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CHAPTER 1

General introduction

IRMA'S STORY

Irma, 39 years old, lives with her husband and her two children of primary school age. After she was diagnosed with breast cancer, she was treated successfully and is now cancer free. However, since her treatment she has been very tired and her arm remains painful. She would like to know how other patients with similar health issues manage family life and returning to work. She therefore decides to search on the Internet for other people's stories.

SITUATION IN 2008

Irma types the words 'breast cancer' and 'stories' into a general Internet search engine. More than 100,000 hits! She does not know where to start. She opens websites and closes them again; they are not what she is looking for. After half an hour, she finds a website that was created by an active group of patients and ex-patients. There are dozens of stories on this website, arranged alphabetically according to the writers' pseudonyms. She starts to read stories. The writers of these stories are all in different situations. How can she find a story by someone in a similar situation to herself and with similar health issues? She continues scrolling through the list of stories. After one hour she finds a story that matches her own situation. However, while scrolling through the stories, she has also seen several stories by women with metastases. These are stories she would rather not have seen. The one story she did find after an hour may have given her support and information, but the other stories she scrolled through made her anxious.

SITUATION IN 2015?

Using natural language, Irma enters an excerpt of her own story into an Internet search engine: "I am 39 years old, married, two children. After having undergone several treatments, I am now cancer free, but I am still very tired and I have problems using my arm. I'm looking for ways to manage family life and returning to work despite these physical limitations". After she types this, a number of websites are retrieved. She opens them and discovers that they contain similar stories to her own. Because the stories perfectly match her situation, they immediately give an answer to her question. With little effort she has found stories written by other breast cancer patients that are very helpful to her, without having to read stories that make her anxious.

During the various phases of disease (diagnosis, treatment, recovery) and facing “normal” life again, people require information. Besides the information that one gets, for example, from nurse practitioners about treatment options and the course of the disease, patients often want to know how they are going to experience this process. In such cases, stories written by other patients and published on the Internet can be an important source of information.

Due to the large number of stories on the Internet, it can be difficult for patients to find stories by other patients who are similar to themselves and whose stories therefore may contain information that is relevant and useful to them. If patients cannot find stories by people in a similar situation, they miss out on the opportunity of gaining information and support that matches their situation.

This thesis aims to gain insight into which search facilities for stories facilitate breast cancer patients in finding stories written by other patients who are in a similar situation to their own. Organizations can use the results to implement these search facilities on their websites.

This chapter provides a general introduction to the main themes and presents the aim and outline of the thesis.

Other breast cancer patients as a source of information

Breast cancer is a severe, life-threatening illness with a high prevalence. In 2009, there were more than 93,000 women in the Netherlands who had been diagnosed with breast cancer between 1999-2009. In 2010, about 14,000 Dutch women were newly diagnosed with breast cancer. Breast cancer also occurs in men, although it is uncommon (it is estimated that carcinoma of the male breast accounts for 0.8% of all breast cancers) [1]. Due to an increasing incidence (aging population, early detection of cancer) and improved survival rates (more effective treatments), the number of breast cancer patients will continue to rise [2].

Being diagnosed with breast cancer is a stressful life event that can cause uncertainty [3], severe distress, anxiety, and depression [4]. Patients have to undergo surgery on an organ that plays an important role in body image and sexual functioning [5]. Moreover, the natural sense of continuity is disrupted due to the possibility of dying [6]. Besides the psychological consequences, the often arduous treatments can cause long-lasting or even irreversible physical side effects, such as tiredness, lymphoedema, nerve pain, and early menopause [7]. Patients may also experience problems with social functioning, for example in their role within the family or in returning to work [8].

As a means of coping with their situation, people diagnosed with breast cancer often seek information [9;10]. Health care professionals are an important source of medical information, such as the likelihood of cure, spread of disease, and treatment options [11].

In addition to medical information from health care professionals, other breast cancer patients are also an important source of information during all phases of the disease. The information that other patients provide is essentially different from the information health care professionals provide. Trial and error of the lived experience makes other patients experts in strategies for coping with day-to-day personal health issues and in managing responsibilities and activities associated with family, friends, work, and the home during and after illness [12].

Nowadays, the Internet is an attractive and important source of other patients' experiences, because it can be accessed 24/7 without the need to leave your own house or to disclose your identity [13-15]. Moreover, the Internet contains a large number of patient experiences [16] that can be accessed by many people, since ninety-four percent of all households in the Netherlands have access to the Internet [17].

Breast cancer patients can read about other patients' experiences on the Internet in several ways: a) online support groups [15;18-20]; b) online patient communities, such as PatientsLikeMe [21]; c) social media, such as Facebook, Twitter and YouTube [22-27]; and d) websites with stories written by patients, such as healthtalkonline.org [28], BreastCancerStories.org [29] and de-amazones.nl [30]. The website healthtalkonline.org was developed by researchers, who interviewed a group of patients about their experiences with breast cancer and published these accounts in an edited form on their site. The stories on the websites BreastCancerStories.org and de-amazones.nl are published spontaneously by patients, without any restrictions or editing. This thesis focusses on searching for and reading these spontaneously published breast cancer stories on the Internet.

Spontaneously published breast cancer stories on the Internet

We define spontaneously published breast cancer stories on the Internet as first-person texts that have been written by breast cancer patients, are not part of an interactive forum and were spontaneously published on the Internet at a given moment. Reading these stories differs from reading other types of patient experiences on the Internet in three ways.

Firstly, spontaneously published breast cancer stories tend to be complete stories, meaning that several phases of the disease trajectory are described, such as experiences with treatments and the illness trajectory, feelings about having cancer, and coping with the consequences of being ill. The power of a complete story is that it can integrate events and the writer's thoughts, actions, decisions, and relationships with other persons into a meaningful narrative [31]. In this way, spontaneously published breast cancer stories differ from online support groups and social media where a reader can only read conversations between patients (mostly relatively short fragments in question-answer format) [32], and which, quite often, contain small talk [33].

Secondly, the writers are not selected and their spontaneously published stories are not edited: each patient can publish their own story on the Internet, with self-chosen topics and in self-chosen words. The reader thus has access to the authentic story of another patient, without any modifications and/or additions by professionals/researchers. Frank [34] indicates that such stories that come directly from the patient are important, because they reflect the narrator's truth. In this respect, spontaneously published stories differ from stories published by researchers which are based on patient interviews (e.g. [28]). A particular group of patients may be invited for the interviews and, during the interviews, patients may be asked to describe or write about specific topics to ensure that the set of stories addresses a broad range of topics. Furthermore, the stories will be edited before publication.

Thirdly, the number of spontaneously published stories available on the Internet is not limited and is constantly increasing, since patients can spontaneously publish their story at any time. This is in contrast to stories published by researchers. When researchers have finished interviewing a defined group of patients, they publish these stories at a given moment on their website. As a consequence, the number of stories on researchers' websites will not grow continuously.

The large and increasing number of spontaneously published stories on the Internet will, on the one hand, increase the likelihood that a story that matches the reader's situation becomes available, yet, on the other hand, may makes it difficult to find such a story.

The three above-mentioned characteristics of spontaneously published breast cancer stories show that they are a unique source of information and support. Therefore, this thesis focusses on these spontaneously published stories. To gain insight into the kind of information a reader may find in spontaneously published stories, we performed a content analysis of a set of stories in which we examined the characteristics of breast cancer patients who spontaneously publish their story and the topics they write about (Chapter 3).

Patients who prefer to read complete, authentic stories written by others will choose spontaneously published stories on the Internet as a source. In particular, stories written by others in a similar situation are expected to provide readers with optimal support and information (see next section). However, because there are so many spontaneously published stories on the Internet, it may be difficult for patients to find those stories that are relevant to them. Therefore, an important task for professionals is to make stories written by others in a similar situation findable for readers. To do so, it is important to know the preferences and needs of the patients who want to read stories, and to consider the context and domain in which the information exchange will take place. The issue of making stories findable for patients is therefore not a simple matter of ICT, but should be addressed from a clinical informatics perspective, in constant dialogue with the patient. The field of clinical informatics is ideally suited to address this issue, since it takes the care domain as its starting point instead of information technology, and, therefore, has knowledge and affinity with the domain in which patient stories are exchanged. For this reason, the first step we took was to examine how spontaneously published stories are presented and disclosed on the Internet (Chapter 2). Because the study described in Chapter 2 was already published in 2006, we have added an addendum of the situation in 2013.

In conclusion: spontaneously published stories are a unique source of support and information. Therefore, patients (readers) should not be deprived of this source and should be facilitated in finding stories written by similar others, since these stories are expected to have the greatest positive impact on the readers.

Impact of reading other patients' stories

The possible impact of reading stories written by other patients can be explained from a narrative approach [31] and a social-psychological approach. The most applicable social-psychological theories in this context are social comparison theory [35] and social cognitive theory [36]. This section describes the three approaches/theories and examines their link with reading other patients' stories on the Internet.

The narrative approach suggests that people construct a story (narrative) of their lives to give it meaning [31]. Narratives can give meaning because of their ability to weave together separate events and human actions into a whole (plot), for example by arranging them causally or temporally. Plots are, in turn, part of larger plots, which make individual human lives comprehensible as a whole. In their narratives, people connect their past, present, and future and integrate events, their own actions, thoughts, decisions, expectations, and relationships to others into a meaningful whole, taking into account the limits and opportunities posed by the physical, cultural and personal environments. In this way, a person's narrative is the very process of identity construction. Constructing a narrative is an ongoing process in which new experiences and events are continuously weaved into the narrative and which may retrospectively lead to revisions of previously constructed parts of the narrative. If the narrative is coherent and satisfying, it can serve as a justification for one's present condition and situation, both for the narrator him/herself and for others [31].

Breast cancer diagnosis is an interruption of one's narrative, since becoming a *patient* is a threat to one's identity: due to the cancer and its treatments, a person will experience physical changes, changes in roles, relationships, social circles and activities, and a changed vision of the future. All these changes may cause a curtailed sense of agency. As a consequence of these changes, the pre-diagnosis narrative no longer fits, motivating the reconstruction of this narrative into a new narrative that incorporates the meaning of illness and renegotiates one's identity [37-39]. Constructing a new narrative gives a sense of control, since the patient narrator asserts him/herself as agent: he/she can determine how the events and his/her own thoughts, actions, decisions, etcetera are interwoven [38;39]. Patients can structure their narrative as a restitution narrative, a chaos narrative, a quest narrative, or a combination of these three. A restitution narrative begins with health, followed by sickness and looking to a return to health in the future.

In a chaos narrative, the patient is not (yet) able to form a coherent story: events and thoughts are not woven together into a meaningful whole and the story lacks a clear direction. Finally, a quest narrative shows how illness may be considered useful and can function as an impetus for change [34;40]. The value of constructing an illness narrative is supported by empirical research: extensive research has revealed that forming a narrative about one's experiences in life is associated with improved physical and mental health across a variety of populations [41]. In addition, breast cancer patients may also benefit from reading stories written by other breast cancer patients on the Internet (this thesis). Other patients' stories may inspire readers to construct or reconstruct their own story, since these stories enable readers to see how other patients have woven together events, thoughts and decisions into a meaningful whole and how they have shaped their new identities.

Social comparison theory [35] suggests that people consider one or more people in relation to the self as a source of support and information. In social comparison, one positions oneself relative to another person on some dimension. People may have three motives to engage in social comparison. Firstly, people may try to evaluate their opinions and abilities by comparing themselves with others (self-evaluation), especially when no objective (i.e. non-social) information is available. Secondly, people may have the desire to feel good about themselves and their situation (self-enhancement). They may achieve this by comparing themselves with others who are worse off (downward comparison), thereby providing an indication that their own situation is better. Thirdly, people may have the desire to improve themselves or their situation (self-improvement). They may reach this goal by comparing themselves with others who are doing better (upward comparison), which may provide opportunities for learning and improving their situation. However, downward and upward comparison can also lower self-esteem and cause fear and uncertainty. People who are doing worse suggest that your own situation could take a similar negative turn, and people who are doing better imply that you are not doing as well at the moment. Thus, social comparison is a complex phenomenon. The desired direction (upward/downward) depends on many factors, including a person's personality traits and the comparison dimension.

There are many dimensions on which a person can compare him/herself with another person. Social comparison theory suggests that the comparison on a particular dimension will have more impact when other dimensions (such as gender, age, etc.) between the persons are similar. In the case of breast cancer patients comparing themselves with writers of breast cancer stories on the Internet (this thesis), they may make comparisons on the following dimensions: the degree of support from family and friends, the severity of treatment, speed of recovery, and coping (e.g. [42;43]). Comparison with a writer on a specific dimension (regardless of the direction of the comparison), will have the most impact when other dimensions of the writer, such as the situation of the writer or personal characteristics of the writer, are similar to those of the reader.

Social cognitive theory [36] suggests that people can learn from others by observing their behaviour (vicarious learning). If this behaviour has beneficial effects, people can decide to copy the behaviour (modelling). Learning will most likely occur when the observer is confident that he can successfully execute the behaviour (self-efficacy) and when there is a close identification between the observer and the model. Based on this theory, writers of breast cancer stories on the Internet can serve as models for readers of the stories (this thesis). Readers may learn most when they can identify with the writer/narrator of the story.

Studies have shown that breast cancer patients were more likely to select and read experiences of other patients who were doing better than themselves than those of other patients who were doing worse than themselves [43]. Furthermore, cancer patients seeking social comparison information on the coping dimension have been found to prefer upward comparison [42]. It could be that these upward comparisons offer better opportunities for vicarious learning since stories of patients who are doing better may contain more effective examples of emotion-focused coping and problem-focused coping. Emotion-focused coping is aimed at managing and reducing negative feelings about the disease, for example by seeking distraction. Problem-focused coping is aimed at solving problems caused by the disease, for example wearing a wig to regain a positive self-image. In problem-focused coping, it is important that the patient estimates that his behaviour will lead to the desired outcome (outcome efficacy) and that he is confident that he can successfully execute the behaviour (self-efficacy). Readers of other patients' stories on the Internet (this thesis) could learn from the effective examples of other patients' coping and may decide to apply these forms of coping themselves.

The possible impact of stories outlined above is also acknowledged in other disciplines. Personal stories are, for example, used in patient education, like patient decision aids [44;45] or health promotion interventions [46-48]. Current research is focusing on how to incorporate personal stories and/or information contained in these stories in a way that enhances the effectiveness of the decision aid or intervention [49;50].

In conclusion: the theoretical frameworks suggest that stories by writers who are/were in a similar situation to the reader are most likely to have positive impacts on readers with regard to: a) constructing their own illness story, b) evaluating themselves and their situation, and c) learning effective ways of coping in order to improve themselves or their situation.

Search facilities

To develop search facilities that enable patients to find stories on the Internet written by other patients who are/were in a similar situation to their own, knowledge from the field of information retrieval [51;52] and from research into search engines [53] is used.

First, it is important to note that when searching for spontaneously published patient stories on the Internet, the most important aspect is that the retrieved stories match the situation of the patient who carried out the search (reader) (see previous section). However, it is not important that *all* stories on the Internet that match the reader's situation are retrieved, since the reader will probably find sufficient support and information from just a few stories that match her situation. In the field of information retrieval, this balance is expressed in terms of precision and recall. A search has high precision when the search results consist mainly of documents that are of relevance to the searcher. A search has a high recall when (almost) all documents that are of relevance to the searcher are included in the search results (i.e., when as few as possible relevant documents remain unfound). Thus, when searching the Internet for stories written by other patients, high precision is important, whereas high recall is less important.

Below, various search facilities are described. It is useful to be aware of two important aspects of a search facility, namely:

1) the interface: this enables a user to enter his/her query, i.e. he/she can indicate what he/she is looking for. In addition, the interface displays summary information about the search results and gives the user access to the underlying documents.
2) retrieval of documents: which documents are retrieved depends on how the query is processed and connected to the set of documents that can be searched. The documents that are found are ranked and summary information is derived.

The interface of a general search engine on the Internet usually consists of a search box in which search terms can be typed. A search in such a general search engine, for example Google, using the terms "*borstkanker*" [*breast cancer*] and "*verhalen*" [*stories*] in the search box entitled "Find pages with all these words" yields more than 115,000 hits (search carried out on 11 February 2013). To help the searcher, the search results of a general search engine are sorted (ranking). For the ranking of search results and retrieval of documents (URLs), Google uses algorithms in which various aspects are weighted, such as recentness of information, and language and country of the user [54]. However, the exact ranking measure used by the search engine might differ from the relevance measure expected by the searcher. As a consequence, high-ranked search results will not always be the most relevant results for the user. In our search, the high-ranked search results consisted mainly of general sites about breast cancer, but not of specific stories. A more specific search query, for example, "*verhalen*" [*stories*], "*borstkanker*" [*breast cancer*], "*vrouw*" [*woman*], "*39 jaar*" [*39 years old*], "*armfunctie*" [*arm function*], "*gezinsleven*" [*family life*] and "*werk*" [*work*], yields more specific search results. However, the high-ranked search results seem to contain no complete stories in which all searched topics are present in relation to each other. Moreover, forum posts are also found. Using a general search engine, it is therefore difficult for patients to find complete stories from other patients in the same situation as themselves, without finding stories or forum posts that may not be helpful to them or may even make them anxious.

In terms of internal search facilities provided by websites that contain patient stories, a manual index is often used. To enable document retrieval, the website owner (domain expert) uses the content or meaning of the texts to determine which words are relevant for inclusion in the index, and subsequently assigns these index words to the documents. This method is applied, for example, on the website Healthtalkonline [28]. Here, the interface consists of a full list of topics and subtopics (but not in alphabetical order as in a typical index), which is visible to the user and from which the user can select single items to search for stories. An important limitation of this method is a possible difference in *vocabulary* between the domain expert and the user: to find relevant documents, the user must use the same terms as the domain expert. This limitation may particularly play a role when searching for patient stories, because readers are looking for experiences rather than facts, with facts being easier to divide into pre-defined categories than experiences. Another limitation is *assigning* the index words to the documents. The way the expert assigns these words to the documents may not be what the user expects and this may affect precision and recall of the search results. In addition, stories on the website Healthtalkonline [28] can be retrieved on the basis of a writer's age: the stories are divided into four age categories and each age category is accessible via a button. Yet, it might be difficult for patients to decide which age category to select if they want to search for an age at either the beginning or the end of the pre-defined age categories. Finally, an overarching disadvantage of the manual indexing according to topics and age groups is the amount of time and manpower required to build and maintain such a search facility.

Another possibility to make patient stories findable on a website is an internal search engine based on full-text indexing. In addition to the aforementioned full list of topics and age categories buttons, the Healthtalkonline website [28] also contains such an internal search engine. Retrieval of documents based on full-text indexing is based on words that occur literally (including singulars, plurals and diminutives) in the documents. The interface consists of a search box in which a user can type search terms. Yet, this form of searching can present the user with problems relating to synonyms (different words with the same meaning) and homonyms (same words with different meanings). Another problem is that the user does not know exactly which words appear in the documents and therefore which search terms he/she should use. The Healthtalkonline website supports the user in this respect, since the user is given suggestions through a dropdown menu that appears while typing search terms into the search box. A different kind of problem with a full-text indexing search engine is that the same set of search terms can have different meanings (polysemy). For example, a patient who uses the search terms "*werk*" [*work*] and "*armfunctie*" [*arm function*] may be looking either for stories about how to reintegrate into work despite an impaired arm function or for stories about situations in which reduced arm function can lead to occupational disability. Thus, the overall intention of a text cannot be expressed in individual words; it is the relationship between the words that is of crucial importance. However, one advantage of a full-text indexing search engine is that relatively little time and money is involved in building and maintaining the search engine.

If patients had an interface at their disposal that consisted of a search box in which they could type natural language queries to search for stories, there would no longer be any need for them to translate their query into search terms, thereby making it easier for patients to search for situations similar to their own. Natural language includes syntax and semantics [55] and therefore, to enable document retrieval using a search engine in which users can enter natural language queries, both the query and the documents that can be searched for have to be analysed for syntax and semantics. A parser can be used to analyse the syntax of a query and thus clarify the intention of the user. For example, does the user have a ‘how’ question, a ‘why’ question or an ‘if’ question? Although a complete automatic semantic analysis of texts is not yet available, there have been steps in this direction, such as shallow parsing, part-of-speech tagging, ontologies etcetera. However, these have not yet led to useful results. Nonetheless, some insight into semantics can be gained by Latent Semantic Indexing (LSI) [52]. LSI does not examine the exact semantics, but rather the word combinations in a text, as opposed to single words. In this way, LSI can yield some information about the semantics of a query or of the documents being searched, and could allow a search facility to be developed in which stories can be searched using natural language queries. This method provides a solution to the above-mentioned problems of a full-text search engine (synonyms, homonyms and polysemy). In principle, it is possible to type a natural language query into the search box of a general search engine or a full-text search engine. However, it is important to be aware that a natural language query in many search engines will be processed as a keyword query instead of a natural language query and, as a result, some words in the query will be disregarded and syntax and semantics will not be examined.

In conclusion: to make patient stories findable various retrieval methods can be used, each with their own advantages and disadvantages.

User-centred design

To examine how spontaneously published stories can be made findable for patients (readers), it is important to ask the patients themselves about their preferences. Often, patients will have a good idea of which stories can give them support and which topics and/or writer characteristics they would like to search for to find these stories. Therefore, the method we applied in this thesis was a user-centred design [56;57]. In a user-centred design, the user is involved in the entire process of developing a product. This process consists of the following steps: a) the baseline situation of the product is described; b) the user is asked for his/her preferences with respect to the product; c) these user requirements are implemented in the product and then the product is evaluated by actual users. The development of a product following a user-centred design is an iterative process: the outcomes of step c may lead to repeating steps b and c once, or even multiple, times to eventually achieve at an end product that is optimal for the user. The philosophy behind user-centred design is that it optimizes the product around the user’s preferences and needs, instead of forcing the user to change so as to conform to the product.

Our user-centred approach to investigating search facilities for spontaneously published breast cancer stories included the following steps. Firstly, we described the baseline situation by examining how breast cancer stories are presented and disclosed on websites (step a: Chapter 2). We then interviewed breast cancer patients about which topics and writer characteristics they would like to search for when seeking stories written by other patients (step b: Chapter 4). Subsequently, we translated these patient preferences into search facilities. We based the retrieval of documents (stories) in these search facilities on manual indexing. The interface consisted of a list of topics and/or writer characteristics of which one or more items could be selected by the user. We implemented these search facilities on a study website and recruited breast cancer patients to actually use these search facilities. We examined which search facilities resulted in satisfaction with the search process and with the stories retrieved, as well as the impact of the retrieved stories on self-reported coping with breast cancer (step c: Chapter 5). Furthermore, we developed a search facility in which document retrieval was based on LSI, where the interface consisted of a search box in which natural language queries could be typed. Breast cancer patients used this search facility and their satisfaction with the search process was examined (step c: Chapter 7). Additionally, we analysed the actual search behaviour of breast cancer patients when seeking stories written by other patients (Chapter 6 and 7).

In conclusion: a user-centred design was applied because patients themselves are in the best position to indicate which topics and writer characteristics they feel are necessary in a search facility to enable them to find stories that provide support.

Aim of this thesis

The primary aim of this thesis was to gain insight into which search facilities for spontaneously published stories facilitate breast cancer patients in finding stories written by other patients who are in a similar situation to their own. A related goal was to provide owners of websites or patient decision aids with information about search facilities for stories so that they could apply this information to their website/aid and thereby make it easier for patients to find stories about others in a similar situation.

Another purpose of this thesis was to provide a basis for the further development of search facilities for patient stories. The results of this thesis can serve as a guide for future steps in the iterative process of developing search facilities for patient stories.

The research was conducted from a clinical informatics perspective, using knowledge from the fields of information retrieval, human-computer interaction and psychology.

Outline of the thesis

Chapter 2 describes a study in which the features of websites with breast cancer stories were examined using a theoretical framework for analysing communication processes. The study focussed on how patient stories are presented and disclosed on websites. The *addendum* to Chapter 2 provides an update of the situation in 2013.

Chapter 3 describes the content analysis of a set of 167 spontaneously published breast cancer stories. This analysis examined writer characteristics, themes in the stories, and how these writer characteristics and story themes relate to the wider population of breast cancer patients.

Chapter 4 reports the results of interviews with 25 breast cancer patients about their preferences with regard to the content and appearance of online breast cancer stories, and the search facilities they feel would help them search for these stories.

Chapter 5 describes an online randomized controlled experiment which examined breast cancer patients' opinions and experiences regarding four different search facilities for stories. The search facilities selected for this experiment were based on the results of the interviews in Chapter 4. The experiment had a 2x2 factorial design (story topics search facility 'yes/no' and writer characteristics search facility 'yes/no') which resulted in four groups: 1) no search facility (control group: writers' nicknames in alphabetical order), 2) search facility for writer characteristics, 3) search facility for story topics, and 4) search facility for writer characteristics and story topics (combination group).

An analysis of the log data of the online randomized controlled experiment is described in *Chapter 6*. This analysis gives insight into breast cancer patients' actual search behaviour when looking for stories by other patients.

Chapter 7 describes an exploratory study of breast cancer patients using a search facility for stories written by other patients in which they could enter natural language queries. This search facility was developed using Latent Semantic Indexing (LSI), a technique from the field of Information Retrieval (IR).

Finally, in *Chapter 8* the main results of the above-mentioned studies are brought together and a reflection is provided on the findings and their meaning in a broader context. This results in an overall conclusion and discussion of the thesis, in which both theoretical and practical implications are discussed.

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