esteem [4], and decreases breast cancer patients' anxiety, depression scores [7], and negative feelings [4]. Though in one study on face-to-face social support, some indications of adverse effects on vitality and physical and social functioning were found [8].

Web-based exchange of illness experiences reduced breast cancer patients' scores on depression [9,10], perceived stress, cancer related trauma measures [9], and reactions to pain [10], and is found helpful by breast cancer patients [11]. Yet, also an increase in emotional suppression was found by Lieberman et al. [10]. Klemm et al. [12] conclude in their review that online cancer support groups help people to cope more effectively with their disease. Eysenbach et al. [13] found no robust evidence for positive effects of online peer-to-peer interactions. However, in their opinion the absence of evidence does not mean that virtual communities have no effect [13]. In conclusion, the positive effects of exchanging illness experiences between patients exceed the negative effects.

The Internet is an interesting channel for exchanging illness experiences. In 2004, 65% of the 7 million Dutch households owned a personal computer with Internet access. A good quarter of the 85% information seekers searched for health topics [14]. Among them there will be many patients searching for illness experience exchange on the Internet.

The Internet differs in several ways from the more traditional face-to-face meetings for exchanging illness experiences between patients. An Internet user can stay anonymous, whereas a participant of a face-to-face meeting has to divulge his identity. In addition, a patient who joins a face-to-face meeting has to be present on a specific time at a specific place, while the Internet can be accessed by the patient on a time and at a place he prefers. Also, the diverse possibilities on the Internet for exchanging illness experiences differ from each other in certain ways. A chat session on the Internet is characterised by same time and different place, while forums and websites are characterised by different time and different place.

In this paper, we will focus on the current practice of using the Internet as a communication medium for exchanging illness experiences. Our purpose is to examine the way in which breast cancer patients' illness stories in the Dutch language are disclosed on websites on the Internet. To our knowledge, this was never done before. We focus on websites containing illness stories for two reasons. Firstly, in contrast to forums and chat rooms, websites are easily accessible without needing a password or login name. This implies that also patients who have little knowledge about and experience with using the Internet are able to visit websites. Secondly, fellow patients' illness stories published on websites are more appropriate for restoring the own life story than short fragments of illness experiences are, which are common in forums and chat rooms. The thought behind this is as follows. Every person has an own life story in which he gives meaning to his life, forms his identity, and accounts for his choices. A breast cancer diagnosis disturbs a person's identity and sense of continuity. Someone else's life story who went through the same situation will help to restore the own life story.

2 Methods

2.1 Selection of websites

Before selecting websites three inclusion criteria were formulated: the websites have (1) to be accessible for every internet user, i.e. without password, (2) to be in the Dutch language, (3) to contain at least two illness stories of two different breast cancer patients. Websites were searched for in three ways: (a) by asking breast cancer patients and researchers whether they know any sites, (b) by using the search engine Google on the Internet, and (c) by searching in literature databases. Five websites that were identified by breast cancer patients and researchers met the inclusion criteria [15–19].

Three searches using the search engine Google were conducted (www.google.nl, accessed 30 March 2005) combining the Dutch word for breast cancer (*borstkanker*) with those for stories consisting of experiences (*ervaringsverhalen*; 355 hits), stories (*verhalen*; 6340 hits), or story (*verhaal*; 15,100 hits). The first 100 sites selected by each of the three searches were checked for meeting the inclusion criteria. Links on the websites were not examined, because it was argued that links appear as a hit automatically. The three searches produced, respectively, four [20–23], three [24–26], and one [27] additional website.

In March 2005, literature searches were conducted in the databases Medline, Embase, CINAHL, PsycINFO, PubMed, and Web of Science. Three search concepts were combined: subject (breast cancer patients' illness stories), medium (ICT), and language (Dutch). Also various synonyms for each of these three search concepts were conducted. No websites that fit the inclusion criteria were found using literature databases. Thus, in total 13 relevant websites were found.

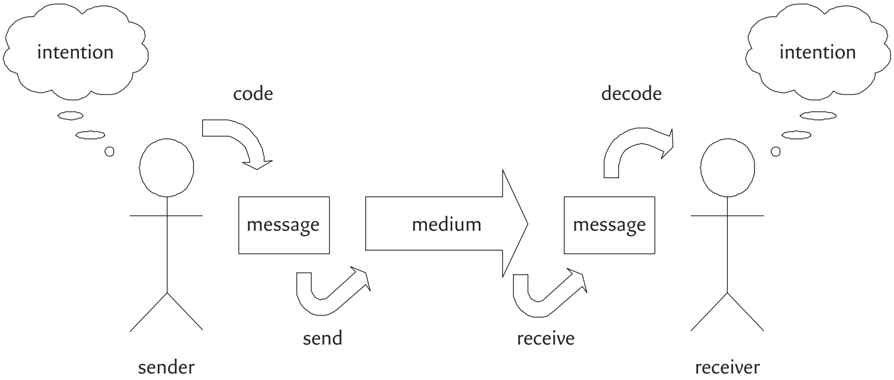

Figure 1 Message exchange between a sender and a receiver

2.2 Evaluation of websites

There are numerous perspectives from which one can look at websites containing illness stories, ranging from technical to functional. We take as our viewpoint that such websites are examples of Computer Mediated Communication applications. Their use is a type of communication practice, and can be best described using features that can also be applied to other communication practices. Communication practices can be described using the message-channel model as basis [28], in which a message is exchanged between a sender and a receiver through a particular medium, as shown in Figure 1. The elements of this model – namely participants, message, medium, and overall situation – are characterised by several features. These features, which are based on the framework presented by Te'eni [29], are listed and explained in Table 1. As depicted in the right column of Table 1, the features' definitions were translated into practice in order to be able to evaluate websites that disclose illness stories in a structural manner. The first author evaluated the selected websites within four weeks of the original search. One site [25] was excluded, because the illness stories were not available at the time this site was evaluated.

3 Results

3.1 Overall features of websites

None of the evaluated websites mentions explicitly the reason why breast cancer patients' illness stories are published on the website. In addition, the time/place context of all the evaluated websites is different time/different place.

Table 1 Features and their definitions for analysing the exchange of illness experiences between patients, and translations of definitions into practice in order to examine websites that disclose illness stories.

Feature		Definition	Translation into website practices
Overall situation	**Goal**	The reason why patients communicate, what they want to achieve with exchanging illness experiences	Which goal is mentioned on the website for publishing the illness stories: to give information, to give recognition, or to express feelings?
	Time/place context	The time and the place at which patients exchange illness experiences	What is the time/place context: same time/same place, same time/different place, different time/same place, or different time/different place?
Participants	**Number**	The number of patients that join the exchange of illness experiences	How many illness stories are available at the web site?
	Anonymity	The state in which the receiving patient can take part in the communication without being identified by the sending patient	Can the visitor of the site (the receiving patient) stay anonymous?
	Authenticity	The degree in which the receiving patient is assured that the sending patient is a genuine patient	Is there a guarantee that the illness stories are from genuine patients?
	Size of common ground	The degree in which personal features (e.g. age, marital status) and disease features (e.g. time since diagnosis, treatment underwent) of a sending patient match with those features of a receiving patient	Can the visitor of the site (the receiving patient) search for illness stories using personal features of the author (the sending patient)?

Table 1 (Continued)

Feature		Definition	Translation into website practices
Message	**Structure**	The degree in which it is beforehand clear to the receiving patient of which parts the illness experience of the sending patient is constructed	Are the illness stories on the site structured by means of a short summary or headings in the text, or are they not structured?
	Accuracy	The degree in which medical facts and spelling in the illness experiences are correct	Does an editorial board review the site including the illness stories?
	Content	The degree in which sending patients' illness experiences fit with the information need of a receiving patient	Can the visitor of the site (the receiving patient) search for stories using content keywords?
Medium	**Capacity**	The degree in which the receiving patient receives non-verbal, additional aspects of a sending patient's illness experience (e.g. sending patient's facial expression, voice/intonation, drawings)	Which modes of information (text, images, video) are used to express the illness stories?
	Evanescence	The degree in which a receiving patient can save or store the sending patient's illness experience	For how long do the illness stories remain available at the site?
	Interactivity	The degree in which a receiving patient can react to a sending patient's illness experiences or can send his/her own illness experience	Can a visitor react on illness stories (react yes/no), or submit his/her own illness story (send yes/no)?

Table 2 Features of websites (n=12) that disclose breast cancer patients' illness stories in the Dutch language.

Feature		Value	Websites % (n)
Participants	**Number**	2-5 illness stories	42 (5)
		6-15 illness stories	25 (3)
		>15 illness stories	33 (4)
	Anonymity	Reading the illness stories without being identified	100 (12)
	Authenticity[a b]	Guarantee that illness stories' authors are genuine patients	8 (1)
	Size of common ground[b]	Search facility for personal features of illness stories' authors	0 (0)
		Brief, separate summary of authors' personal features	8 (1)
Message	**Structure**[ab]	Structure by means of a brief summary of or headings in illness stories	58 (7)
	Accuracy[b]	Review by editor	42 (5)
	Content	Search facility with content keywords	0 (0)
		General search facility with text words	83 (10)
		No search facility, only 'Find (on This Page)' delivered by Internet browser	17 (2)
Medium	**Capacity**[a]	Only text	83 (10)
		Text supported by photos	8 (1)
		Text supported by video fragments with patient's voice	8 (1)
	Evanescence[ab]	Publication dates of illness stories mentioned	50 (6)
	Interactivity	Reacting and sending possible	17 (2)
		Reacting possible	42 (5)
		Sending possible	17 (2)
		No reacting nor sending possible	25 (3)

[a] Feature x is attached to a website if at least half of the illness stories on that website do have feature x. For example, if three out of six illness stories on a website are structured the feature structure is attached to this website.

[b] Does not count till 100 percent (n=12), because only one or a few values of the feature are inserted in this table.

3.2 Participants features of websites

Participants features of the websites are presented in the first part of Table 2. Forty-two percent of the websites contain 5 or fewer illness stories. A quarter of the websites comprise of 6–15 illness stories, while 33% comprise of more than 15 illness stories. The highest number of illness stories on a website is 49 [16], and the highest but one is 40 [21]. Not included in this calculation are: (a) illness stories of cancer patients with a cancer type other than breast cancer, (b) illness stories of male breast cancer patients, (c) stories of persons who are not yet diagnosed with breast cancer, but who have a mutation in the BRCA-1 or BRCA-2 gene, (d) illness stories that are not physically presented on a website, but to which is only referred, and (e) stories that do not contain illness experiences. An example of the latter is a story about fashion for women with only one breast caused by mastectomy [15]. If the same illness story is presented on several websites, this illness story was counted multiple times. One website [21] presents 11 illness stories from another site [15], and two illness stories from yet another website [17]. These thirteen illness stories are counted twice.

A patient who visits the websites in order to read fellow patients' illness stories can stay anonymous in all cases.

None of the evaluated websites guarantee that the authors of the illness stories are genuine breast cancer patients, except one [19]. On this website, the patients/authors of three out of the six illness stories on the site are followed with a camera. Conversations between the patients/authors and specialists are filmed, which points out that the patients are genuine breast cancer patients. On the other 11 websites, no guarantees are given about the genuineness of the patients/authors. However, one of the sites [22] warns visitors that some persons present themselves as a cancer patient without being one.

A search facility based on personal features of authors of illness stories is offered by none of the evaluated websites. In practice, this means that a visitor cannot search for illness stories written by, for example, breast cancer patients between 20 and 30 years of age, or by single breast cancer patients, or by breast cancer patients who underwent radiotherapy but no chemotherapy. In order to find out which illness stories are written by breast cancer patients with a certain personal feature, the illness stories must be read. However, in quite a lot of illness stories personal features of an author, such as age or time since diagnosis, are not mentioned at all. On one website [16], personal features of authors are summarised briefly, separately from the illness stories. Yet, in a few cases the personal features in the brief summary do not fit with the personal features in the illness story. Finally, on a quarter of the websites (n = 3) it is not immediately clear for the visitor which illness stories are from breast cancer patients and which illness stories are from patients with another type of cancer.

3.3 Message features of websites

In the middle part of Table 2 message features of websites are presented. On the majority of the websites (58%) at least half of the illness stories do have structure by means of a short summary beforehand or by means of headings in the text. On the remaining websites (42%), a minority of the illness stories or none of the illness stories do have structure. Headings of the format day-month-year are not seen as structure, because these headings give no information about the content of the text that follows such a heading. If an illness story is not structured it is more difficult for a reader to determine quickly what the story is about. In general, readers are not warned in case an author of an illness story dies.

A majority of the websites (58%) is not reviewed by an editor or nothing is mentioned about editing. A minority of the websites (42%) is reviewed by an editor. Though, it remains unclear whether the illness stories on websites that are reviewed by an editor are checked on correctness of medical facts in the stories.

None of the websites offers a search facility based on content keywords, 10 websites (83%) offer a general search facility with text words, and 2 websites (17%) offer no search facility, only the 'Find (on This Page)' facility delivered by the Internet browser. The general search facility with text words searches the whole website, and the 'Find (on This Page)' facility searches per page. Thus, neither the general search facility with text words nor the 'Find (on This Page)' facility searches exclusively in the illness stories presented on the site. Moreover, both the general search facility with text words as well as the 'Find (on This Page)' facility do not search for synonyms. A search using the Dutch word for radiotherapy that patients often use (*bestraling*) retrieves texts in which the exact word '*bestraling*' occurs; texts in which the Dutch word for radiotherapy that specialists often use '*radiotherapie*' occurs are not retrieved. However, the meanings of '*bestraling*' and '*radiotherapie*' are exactly similar. With a search facility based on content keywords a search for '*radiotherapie*' will also retrieve texts about '*bestraling*'.

3.4 Medium features of websites

The last part of Table 2 shows medium features of evaluated websites. On the majority of the websites (83%), most illness stories are presented in the format of only text. On one website [23] the texts of 10 out of the 12 presented breast cancer patients' illness stories are supported by photos of the patients. On another website [19], three out of six illness stories are presented in the format of video fragments.

On half of the websites information is given about the dates on which the illness stories were published on the websites. The publication dates are ranging from quite long ago till very recently. None of the websites gives information about the period of time the illness stories will be available in future.

A minority of the websites (17%) offers a special button for reacting on illness stories as well as a special button for sending an own story. Forty-two percent of the websites offers only a special button for reacting on illness stories, while 17% of the websites offers only a special button for sending an own story. A quarter of the websites offers neither a button for reacting nor a button for sending. In addition, almost all websites mention an e-mail address to contact the website's owner, but this is in general not meant for reacting on or sending illness stories.

4 Discussion and conclusion

4.1 Discussion

The purpose of this paper was to examine the way in which breast cancer patients' illness stories are disclosed on the Internet. The most striking finding is that none of the websites offers the possibility to search for or within illness stories using either personal features of authors or content keywords. Due to the lack of search facilities, patients have to read the illness stories to find out whether they fit with their own situation and interests. In our opinion, search facilities must be offered to patients looking for illness stories on the Internet, because in that case patients will find stories that fit their needs quicker and easier. A majority of websites offers some kind of structure in the illness stories. This could help patients to get an idea of the content of the illness stories quickly. However, even then a patient has to read all summaries and headings. The medium ICT can be implemented in such a way that searching illness stories is possible, in contrast to, for example, books. It's a pity that the possibilities of Internet are not used at this point.

The results show that the highest number of illness stories on one website is 49. This is quite a lot. Yet, we assume that approximately 10% is relevant for a patient. In addition, we think that the more stories a patient reads/hears, the better she will be able to reconstruct her own life story that was disrupted by a breast cancer diagnosis. ICT has no restrictions at this point, it can contain hundreds or thousands illness stories, in contrast to, for example, a face-to-face meeting at which a limited number of persons can be present. The search facilities become more important if more stories are available to a visitor. If there is no accurate search facility and when a huge number of illness stories is available, a visitor can be overwhelmed. In the case of offering a huge set of illness stories, attention must be paid to the representativeness: stories of patients with diverge personal features (of all ages, marital status, with and without children, long and short time since diagnosis, all kinds of treatment underwent) and with diverge viewpoints (positive, negative, neutral). This diversity will increase the chance that a visitor finds an illness story in which he will recognise himself completely.

Another important aspect which only few websites offer is information about illness stories from which a visitor can distract whether illness stories are reliable or not. Firstly, we saw that only one website guaranteed the genuineness of the authors. Ethically seen it is not justified to offer patients illness stories that are not written by genuine fellow patients. This is not an issue at face-to-face meetings, because it is difficult to fake being a patient when you are not anonymous. However, it is an important issue for ICT. Secondly, only half of the websites mention how old the illness stories are, while this is important information in view of medical developments. For example, a couple of years ago removal of lymph glands was common, nowadays it is first tested if it is necessary to remove them. A patient who reads a story of a couple of years ago in the supposition that it is a recent story, can get very confused. Finally, only a minority of websites is reviewed by an editor whereby it remains unclear whether medical facts in the illness stories are checked. In our opinion, it is very important that the medical facts in illness stories are correct, because otherwise readers can become confused or frightened.

The implementation of the features capacity and interactivity is diverse. Some websites offer a high capacity, others do not. And some websites offer a high interactivity, others do not. We think that patients' preferences with respect to these features differ. Maybe, the best solution is to offer a high capacity and a high interactivity – this is possible with ICT after all – and that patients can switch it off when they do not want to use it.

A website that offers more possibilities than the Dutch sites is the English DIPEx website, Database of Individual Patients' Experience [30]. With respect to breast cancer, 40-50 people are interviewed to find out their individual experiences about the illness. The illness experiences are categorised on age of the author, and on subject. Thus, a visitor can find relatively quickly illness experiences in which he recognises himself and in which subjects appear that interest him. Moreover, a visitor can choose to read the illness experiences (texts are presented), to hear them (audio fragments are presented), or to see them (video fragments are presented) [31]. Access to practical and experiential information from other patients was highly valued by patients who visited the DIPEx website. A few features were specifically valued by patients: total privacy, no emotional demand of attendance, 24 h and 7 days a week availability, the possibility to click off distressing or irrelevant information, and no necessity to engage with patients in return [32]. Thus, this study confirms that there is a need for websites that disclose illness stories.

The present study of websites that disclose breast cancer patients' illness stories had a few limitations. Only websites in the Dutch language were examined. Dutch patients also have access to English sites, so why did we restrict to the Dutch language? We argued that it is the best to read/hear illness experiences in your native language, because you can make nuances in your native language and in general it will be more close to you. Furthermore, not every one understands English very well. Misunderstanding can lead to fear. A second limitation is that this study gives only information about the situation on the Internet in March/April 2005. Changes over time are not considered. Existing websites may have been closed down, and new websites may have been started. However, we think this is inherent to the Internet, and unavoidable when studying it. The last limitation is that only one researcher evaluated the websites. Though, factual features instead of interpretable features were checked, so we think that evaluating by one researcher only gives accurate and reliable results.

4.2 Conclusion

In conclusion, quite a lot breast cancer patients' illness stories in the Dutch language are presented on the Internet. Though, websites that disclose illness stories do not offer accurate search facilities. In addition, the reliability of the illness stories is in many cases unclear. Finally, the capacity and interactivity of the Internet are limited with respect to illness stories. Thus, the opportunities of the Internet are not yet fully utilized with respect to disclosing breast cancer patients' illness stories in the Dutch language.

4.3 Practice implications

It is a pity that not all possibilities of the Internet are used with respect to disclosing illness stories. Patients will benefit if illness stories are better disclosed. That is why we are currently in a process of developing a prototype application for storage and retrieval of illness stories in an Internet environment that enables a user to retrieve illness stories:

- using personal features of the author (size of common ground);
- using content keywords (content);
- knowing that the stories are from genuine patients (authenticity);
- knowing that the content has been checked (accuracy).

With respect to the first two requirements our idea is as follows. Patients who use our future application will be able to enter several personal features, such as their age, marital status, time since diagnosis, and treatment underwent. Moreover, they will be able to enter a search query in natural language, for example: ‘‘How to cope with being bald after chemotherapy?’’ Illness stories which fit the personal features and the search query will be retrieved from the database and presented to the patient. In order to make retrieval of illness stories based on personal features and search queries in natural language possible, we propose a design that combines symbolic and statistical semantic analysis techniques of illness stories [33].

Acknowledgements

This paper is part of the Narrator project, funded by The Netherlands Organisation for Scientific Research (NWO), addressing the problem of storage and accurate retrieval of illness narratives using Natural Language Processing and Dialogue Management Techniques. The umbrella programme ToKeN2000 (Access to knowledge and its enhancement Netherlands 2000) is an interdisciplinary research programme that focuses on fundamental problems affecting the interaction between human beings on the one hand, and knowledge and information systems on the other hand. ToKeN2000 is concentrated around three fields of application, namely (1) education and culture, (2) law enforcement and the judicial system, and (3) health care.

References

1. Incidence of cancer in the Netherlands 1999/2000. Visser O, Siesling S, Van Dijk JAAM, editors. Eleventh report of the Netherlands cancer registry. Utrecht: Vereniging van Integrale Kankercentra, 2003.
2. Spiegel D. Psychosocial aspects of breast cancer treatment. Semin Oncol 1997;24(S1):36-47.
3. Payne DK, Sullivan MD, Massie MJ. Women's psychological reactions to breast cancer. Semin Oncol 1996;23:89–97.
4. Van Den Borne HW, Pruyn JFA, Van den Heuvel WJA. Effects of contacts between cancer patients on their psychosocial problems. Patient Educ Couns 1987;9:33–51.
5. Isaksen AS, Gjengedal E. The significance of fellow patients for the patient with cancer: what can nurses do? Cancer Nurs 2000;23: 382–91.
6. Ashbury FD, Cameron C, Mercer SL, Fitch M, Nielsen E. One-on-one peer support and quality of life for breast cancer patients. Patient Educ Couns 1998;35:89–100.
7. Montazeri A, Jarvandi S, Haghighat S, Vahdani M, Sajadian A, Ebrahimi M, et al. Anxiety and depression in breast cancer patients before and after participation in a cancer support group. Patient Educ Couns 2001;45:195–8.
8. Helgeson VS, Cohen S, Schulz R, Yasko J. Education and peer discussion group interventions and adjustment to breast cancer. Arch Gen Psychiatry 1999;56:340–7.
9. Winzelberg AJ, Classen C, Alpers GW, Roberts H, Koopman C, Adams RE, et al. Evaluation of an internet support group for women with primary breast cancer. Cancer 2003;97:1164–73.
10. Lieberman MA, Golant M, Giese-Davis J, Winzlenberg A, Benjamin H, Humphreys K, et al. Electronic support groups for breast carcinoma: a clinical trial of effectiveness. Cancer 2003;97:920–5.
11. Weinberg N, Schmale J, Uken J, Wessel K. Online help: cancer patients participate in a computer-mediated support group. Health Soc Work 1996;21:24–9.
12. Klemm P, Bunnell D, Cullen M, Soneji R, Gibbons P, Holecek A. Online cancer support groups: a review of the research literature. Comput Inform Nurs 2003;21:136–42.
13. Eysenbach G, Powell J, Englesakis M, Rizo C, Stern A. Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. BMJ 2004; 328:1166–70.
14. Database of Statistics Netherlands (Statline – Centraal Bureau voor de Statistiek). Available at: <http://statline.cbs.nl>. Accessed 9 May 2005.
15. Website of the Dutch Patient Organization for Breast Cancer (Website van BorstkankerVereniging Nederland). <http://www.borstkankervereniging.nl>. Accessed 30 March 2005.
16. Website of De Amazones, young women with breast cancer (Website van De Amazones, jonge vrouwen met borstkanker). <http://www.deamazones.nl>. Accessed 30 March 2005.
17. Website of the Dutch Federation of Cancer Patient Organizations (Website van de Nederlandse Federatie van Kankerpatie¨ntorganisaties). <http://www.kankerpatient.nl>. Accessed 30 March 2005.
18. The breast cancer information pages (De borstkanker informatiepagina's). <http://www.borstkanker.net>. Accessed 30 March 2005.
19. Website of the Dutch Cancer Society: information about cancer and combatting cancer (Website van KWF Kankerbestrijding: informatie over kanker en kankerbestrijding). <http://www.kankerbestrijding.nl>. Accessed 30 March 2005.

20. Website of the Foundation Health-of present interest (Website van de Stichting Gezondheid-actueel). <http://www.kanker-actueel.nl>. Accessed 30 March 2005.
21. Breast cancer information pages: contact with fellow patients, chemotherapy, radiotherapy, breast reconstruction, hormone therapy, immune system (Borstkanker informatiepagina's: lotgenotencontact, chemotherapie, bestraling, borstreconstructie, hormoontherapie, immuunsysteem). <http://www.levenmetborstkanker.nl>. Accessed 30 March 2005.
22. Website of KANKER SDK: starting point for cancer patients and their family (Website van KANKER SDK: startpunt voor kankerpatiënten en hun naasten). <http://www.diagnose-kanker.nl>. Accessed 30 March 2005.
23. Website of the Flemish League against Cancer (Website van de Vlaamse Liga tegen Kanker). <http://www.tegenkanker.be>. Accessed 30 March 2005.
24. Breast cancer meeting point: a meeting point for people who feel involved in breast cancer (BorstkankerTrefpunt: een ontmoetingsplek voor mensen die zich betrokken voelen bij borstkanker). <http://www.borstkankertrefpunt.web-log.nl>. Accessed 30 March 2005.
25. Website of a Dutch health care insurer: Achmea Health (Website van een Nederlandse zorgverzekeraar: Achmea Health). <http://www.achmeahealth.nl>. Accessed 30 March 2005.
26. Bosom friends: a website about breast cancer and friendship (Boezemvriendinnen: een website over borstkanker en vriendschap). <http://www.boezemvriendinnen.nl>. Accessed 30 March 2005.
27. Website of the Working party Heredity of the Dutch Patient Organization for Breast Cancer (Website van deWerkgroep Erfelijkheid van de BorstkankerVereniging Nederland). <http://www.brca.nl>. Accessed 30 March 2005.
28. Cragan JF, Shields DC. Understanding communication theory. In: The communicative forces for human action. Boston: Allyn and Bacon, 1998.
29. Te'eni D. Review: a Cognitive-affective model of organizational communication for designing IT. MIS Q 2001;25:1–62.
30. Herxheimer A, McPherson A, Miller R, Shepperd S, Yaphe J, Ziebland S. Database of patients' experiences (DIPEx): a multi-media approach to sharing experiences and information. Lancet 2000;355:1540–3.
31. DIPEx: Personal experiences of health and illness. <http://www.dipex.org>. Accessed 10 May 2005.
32. Rozmovits L, Ziebland S. What do patients with prostate or breast cancer want from an Internet site? A qualitative study of information needs. Patient Educ Couns 2004;53:57–64.
33. Wolf L, Hoenkamp E, Overberg R, Reckman H, Toussaint P. Design of the narrator system: processing, storing and retrieving medical narrative data. SDPS Transactions-ISoLA, in press.

ADDENDUM TO CHAPTER 2

1 Introduction

The Internet contains many stories written by breast cancer patients that form an important source of support and information for other breast cancer patients. In 2006, we examined how breast cancer stories were presented and disclosed on the Internet [1]. Since the Internet is dynamic and subject to rapid developments, it is useful to repeat the 2006 study to gain insight into how breast cancer stories are now presented and disclosed (March 2013).
The aim of this addendum was twofold:

1. To provide an update to Chapter 2 that was published in 2006 [1], i.e. to examine how Dutch-language breast cancer stories are now presented and disclosed on the Internet (March 2013).
2. To describe differences and similarities between the presentation and disclosure of breast cancer stories on the Internet in 2006 and in 2013.

2 Methods

To provide an update and to make a comparison between 2006 and 2013, we used the same method as in 2006. This 2006 method is described briefly below.

2.1 Describing the websites

The presentation and disclosure of breast cancer stories on websites was described on the basis of a checklist that had been developed using a theoretical framework for analysing communication processes [2]. This framework distinguishes four elements of a communication process, each of which can be divided into different aspects:

1. overall situation: goal, time/place context
2. participants: number, anonymity, authenticity, extent of common ground
3. message: structure, accuracy, content
4. medium: capacity, evanescence, interactivity.

These aspects were translated into the practical context of websites with breast cancer stories. For each of the aspects, a definition was formulated (for details see Table 1 of Chapter 2).

2.2 Selection of websites

Breast cancer stories were defined as texts or videos which were not part of an interactive forum and which were written/narrated in the first person. Three inclusion criteria for websites were formulated: (1) the stories should be accessible to all web users, i.e. without password; (2) the stories should be written/narrated in the Dutch language; and (3) the websites should contain at least two stories by two different breast cancer patients.

The 12 websites that were described in 2006 were re-examined in 2013 to assess whether these websites still met the inclusion criteria and how the stories on the websites were presented and disclosed in 2013.

In addition, the three Google searches that had been performed in 2006 were repeated: 1) *borstkanker* AND *ervaringsverhalen* (20,800 hits), 2) *borstkanker* AND *verhalen* (131,000 hits), and 3) *borstkanker* AND *verhaal* (281,000 hits) (searches performed on 2 March 2013). The first 100 sites selected by each of the three searches were checked to assess whether they met the inclusion criteria. Links on the websites were not examined, because it was argued that links should automatically also appear as a hit. In comparison to 2006, the three searches produced seven, three and two additional websites, respectively.

3 Results

3.1 Update regarding websites described in 2006

Of the 12 websites with breast cancer stories described in 2006, seven no longer met the inclusion criteria. Three of these websites no longer seemed to exist: www.levenmetborstkanker.nl, www.borstkankertrefpunt.web-log.nl and www.boezemvriendinnen.nl. One website, www.borstkanker.net, contained only one story that had been written by the founder of the website, who had since passed away. The remaining three websites that failed to meet the inclusion criteria no longer presented patient stories. However, visitors to these websites were referred to other websites with patient stories. For example, the website www.nfk.nl (formerly kankerpatient.nl) referred to the website of the Dutch Patient Organisation for Breast Cancer and the websites www.diagnose-kanker.nl and www.tegenkanker.be referred visitors to four and twelve breast cancer patient blogs, respectively. The website www.tegenkanker.be also included all editions of its digital magazine published since 1999, with 26 articles about breast cancer in which patients often recounted their experiences.

Table 1 gives a description of the five remaining websites that still met the inclusion criteria in 2013. Because the website www.brca.nl is part of the website www.borstkanker.nl, these two websites have been considered together in Table 1.

Table 1 Update of the websites described in 2006 that still met the inclusion criteria in 2013.

Framework[a]		www.borstkanker.nl (including www.brca.nl)	www.de-amazones.nl	www.kankerbestrijding.nl (including YouTube-channel)	www.kanker-actueel.nl
Overall situation	Goal	Borstkankervereniging Nederland is a professional association for people with breast cancer, their social environment, and people/ families with hereditary breast cancer genes.	Website of Stichting Amazones, founded in 2005 by a group of active breast cancer and ex-breast cancer patients.	KWF Kankerbestrijding is engaged in scientific research, education, patient support and fundraising.	Website containing the latest information about regular and complementary, non-toxic treatments and resources for cancer disease.
Participants	Number	68 (25 'closed' stories, 33 blog stories and 10 stories by patients with hereditary cancer).	Approximately 790 stories / blogs.	4 women are followed in video diaries, 68 women submitted their own story to the website; 2 videos on the YouTube-channel contain breast cancer stories.	13 (text) + 7 (videos) of breast cancer patients; the website also contains experiences of patients with other cancers. Some patients who appear in a video story have also written a text story.
	Authenticity	Unknown. The 25+33 stories were spontaneously published, the patients with hereditary cancer (10 stories) were probably asked to write their story.	Unknown. After a person has created an account (whether someone is a real patient is not checked), he/she can publish his/her story/blog. Persons with an account are called Amazones.	It is likely that the videos follow real patients.	Unknown.
	Extent of common ground	No search facilities for writer characteristics. Sometimes a writer gives a short description of herself at the beginning of her story.	Amazones can be searched according to personal characteristics, medical condition or specific profile/ name.	No search facilities for writer characteristics, neither in the videos, nor in the stories.	No search facilities for writer characteristics.

Table 1 (Continued)

Framework[a]		www.borstkanker.nl (including www.brca.nl)	www.de-amazones.nl	www.kankerbestrijding.nl (including YouTube-channel)	www.kanker-actueel.nl
Message	Structure	Some stories contain headings; after opening blog stories, the topics covered are indicated.	Varies.	Varies.	Varies.
	Accuracy	The 33 blog stories are probably not edited. For the 25 'closed' stories, the site indicates that the stories are published after an editorial check.	Anyone can create an account and publish a story/blog; there is no editor.	The videos are directed. Patients can submit their text story using a web form, whereupon an editor decides whether the story will be published, possibly after shortening the story.	The own story can be published after consultation with an editor.
	Content	No search facility for story topics. The part of the website with blog stories has a full text search engine, which often gives no results.	No search facility for story topics. Amazones can be searched for according to personal characteristics, medical condition or specific profile/name. (There is an overall full text search engine for the entire website.)	Both the video diaries and the text stories can be searched for by a full-text search engine. In addition, the video diaries are disclosed with a search tree containing 14 themes and 6 stages in the disease course.	No search facility for story topics (only an overall search engine for the entire website).

Table 1 (Continued)

Framework[a]		www.borstkanker.nl (including www.brca.nl)	www.de-amazones.nl	www.kankerbestrijding.nl (including YouTube-channel)	www.kanker-actueel.nl
Medium	**Capacity**	Mostly stories in text; some blog stories are supported by photos. The brca.nl website contains one video.	Mostly text (supported by smileys).	Text and videos.	Text and videos.
	Evanescence	For the 33 blog stories, dates of publication are specified. For the other stories no publishing dates are specified, but often years are mentioned in the texts.	For the stories as well as the reactions to the stories, the date on which they were published is specified.	For the stories as well as the YouTube-videos, month and year of publication is specified.	For most stories no date of publication is specified.
	Interactivity	Visitors can submit/publish their own (blog) story and/or respond to stories of others. It does not seem possible to submit an own story for publication on the hereditary cancer site.	After creating an account, visitors can publish their own story/blog and can respond to stories/blogs of others.	Patients can submit their text story using a web form, whereupon an editor decides whether the story will be published, possibly after shortening the story.	The own story can be published after consultation with an editor; visitors can respond to stories using a web form.

[a] The aspects time/place context and anonymity are not included in the table, because, for all websites, stories can be read at a self-selected time and from a self-selected location, and readers of stories remain anonymous on all websites.

Table 2 New websites in 2013

Framework[a]		www.pinkribbon.nl	www.borstborst.nl	www.kanker voorbij.com	www.gezondheids plein.nl	www.youtube.com	Theme websites (n=7)
Overall situation	Goal	Foundation that calls for attention to breast cancer.	Foundation engaged in research and treatment plans, patient education, education for professionals, and raising awareness of breast cancer.	Website created by a patient aiming to raise awareness of breast cancer and all aspects of the disease.	Website owned by Medical Media B.V. aiming to provide independent, accessible, reliable and educational information on health.	Website that allows people to discover, watch and share originally-created videos. YouTube provides a forum for people to connect, inform and inspire others.	Websites with a specific goal owned by foundations, pharmaceutical companies and health centres. Goals are, for example, to stimulate sports activities, promote certain treatments or inform about drug side effects.
Participants	Number	6 stories, including one by a man with breast cancer (all in PDF format)	2 stories	24 stories, of which at least 9 stories by breast cancer patients (some stories do not mention the type of cancer)	3 text stories and 4 videos about breast cancer	Searching for 'borstkanker' AND 'verhaal' on the homepage of YouTube retrieves about 43 videos.	Varies from 3-20 stories per website.

Table 2 (Continued)

Framework[a]		www.pinkribbon.nl	www.borstborst.nl	www.kankervoorbij.com	www.gezondheidsplein.nl	www.youtube.com	Theme websites (n=7)
Participants	Authenticity	It probably involves real patients (stories are not spontaneously published).	Unknown.	Unknown, the stories are spontaneously published.	The 3 text stories are spontaneously published; the videos are edited and probably involve real patients.	Some of these videos are published by organisations, for example by KWF Kankerbestrijding. Other videos are published by individuals whose authenticity is unknown.	Unknown. On mijnmedicijn.nl the stories are spontaneously published; on the other sites stories are probably not published spontaneously.
	Extent of common ground	No search facilities for writer characteristics. A few sentences summarize what the stories are about; in general, age of the writers is mentioned.	Search facility based on age, type of diagnosis, type of surgery, type of lymph nodes, type of medication, type of radiation, type of reconstruction and/or other characteristics.	No search facilities for writer characteristics. The first few sentences of each story are shown in a list. Visitors must click on the title of a story to see the whole story.	No search facilities for writer characteristics. Text stories are arranged alphabetically according to illness/disease.	No search facilities for writer characteristics.	No search facilities for writer characteristics on most of the websites. Sex and age of the writer is mentioned for every story on mijnmedicijn.nl.

Table 2 (Continued)

Framework[a]		www.pinkribbon.nl	www.borstborst.nl	www.kanker voorbij.com	www.gezondheids plein.nl	www.youtube.com	Theme websites (n=7)
Message	Structure	Headings in the stories.	Headings in the stories.	Varies/none.	None.	None.	Varies/ none.
	Accuracy	Edited.	Unknown.	No editor.	Videos are edited.	Videos provided by organisations are edited.	Almost all websites seem to have edited stories.
	Content	No search facility within stories. Ctrl-F on the summary page allows no search within PDFs.	No search facility with content keywords, no search facility with text words (only Ctrl-F).	No search facilities for story topics. The first few sentences of each story are shown in a list. Visitors must click on the title of a story to see the whole story.	No search facility for story topics (only an overall full text search engine for the entire website).	Only overall search engine for the entire website. Within the set of 43 videos, no search facilities are available for story topics.	In general, no search facilities for story topics.

Table 2 (Continued)

Framework[a]		www.pinkribbon.nl	www.borstborst.nl	www.kankervoorbij.com	www.gezondheidsplein.nl	www.youtube.com	Theme websites (n=7)
Medium	Capacity	Text supported by photos.	Only text.	Predominantly text; some stories are supported by photos.	Text and videos.	Videos.	Predominantly text; some stories are supported by photos.
	Evanescence	No dates of publication are specified.	No dates of publication are specified.	The reactions to the stories include a date of publication; the stories do not.	No dates of publication are specified.	For the videos as well as the reactions to the videos, month and year of publication is specified.	For some stories, a publication date is specified. (On mijnmedicijn.nl all stories include a date of publication).
	Interactivity	Visitors cannot submit their own story, nor can they respond to other stories.	Visitors cannot submit their own story, nor can they respond to stories by others.	All stories allow for visitor comments and visitors are encouraged to publish their own story.	Visitors can submit their own text story and respond to the text stories by others.	After creating an account, a visitor can publish their own video and can respond to videos by others.	In general, visitors cannot submit their own story, nor can they respond to stories by others (with the exception of mijnmedicijn.nl).

[a] The aspects time/place context and anonymity are not included in the table, because, for all websites, stories can be read at a self-selected time and from a self-selected location, and readers of stories remain anonymous on all websites.

Table 3 Features of websites (n=16) that disclose Dutch-language illness stories written by breast cancer patients: situation in 2013.

Feature		Value	Websites % (n)
Participants	**Number**	2-5 illness stories	38 (6)
		6-15 illness stories	13 (2)
		>15 illness stories	50 (8)
	Anonymity	Reading the illness stories without being identified	100 (16)
	Authenticity	Guarantee that illness story writers are real patients	19 (3)[a]
	Extent of common ground	Search facility for personal features of illness story writers	13 (2)
		Brief, separate summary of writers' personal features	19 (3)[a]
Message	**Structure**	Structure by means of a brief summary of story or headings in story	19 (3)[a]
	Accuracy	Review by editor	38 (6)[a]
	Content	Search facility with content keywords	0 (0)
		General search facility with text words / search engine for entire website	56 (9)
		No search facility (or only 'Find (on This Page)' delivered by Internet browser)	44 (7)
Medium	**Capacity**	Only text	31 (5)
		Text supported by photos	38 (6)
		Text supported by video fragments with patient's voice	31 (5)
	Evanescence	Publication dates of illness stories mentioned	44 (7)[a]
	Interactivity	Responding and submission is possible	44 (7)
		Responding is possible	6 (1)
		Submission is possible	6 (1)
		Responding or submission is not possible	44 (7)

[a] Feature x is associated with a website if at least some of the stories on that website have feature x.

3.2 New websites in 2013

The searches performed in 2013 yielded twelve additional websites. These websites are described in Table 2. The stories on seven websites illustrate a particular theme: www.geefhaareenkans.com, www.tegenkracht.nl, www.mijnmedicijn.nl, www.loopvoorleven.nl, www.hyperthermie.info, www.noadin.nl, and www.breastfriends.nl. These seven websites are considered together in Table 2. The stories on the other five websites include more diverse aspects of breast cancer: www.pinkribbon.nl, www.borstborst.nl, www.kankervoorbij.com, www.gezondheidsplein.nl and www.youtube.com. These five websites are described separately in Table 2.

3.3 The complete picture in 2013

Table 3 summarizes the complete picture in 2013. This table is constructed in the same way as Table 2 in Chapter 2, enabling a clear comparison with 2006.

4 Conclusion

The goal of this addendum was to compare how patient stories are presented and disclosed on websites in 2006 and in 2013. There were three clear results. Firstly, the number of stories per website has increased. While in 2006 the highest number of stories on a website was 49, in 2013 the highest number of stories was about 790. Secondly, the format in which stories appear has changed. In 2013, there is now a trend favouring photos and videos, instead of text only. Thirdly, in 2013 two websites offered a search facility for writer characteristics, while in 2006 none of the websites offered such a search facility. However, in 2013 there were still no websites offering a search option for content keywords.

References

1. Overberg R, Toussaint P, Zwetsloot-Schonk B. Illness stories on the Internet: Features of websites disclosing breast cancer patients' illness stories in the Dutch language. Patient Educ Couns 2006;61:435-42.
2. Te'eni D. Review: A Cognitive-Affective Model of Organizational Communication for Designing IT. MIS Quarterly 2001;25(2):1-62.