Online Peer Support for Patients with Somatic Diseases

Nelly van Uden-Kraan

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ONLINE PEER SUPPORT FOR PATIENTS WITH SOMATIC DISEASES

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Contents

1

General introduction

> By participating in the peer support group I became calmer in dealing with my illness. I was of course totally freaking out because I was the only one who had arthritis. That's how I experienced it. And very lonely. Something like 'Oh well, my life has ended and everyone else is carrying on'. Now I know there are more people who are going through the same as I am and who are in an even worse state than me.

This citation, taken from an interview with a patient suffering from rheumatoid arthritis, illustrates the value peer-to-peer contact can have when people have to deal with stressful life difficulties, such as serious health conditions. In this thesis, peer-to-peer contact refers to the contact between people suffering from the same illness. Whereas this might be limited to occasionally meeting an acquaintance with the same illness, often sufferers can also join a peer support group. In the Netherlands patients have actively met one another in peer support groups for decades.

Support groups can be helpful due to various reasons. First, they offer patients the opportunity to share their experiences. For obvious reasons physicians have limited time to listen to patients' lengthy accounts of their illness and, moreover, have not experienced the same situation themselves [1]. Sharing similar experiences with peers can lead to the exchange of social support [2]. Peer support groups also allow for social comparison with peers [3]. For patients, the opportunity to compare themselves with others who face similar challenges can make them feel 'less alone' in coping with their disease [4]. Another function of peer support groups is the exchange of information about the illness. This can lead to an increase in the patient's knowledge and may empower his/her position in the health care process [5]. Finally, an almost certainly important part of the therapeutic value of these groups lies in the fact that participants not only receive help but also have the opportunity to help others, which in turn can enhance their psychological well-being [6].

However, participating in peer support groups can also have negative consequences, such as an increase in fear, uncertainty or depression. This might happen when other participants express too many negative feelings, or when others in the group have other experiences than you do or do not understand yours [2]. In addition, the social support provided can also be experienced as negative, for example, when others criticize you or offer well meant but unwanted advice. This may lead to a reduced mental well-being [7].

Although relatively few studies have been conducted to examine the effectiveness of peer support, some have shown that patients tend to profit from participation in peer support groups and that this can lead to better coping styles [8], less distress [9] and an improvement of the participants' quality of life [10].

Despite the promising outcomes of engagement in peer support, studies showed that many face-to-face peer support groups have encountered less than enthusiastic participation [11-13]. One of the reasons for this is the geographical distance that has to be bridged in order to attend [11]. A solution to overcome such barriers arose with the emergence of peer support groups via the Internet.

Peer support groups for patients via the Internet

The Internet has enabled peers to share concerns and experiences online. Nowadays patients can choose between several types of peer support groups (forums, discussion groups, chat boxes and email groups) that focus on a wide range of illnesses. It is anticipated that participation in peer support will increase with the growing number of online peer support groups owing to their specific advantages as compared to face-to-face support groups, such as the absence of geographical barriers, 24-hour availability, reasonable costs and anonymity [14-17]. Online support groups also allow passive participation: people can read along with an online support group without actively taking part in the discussion. This is an interesting option for physicians and carers to achieve greater insight into the questions and problems patients have and for potential participants who in this way can see how such a group operates and what kind of people are taking part [18]. Another advantage of participation in peer support groups via the Internet is that people can reach a wider range of peers and thereby gain access to even more information [19].

Little evidence exists on the effectiveness of online patient support groups. Despite this, it is suggested that online patient support groups might be the health-related Internet application with the biggest impact on health outcomes [20]. Figure 1 shows Eysenbach's conceptual framework for how Internet use may affect health outcomes. The framework illustrates the central role of online patient support groups besides the other two domains of health-related Internet use: communication and content. Online patient support may improve psychological, social and health outcomes through the facilitation of social networks, and reduce loneliness and depression. Nevertheless, online patient support groups also have other positive functions that are analogous with the functions of face-to-face peer support groups, such as the exchange of information [20].

However, online patient support groups are not without potential problems. An anxiety often expressed is that online support groups are not accessible to certain groups, such as the illiterate and people without an Internet connection. Furthermore, the inability to make use of non-verbal cues through the Internet makes it more difficult to detect some nuances of communication [14]. Other disadvantages are the lack of control on both the quality and validity of the information exchanged in online support groups [15, 21, 22] and the compilation of the groups [23, 24]. Since there are no formalized guidelines or professional facilitators for online support groups, the exchange within the group might include negative, aggressive and socially inappropriate remarks (or flaming) [14, 15]. It might also be the case that people in anonymous online support groups have difficulty comparing themselves with, or learning from, other participants, since they do not know enough about each other [25]. Finally, there is a concern that participants delay seeking regular medical help because they depend entirely on the support group [26, 27].

Although several advantages and disadvantages of online support have indeed been identified in literature, empirical studies focusing on positive functions and negative consequences of participation in online patient support groups are still scarce.

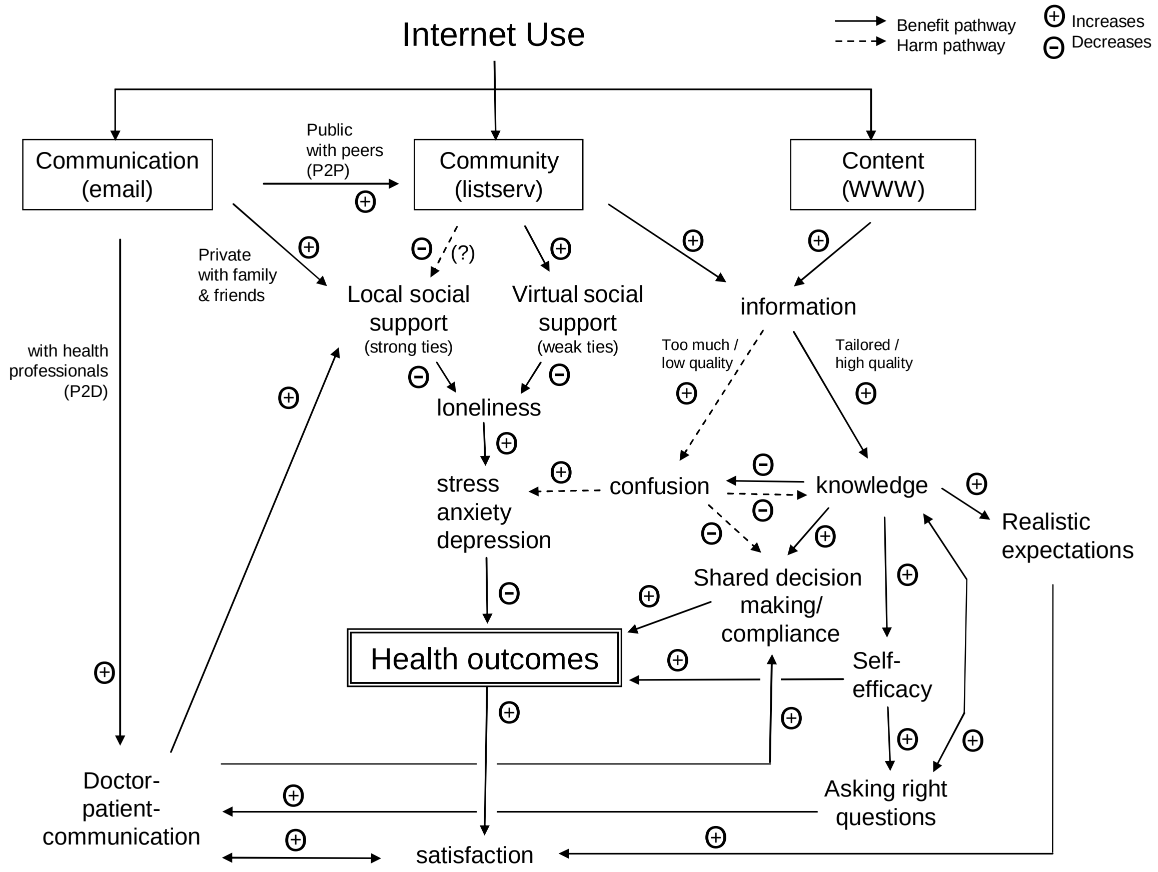

Figure 1 Conceptual framework of how Internet use (communication, community, content) may affect health outcomes, illustrating the central role of online patient support groups [20]

Conducted studies originate mainly from the United States and it is unclear to what extent the results of these can be generalized. In addition, studies of online patient support groups have mostly focused on patients suffering from a life-threatening illness. It can, however, be expected that the degree of support patients gain from online peer participation can differ per illness. For example, in a content analysis of postings from diverse online peer support groups, Davison en Pennebaker [28] found that the extent to which patients expressed positive or negative feelings actually differed strongly per illness.

Moreover, studies focusing on the use of online patient support groups have often taken place from the 'service' side. These studies examined how often certain online patient support groups were visited and how often people sent postings to an online patient support group during a certain period [21, 29, 30]. Little is known about the patients who do or do not engage in online peer support, their characteristics and their reasons for (not) participating. Therefore studies on the 'demand' side are important to gain more insight into the proportion and the characteristics of these patients.

Finally, whereas substantial research has been conducted as part of a study on online patient support groups initiated by researchers or health care providers, relatively few studies have addressed online support groups that were spontaneously initiated by the patients themselves [31]. This type of online support group warrants closer investigation [31, 32].

Aim of this thesis

The main objective of this thesis was to gain further understanding of the meaning of participation in online patient support groups from the viewpoint of various stakeholders (participants, patients, webmasters and health care providers). To this end we employed various methods (content analysis, interviews and surveys).

We explored the concept of online patient support groups for three groups of patients: a) people with a chronic but not life-threatening disease (rheumatoid arthritis), b) people with a life-threatening, but treatable disease (breast cancer), and c) people with an unexplained disease (fibromyalgia).

In the studies in this thesis we only focused on online support in discussion groups or forums and did not include chat boxes or email groups. In addition, we focused solely on online support groups initiated by Dutch patients or patient organizations.

Each study will be elaborated on in the following subsections.

Outline of this thesis

Chapter 2: Content analysis of messages posted in online patient support groups

Various authors have raised potential disadvantages of online patient support groups. One concern often expressed is the lack of control on the quality of the information exchanged. Members may be misinformed or referred to incorrect health information [15, 21, 22]. In addition, the concern exists that the exchange within the group might include socially inappropriate remarks (flaming) as there are no formalized guidelines for online support groups [14, 15]. The study described in chapter 2 investigated to what extent these potential disadvantages actually occurred. In addition, two more research questions guided this study, namely: 1) Who uses online support groups? and 2) What topics are discussed and what self-help mechanisms are used in online support groups? To answer these we conducted a 'content analysis'. We analyzed a random sample of messages sent to publicly available online support groups for patients with breast cancer, arthritis and fibromyalgia.

Chapter 3: Qualitative study among participants of online patient support groups

Ever since the onset of online support groups, much has been expected of the potentially empowering effect of participation in these groups for patients [33-35]. Thus far, however, there is no direct evidence for the effects of participation in online support groups on patient empowerment [36, 37]. In the study described in chapter 3 we qualitatively questioned 32 participants of various online support groups about their using these groups, and if and how they felt empowered by their participation. In addition, we studied which empowering and disempowering processes take place in online patient support groups.

Chapter 4: Quantitative study among participants of online patient support groups

Chapter 4 describes a follow-up to the qualitative study described in chapter 3. Despite the fact that this study revealed relevant information about the empowering processes and outcomes of online support groups, a qualitative study has its limitations. In order to overcome these methodological shortcomings, we conducted a quantitative study whereby an online questionnaire was completed by 528 individuals who were active in various public and private online support groups for patients with breast cancer, fibromyalgia and arthritis. The primary purpose of this quantitative study was to explore to what extent patients feel empowered by their participation in online support groups and with which frequency empowering processes occur. In addition, two further research questions guided this study, namely: 1) Which processes are related to these outcomes? and 2) Are there any differences between patient groups with regard to empowering processes and outcomes?

Chapter 5: Comparison between lurkers and posters in online patient support groups

It is assumed that a considerable number of patients use online support groups passively [38-40]. These so-called 'lurkers' read along with an online patient support group, but do not actively participate by sending postings. As most studies on online patient support groups only focused on the members who sent postings, it is not known if lurkers profit to the same extent from participation as posters do. Hence the study in this chapter, in which we also explored to what extent 'lurking' patients differed from 'posting' patients with regard to demographic characteristics, usage and satisfaction with the online support group. To answer these research questions we used the same online questionnaire as in chapter 4 and compared those respondents who indicated that they lurked in an online patient support group (n=109) with the respondents who indicated that they were active participants (n=419).

Chapter 6: Quantitative study among patients with breast cancer, fibromyalgia and rheumatoid arthritis

The Internet can provide patients suffering from a chronic or life-threatening health condition with information about their illness, treatment options and health improvement strategies [41, 42]. Owing to the increasing availability and popularity of the Internet, it can be expected that even more patients will use it for health-related reasons. There is therefore a constant need for studies that explore the proportion of patients that use the Internet for these reasons [43]. The aim of the study described in this chapter was to explore how many Dutch patients with breast cancer, fibromyalgia and rheumatoid arthritis used the Internet to search for information about their illness. In addition, we studied patients' usage of health-related Internet applications, such as online patient support groups. The final objective of this study was to explore which demographic, health and psychological characteristics are related to patients' health-related Internet use. To this end we conducted a cross-sectional self-reported study. We sent a written questionnaire to a representative sample of patients with breast cancer, rheumatoid arthritis and fibromyalgia, acquired from 2 hospitals. The overall total response rate was 69% (N=679).

Chapter 7: Mixed methods study among participants and non-participants of peer support groups

Patients tend to profit from engaging in face-to-face and online peer support [8-10]. Yet despite the empowering outcomes, studies have shown that many face-to-face peer support groups encountered a less than enthusiastic participation [11-13]. Although it was anticipated that engaging in peer support would increase with the emergence of online peer support, the study described in chapter 6 revealed that only a limited number of patients make use of online peer support. In the study described in this chapter we explored factors that facilitate or impede engagement in face-to-face and online peer support. The Theory of Planned Behavior (TPB) [44] was used to explain patients' participation behavior. The primary purpose of the study described in this chapter was to explore to what extent TPB variables can predict patients' intention to engage in face-to-face and online peer support. In addition, we studied whether demographic characteristics, health-related quality of life (physical and mental) and social support factors are associated with an intention to engage in face-to-face and online peer support. Finally, we explored if face-to-face and online peer support had the same or differing predictors. To answer these questions, we applied a mixed methods strategy: Creswell's [45] concurrent procedure. We used the same written questionnaire as mentioned in chapter 6. In addition, we interviewed a random sample of 19 patients with rheumatoid arthritis who did not engage in peer support about their perceptions of participation in face-to-face and online peer support groups.

Chapter 8: Qualitative study among webmasters of online patient support groups

Nowadays, patients are able to choose between many online patient support groups, most of them initiated by individual patients or patient organizations. Little is known about the motives and goals of people who voluntarily take the initiative to start an online patient support group, the so-called webmasters. Therefore, the first objective of the qualitative study described in this chapter was to explore these webmasters' motives and goals. Some of them succeeded in initiating groups which developed into successful ones. The online groups of others never got off the ground, or bled to death at a later stage. Success of the group is important, since it can be expected that effects of participation in an online support group for patients may vary, depending on the group's success. The second objective of this study was thus to learn more about how webmasters of online support groups define success, and if they were of the opinion that their own groups were a success. Finally, we explored the factors that according to the webmasters determine the success of online patient support groups. To this end we interviewed 23 webmasters of Dutch online support groups for patients with breast cancer, rheumatoid arthritis and fibromyalgia.

Chapter 9: Quantitative study among Dutch rheumatologists and oncologists

It has not gone unnoticed by physicians in their daily practice that their patients are increasingly broaching health-related information they retrieved from the Internet [46, 47]. Little is known, however, about physicians' attitudes with regard to their patients' health-related Internet use [48-50]. The purpose of the study described in this chapter was thus to explore the experiences of rheumatologists and oncologists with their patients' health-related Internet use and their attitudes towards the consequences thereof (for patients themselves, for the physician-patient relationship and for the health care). We were also interested if and how often physicians referred their patients to health-related Internet sites. In addition, we were interested if the age, sex and profession of the rheumatologist or oncologist are related to their experiences, attitudes and referral behavior. To answer these questions we sent a questionnaire to all Dutch rheumatologists and oncologists. The response rate was 46% (N=238; 134 rheumatologists and 104 oncologists).

Chapter 10: Summary and general discussion

Finally, chapter 10 summarizes the results of the preceding studies and evaluates them in the light of the existing knowledge and recent developments in the field of online peer support.

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2

Coping with somatic illnesses in online support groups: do the feared disadvantages actually occur?

C.F. van Uden-Kraan
C.H.C. Drossaert
E. Taal
C.E.I. Lebrun
K.W. Drossaers-Bakker
W.M. Smit
E.R. Seydel
M.A.F.J. van de Laar

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Abstract

People in stressful circumstances, such as serious health conditions, often turn to support groups. With the increase in the availability and popularity of the Internet, the possibility has arisen to join support groups online. Various authors have raised potential disadvantages of these groups, such as the lack of control of the quality of the information that is exchanged and the concern that the exchange within the group might include socially inappropriate remarks. In this study we explored to what extent these potential disadvantages actually occur. In addition, we explored who uses Dutch online support groups and what is exchanged by the participants. By means of ''content analysis'' we analyzed a random sample of 1500 messages from publicly available online support groups for patients with breast cancer, arthritis and fibromyalgia. It appeared that the online support groups under study were mainly used by female patients. A major part of the postings contained ''off topic'' remarks. Popular health related topics were ''restrictions in daily life'' and ''regular medication''. Only in a minor proportion of the postings, potential disadvantages were present. Therefore this study suggests that online support groups are a viable option for support.

Introduction

People need support when they find themselves in stressful circumstances, such as serious health conditions. In this respect, support groups may be helpful because members share comparable experiences and face similar challenges, which can lead to the exchange of social support [1]. These groups may also provide the opportunity for social comparison with peers [2]. In addition, a probably important part of the therapeutic value of these groups lies in the fact that participants not only receive help, but also have the opportunity to provide help to others, which can enhance psychological well-being [3].

With the increase in the availability and popularity of the Internet, the opportunity to join support groups online has improved. Because of the increasing number of Internet users, it can be expected that in the future even more people will share their concerns and experiences online. Taking part in online support groups compared to face-to-face support groups has specific benefits such as the absence of geographical barriers, 24-h availability, reasonable costs and anonymity [4-7]. Additionally, patients can use the ability to ''lurk'', until one is more comfortable with the group norms or patients can even obtain vicarious support without disclosing themselves at any time [8].

However, online support groups are not without potential problems. A worry that is often expressed, is that online support groups are not accessible for certain groups, such as illiterates and people without an Internet connection [4]. Those who do have the necessary equipment and skills to access online support groups can encounter a variety of disadvantages.

First, there are disadvantages that can be attributed to the specific characteristics of online asynchronous communication. Among these is the inability to make use of non-verbal cues through the Internet making it more difficult to detect some nuances of communication [4]. Another aspect is the possible time lag between the time an individual poses a question and receives a response [9]. Finally, it has also been suggested that many forums are so active that it can be very hard to keep up with all postings [10].

Second, there are disadvantages that are linked with the lack of control on the quality and validity of the information that is exchanged in online support groups. Members may receive misinformation or be referred to false health information [5, 11, 12].

Third, there are disadvantages related to the use and the evaluation of health care services. Among these are the concern that postings criticizing health care professionals and medical institutions might contain identifying information, like the name of a health professional and the worry that participants delay seeking regular medical help, because they fully depend on the support group [13, 14].

Finally, there are disadvantages that have to do with negative postings. Postings containing negative aspects, such as negative feelings and negative disease stories, may not be negative per se [15]. However, if other participants reinforce such feelings, a negative, so called destructive thread, may arise [16]. In addition since there are no formalized guidelines or professional facilitators for online support groups, the exchange within the group might include negative, aggressive and socially inappropriate remarks or flaming [4, 5].

Present study

Although several disadvantages of online support have thus been identified in literature, data are scarce [4, 5, 17]. Conducted studies originate mainly from the United States and it is unclear to what extent the results of these studies can be generalized. The primary purpose of the current study is to explore to what extent the disadvantages of online support groups, as mentioned in the literature, actually occur. In addition, two more research questions guide this study. First, who uses online support groups? Second, what topics are discussed and what self-help mechanisms are used in online support groups? Since this study is explorative of nature, we did not formulate working hypotheses.

To answer these research questions, we used the research technique ''content analysis''. Content analyses can provide useful and important information about conversations held without the researcher being present [18, 19].

Methods

Sample

We focused our study on online support groups for patients with breast cancer, fibromyalgia and arthritis. We have chosen to explore these three groups, because of the contrast between the illnesses (life threatening, unexplained and chronic disabling). We used the search engine Google™ and the following search keys: forum, support group and discussion group, combined with breast cancer, fibromyalgia and arthritis, to make an overview of all Dutch online support groups. In addition, we asked experts in the field of these illnesses to name all the online support groups they were aware of. In total we found 34 online support groups (10 breast cancer, 16 fibromyalgia and 8 arthritis). Those groups that were not publicly accessible or received less than 50 postings a month were excluded [5, 9]. This left a total number of eight groups (three breast cancer, three fibromyalgia and two arthritis). These groups were all self-initiated by a patient or a patients' association. In addition, all groups could be considered as self-help groups, which were not led by professionals. As most online support groups, these groups existed in a broad context of other online health resources. For example, four of the online support groups were a component of a website containing health information.

Selected support groups were studied during three consecutive months (December 2004, January and February 2005). All new postings were downloaded. Downloading was done on a daily basis to minimize the chance that postings were missed, due to removal by the moderator. In total, we downloaded 27.384 postings: 15.171 postings from the breast cancer groups, 11.281 postings from the fibromyalgia groups and 932 postings from the arthritis groups. From these sets of postings, a random sample of 500 postings was obtained from each illness group.

Measures

Characteristics of the postings and the participants

For all postings it was determined on which day and at which time of the day the posting was sent. These data were then divided into three categories: during the day (7 a.m.– 6 p.m.), during the evening (6 p.m.–11 p.m.) and during the night (11 p.m.–7 a.m.).

Each posting was coded for the characteristics of the sender, including sex, age, primary role (e.g. a patient, a family member), time that had elapsed since the diagnosis. Not all these characteristics could be extracted from the postings. Therefore, the so called membership profiles of online support groups were consulted as well.

The text of each posting was content coded. Three coding systems were developed for this study. The first coding system coded for topics of the postings, the second coded for the self-help mechanisms used and the third coding system was developed to detect potential disadvantages.

Topics

We isolated 12 unique coding categories for topics. Several of these were adopted from a coding system developed by Perron [20], to detect patterns of content within an online support group for caregivers of mentally ill.

Seven coding categories were directly related to the experience of being ill: diagnoses, symptoms, regular treatment, alternative treatment, regular medication, alternative medication and interaction with health care professionals.

Four other coding categories dealt with the consequences of being ill: financial issues, vocational issues, social network and issues concerning the restrictions patients experienced in everyday life. Finally, the coding category chit chat was added, because we expected many of the postings to contain off topic, everyday talk [5].

Each posting could receive one or multiple codes, based on the content of the postings. For example, the following posting contains chit chat at the beginning, but later on deals with regular medication:

> I promised my two girls that we will decorate the Christmas tree tomorrow morning. I'm curious when you will start decorating?!!! By the way, I feel pretty good today except for the aches and pains due to Arimidex. . .

Self-help mechanisms

Eight coding categories were derived from Perron [20] and included: providing information, requesting information, sharing personal experiences, providing empathy or support, gratitude, friendship and creative expression.

Potential disadvantages

These coding categories were divided into four groups.

1. Disadvantages due to online asynchronous communication: We coded if a posted question received an answer and the time passed until the first answer was received. Besides this, we coded for compensations of non-verbal communication, such as emoticons, capitals and pictures. We also coded for postings containing statements indicating that the participants missed being able to make use of non-verbal cues, like for example the opportunity to hug each other. Finally, we coded for postings containing statements indicating that participants were overwhelmed by the number of postings sent to the online support group.

2. Quality of the medical information: We first coded if a posting contained medical information and if so whether and what source was mentioned. Medical information was defined as factual information about diagnoses, symptoms, regular and alternative treatment, regular and alternative medication. Postings that contained medical information were evaluated by medical experts. Postings that derived from the arthritis and fibromyalgia groups were evaluated by a rheumatologist in training (CEIL) and by a rheumatologist (KWDB) and postings that derived from the breast cancer groups were evaluated by an oncologist (WMS). These experts coded the medical information into *conventional* or *unconventional*. According to Culver, Gerr, and Frumkin [21], conventional information is information that is consistent with generally accepted medical practice, based on either published, peer-reviewed scientific evidence or standard practice. For postings containing unconventional medical information, the medical experts also coded if the information was potentially dangerous to others.

3. Disadvantages related to the use and the evaluation of health care services: The first coding category ‘’criticism on health care services’’ was formulated, to detect the occurrence of postings containing negative comments on medical institutions, health care professionals or (the result of) treatments [14]. We were especially interested in the percentage of these postings that contained identifying information, like the name or a description of a health care professional. We also coded for postings in which participants urged each other to ask for another medical specialist, for a different type of treatment or for a second opinion. Finally, we coded for postings containing clues that participants delayed visiting a health professional, because of the advice provided in the online support group.

4. Negative postings: Postings were coded for the presence of negative feelings such as fear, anger and sadness concerning the illness. In addition, we looked at the responses to such postings. We coded for a destructive thread if more than 50% of the responses contained statements that reinforced the negative feelings of the initial sender. We also coded for postings which displayed a lack of understanding of fellow participants and postings in which participants were criticized or scolded at.

Each posting was coded for the presence of the disadvantages mentioned. If a disadvantage appeared several times in a posting, the disadvantage was only counted once [6].

Procedure

The first author and an independent coder separately coded a random half of the postings. As advised by Finn [5] the coders did not code each posting on its own merits, but in relation to the thread as a whole. According to Finn [5] more valuable judgments of codes can be made if postings are analyzed in relation to other postings, rather than out of context. The coders were trained using a sub-sample of the postings from the online support groups under study.

To check inter-rater reliability the coders both coded 10% of the postings. Inter-rater reliability was calculated using Cohen's kappa, which ranged from 0.66 (alternative medication) to 1.00 (financial issues), indicating acceptable levels of inter-rater reliability.

Results

Characteristics of the postings and the participants

Most of the postings were posted on weekdays (80%) and during daytime (59%). No differences between the diseases were found.

The 1500 postings in our sample originated from 347 unique participants. The average number of postings per person was 4.3 (range: 1–50). However, most of the participants (n=207) only posted one or two messages, indicating a small number of active participants. In Table 1 the characteristics of the participants are presented.

The far majority of participants were women and identified themselves as patients. Mean age of the participants was 38 years. Elderly patients (>65 years) did not participate in the support groups. Most of the participants, who identified themselves as patients, indicated that they were diagnosed more than one year ago (64%).

Table 1 Characteristics of the participants

	Breast cancer (n=88)		**Fibromyalgia** (n=87)		**Arthritis** (n=172)		**Total** (N=347)	
Sex (n, %)								
Female	81	95%	84	98%	128	85%	293	91%
Male	4	5%	2	2%	23	15%	29	9%
Unknown	3	-	1	-	21	-	25	-
Age in years								
Mean (SD)		39 (8.0)		39 (9.0)		36 (9.6)		38 (8.8)
Minimum		27		21		21		21
Maximum		65		57		60		65
Unknown (n)		29		38		133		200
Primary role (n, %)								
Patient	66	90%	71	99%	134	87%	271	91%
Presumable patient	1	1%	1	1%	9	6%	11	4%
Family member	1	1%	-	-	3	2%	4	1%
Acquaintance	2	3%	-	-	2	1%	4	1%
Health care professional	1	1%	-	-	1	1%	2	1%
Student / researcher	-	-	-	-	4	3%	4	1%
Moderator	2	3%	-	-	1	1%	3	1%
Unknown	15	-	15	-	18	-	48	-
Time passed since diagnosis (n, %)								
No diagnosis yet	1	2%	1	4%	9	13%	11	7%
< 1 year	30	51%	4	17%	10	14%	44	29%
> 1 year	28	47%	18	78%	51	73%	97	64%
Unknown	29	-	64	-	102	-	195	-

Topics

Table 2 presents an overview of the topics discussed by illness group. Because each posting could contain multiple topics, the total percentages add up to more than 100%.

Many postings contained chit chat. A minority of the postings contained topics related directly to the illness or to the consequences of being ill. However, significant differences between the three illness groups were observed: the participants of the arthritis groups used less chit chat, and discussed relatively more about their illness and about the consequences of being ill, than the participants of the breast cancer and the fibromyalgia groups.

The most frequent illness related topics discussed were regular medication or regular treatment and symptoms. Only a small number of the postings discussed alternative treatment and alternative medication. With regard to the consequences of being ill, the most frequent topic was restrictions in daily life: ''I think that the most unpleasant thing about this illness really is, the fact that you are hampered. I hardly ever go out these days. I can only walk with difficulty you see. . .''

Table 2 The presence of topics in the postings in the three illness groups

Topics	**Breast cancer** (n=500)		**Fibromyalgia** (n=500)		**Arthritis** (n=500)		**Total** (N=1500)	
	n	**%**	**n**	**%**	**n**	**%**	**N**	**%**
Illness related topics								
Regular medication***	17	3%	20	4%	244	49%	281	19%
Regular treatment***	113	23%	16	3%	44	9%	173	12%
Symptoms***	31	6%	17	3%	121	24%	169	11%
Diagnoses***	40	8%	11	2%	58	12%	109	7%
Health care professionals***	19	4%	10	2%	38	8%	67	5%
Alternative treatment***	-	-	13	3%	40	8%	53	4%
Alternative medication**	2	<1%	1	<1%	11	2%	14	1%
Total illness related topics***	150	30%	64	13%	363	73%	577	38%
Consequences of being ill								
Restrictions***	73	15%	55	11%	266	53%	394	26%
Financial issues***	9	2%	9	2%	42	8%	60	4%
Vocational issues	15	3%	16	3%	28	6%	59	4%
Social network	18	4%	7	1%	15	3%	40	3%
Total consequences of being ill***	97	19%	75	15%	298	60%	470	31%
Chit chat***	253	51%	354	71%	26	5%	633	42%

*p<0.05 **p<0.01 ***p<0.001 for Chi-square tests comparing the three illness groups

Self-help mechanisms

Table 3 presents an overview of the used self-help mechanisms by illness group. The most common type of self-help mechanism used in all three illness groups was sharing personal experiences, including introductions of new participants and updates of what already active participants experienced in daily life. The second mechanism most used was providing information. Many postings that provided information also contained personal experiences of the sender: "My hair is as straight as it was before but unfortunately totally grey. I'll take that. I'm so tired of wearing wigs."

Empathy or support was the third most frequent type of self-help mechanism used. Postings in which empathy or support was offered, included comments of encouragement and sharing, like ''So glad you are feeling better now'' and ''I know. . . these kinds of drugs can really knock a person out!''. In 16% of the postings information was requested. The participants mainly asked questions about how other members were doing and if they had similar experiences. Less often, the participants requested for objective or factual information or advice. Remarks of gratitude occurred in 8% of the postings. These postings were usually posted as a response to previous postings in which information, advice or support was provided. Also in 8% of the postings, comments were included that specifically expressed experiencing friendship: "It's nice to know that I can come here to caring people like yourself with problems of their own for comfort or just to vent. Thank you for taking time for me." When comparing the three illness groups, it appears that the participants of the fibromyalgia groups make less use of self-help mechanisms in general. The participants of the arthritis groups focus mainly on exchanging (personal) information. In addition, among the participants of the arthritis groups, posing questions is more common. The presence of postings containing comments of empathy and support was by far the highest in the breast cancer support groups.

Table 3 The presence of self-help mechanisms in the postings in the three illness groups

Self-help mechanisms	Breast cancer (n=500)		Fibromyalgia (n=500)		Arthritis (n=500)		Total (N=1500)	
	n	%	n	%	n	%	N	%
Personal experience***	256	51%	151	30%	354	71%	761	51%
Providing information***	178	36%	131	26%	348	70%	657	44%
Empathy or support***	198	40%	117	23%	131	26%	446	30%
Requesting information***	59	12%	39	8%	135	27%	233	16%
Gratitude***	23	5%	25	5%	78	16%	126	8%
Friendship***	50	10%	70	14%	3	1%	123	8%
Creative expressions***	6	1%	18	4%	-	-	24	2%

*p<0.05 **p<0.01 ***p<0.001 for Chi-square tests comparing the three illness groups

Potential disadvantages of online support groups

Disadvantages due to online asynchronous communication

Table 4 shows the frequency with which the disadvantages due to online asynchronous communication appeared in the postings. In total, 233 postings contained a question. Generally questions received an answer within 24 h; 15% of the questions did not receive a response.

Members compensated for the lack of non-verbal cues by making use of emoticons (35%) and other ways of compensation like excessive punctuation (38%), capitals (6%) and the transformation of words into specific support group language (19%). One of the breast cancer support groups even had a dictionary for newcomers, in which they could find that a ''marmot'' was in fact a wig.

A statement indicating that the participant missed being able to make use of non-verbal cues, was only found in one of the postings. In four of the postings from the most active breast cancer support group under study, a statement was detected indicating that the participant was overwhelmed by the number of postings sent to the online support group: "Perhaps I don't react that often anymore, but I still read the postings each day. Otherwise I can't keep up with the developments. . ."

Table 4 Disadvantages due to online asynchronous communication

	Breast cancer (n=500)		**Fibromyalgia** (n=500)		**Arthritis** (n=500)		**Total** (N=1500)	
	n	**%**	**n**	**%**	**n**	**%**	**N**	**%**
Number of postings containing a question (n, %)***	59	12%	39	8%	135	27%	233	16%
Questions not answered (n,%)	8	14%	4	10%	24	18%	36	15%
Lag time (in days)								
Mean (S.D.)	0.04 (0.28)		0.56 (1.46)		0.97 (2.36)		0.66 (1.92)	
Minimum		0		0		0		0
Maximum		2		8		18		18
Substitution of non-verbal cues (n,%)								
Emoticons***	186	37%	323	65%	21	4%	530	35%
Other substitution***	331	66%	386	77%	185	37%	902	60%
Missing non-verbal cues (n, %)	1	<1%	-	-	-	-	1	<1%
Overload of postings (n,%)*	4	1%	-	-	-	-	4	<1%

*p<0.05 **p<0.01 ***p<0.001 for Chi-square tests comparing the three illness groups

Quality of the information

Only a small number of the postings contained medical information (Table 5). The participants of the arthritis groups exchanged relatively more medical information than the participants of the other two groups.

Most postings containing medical information were classified as conventional. None of the postings contained information that was potentially dangerous to others.

In almost half of the postings that contained medical information a source was mentioned. However, most of the sources mentioned were lay sources (61%), such as personal experiences and personal communication.

Table 5 Quality of the information

	Breast cancer (n=500)		**Fibromyalgia** (n=500)		**Arthritis** (n=500)		**Total** (N=1500)	
	n	**%**	**n**	**%**	**n**	**%**	**N**	**%**
Medical information***	25	5%	13	3%	127	25%	165	11%
Quality of the medical information								
Conventional	22	88%	9	69%	99	78%	130	79%
Unconventional	3	12%	4	31%	28	22%	35	21%
Potentially dangerous information	-	-	-	-	-	-	-	-
Source mentioned	13	52%	5	39%	62	49%	80	48%

*p<0.05 **p<0.01 ***p<0.001 for Chi-square tests comparing the three illness groups

Disadvantages related to the use and evaluation of health care services

Table 6 shows the frequency with which the disadvantages related to the use and evaluation of health care services were detected in the postings.

In 37 postings (2%) health care services were criticized. In most of these postings criticism about health care professionals was uttered: "Unfortunately my doctor did not take me, as a young woman, seriously. I felt it during breastfeeding. He convinced me that it was because of my breastfeeding, but eventually I was diagnosed with breast cancer." However none of these postings contained the name of a health care professional, and in only one posting the name of a medical institution was given.

In less than 1% of the postings (n=13) statements were found containing advice as to switch to another health care professional, another type of treatment or to ask for a second opinion. Usually these postings responded to previous postings containing criticism of health care services.

In only four of the 1500 postings indications were found that the senders relied too much on the online assistance instead of seeking professional help. In the case of three of these four postings other participants instantly reacted with the advice to contact a health care professional: "The only advice that I can give is. . . 'be sensitive and go to a doctor'. Good luck!"

Table 6 Disadvantages related to the use and evaluation of health care services

	Breast cancer (n=500)		**Fibromyalgia** (n=500)		**Arthritis** (n=500)		**Total** (N=1500)	
	n	**%**	**n**	**%**	**n**	**%**	**N**	**%**
Comments on health care services	14	3%	11	2%	12	2%	37	2%
Comments on medical institutions	5	36%	2	18%	1	8%	8	22%
Comments on health care professionals	12	86%	10	91%	9	75%	31	84%
Comments on (the result of) treatments	2	14%	-	-	2	17%	4	11%
Postings with identifying information*	5	36%	1	9%	-	-	6	16%
Name of health care professional	-	-	-	-	-	-	-	-
Description of health care professional	3	60%	1	100%	-	-	4	67%
Name of medical institution	1	20%	-	-	-	-	1	17%
Description of medical institution	2	40%	-	-	-	-	2	33%
Urging for other professional, treatment or second opinion**	1	<1%	2	<1%	10	2%	13	1%
Delay seeking professional help*	-	-	-	-	4	1%	4	<1%

*p<0.05 **p<0.01 ***p<0.001 for Chi-square tests comparing the three illness groups

Negative postings

In Table 7 the results are presented concerning the negative postings exchanged in online support groups.

In total 9% of the postings contained negative feelings related to the illness. Sadness was the negative feeling most frequently uttered in all three illness groups. A ''destructive'' thread was found for 25% of the postings that contained negative feelings:

> Cry. . . It's though... I want so much, but my body just does not want to cooperate. It's going worse and worse and I can do less each day.
>
> I share your feelings!! It is awful to know that fibromyalgia is a progressive disease!! Last week my boyfriend reminded me that I could do even less this year, than I could last summer…

Only 20 postings contained negative remarks directed at other participants. Most of these remarks showed a lack of understanding of a statement made earlier by another participant of the online support group.

Table 7 Negative Postings

	Breast cancer (n=500)		**Fibromyalgia** (n=500)		**Arthritis** (n=500)		**Total** (N=1500)	
	n	**%**	**n**	**%**	**n**	**%**	**N**	**%**
Negative feelings**	53	11%	28	6%	61	12%	142	9%
Fear*	18	34%	2	7%	19	31%	39	27%
Anger***	16	30%	14	50%	3	5%	33	23%
Sadness	27	51%	14	50%	40	66%	81	57%
Destructive thread*	20	38%	7	25%	9	15%	36	25%
Negative remarks*	5	1%	3	1%	12	2%	20	1%
Lack of understanding	3	1%	2	<1%	8	2%	13	1%
Criticism	4	1%	1	<1%	3	1%	8	1%
Scolding	-	-	-	-	1	<1%	1	<1%

*p<0.05 **p<0.01 ***p<0.001 for Chi-square tests comparing the three illness groups

Discussion

Who uses Dutch online support groups?

Given the enormous number of postings encountered, it can be concluded that online support groups are popular. The relative frequency with which the participants contributed from each illness group, however, differed significantly. Most of the postings downloaded, were sent by participants of the support groups focusing on breast cancer and fibromyalgia. The participants of the arthritis groups only contributed 3% of the total number of postings. These proportions are in line with those found by Davison and Pennebaker [22] in their study of online support groups. According to Davison and Pennebaker [22] the explanation for these differences must be sought in the characteristics of the illnesses such as cause and consequences. The high participation rate of the participants of the breast cancer groups might be due to the fact that breast cancer is a life threatening disease, whereas the high participation rate of the participants of the fibromyalgia groups, might be due to the ambiguity of this illness. Additionally, because of the high level of public empathy for breast cancer there has been a lot of media attention for online support groups for breast cancer patients. This might have led to the relative high participation rate of breast cancer patients compared to the other patient groups.

Most of the postings in our sample were sent during working hours. This is in contrast with studies derived from the USA, in which most of the postings were sent at times traditional sources of support have limited availability or are not available at all [7, 23-25]. Although it is not possible from this study to determine whether the use of online support groups leads to decreases in other primary relationships as suggested by Kraut et al. [26], our results suggest this is not the case. In the evening when the family members are at home from work or school, the use of online support groups reduces.

Although the number of postings were high, they were posted by relatively few participants. These results are in line with results of previous studies focusing on online support groups [7, 20, 21, 23, 27]. On the basis of these results it can, however, not be concluded that only a small number of patients make use of online support groups. Occasional participants and so called ''lurkers'' – those who do not actively participate in the public dialogue – are reported to make up a huge proportion of online support groups. It is estimated that the lurker-to-poster ratios run as high as 100:1 [8]. Further research among Dutch patients to find out what percentage of them is actively or passively using online support groups is in preparation.

The online support groups under study were mainly used by women (91%), who identified themselves as patients. These results were to be expected, since the illnesses included in our study, are predominated by female patients. The mean age of the participants was 38. This is relatively young, when comparing it to the mean age of the patients of the three illness groups in the Netherlands. Although it was expected that mainly people who were recently diagnosed participated in online support groups, it must be concluded that patients in all different stages of their illness were participating in these groups.

What is exchanged by the participants?

Strikingly, we found that a substantial part of the postings in the breast cancer and fibromyalgia groups contained chit chat. With the exception of the study of Finn [5], no other studies coded for chit chat. It is difficult to compare our results, because Finn [5] coded each posting in one coding category only. His results showed that 11% of the postings in his sample had as ''primary focus'' chit chat. Postings containing chit chat provide a normalizing experience [5]. In addition, we suggest that these postings also contribute to the establishment of trust, warmth and concern among group members, because interpersonal impressions are often exchanged.

The participants of the arthritis groups used relatively less chit chat, but mostly sent ''on-topic postings''. When focusing on the ''on-topic'' postings of all three illness groups it appears that restrictions in daily life, regular medication and regular treatment were the topics most often discussed.

Self-help mechanisms facilitate the development of supportive or helping relations among participants of online support groups [20]. Of the self-help mechanisms coded, sharing of personal experiences, provision of information and empathy and support, were the most common. The ranking found in this study is similar to the one found by Perron [20] in his study among caregivers of mentally ill.

To what extent do the potential disadvantages of online support groups actually occur?

To our knowledge, this study is the first comprehensive study that empirically established how often potential disadvantages of online support groups actually occur. In general it can be concluded that the potential disadvantages were only detected in a very small number of postings.

Disadvantages due to online asynchronous communication

It is deemed disadvantageous that it remains unclear for the participants of online support groups if and when to expect a reaction to a posted question. However, this worry should not be overstated, because our study revealed that most of the postings containing a question, received a response within a reasonable period of time.

Missing of non-verbal cues and overload have been mentioned by several authors as potential disadvantages. Our results suggest, however, that the participants adapt to these specific features of asynchronous online communication. Compensation for the lack of non-verbal cues, such as emoticons, were very frequently used and seemed satisfactory. Only one statement was found that indicated that non-verbal cues were missed. In addition, hardly any indications for overload were found. It might be that individuals who are active in online groups make use of certain strategies for coping with overload. Jones et al. [28] found that as the overloading grows users are more likely to only respond to simpler messages, are more likely to generate simpler responses and are more likely to end active participation. However, content analysis is not the most suitable manner to detect these problems. To study this, participants of online forums should be consulted directly.

Quality of the information

Probably the most feared disadvantage of online support groups is the lack of control on quality of information. Our study reveals, however, that actual medical information was only exchanged in a small number of postings. Most likely this has to do with the empathic function of online support groups: physicians are there to provide the facts, but other patients can tell you what it really feels like and what to expect next [29]. Preece [29] stressed that a balance between empathic and factual communication must be supported in online communities. Namely, people wanting ‘‘the facts’’ about their illness should be served in an efficient way in online support groups too. However, we should also consider the fact that online support groups exist in a broad context of diverse online health resources. The online consumer is not a passive recipient: they use multiple information sources [30]. Future research among patients must reveal if participation in online support groups caters for both the empathic and the information need, considering the fact that only little medical information is exchanged in the online support groups under study.

Despite the fact that the medical information provided in the postings was most often based on personal experience or personal communication of non-medical trained participants, most postings containing medical information were classified by experts as conventional. None of the postings containing medical information were considered as potentially dangerous to others. It can thus be concluded that this feared disadvantage of online support groups is unfounded.

Disadvantages related to the use and evaluation of health care services

One of the major concerns among health care professionals is that users of online support groups express criticism concerning health care services or individuals [14]. However, our study revealed that only in a minimal number of postings health care services were criticized. Of these postings only a few contained either a description of a health care professional or a description or name of a medical institution. In accordance with the rules of most of the online support groups, the names of health care professionals were not mentioned at all in the postings included in our sample.

Neither were there many indications for participants urging each other to switch to another health care professional or to ask for a second opinion.

Finally, only four of the postings contained clues that participants delayed visiting a health professional. Although these results indicate that delay due to online support groups only rarely occurs, additional research among participants and health professionals is needed.

Negative postings

Our study reveals that the expressions of negative emotions, such as anxiety, anger and sadness are limited and seldom result in a destructive thread.

Also flaming was not frequently found in contrast to the concern raised in literature [4]. In accordance with the study of Finn [5] the negative remarks that were posted were, with the exception of one posting, not considered as humiliating. The posting that did contain terms of abuse was obviously posted by someone who was not a regular participant of that support group. Of course, by means of a content analysis we could not find out what the participants felt about the content of the postings. Some of them might have felt offended by postings, we did not consider as negative.

Limitations of the present study

Previous studies on online support groups have nearly always focused on only one illness, which might limit generalization of the results. The added value of this study is that we included several online support groups concerning three different illness groups.

However, it is important to also be aware of the limitations of the present study. First of all in the online support groups studied, the participants had the option of sending each other private postings. We do not know anything about the extent to or the content of the exchange taking place in these private dialogues. Further, it might be that in the online support groups, postings containing disadvantages, were removed by the moderator before we had the chance to download these postings. However, because we downloaded all new postings on a daily basis this chance is minimal. In addition, all judgments were made on the basis of an analysis of the content of the postings. Although this is a valuable method, not all aspects concerning online support groups can be studied by means of a content analysis. For example, we do not know which outcomes are experienced by the target group as a result of participation. Other studies do report on these outcomes: for example Radin [31] conducted a case study on an online support group for native English speaking breast cancer patients. The participants of this group successfully managed to convince the New Zealand Health Minister to provide expensive new treatment, Herceptin®, through its national health system. In our opinion, aspects of online support groups such as outcomes should be studied by obtaining information from participants of online support groups directly. Finally, the results of this study are limited by the inclusion of online support groups for three specific somatic illnesses only. Given the fact that these online support groups differ amongst themselves, it is most likely that these groups also differ from online support groups for other types of diseases. The extent to which the results of this study are representative for online support groups aimed at patients with a mental disease, a sexually transmitted disease or a disease associated with high-risk behavior is not known. For example, studies on other diseases such as HIV/ AIDS might have a different kind of outcome because of the social stigmatization involved. In addition, we only included illnesses that mainly affect women. We do not know to which extent the results are also representative for online support groups dominated by male participants.

Conclusions

The various disadvantages that were mentioned in literature could not be confirmed by the present empirical research. Therefore this research suggests that online support groups are a viable option for support.

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3

Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis and fibromyalgia

C.F. van Uden-Kraan
C.H.C. Drossaert
E. Taal
B.R. Shaw
E.R. Seydel
M.A.F.J. van de Laar

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Abstract

Ever since the rise of online support groups it has been presumed that there is an empowering effect from patients' participating in these groups, despite a lack of evidence to back up this assumption. In this study we explored if, and in which ways, patients feel empowered by participation. Additionally, we studied which empowering and disempowering processes take place in these groups. To accomplish this aim, we interviewed 32 participants of online support groups. This analysis revealed the following empowering processes: exchanging information, encountering emotional support, finding recognition, sharing experiences, helping others, and amusement. Disempowering processes were mentioned far less often. Empowering outcomes mentioned were being better informed; feeling confident in the relationship with their physician, their treatment, and their social environment; improved acceptance of the disease; increased optimism and control; enhanced self-esteem and social well-being; and collective action. This article demonstrates that participation in online support groups can make a valuable contribution to the emergence of empowered patients.

Introduction

People often join support groups when they find themselves in stressful circumstances, such as having a serious health condition. With the increase in access to and the popularity of the Internet, the opportunity to join support groups online has arisen. Because of the specific benefits of online support groups as compared to face-to-face support groups, such as the absence of geographical barriers, 24-hour availability, reasonable cost, and anonymity [1-4], and the increasing number of Internet users, it can be anticipated that the number of people sharing their concerns and experiences online will increase.

Ever since the rise of online support groups, much has been expected of the potential empowering effect of taking part in these groups for patients [5-8]. However, thus far there is no direct evidence of the effects of participation in online support groups on patient empowerment [9, 10]. Empowerment reflects the belief in patient autonomy, and the right and responsibility of patients to access health information and to make their own health-related decisions [11, 12].

Empowered patients are considered to be successful in managing their condition, collaborating with their healthcare providers, maintaining their health functioning, and accessing appropriate and high-quality care [13]. According to Roberts [14], patient empowerment entails a redistribution of power between patients and physicians, such that patients are more in control over their health and in their encounters with healthcare professionals.

An explanation for the deficiency of studies investigating the effect of participation in online support groups on patient empowerment might be that there remains a great deal of ambiguity with regard to the precise nature of patient empowerment [15]. Although patient empowerment is considered to be one of the key principles in the field of public health [16, 17], the concept is inconsistently defined [18, 19].

First, empowerment is a multifaceted concept. A number of characteristics are associated with the concept of empowerment, such as disease knowledge, locus of control, trust, and choices [9]. This makes it difficult to think of empowerment consistently [20]. Therefore, Gibson [20] suggests that empowerment is best understood as the absence or decrease of concepts such as powerlessness, helplessness, hopelessness, alienation, victimization, subordination, oppression, paternalism, loss of a sense of control over one's life, and dependency. Second, empowerment is a multilevel construct that can occur at different levels, including individual, group, and community [14, 19]. Individual patient empowerment refers to an individual's own personal sense of efficacy, esteem, or personal competence, and an individual's ability to make personal life decisions [14, 21]. Group empowerment refers to aggregations of individuals who come together to share knowledge and raise their critical consciousness, whereas community empowerment refers to social/ political activities in which individuals or groups participate [14]. Third, empowerment is considered as both a process through which individuals or groups take control over their lives and managing disease, as well as an outcome—a state of psychologically being enabled [11, 14]. Finally, patients themselves also have different ideas about what it means to be empowered. According to Broom [22], empowerment is unique to the individual patient. The experience of empowerment can fluctuate over time, depending on the context [19, 23].

Within the context of online support groups, a couple of studies have focused on the concept of patient empowerment. The focus of most of these studies was to identify the processes that take place in online support groups, with or without specifically referring to these processes as empowering. Primarily, content analyses of postings exchanged in online support groups were conducted to identify ways in which the participants empowered each other [2, 3, 24-26]. Study results indicated that the main empowering processes that took place within the support groups were the exchange of knowledge and the sharing of experiences. Although these content analyses bring up relevant information about the types of empowering processes that take place, these studies do not reveal which of these processes are considered as empowering by the participants themselves. Considerably fewer studies asked for the perspective of the participants themselves [27-29]. In those studies that have been conducted, the participants were asked to indicate the empowering processes that took place in online support groups. These studies revealed similar processes as the content analyses did, such as the exchange of information and the exchange of social support. Studies in which empowering outcomes are studied from the perspective of the participants have only recently been conducted [22, 30-32]. These studies showed that participants profit from participating in online support groups in terms of feeling better informed, feeling more in control, and having an improved relationship with their physicians.

However, in our opinion, the empowerment concept is operationalized in a limited fashion within the abovementioned studies. Some studies claim that they study empowerment, but they focus mainly on one aspect of the empowerment concept, such as the doctor-patient relationship. In our study, we enlarged the concept of empowerment by conducting a systematic inventory of this concept from the participants' perspective. In addition, previous studies on online support groups have nearly always focused on only one illness. For the most part, online support groups for patients with a life threatening illness have been studied, which might limit generalization of the results. Because of this, we included several online support groups concerning three different illness groups: arthritis, fibromyalgia, and breast cancer, in a non-English-speaking region.

The primary purpose of the current study was to explore if and in which ways patients feel empowered by participating in online support groups. Because we consider empowering outcomes to be inextricably tied to empowering processes, we focused on empowerment as a process as well as on empowerment as an outcome. We decided to explore empowering as well as disempowering processes, because disempowering processes are expected to have a negative influence on the positive consequences of empowering processes [33].

This study focused on two research questions: First, which empowering and disempowering processes take place in the online support groups, according to the participants? Second, which empowering outcomes are experienced by the participants of online support groups?

Methods

Sample

We searched the Internet with the search engine Google™ to identify all Dutch online support groups for patients with breast cancer, fibromyalgia, or arthritis that were publicly accessible and active (receiving > 50 postings a month). In total, we found 9 groups (4 breast cancer, 3 fibromyalgia and 2 arthritis). We asked the webmasters of these groups for permission to approach the participants for the study. The webmasters of 8 groups (3 breast cancer, 3 fibromyalgia and 2 arthritis) supported our study. We sent postings to these groups in which we asked the participants to contact the researcher if they were willing to take part in the study. Criteria for inclusion were listed in the postings. The participants had to be either breast cancer, fibromyalgia, or arthritis patients, and had to engage passively or actively in online support groups (the medical diagnoses of the interviewed participants were not verified with their doctors). In total, 44 individuals were willing to participate in the study and met the criteria for inclusion. Four of the participants withdrew from participation because of aggravation of their illness, and one respondent did not respond to a follow-up e-mail. This left 39 participants eligible for the study. Because of time constraints of the researcher, the final sample was comprised of the 32 patients who responded first to the call (10 breast cancer, 11 fibromyalgia, and 11 arthritis patients).

Measures

We used a semistructured interview schedule to allow flexibility, individual contextualization, and probing of issues that arose [34]. Areas explored included the reasons for participating in an online support group, the participants' opinion about the support group in which they participated, the empowering and disempowering processes the participants experienced during their participation, and the empowering outcomes experienced by the participants as a result of joining an online support group.

Procedure

The participants were interviewed in their homes or at another place they preferred, with the exception of 3 patients who were interviewed by telephone. The interviews were audiotaped with the prior consent of all participants, and transcribed verbatim. The interviews lasted between 45 minutes and 2 hours.

Data analysis

Data were analyzed by two coders using inductive analysis. According to Patton [35], inductive analysis means that the patterns, themes and categories of analysis come from the data: "They emerge out of the data rather than being imposed on them prior to data collection and analysis" (p. 390). Both coders separately read 12 of the transcripts entirely, several times, to familiarize themselves with the data and to identify emerging themes by which the data could be examined. Then the two coders met to discuss their findings to resolve differences. On the basis of these analyses, the coders together developed a thematic framework. All transcripts were coded using this thematic framework independently by the two coders. Results were discussed to fully reach consensus, following which themes were refined and sub themes were identified [36]. The final step consisted of revisiting the literature and seeking conceptual tools that could be used to make sense of the themes and sub themes that emerged from the data [22].

All quotes provided in this article were translated from Dutch into English by a native English-speaker. To ensure anonymity, we removed all identifying information from the quotes.

Results

Demographics of the participants

The majority of the participants were women (n=30). The mean age of the participants was 43 years (SD 12.3 years) with a range of 21 to 75 years. Of the total group, 26 were either married or living with someone. In total, 5 participants had a lower level of education, whereas 14 had a medium level of education and 13 had a higher level of education. Most participants were not employed or not able to work (n=25). The median disease duration of the participants was 2 years, with a range of 0 to 19 years.

Use of online support groups

The median duration of participation in an online support group was 1 year, with a range of 0 to 6 years. One of the respondents could not remember when he first joined an online support group. Some of the participants (n=8) joined the online support group directly after they were diagnosed, or even before they were officially diagnosed (n=4).

The most frequently mentioned way in which the participants had found an online support group was while surfing the Internet looking for health-related information (n=18). Other ways mentioned were hearing about the online support group from a patient organization (n=6) or family member (n=3), or via direct marketing by active members of the online support group (n=2).

Most participants (n=22) were highly active users who visited their online support group at least once a day. All participants were active users in the sense that they frequently contributed postings, instead of only reading postings.

Empowering processes

In this section we present the empowering processes that emerged from the analysis of the transcripts.

Exchanging information. The participants noted that useful information is exchanged about numerous medical topics (e.g., the course and symptoms of the disease, medication, treatment) as well as about topics that dealt with the consequences of being ill (e.g., restrictions in daily life, financial and vocational consequences). Several participants noted that they would have received this information anyhow. However, by means of participation in the online support group they received the information more quickly:

> I would have found out about that anyway. I don't think you need a forum for that, but the great advantage is the speed with which it happens. Also the information you happen to be looking for is generally available.

According to most participants, the information provided on the forum was understandable because it was formulated in their "own language": "On the [name of the online support group] are really good explanations, extensive explanations and no 'medic's speak,' if you understand what I mean." In addition, most participants mentioned that the information provided was tailored to their personal needs.

Encountering emotional support. All participants felt emotionally supported through participation. The participants described the emotional support provided by the support group in several ways: "It is like being wrapped in a warm blanket" and "You get so much support, it was just a warm bath." Nearly all of the participants mentioned a sense of belonging to the group. They had actually made friends through their participation in the online support group and most of them even reported face-to-face encounters with one or more people they had met online.

Finding recognition and understanding. Almost all participants mentioned that the main reason for participating in an online support group was recognition: "Particularly with regard to recognition. What I feel, does someone else in the same situation feel that too?" They appreciated the opportunity of comparing themselves with others. For some this proved to them "that they were not crazy," and it made the participants feel "less alone" in coping with their disease: "I once mailed about the nausea, like hey, who else feels sick? Honestly, in one day I already received 25 reactions to my first mail. Well it's just good to hear you're not the only one."

Besides lateral comparison, downward comparisons (looking at people who are doing worse) were stated to be especially helpful:

> Sometimes I compare myself to one of the others. Someone who simply . . . yes with whom the disease is not under control and so. Then I think, things are not turning out that bad for me after all.

In addition, most of the participants also came up with the concept of understanding. They explained that they felt better and easily understood by the other members of the online support group. This was mainly because they shared the same experiences:

> I do have the feeling that they understand me better, the way I feel. Yes, one day I feel good and the other day I'm very tired and everything is bothering me. And for someone who

> doesn't have this I think it is hard to understand that it can be so variable. And on the forum they do understand this better.

Sharing experiences and helping others. The participants appreciated the opportunity to share their personal experiences in an online support group, especially because they had the feeling that it was "allowed over there to talk about their disease." With people in their social environment, it was discussed too often already. Some of them had the feeling that other people got tired of talking about their disease: "And I also noticed that people got fed up with you. They don't want to discuss your cancer with you all the time, they also want to talk about their own garden."

Others preferred to share their experiences in the online support group because they were afraid that people in their social environment would otherwise worry too much: "I'm afraid that other people immediately think that I'm really down and that they really have to worry or something."

All participants pointed out during the interview that one of the reasons for them to participate in an online support group was to help other members: "You also try to help others, that's why you're on the forum." The participants mentioned several ways of helping others: "providing information and advice," "providing support," and "sharing your own experiences." Most participants explained that they tried to pep up the other members by sharing their own experiences: "And also to carry on putting courage into people. I was in a bad way, but that was at least four years ago."

Amusement. For most fibromyalgia and breast cancer patients, and a few of the patients with arthritis, visiting the online support group had become a part of their daily routine. They saw participation in the online support group as a way to relax, or visited the online support group out of curiosity: "You should really see it as a book. You're in the middle of a story. And when you put the book down at night, you really want to continue reading the next morning." Most fibromyalgia and breast cancer patients noted that they could also share their "daily experiences that did not have to do with the disease" and "humor" on the forum.

Disempowering processes

Although most participants were very positive about the support group, some disempowering processes were also mentioned.

Being unsure about the quality of the information. Some of the participants were concerned about the quality of the information and about the possibility of receiving bad advice:

> The danger is that people tell one another tales all the time, spread information that isn't tested and which you can't base on anything. Also wrong advice. And there's a lot of wrong advice being given and playing the role of a doctor on a forum like that.

However, others mentioned that the information on the forum was of high quality. In addition, in the rare case that misinformation was posted, they said there was always someone who intervened: “I think the quality of the information is high. And if something’s not quite right, there’s always somebody who will correct it. I think that’s what gives our forum that extra edge.”

Some of the participants mentioned that they did not always receive the information they were looking for, or that they sometimes had to deal with an overload of information. Participants who were active in an online support group for a longer period of time mentioned that they “outgrew” the forum, because certain questions and topics kept reappearing.

Being confronted with negative sides of the disease. Some participants noted that it was difficult to be confronted with the negative sides of the disease:

> Of course you read a lot of awful things, women to whom the cancer returns or metastases in bones and liver. In fact, you do not want to know about those things. But yes, you are confronted with the fact that it is a life-threatening disease. And that it doesn’t end well for everyone.

All participants of the online support groups for breast cancer patients mentioned that they found it difficult when another participant of the online support group died: “And what was really difficult, of course, was when one of our forum members died. That was really difficult for a lot of women.” However, for none of the participants was this a reason to leave the online support group.

Being confronted with complainers. Some of the participants were irritated by people who constantly complained or talked about themselves too much: “They [the participants] can also be a bit of a pain sometimes, with any futility they start on about it again.” Others put this into perspective, by mentioning that everyone experiences pain in a different way, or by realizing that they had dealt with the disease for a longer period of time than the “complainers.”

Empowering outcomes

We asked the participants how involvement within online support groups had empowered them. The following themes arose from the interviews:

Being better informed. Almost all participants noted that their knowledge about their disease had increased by participating in an online support group:

> I now know all about it. When I visited my internist, he sort of wondered whether I’d had medical training. I know exactly what kinds of breast cancer there are, what kind of treatments and what the chances are of it coming back.

Most participants mentioned that they became "well-informed patients" by being a member: "I'm now more an expert than I was before. Because before we did not know what happened to us."

On the basis of information provided in the support group, most arthritis and fibromyalgia patients shared that they purchased assistive devices:

> When I just started on the forum, I read a posting about a pillow. I purchased that pillow. Normally I would have never heard about such a pillow. Because yes, a pillow is a pillow, but I have a 'horseshoe shape' pillow. Such things you normally never find out, but because of the information on the forum, I have it.

The patients who started on the forum soon after they were diagnosed or even before they were diagnosed profited most. Others mentioned that they were already well informed by their physician or by other (online) information sources before they started to participate. For them the forum only filled in the details: "I was lucky that, thanks to my own research, I already knew quite a lot, but it was the forum that helped me dot my i's."

Feeling confident in the relationship with their physician. Almost all participants mentioned that by participating in the online support group they felt more confident in the relationship with their physician. For example, some of the participants now felt able to ask their physicians questions: "I now dare to ask everything and I know at least that it is not crazy if you ask something." For others, the online support group gave them just that moral support that they now felt able to secure the attention of their physicians or to elicit more information from their physicians, e.g., concerning specific symptoms, such as lymphedema.

In general, the participants felt more prepared for a visit to their physician. This resulted from the fact that they felt better informed and because they received useful advice on the forum, like the advice to write down their questions beforehand and the advice to take someone along when seeing their physician:

> Most people clam up with their rheumatologist. You see that a lot on the forum. When you walk in there you forget just about everything. And now with the message board, you know what you have to ask and that you shouldn't go to a rheumatologist on your own.

Some of the participants also indicated that they could now better assess whether they needed to consult their physician:

> Now I'd sooner look at the message board than that I bother the rheumatologist with a question. In the initial stages, I would phone the rheumatologist about feeling so nauseous and what I could do about it. But you shouldn't do that. Of course the rheumatologist sneers a bit, that's no news to him, and he brushes it to one side with "Oh yes, side-effects. You'll have to get used to them."

It was notable that most participants did not tell their physician that they were active in an online support group, mostly because they feared a negative reaction from their physicians: "I think he probably feels we're all making ourselves mad there. But that's not the case."

Feeling confident about the treatment. For some of the individuals, participating in the online support group also improved the confidence they experienced related to their treatment. Some mentioned that they became convinced about the usefulness of the medicine prescribed to them by their physicians, thanks to the additional information provided by the other participants:

> At one point I started with [brand name medication] and I'd had it for a while but didn't dare to take it. The rheumatologist had told me that some people completely lost their marbles with this medication. So then I requested information from the members themselves . . . and then you hear it's not so bad after all.

Others noted that they were now more convinced about the decisions they had to make concerning their therapies. Based on experiences shared by other group members, one of the participants had the feeling that she could now make a more deliberate decision between several types of medication:

> I switched to another type of medicine, and I had a lot of questions about it. That is very easy on the forum, you post one question and within no time, you have a lot of reactions. Like, don't worry, stay under control and that kind of advice. These are things that you actually know, but that you maybe need as a confirmation or that you have something like eh . . . you see my doctor did it all right.

A couple of participants noted that they had asked their doctors for a different type of administration of their medicines because they heard from other participants that they would then suffer fewer side effects. Arthritis patients in particular provided each other with daily practical advice to prevent side effects like nausea. In addition, others managed to be qualified for a specific type of therapy, thanks to the fact that other participants shared their treatment protocols in the support group:

> The surgeon told me that Herceptin® was still not being issued in the country. And I said yes, but there are three participants on my forum who do get it. And then he said okay, I'll refer you to an internist. So then, you could say, he admitted it.

Improved acceptance of the disease. Nearly all participants noted that participating in the online support group helped them to cope with their disease. They mentioned that they learned to accept their disease easier and quicker:

> By participating, I learned to accept it easier. When I heard that I had rheumatoid arthritis, I was 23. Are there other young people who have it? And how will my job work out and my study? These are all questions that you have to face. And therefore the forum was helpful.

Others mentioned that they felt that the forum accompanied them in the process of coping with their disease on a daily basis. They also learned specific coping strategies from other participants, such as: “From them I learned that being positive about it helps you to endure the pain better than when you’re in a more negative frame of mind. The fun and laughs on the forum do help you get through it. Just have a laugh together.”

Confidence in dealing with the social environment. A couple of participants explained that participating in the support group helped them to “open up” about their disease to the people in their social environment. They now felt more confident to divulge details of their disease to other people:

> I now dare to admit sooner that I am at a loss with what to do or that something does not work out. I now dare to ask more easily if someone wants to help me. It made me somewhat less stubborn. When I, for example, discussed about a certain topic in the forum, I feel strengthened and more certain when I raise that topic in my social environment.

Increased optimism and control over the future. Some of the participants mentioned that they became more optimistic about their own future by reading the disease stories of other participants who served as positive role models: “For me the forum has a really soothing effect. After all, there are women there who had breast cancer 8 years, 10 years ago, and they’re doing just fine.”
Learning from the personal experiences of peers was considered as positive encouragement for other participants: “On the message board, I read that another patient had been using [name of medication] for 9 years. That made me feel less worried . . . you know . . . then you think ‘she’s still alive’.”

Sharing experiences could even lead to a feeling of regaining control over the participants’ personal lives:

> At a moment, when I have something like blow it why didn’t I qualify for [name therapy], then I hold on to [name of other participant]. She says I was operated a long time before you. I had exactly the same tumor factors and at that moment that treatment was not there anyhow… And I’m convinced that I had a good treatment. Try to hold on to that. And that does help me, yes it does.

Enhanced self-esteem. Some of the participants noted that their involvement helped them to feel and think more positively about themselves. In some case this was accomplished by advice from, and by discussing with, others in the group:

> We also discuss how to feel good about your day. How you can get to that point, while you maybe did less useful and practical things, and that you still feel like a useful nice person, with a nice timetable.

In addition, some of the participants felt more valuable because of the appreciation they received from other group members and because being active online gave them a feeling of gratification:

> And satisfaction. For example, we have one woman who came in feeling really depressed. And purely through receiving four, five personal messages and a little support in the form of a hobby, she completely bloomed. Yes, then you get a certain satisfaction.

Social well-being. Most participants noted that the number of social contacts they had increased by participating in a support group. For some of the participants, this was supplementary to the social contacts they already had, whereas others noted that these new contacts replaced the friends they lost because of their disease:

> Through fibromyalgia you lose a lot of your personal contacts. Because you can't go to birthday celebrations anymore, because you forget things, you're often too tired and so on. And in this way you rebuild your social contacts.

For a few participants it meant even more. They had the feeling that participating helped them to get out of their social isolation:

> Well, your husband goes to work, he's away from home ten hours a day. What do I do? I sit here. If I didn't have the forums, then you'd, ah yes, to put it bluntly, go mad. Because you're constantly stuck between four walls. I suppose it's your contact with the outside world.

Collective action. Participants also mentioned that they undertook action concerning their disease thanks to the forum. One of the participants said that, with the support of other members, she managed to write an objection against the decision that she was declared fit for her job again. In addition, other participants were advised by submitting an application for assistive devices: "I've applied with [name of Dutch organization] for a mobility scooter. And I put that application on the forum first. . . . And then they give you advice about other ways to do it."

Political action was also undertaken. A petition accompanied by signatures of all members of an online support group was offered to the Minister of Health, to request that he would declare fibromyalgia as an official disease in The Netherlands.

Finally, the participants from one specific breast cancer support group said that together they decided to ask for a different type of medical examination:

> I have had a painful mammogram, because there are staples in there. After radiotherapy they put a lot of staples in the operated area. Can you imagine that there are all of these metal

> things in there and that it is flattened? So that is not nice. And we discussed this on the forum and we all said from now on, we will all do an MRI, they can suit themselves.

Three of the participants who were already active in the online support group before they were officially diagnosed managed to get their diagnoses on the basis of recommendations and support of other participants:

> When I became a member of the forum, I still didn't really have the diagnosis of fibromyalgia. Then the other members advised me: "Go to the rheumatologist, have it put down in black-on-white that you've got fibromyalgia . . . it has a lot of advantages." Now I get a refund for part of my medication. And I didn't before.

Discussion

The general impression that arose from the interviews was that the patients interviewed were all highly active participants who were of the opinion that their participation in the online support groups was very positive and empowering.

Which empowering processes take place in the online support groups, according to the participants?

To the best of our knowledge, this study is the first that illustrates the full range of empowering and disempowering processes that take place in online support groups from the participants' perspective. The empowering processes that appeared from the interviews were: exchanging information, encountering emotional support, finding recognition and understanding, sharing experiences, helping others, and amusement. These processes are similar to the processes that take place in face-to-face support groups [37] and are in line with previous studies on online support groups [2, 3, 24-26, 28, 29].

In addition, our study adds some interesting aspects from the perspective of the patients. First, our study indicated that not the factual information exchanged, but rather the way in which the information is provided in the online support groups is unique. According to the participants, the information is received quickly and is considered as understandable and tailored to their personal needs. Most participants interviewed in our study stressed that they had or that they could have retrieved information from other sources as well, but that the way the information was provided in the online support group was most convenient for them.

A prominent topic discussed during all interviews was that by encountering emotional support and finding recognition and understanding in the online support group participants felt less alone in coping with their disease. These findings are comparable to the study results of others [26, 29, 38]. Unwanted isolation is one of the most significant psychosocial stressors that people face following the diagnosis of a chronic illness. Online support groups can help to reduce this stressor, especially because of the presence of other participants who have been through similar experiences and the same coping processes themselves [31].

Strikingly, examples of upward social comparison (looking at people who are doing better) were not often mentioned, compared to examples of downward social comparison (looking at people who are doing worse). This is in contrast to the findings of Helgeson and Taylor [39], who found that patients have a need for upward social comparison, because it can be a source of inspiration and advice. It might be that an online social support group is not the right context for upward social comparison. Bane et al. [40] suggest that the absence of visual information in online support groups can allow group members to be more biased when considering comparison targets. Participants with low self-esteem tend to avoid exposure to upward social comparison when experiencing a threat to self-esteem. Avoiding is easy in online support groups because participants can choose for themselves whether or not to read postings with a title revealing positive information.

Almost all participants interviewed mentioned the opportunity to share their personal experiences in an online support group as one of the most valuable functions. They saw the online support groups as an ideal space for sharing their experiences because they did not bore, annoy, or worry the people in their surroundings by sharing their disease-related experiences repeatedly. An interesting follow-up study would be to find out whether sharing experiences has a significant effect on the effectiveness of participating in an online support group, because a major percentage of people who use online support groups do not actively participate in the public dialogue, but only “lurk.” It is estimated that the lurker-to-poster ratios run as high as 100:1 [41].

Sharing experiences was also the most frequently mentioned way to help other members. By helping others, the participants indicated that they in fact helped themselves. Participants felt better by telling other members how well they were doing, and felt more valuable, because of the appreciation they received from other members and because being active online gave them a feeling of gratification. These results can be generalized to other patients’ groups as well, as Reeves [42], Cummings et al. [43], and Walstrom [44] found similar results among people who have to cope with AIDS, hearing loss, and eating disorders, respectively.

Summarizing, in this study a range of diverging empowering processes have been mentioned. We suggest that future studies should include the full range of these empowering processes.

Which disempowering processes take place in the online support groups, according to the participants?

In general, disempowering processes were mentioned far less during the interviews. The disempowering processes mentioned most by the participants were: being unsure about the quality of the information, being confronted with the negative sides of the disease, and the presence of complainers.

Some of the participants worried about the quality of the information provided; however, according to another study in which postings containing medical information from online support groups were evaluated by medical experts, the medical information provided was of good quality and none of these postings contained information that was considered as potentially dangerous to other participants [45].

Our study also revealed that participants, mainly in online support groups for breast cancer patients, found it difficult to be confronted with the negative aspects of the disease. To diminish confrontation with negative aspects of the disease, patients could be grouped by stage of their disease. This could, in our opinion, also decrease the presence of other disempowering processes mentioned, such as dealing with the repetition of questions and topics on the forum.

The fact that in this study disempowering processes have only been reported to a minor degree does not, however, mean that disempowering processes do not take place often in online support groups, as this study did not include people who discontinued using an online support group. Therefore, we suggest that future studies should still reflect both on disempowering as well as empowering processes.

Which empowering outcomes are experienced by the participants of online support groups?

This study showed considerable support for the potential of online support groups to provide the participants with a feeling of being empowered. The results indicated that the empowering and disempowering processes that take place in the online support groups can have a profound effect on participants' feelings about their level of being informed, the confidence they have in the relationship with their physician, the confidence they have in the treatment, the confidence they have in dealing with the social environment, the acceptance of the disease, the level of optimism and control over the future, enhanced self-esteem and social wellbeing, and collective action. Whereas former studies focused mainly on the effect of participation in online support groups on doctor-patient relationships, this study is the first that illustrates the full range of empowering outcomes that are experienced by participants of the online support groups.

A notable finding of our study was that all participants mentioned that they felt better informed; however, those patients who started on the forum soon after they were diagnosed or even before they were diagnosed seemed to profit most. In some cases, the patients received the information too late. At the moment they became active in the online support group, decisions about the treatment had already been made. These results can also be concluded from interviews conducted by Broom [22] among patients with prostate cancer. This suggests that in the most ideal situation patients should be referred to these groups by their medical professionals soon after being diagnosed. However, future research is necessary to confirm these results among a larger sample of participants.

Our study indicated that the level of confidence of the participants increased concerning the relationship with their physicians and concerning their treatment. Participation in online support groups seems to offer the patient assistance with what is demanded of the new "expert patient." Patients should nowadays, for example, be able to decide together with their medical specialist which medicines they are going to take. The uncertainty that patients can experience when a certain decision needs to be made [46] seems to be partially alleviated through participation in the online support group.

Improved acceptance of the disease, as experienced as an empowering outcome by most of the participants, seemed to result directly from the opportunity for social comparison offered by online support groups. However, this needs to be studied in a future quantitative study with a larger sample size, offering the potential for statistically analyzing interrelationships between the empowering processes and outcomes.

Participation in an online support group led to enhanced self-esteem in some of the participants. This outcome was typically linked by the participants to the possibility of helping other members of the online support group and the feeling of "being valuable" that resulted from this. These results confirm once more the helper-therapy principle introduced by Riessman [47], which asserts that an important part of the therapeutic value of support groups lies in the fact that participants not only receive help, but also have the opportunity to provide help to others.

Contradictory to inferences in the literature that use of the Internet leads to increased loneliness [48, 49] most participants interviewed noted that the number of social contacts they had rose by participating in a support group. Some even mentioned that participating helped them to get out of their social isolation. These study results should give rise to future research among patients with a physical handicap, for whom the use of the Internet and especially the use of online support groups seems to lead to a decrease in loneliness.

Our study revealed that the participants of the online support groups under study collectively undertook action concerning their disease. These results are in accordance with the findings of Radin [50], who conducted a case study on an online support group for native-English- speaking breast cancer patients. The participants of this group successfully managed to convince the New Zealand Health Minister to provide expensive new treatment, Herceptin®, through its national health system. Whereas all other empowering outcomes mentioned by the participants are typical examples of empowerment at the individual level, collective action is an example of empowerment at the community level. We suggest that in future research on empowerment in the context of online support groups researchers should be mindful not to treat empowerment merely as a personality variable. Individual empowerment is, after all, linked with group and community empowerment in a dialectical relationship [14, 21].

In contrast to our expectations that there were differences concerning the empowering and disempowering processes and outcomes between the three illness groups included in our study, we did not find any clear or consistent differences. As indicated in the results section, the breast cancer patients mentioned the disempowering process of "being confronted with negative aspects of the disease" more often than the patients of the other two illness groups. In addition, patients with arthritis mentioned the empowering process of "amusement" less often compared to the fibromyalgia and breast cancer patients. However, none of the differences detected between the three illness groups were totally consistent. Because this is the first study in which online support groups for several illness groups were compared, we suggest replicating this study among a larger sample of participants of other online support groups to provide supporting evidence.

Limitations of the present study

The findings of this study are limited by the fact that the respondents are all highly active users of online support groups, who are not necessarily representative of all participants joining online support groups for patients with breast cancer, fibromyalgia, or arthritis. Those who do not actively participate in the public dialogue—so called lurkers—and those who left the online support group out of dissatisfaction, are not included in this study. According to Bane et al. [40] and Preece et al. [41], lurkers are less likely to perceive online support groups as a source of support. In future research, these groups should be studied also to fully understand the impact of online support groups for those who choose not to contribute by means of postings.

A second limitation of this study is the small sample size, which limits the ability to generalize the findings. A quantitative study questioning a larger sample of participants of online support groups for the three patients groups might be an appropriate method to validate the results of this qualitative study.

Finally, the results of this study are limited by the inclusion of participants of online support groups for somatic illnesses that mainly affect women. The extent to which these results are representative for online support groups aimed at patients with a mental illness or online support groups dominated by male participants is not known.

Conclusions

Our data suggest that patients feel empowered by their participation in online support groups. The findings from this study not only demonstrate the types of empowering outcomes that are experienced by the participants, but also provide insight into the processes that lay the foundations for these empowering outcomes. Therefore this study suggests that participation in online support groups can make a valuable contribution to the emergence of empowered patients, who set their own health agendas and who take control of their own health status, as is deemed necessary in the current transformation toward a modern healthcare consumer model. Of course more structural research is needed into the efficiency of online support groups for the promotion of patient empowerment. Only when structural empirical evidence is provided will governments, health insurers, and medical professionals proceed to stimulate large scale implementation of online support groups for patients.

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4

Participation in online patient support groups endorses patients' empowerment

C.F. van Uden-Kraan
C.H.C. Drossaert
E. Taal
E.R. Seydel
M.A.F.J. van de Laar

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Abstract

Objective Although much has been expected of the empowering effect of taking part in online patient support groups, there is no direct evidence thus far for the effects of participation on patient empowerment. Hence our exploring to what extent patients feel empowered by their participation in online support groups, and which processes that occur in these groups are related to the empowering outcomes.

Methods An online questionnaire was completed by 528 individuals who were active in online groups for patients with breast cancer, fibromyalgia and arthritis.

Results The respondents felt empowered in several ways by their participation. The empowering outcomes that were experienced to the strongest degree were 'being better informed' and 'enhanced social well-being'. No significant differences in empowering outcomes between diagnostic groups were found. The empowering outcomes could only be predicted in a modest way by the processes that took place in the online support groups.

Conclusion This study indicates that participation in online support groups can make a valuable contribution to the empowerment of patients.

Practice implications Health care providers should acquaint their patients with the existence of online support groups and with the benefits that participation in these groups can offer.

Introduction

Empowerment reflects the belief in patient autonomy and the right and responsibility of patients to access health information and to make their own health-related decisions [1, 2, 3]. Empowered patients are considered to be successful in managing their condition, collaborating with their health providers, maintaining their health functioning and accessing appropriate and high quality care [4].

Much has been expected of the potential empowering effect of taking part in online support groups for patients [5-9]. So far, however, there is no direct evidence for the effects of participation in online support groups on patient empowerment [10, 11].

An explanation for the deficiency of studies investigating the effect of participation in online support groups on patient empowerment might be that the concept is inconsistently defined [12-14]. There is a great deal of ambiguity with regard to the precise nature of patient empowerment [15, 16].

Within the context of online support groups, only a couple of studies have focused on the concept of patient empowerment. The focus of most of these studies was to identify the processes that take place in online support groups [17-21], while some studies focused on the outcomes experienced by the participants [22-25]. In our opinion, the empowerment concept is operationalized in a limited fashion within these studies. Some studies claim that they study empowerment, but they focus mainly on one aspect of the empowerment concept, such as the doctor-patient relationship. Therefore, we first conducted a qualitative study among participants of online patient support groups to obtain a complete overview of patient empowerment [26]. Results revealed that the following empowering processes occurred in the online support groups: exchanging information, encountering emotional support, finding recognition, sharing experiences, helping others and amusement. The respondents mentioned the following empowering outcomes: being better informed, feeling confident with their physician, their treatment and their social environment, improved acceptance of the illness, increased optimism and control, enhanced self-esteem and social well-being and collective action.

Despite the fact that this qualitative study revealed relevant information about the empowering processes and outcomes of online support groups, a qualitative study has its limitations. We could not draw any conclusions on the frequency with which the empowering processes and the empowering outcomes of online support groups occurred. Relationships between processes and outcomes could not be determined on the basis of the interviews. Finally, the results of the qualitative study revealed indications for possible differences in empowering processes and outcomes between the patients groups studied. However, because of the small sample size, no clear or consistent differences could be confirmed.

The primary purpose of this quantitative study was to explore, by means of a questionnaire, to what extent patients feel empowered by their participation in online support groups and with which frequency empowering processes occur. In addition, two more research questions guided this study. First, which processes that occur in online support groups are related to these outcomes? Second, are there any differences between patient groups with regard to empowering processes and outcomes?

Methods

Sample and procedure

We focused our study on online support groups for patients with breast cancer, fibromyalgia and arthritis. We chose to explore these three groups because of the contrast between the illnesses (life-threatening, unexplained and chronic disabling). We searched the Internet with the search engine Google™ to identify all Dutch online support groups for patients with breast cancer, fibromyalgia and arthritis that were active (receiving >30 postings a month). In total, we found 20 groups. We asked the web owners of these groups for permission to approach the participants for the study. The web owners of 19 groups (7 breast cancer, 6 fibromyalgia and 6 arthritis) supported our study. We sent postings to these groups to ask participants to complete our online questionnaire. Criteria for inclusion were listed in the postings. The participants had to state that they had been diagnosed with either breast cancer, fibromyalgia or arthritis and had engaged passively or actively in online support groups. The medical diagnoses of the respondents were not verified with their physicians. In total, 593 participants responded to our request. Obviously, a response percentage is not available due to the fact that it is not known how many patients participated in the online support groups under study. Of these participants, 65 only filled in the questions concerning their background and were thus not included in the data analysis, leaving a group of 528 respondents.

Instrument

Demographic and health characteristics

The respondents were asked to provide information about demographic characteristics such as age, sex, education and diagnosis. Health-related quality of life was assessed with the SF 12, version 2. Standardized scores were calculated for the physical and mental well-being varying from 0 (poor well-being) to 100 (excellent well-being), with a mean of 50 and a standard deviation of 10 in the general population of the United States [27].

Use of the support group

Respondents were asked to indicate since when they had visited the online support group, how frequently they visited it, how long a visit lasted, whether or not they contributed postings and if so, how many postings they had contributed during the last four weeks.

Empowering processes

On the basis of the results of the qualitative study among participants of online support groups [26], 29 items were formulated that described the processes that took place in the online support groups. In all items we asked for the frequency with which certain events happened in the online support group. Respondents could answer on a 4-point scale, ranging from 'seldom or never' (1) to 'often' (4). For each process the internal consistency (Cronbach's alpha) was determined. 'Exchanging information' was measured with 9 items (alpha=0.88). 'Encountering emotional support' was measured with 12 items (alpha=0.95), which was based on the "Social Support List – Interaction" [28]. 'Finding recognition' was measured with 4 items (alpha=0.70). 'Helping others' was measured with 2 items (alpha=0.82) and finally 'Sharing experiences' was measured with 2 items (alpha=0.87).

Empowering outcomes

On the basis of the results of the qualitative study [26], 38 items were formulated that described empowering outcomes from participation in online support groups. All items had the format of a statement that began with 'Through my participation in online support groups…'. Respondents could answer on a 5-point scale, ranging from 'completely disagree' (1) to 'completely agree' (5). 'Being better informed' was measured with 4 items (alpha=0.85). 'Feeling more confident in the relationship with their physician' was measured with 11 items (alpha=0.91). 'Improved acceptance of the illness' was measured with 5 items (alpha=0.90). 'Feeling more confident about the treatment' was measured with 5 items (alpha=0.89). 'Increased optimism and control over the future' was measured with 8 items, (alpha=0.76), partially based on the revised illness perception questionnaire [29] and on the Dutch version of the Mastery Scale [30]. 'Enhanced self-esteem' was measured with 3 items (alpha=0.93), partially based on the Dutch version of the Rosenberg self-esteem scale [31]. Finally, 'Enhanced social well-being' was measured with 2 items (alpha=0.70).

For an overview of the items belonging to all the abovementioned constructs, see the appendix. For each construct a mean total score was calculated.

Data analysis

The data were analyzed with the statistical software package SPSS 12.0. Differences in continuous variables between the three patient groups were tested by means of one-way analysis of variance (ANOVA) followed by a Bonferroni post hoc test and differences in categorical variables by Chi-square. To correct for multiple testing we made use of Bonferroni adjustment. The significance level was set on $p<0.002$ (0.05/25).

We also compared the three illness groups by means of non-parametric statistics. The non-parametric statistics rendered the same results as the parametric statistics.

Relationships between the processes that took place within the online support groups and the outcomes experienced by the participants were determined by a Pearson correlation analysis. Since the correlation analysis was carried out only as a guide to the choice of variables to be included in regression analyses, and no conclusions were based on its results, we did not correct for multiple comparisons. A hierarchical multiple regression analysis was used to determine to what extent the empowering outcomes could be predicted by the processes that took place in the online support groups. In the first block of the regression analysis, the background variables that correlated significantly with the empowering outcomes were entered. In the second block of the regression analysis, the processes that correlated significantly with the empowering outcomes were entered.

All analyses were repeated for women only, because of the small number of participating men.

Results

Demographic and health characteristics

Of the respondents 41% had the diagnosis breast cancer, 22% had the diagnosis fibromyalgia and 23% of the respondents indicated to have arthritis. The other respondents (14%) indicated to have more than one of these three diagnoses.

Most of the respondents were women (94%) (Table 1). The average age of the respondents was 44 years. The majority of the respondents were married or living with a partner (79%). In total 33% of the participants had a low level of education, while 41% had a medium level of education and 26% had a high level of education. Most participants were not employed (56%). However, breast cancer patients were more often employed compared to the other patient groups.

The mean duration of the participants' illness was 5 years, with a range of 0 to 51 years. Breast cancer patients were more recently diagnosed.

The respondents of our questionnaire had an average score of 36.5 on the physical component of the SF12 and an average score of 40.1 on the mental component of the SF12. This indicates that the respondents' physical and mental well-being was worse than the average of the general population. Breast cancer patients had a higher score compared to the other patient groups concerning the physical component.

Use of online support groups

On average the respondents had been active for a period of 2.2 years in an online support group (Table 2). Breast cancer patients had joined the online support group more recently. Over half of the respondents (58%) visited the online support group daily. For most respondents the visits to the online support group lasted between 10 and 30 minutes. The majority of the respondents (79%) indicated that they had at some time contributed a posting to an online support group. During the last four weeks, about half of the respondents had posted at least once a week.

Table 1 Demographic and health characteristics

	Breast cancer (170≤n≤214)		**Fibromyalgia** (96≤n≤117)		**Arthritis** (82≤n≤121)		**More diagnoses** (59≤n≤76)		**Total** (407≤N≤528)		**χ2 (df)**	**F (df)**	**P value**
Sex* (n, %)											59.6 (3)		0.000
Female	211	99%	115	98%	95	79%	73	96%	494	94%			
Male	3	1%	2	2%	26	22%	3	4%	34	6%			
Age in years*												11.9 (3)	0.000
Mean (SD)	46 (8.9)		40 (9.2)		43 (12.5)		48 (10.3)		44 (10.4)				
Minimum	25		17		18		28		17				
Maximum	72		58		75		73		75				
Marital status (n, %)											1.9 (3)		0.589
Single	46	22%	21	18%	26	22%	20	26%	113	21%			
Together	168	79%	96	82%	95	79%	56	74%	415	79%			
Education*(n, %)											31.7 (6)		0.000
Low	52	25%	46	41%	34	29%	39	51%	171	33%			
Middle	88	42%	49	43%	48	40%	28	37%	213	41%			
High	71	34%	18	16%	37	31%	9	12%	135	26%			
Labour* (n, %)											44.4 (6)		0.000
Paid job (>20 hours)	99	47%	22	19%	32	26%	14	18%	167	32%			
Paid job (<20 uur)	26	12 %	19	17%	15	12%	5	7%	65	12%			
Unemployed	88	41%	74	64%	74	61%	57	75%	293	56%			
Time passed since diagnosis* (in years)												19.3 (3)	0.000
Mean (SD)	2.9 (3.0)		5.0 (5.6)		7.6 (7.0)		6.8 (7.7)		5.0 (5.9)				
Minimum	0		0		0		0		0				
Maximum	15		38		31		51		51				
Well-being (SF 12) (mean, SD)													
Physical well-being*	43.0 (10.9)		32.1 (8.8)		33.2 (9.8)		29.5 (8.7)		36.5 (11.4)			43.4 (3)	0.000
Mental well-being	40.4 (6.5)		39.3 (6.1)		41.7 (6.0)		38.3 (6.9)		40.1 (6.4)			3.8 (3)	0.009

* Test values for Chi-square tests or one-way analysis of variance (ANOVA) comparing the three illness groups were considered significant if $p<0.002$

Table 2 Use of the online support group

	Breast cancer (167≤n≤214)		**Fibromyalgia** (95≤n≤117)		**Arthritis** (97≤n≤121)		**More diagnoses** (61≤n≤76)		**Total** (420≤N≤528)		**χ2 (df)**	**F(df)**	***P* value**
Number of years active in an online support group*												7.2 (3)	0.000
Mean (SD)	1.7 (1.8)		2.4 (2.1)		2.4 (2.3)		2.9 (2.4)		2.2 (2.1)				
Minimum	0		0		0		0		0				
Maximum	8		9		9		9		9				
Frequency visit online support group (n, %)											19.6 (15)		0.187
More times a day	68	34%	31	29%	24	21%	23	34%	146	30%			
About once a day	58	29%	29	27%	36	32%	16	24%	139	28%			
More times a week	52	26%	25	24%	31	27%	16	24%	124	25%			
About once a week	17	8%	14	13%	9	8%	10	15%	50	10%			
More times a month	0	0%	0	0%	0	0%	0	0%	0	0%			
About once a month	3	2%	3	3%	5	4%	2	3%	13	3%			
Less than once a month	4	2%	4	4%	9	8%	1	2%	18	4%			
Duration visit online support group (n, %)											8.9 (9)		0.443
Less than 10 minutes	54	26%	22	20%	34	29%	14	19%	124	24%			
10 to 30 minutes	120	57%	67	60%	60	50%	40	56%	287	56%			
30 minutes to one hour	28	13%	16	14%	16	13%	15	21%	75	15%			
More than one hour	7	3%	6	5%	9	8%	3	4%	25	5%			
Contributing postings (n, %)											0.75 (3)		0.863
Yes	166	78%	95	81%	97	80%	61	80%	419	79%			
No, I never contributed a posting	48	22%	22	19%	24	20%	15	20%	109	21%			
Number of postings during the past 4 weeks (n, %)											13.0 (15)		0.605
None	26	16%	11	12%	18	19%	11	18%	66	16%			
Some postings, but less than one a week	55	33%	38	40%	41	42%	20	33%	154	37%			
One during a week	19	11%	11	12%	12	12%	4	7%	46	11%			
More during a week, but not everyday	38	23%	24	25%	19	20%	17	28%	98	23%			
Everyday one posting	5	3%	3	3%	0	0%	2	3%	10	2%			
Everyday more postings	24	14%	8	8%	7	7%	7	12%	46	11%			

*Test values for Chi-square tests or one-way analysis of variance (ANOVA) comparing the three illness groups were considered significant if $p<0.002$

Empowering processes

The processes that took place most frequently in the online support groups are 'exchanging information' and 'finding recognition' (Table 3). The scores on the separate items (data not shown) revealed that the information exchanged in the online groups was regularly to often considered understandable (94%) and valuable (83%) by the respondents (data not in table). It appeared that the information was not always new: the majority of the respondents (61%) even indicated that they only sometimes or even seldom read new information in the online support group. In total, 83% of the respondents indicated to recognize themselves regularly to often in the stories of the other participants (data not in table).

To a lesser degree, the respondents also 'encountered emotional support', 'helped others' and 'shared experiences' in the online support groups. For example, 42% of the respondents indicated that they regularly to often provided advice and support to other participants (data not in table). The majority of the respondents (53%) regularly to often received good advice of other participants, and many felt regularly to often comforted (44%) or reassured (35%) (data not in table).

The arthritis patients indicated that the processes 'exchanging information' and 'finding recognition' occurred significantly less often in the online support groups in which they participated, compared to the other patient groups.

The analyses for women only gave similar results, only the difference in 'finding recognition' between the arthritis and fibromyalgia patients was not significant anymore.

Empowering outcomes

The empowering outcomes that were experienced to the strongest degree were 'being better informed', followed by 'enhanced social well-being' (Table 4). Frequency distributions on separate items (data not in table) revealed that 74% of the patients had the feeling that they now had the right knowledge to manage their illness. Almost half of the participants felt less lonely (47%) as a result of participation in an online support group. Many participants (58%) indicated that their social contacts increased by participating in an online support group (data not in table).

The empowering outcomes 'feeling more confident in the relationship with their physician', 'improved acceptance of the illness', 'feeling more confident about the treatment' and 'increased optimism and control' were experienced to a similar degree by the participants. For example, over half of the respondents (61%) indicated that they knew better which questions to ask their doctor. Also the majority of the respondents (53%) felt better prepared for a doctor's appointment and some of the respondents (56%) had the feeling that they could clarify their needs better to their doctor. In total 55% of the respondents indicated that they dared to be more open about their illness as a result of their participation in an online support group. The majority of the respondents (53%) had the feeling that they took the right decisions regarding their illness by participating in an online support group (data not in table).

Table 3 Mean scores for empowering processes by diagnostic group

	Breast cancer (190≤n≤205)	**Fibromyalgia** (105≤n≤114)	**Arthritis** (99≤n≤116)	**More diagnoses** (66≤n≤75)	**Total** (460≤N≤510)	**F(df)**	***P* value**
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)		
Exchanging information* (1-4) (1, 2)	3.1 (0.53)	3.0 (0.54)	2.8 (0.53)	2.9 (0.58)	3.0 (0.56)	12.5 (3)	0.000
Finding recognition* (1-4) (3, 4)	2.9 (0.60)	2.9 (0.55)	2.6 (0.50)	2.7 (0.54)	2.8 (0.58)	9.3 (3)	0.000
Sharing experiences (1-4)	2.7 (1.00)	2.8 (0.86)	2.5 (0.83)	2.6 (0.90)	2.7 (0.94)	2.7 (3)	0.043
Encountering emotional support (1-4)	2.2 (0.87)	2.3 (0.73)	2.0 (0.68)	2.1 (0.75)	2.2 (0.79)	2.7 (3)	0.046
Helping others (1-4)	2.2 (0.83)	2.2 (0.66)	2.2 (0.69)	2.2 (0.72)	2.2 (0.75)	0.18 (3)	0.913

*Test values for one-way analysis of variance (ANOVA) comparing the three illness groups were considered significant if p<0.002

1. Patients with more than one diagnosis and breast cancer patients differed significantly
2. Patients with arthritis differed significantly from patients with breast cancer and patients with fibromyalgia
3. Patients with arthritis differed significantly from patients with breast cancer and patients with fibromyalgia
4. Patients with more than one diagnosis and breast cancer patients differed significantly

Table 4 Mean scores for empowering outcomes by diagnostic group

	Breast cancer (171≤n≤182)	**Fibromyalgia** (96≤n≤98)	**Arthritis** (85≤n≤90)	**More diagnoses** (59≤n≤64)	**Total** (411≤N≤434)	**F(df)**	***P* value**
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)		
Being better informed (1-5)	3.8 (0.78)	3.8 (0.71)	3.5 (0.69)	3.8 (0.76)	3.7 (0.75)	2.4 (3)	0.071
Enhanced social well-being (1-5)	3.4 (0.99)	3.4 (0.94)	3.2 (0.82)	3.4 (1.02)	3.4 (0.95)	0.69 (3)	0.557
Feeling more confident in the relationship with their physician (1-5)	3.4 (0.73)	3.4 (0.65)	3.2 (0.62)	3.4 (0.80)	3.3 (0.70)	1.0 (3)	0.373
Improved acceptance of the illness (1-5)	3.1 (0.99)	3.4 (0.82)	3.2 (0.74)	3.3 (1.03)	3.2 (0.92)	2.1 (3)	0.106
Feeling more confident about the treatment (1-5)	3.2 (0.83)	3.4 (0.66)	3.1 (0.76)	3.2 (0.91)	3.2 (0.79)	1.8 (3)	0.142
Increased optimism and control (1-5)	3.2 (0.59)	3.3 (0.69)	3.0 (0.46)	3.1 (0.57)	3.2 (0.60)	2.8 (3)	0.041
Enhanced self-esteem (1-5)	3.2 (0.95)	3.3 (0.93)	2.9 (0.85)	3.2 (0.94)	3.1 (0.93)	2.6 (3)	0.054

Enhanced self-esteem was experienced to a lesser degree. Some of the patients (43%) indicated that participation in online support groups led to a more satisfied feeling about themselves (data not in table).

With regard to the empowering outcomes no significant differences between the patient groups were found. The analyses for women only gave similar results.

Relationships between processes and outcomes

All processes that took place in the online support groups were significantly correlated, although weak (<0.30) to moderate (>0.30 <0.60), with the outcomes of participation experienced (Table 5).

It can be concluded that the empowering outcomes could only be predicted partially on the basis of the processes that took place in the online support groups (Table 6). R^2 varied from 0.13 to 0.31. The outcomes that could be predicted best are 'being better informed' and 'enhanced social well-being'.

The most important predictors of the outcome 'being better informed' appeared to be 'exchanging information' and 'finding recognition'. In total, 31% of the variance could be explained.

The most important predictors of the outcome 'enhanced social well-being' appeared to be 'encountering emotional support' and 'sharing'. In total, 30% of the variance could be explained.

When focusing on the background variables, education and time passed since diagnosis appeared to be predictors of the empowering outcomes.

The analyses for women only gave similar results.

Discussion and conclusion

Discussion

To the best of our knowledge, this study is the first quantitative study that illustrates how participants in online support groups feel 'empowered' by their participation. Earlier research was mainly qualitative, as a result of which the extent to which participants felt empowered, and the frequency with which the empowering processes occurred in the online support groups could not be determined.

Results of the present study were in line with the results of our earlier qualitative study, by confirming the potential of online support groups in providing the participants with a feeling of 'being empowered' in several areas [26]. However, this study adds some interesting information concerning the extent to which the participants of online support groups feel empowered. Results indicate that participation did not have a similar profound effect on feelings of 'being empowered' in all areas studied.

Table 5 Pearson correlation coefficients for the relationships between the processes that took place within the online support groups and the outcomes experienced by the participants

	Being better informed (n=427) **r**	Feeling more confident in the relationship with their physician (n=427) **r**	Feeling more confident about the treatment (n=422) **r**	Improved acceptance of the illness (n=421) **r**	Increased optimism and control (n=413) **r**	Enhanced self-esteem (n=411) **r**	Enhanced social well-being (n=411) **r**
Exchanging information	0.43*	0.35*	0.31*	0.21*	0.30*	0.30*	0.28*
Encountering emotional support	0.35*	0.32*	0.34*	0.27*	0.35*	0.38*	0.51*
Finding recognition	0.42*	0.39*	0.34*	0.26*	0.34*	0.28*	0.31*
Helping others	0.25*	0.25*	0.28*	0.24*	0.30*	0.31*	0.37*
Sharing experiences	0.26*	0.27*	0.25*	0.28*	0.30*	0.33*	0.48*

*p<0.01

Table 6 The extent to which empowering outcomes can be predicted by the processes that take place in the online support groups

		Being better informed (n=394) **β**	Feeling more confident in the relationship with their physician (n=387) **β**	Feeling more confident about the treatment (n=382) **β**	Improved acceptance of the illness (n=381) **β**	Increased optimism and control (n=373) **β**	Enhanced self-esteem (n=371) **β**	Enhanced social well-being (n=371) **β**
Step 1	Sex	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.
	Age	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.
	Marital status	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.
	Education	-0.13*	-0.19**	-0.20**	n.s.	n.s.	n.s.	n.s.
	Time passed since diagnosis	-0.15*	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.
Step 2	Exchanging information	0.25**	0.16*	n.s.	n.s.	n.s.	n.s.	n.s.
	Encountering emotional support	0.22*	n.s.	0.19*	n.s.	n.s.	0.21*	0.30**
	Finding recognition	0.23**	0.24**	0.20*	n.s.	0.18*	n.s.	n.s.
	Helping others	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.
	Sharing experiences	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	0.19*
		R^2=0.31 F (10, 384)=16.9**	R^2=0.25 F (10, 377)=12.3**	R^2=0.23 F (10, 372)=10.8**	R^2=0.13 F (10, 371)=5.4**	R^2=0.20 F (10, 363) = 8.8**	R^2=0.19 F (10, 361)= 8.6**	R^2=0.30 F (10, 361)=15.6**
		R^2 change=0.23**	R^2 change=0.18**	R^2 change=0.16**	R^2 change=0.11**	R^2 change=0.17**	R^2 change=0.18**	R^2 change=0.27**

*p<0.01 **p<0.001 n.s.=non-significant

The empowering outcome that was experienced to the strongest degree was 'being better informed'. This outcome is mentioned as a benefit of participation in online support groups in several other studies [e.g. 21, 32, 33]. Campbell, Phaneuf, & Deane [34] mentioned in their review of cancer peer support programs that several studies incorporated in their review found that participants had a better understanding of their illness and were better informed as a result of receiving peer support.

'Enhanced social well-being' was also experienced to a strong degree. Respondents indicated that participating in an online support group led to a rise in their number of social contacts and to a decrease in loneliness. These findings are comparable to the study results of other qualitative studies [21, 24, 33]. Unwanted loneliness is one of the most significant psychosocial stressors that people face following a diagnosis of a chronic illness [24]. Our results show that participation in online support groups can help to reduce this stressor.

The empowering process that took place most frequently in the online support groups was 'exchanging information'. Despite the fact that 'exchanging information' is the most important process demonstrated, online support groups should not solely be seen as a source of information. Earlier research showed that when information is exchanged in online support groups, it is rarely medical factual information but sooner personal experience [35]. Doctors are there to provide the factual information, but other patients can tell you how it feels and what the patient can expect in the future [36]. Support groups should thus not be seen as the sole provider of information for participants, but more as an additional resource [26, 37].

According to our study results, 'helping others' is the process that occurred to the least degree. These results are not surprising, because 'helping others' is a process that can only be executed by those who actively contribute postings to an online support group. Those who do not post, so called lurkers, are unable to help other participants in the online support group. In addition, we found that high-frequency posters indicate helping other participants more often ($r=0.38$, $p<0.01$). These study results are in line with the results of Winefield [38], who found that high-frequency posters referred less often to seeking and more often to providing support in their messages than the less frequent posters did.

In general, it has to be concluded that the empowering outcomes could only be predicted in a modest way by the processes that took place in the online support groups. The outcomes that could be predicted best are 'being better informed' and 'enhanced social well-being'. As could be logically predicted, the process 'exchanging information' played an important part in the prediction of 'feeling better informed', and 'encountering emotional support' was especially important when predicting the outcome 'enhanced social well-being'.

'Finding recognition' appeared to play a significant role when predicting the empowering outcomes 'being better informed', 'feeling more confident in the relationship with their physician', 'feeling more confident about the treatment' and 'increased optimism and control'. The important role of finding recognition also appeared from our qualitative study. Almost all participants mentioned that 'recognition' was the main reason for them to participate in an online support group [26]. In addition, the importance of recognition is frequently raised in the literature on online support groups. For example, Buchanan and Coulson [32] found in their study on a dental anxiety online support group that by accessing the messages posted by others facing similar challenges, members appeared empowered to conquer their fears and to move forward. On the basis of these results, it can again be concluded that online support groups are an ideal platform for finding recognition. There are several reasons as to why finding recognition has an impact on the empowering outcomes experienced by the participants. First, it is argued that people may accept information provided by peers, people who they can identify with, as more acceptable compared to other sources of information [39]. In addition, peers can act as positive role models [26, 39-41]. The participants of our qualitative study mentioned that they became more optimistic about their own future by reading the disease stories of other participants who served as positive role models. Also, learning from the personal experiences of peers, e.g. about their experiences with a specific type of treatment, was considered as a positive encouragement for other participants [26].

'Time passed since the diagnosis' appeared to play a significant role when predicting the empowering outcome 'being better informed'. The participants who were diagnosed more recently felt better informed. These results are in line with the results of earlier qualitative studies [26, 22]. Interview results revealed that patients who started to participate in the online support group a considerable time after being diagnosed, in some cases received the information too late. At the moment they became active, decisions about the treatment had already been taken [26]. Broom [22] thus advises that patients should be referred to these groups by their physician soon after being diagnosed.

Results of this study showed that those with a lower educational level score higher on the empowering outcomes 'being better informed', 'feeling more confident with the physician' and 'feeling more confident about the treatment'. These results are in contrast to statements made concerning the digital divide. According to this theory, minorities, such as the lower educated, the elderly, the unemployed and immigrants, are expected to profit less from using the Internet because of a lack of digital skills [42]. A specific concern is that in order to be able to comprehend health-related information on the Internet high reading levels are required [43, 44]. De Nooijer et al. [45] thus suggest that different groups have to be approached in different ways concerning health promotion interventions on the Internet. Specific skills and usability possibilities of minorities should be taken into account. Our results indicate that online support groups might be a specific appropriate option for those with a lower educational level.

This study is unique due to the fact that we involved several patients' groups. A notable finding of our study was that we did not find any differences between the diagnostic groups concerning the empowering outcomes. However, we did find differences between the patient groups concerning the frequency with which the processes took place in the online support groups. The processes 'exchanging information' and 'finding recognition' occurred significantly less often in the online support groups for arthritis patients. Perhaps there is coherence with the lesser degree of activity in the online support groups for arthritis patients in comparison to other patient groups. In earlier research [35] it was detected that online support groups for patients with arthritis are the least active. During a period of 3 months there were 932 postings exchanged by the members of online support groups for arthritis patients, while in the same period 15,171 postings were exchanged in the online support groups for breast cancer patients. According to Davison & Pennebaker [46], the explanation for these differences must be sought in the characteristics of the illnesses such as cause and consequences. The high participation rate of the participants of the breast cancer groups might be due to the fact that breast cancer is a life-threatening disease, whereas the high participation rate of the participants of the fibromyalgia groups might be due to the ambiguity of this illness [35]. On the other hand these differences might also be caused by the fact that the arthritis group contains by far the most male participants. Since it is suggested that gender can be an important factor in motives and use of support networks [47], we also conducted the difference analyses concerning the empowering processes between the patient groups without the male participants. The differences did not differ with the exception of the difference between patients with rheumatoid arthritis and fibromyalgia concerning the empowering process “finding recognition”: this difference was not significant anymore.

The following limitations of the present study should be considered. Those who chose to complete our online questionnaire are not necessarily representative for all participants in online support groups for patients with breast cancer, fibromyalgia and arthritis. The respondents are probably the most active participants of the online support groups.

In addition, it should be considered that we made use of self-perceived measures. Participants themselves estimated to what extent they felt empowered by participation in online support groups. This does not prove that the patients are truly empowered as a result of participation. It should also be taken into account that we conducted a retrospective study. Because patients used the online support group over a long period of time, the outcomes they reported retrospectively may be either underestimated because the impact was gradual and therefore not sharply detected or they overestimated in order to justify their extended use. Although this study provided us with relevant insights in the empowering outcomes as experienced by the participants, a randomised controlled trial or a longitudinal study is required to evaluate whether the participants are truly empowered.

Conclusion

This study indicates that patients feel empowered by their participation in online support groups. The findings from this study not only demonstrate the types of empowering outcomes experienced by the participants but also indicate the extent to which patients feel empowered in several areas. The empowering outcome that was experienced to the strongest degree was ‘being better informed’. In addition, this study provides insight into the processes that take place in the online support groups and the extent to which these processes could predict the empowering outcomes. The empowering process that took place most frequently in the online support groups is ‘exchanging information’. ‘Helping others’ is the process that occurred to the least degree according to our study results. In general it has to be concluded that the empowering outcomes could only be predicted in a modest way by the processes that took place in the online support groups.

Strikingly, we did not find any significant differences in this study between the diagnostic groups with regard to empowering outcomes. Therefore, we can conclude that empowerment is a generic mechanism.

Practice implications

Participation in online patient support groups can make a valuable contribution to empowerment of patients. Our study suggests that these groups are a useful resource for patients and a good alternative to face-to-face support groups. Health care providers should thus acquaint their patients with the existence of online support groups and with the benefits that participation in these groups can provide.

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5

Self-reported differences in empowerment between lurkers and posters in online patient support groups

C.F. van Uden-Kraan
C.H.C. Drossaert
E. Taal
E.R. Seydel
M.A.F.J. van de Laar

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Abstract

Background Patients who visit online support groups benefit in various ways. Results of our earlier study indicated that participation in online support groups had a profound effect on the participants' feelings of "being empowered." However, most studies of online patient support groups have focused on the members of these groups who actively contribute by sending postings (posters). Thus far, little is known about the impact for "lurkers" (i.e., those who do not actively participate by sending postings).

Objective In the present study, we explored if lurkers in online patient support groups profit to the same extent as posters do.

Methods We searched the Internet with the search engine Google™ to identify all Dutch online support groups for patients with breast cancer, fibromyalgia, and arthritis. Invitations to complete an online survey were sent out by the owners of 19 groups. In the online questionnaire, we asked questions about demographic and health characteristics, use of and satisfaction with the online support group, empowering processes, and empowering outcomes. The online questionnaire was completed by 528 individuals, of which 109 (21%) identified themselves as lurkers.

Results Lurkers (mean age 47 years) were slightly older than active participants (mean age 43 years, p=0.002), had a shorter disease history (time since diagnosis 3.7 years vs 5.4 years, p=0.001), and reported lower mental well-being (SF 12 subscore 37.7 vs 40.5, p=0.004). No significant differences were found in other demographic variables. Posters indicated visiting the online support groups significantly more often for social reasons, such as curiosity about how other members were doing, to enjoy themselves, as a part of their daily routine (all p<0.001), and because other members expected them to be there (p=0.003). Lurkers and posters did not differ in their information-related reasons for visiting the online support group. Lurkers were significantly less satisfied with the online support group compared to posters (p<0.001). With regard to empowering processes such as "exchanging information" and "finding recognition," lurkers scored significantly lower than posters. However, lurkers did not differ significantly from posters with regard to most empowering outcomes, such as "being better informed," "feeling more confident in the relationship with their physician," "improved acceptance of the disease," "feeling more confident about the treatment," "enhanced self-esteem," and "increased optimism and control." The exception was "enhanced social well-being," which scored significantly lower for lurkers compared to posters (p<0.001).

Conclusion Our study revealed that participation in an online support group had the same profound effect on lurkers' self-reported feelings of being empowered in several areas as it had on posters. Apparently, reading in itself is sufficient to profit from participation in an online patient support group.

Introduction

Studies have suggested that patients who use online support groups benefit in various ways [1-10]. Results of our earlier study indicated that participation in online support groups had a profound effect on the participants' feelings of "being empowered" in several areas. Empowering outcomes mentioned by participants were being better informed; feeling confident with their physician, their treatment, and their social environment; improved acceptance of the disease; increased optimism and control; and enhanced self esteem and social well-being [11].

Most studies of online support groups for patients have focused on the members of these groups who actively contribute by sending postings (ie, posters). However, it is assumed that a considerable number of patients use online support groups in a passive way. Thus far, it is not known if those who do not actively participate by sending postings, the so-called lurkers, profit to the same extent from participating in online support groups as posters do.

Although little is known about lurkers in online patient support groups, some studies have been conducted on lurkers in other online communities. Opinions about lurking and lurkers vary considerably. On the one hand, lurking is considered negative behavior. Smith and Kollock [12] describe lurkers as "free-riders": they use the resources of online groups without giving back to them. Others consider lurking as acceptable and even beneficial. Many groups encourage lurking because in this way potential new users get a feeling for how the group operates and what kind of people participate in it [13, 14]. Lurking can be desirable for very busy groups; if all subscribers to a group were to participate actively, it could cause repetition of queries and result in an overload of postings [15].

Study results indicated that lurking rates are highly variable: 0% to 99% [15-18]. Nonnecke and Preece [17] reported an average of 45.5% of lurkers in health-related online support groups.

Only a few studies have examined lurkers' motives and experiences. In those studies, the participants were asked to indicate the reasons why they lurked instead of actually participating in the online communities. Reasons mentioned were concerns for privacy, no need to post, need to find out more about the group before participating, respect for others' time and attention restrictions, no skills to make the software work, and no "click" with the group dynamics or a poor fit with the group [13, 14, 19, 20]. Lurkers mostly indicated that they participated in an online group in order to receive information. In contrast, posters mentioned reasons such as to offer expertise, enjoy oneself, entertain others, build a professional relationship, tell stories, participate in conversations, make friends, get empathic support, and be a group member [13, 14]. Nonnecke et al [14] also investigated possible differences in attitudes between lurkers and posters. Results showed that lurkers were less positive with regard to their online support group than those who post.

Although the above-mentioned studies provided us with valuable information concerning the characteristics of lurkers, little is known about the impact of lurking in online support groups [4]. Moreover, the previous studies focused on a wide range of online communities in which topics were discussed relating to the government, organizations, health, and e-commerce. It is unclear whether these results can be generalized to online patient support groups. In the present study, we therefore explored if lurkers in online patient support groups profit to the same extent as posters do. In addition, we explored to what extent lurking patients differed from posting patients with regard to demographic characteristics and usage and satisfaction with the online support group.

Methods

Sample and procedure

We focused our study on online support groups for patients with breast cancer, fibromyalgia, and arthritis. We chose to explore these three groups because of the contrast among the illnesses (life-threatening, unexplained, and chronic disabling, respectively). We searched the Internet using the Google™ search engine to identify all Dutch online support groups for patients with breast cancer, fibromyalgia, and arthritis. In total, we found 20 groups. The online support groups differed in size and extent of activity; in the most active public support group under study, several hundred messages were exchanged daily, while in the least active support group, only 30 messages were exchanged during the last month. In total, 6 support groups under study were private groups to which we as researchers had no access. Therefore, we could not verify the number of messages exchanged in these groups.

Contact was established between the first author and the Web owners of the groups. The purpose of the study and methodology were explained to the Web owners. In addition, they were asked if they had any comments on the online questionnaire. We then asked the Web owners of these groups for permission to invite the participants to fill out our questionnaire. The Web owners of 19 groups (7 breast cancer, 6 fibromyalgia, and 6 arthritis) supported our study. In order not to intrude in the online support groups as researchers, we asked the Web owners of these 19 groups to send a posting in which participants were invited to fill out our online questionnaire. Criteria for inclusion were listed in the postings. The participants had to state that they had been diagnosed with breast cancer, fibromyalgia, or arthritis and had engaged passively or actively in online support groups. The medical diagnoses of the respondents were not verified with their physicians. Participants who were willing to fill out our questionnaire were invited to visit a Web page which provided information about our study and contact details of the first author. In total, 593 participants responded to our request. Obviously, a response percentage is not available due to the fact that it is not known how many patients participated in the online support groups under study. Of these participants, 65 filled in only the questions concerning their background and were thus not included in the data analysis, leaving 528 respondents. Of these respondents, 109 (21%) identified themselves as lurkers, which we defined in line with Preece et al [13] as "members who had never contributed a posting to an online group."

Instrument

Demographic and health characteristics

The respondents were asked to provide information about demographic characteristics such as age, sex, education, and diagnosis. Health-related quality of life was assessed with the SF 12, version 2. Standardized scores were calculated for physical and mental well-being, varying from 0 (poor well-being) to 100 (excellent well-being), with a mean of 50 and a standard deviation of 10 in the general population of the United States [21].

Use of and satisfaction with the online support group

Respondents were asked to indicate when they started visiting the online support group, how frequently they visited it, how long a visit lasted, and for what reasons they turned to the online support group. Lurking was measured with one single dichotomous item: “Did you ever contribute a posting to an online patient support group?” The questionnaire also contained one item to measure general satisfaction with the online support group: “In general, how satisfied/dissatisfied are you with the online support group?” Respondents could answer on a 5-point scale that ranged from “very dissatisfied” (1) to “very satisfied” (5).

Empowering processes

On the basis of the results of an earlier qualitative study [11], 29 items were formulated that described the empowering processes that took place in the online support groups. In all items, we asked for the frequency with which certain events happened in the online support group. Respondents could answer on a 4-point scale that ranged from ‘seldom or never’ (1) to ‘often’ (4). ‘Exchanging information’ was measured with 9 items (alpha=0.88). ‘Encountering emotional support’ was measured with 12 items (alpha=0.95), which was based on the Social Support List – Interaction [22]. ‘Finding recognition’ was measured with 4 items (alpha=0.70). ‘Helping others’ was measured with 2 items (alpha=0.82). Finally, ‘Sharing experiences’ was measured with 2 items (alpha=0.87).

Empowering outcomes

On the basis of the results of an earlier qualitative study [11], 38 items were formulated that described empowering outcomes from participation in online support groups. All items had the format of a statement that began with ‘Through my participation in online support groups….’ Respondents could answer on a 5-point scale that ranged from ‘completely disagree’ (1) to ‘completely agree’ (5). ‘Being better informed’ was measured with 4 items (alpha=0.85). ‘Feeling more confident in the relationship with their physician’ was measured with 11 items (alpha=0.91). ‘Improved acceptance of the illness’ was measured with 5 items (alpha=0.90). ‘Feeling more confident about the treatment’ was measured with 5 items (alpha=0.89). ‘Increased optimism and control over the future’ was measured with 8 items (alpha=0.76), partially based on the revised Illness Perception Questionnaire [23] and on the Dutch version of the Mastery Scale [24]. ‘Enhanced self-esteem’ was measured with 3 items (alpha=0.93), partially based on the Dutch version of the Rosenberg Self-Esteem Scale [25]. Finally, 'Enhanced social well-being' was measured with 2 items (alpha=0.70).

For an overview of the items belonging to all the abovementioned constructs, see the appendix. For each construct a mean total score was calculated.

Data analysis

The data were analyzed with the statistical software package SPSS 12.0 (SPSS Inc, Chicago, IL, USA). Differences in continuous variables between the posters and the lurkers were tested by means of Mann-Whitney U tests and differences in categorical variables by chi-square tests. In the data analysis, we excluded the respondents only if they were missing the data required for the specific analysis. Because of the great number of comparisons conducted, statistical significance was assumed when alpha<0.01.

Results

Demographic and health characteristics of the posters and lurkers

Lurkers were somewhat older and were more recently diagnosed compared to posters (Table 1). No significant differences were found in sex, marital status, education, employment status, or type of diagnosis. Lurkers had a poorer mental well-being than posters. No significant differences between posters and lurkers were found in the physical component of the SF12.

Use of the online support groups by posters and lurkers

The lurkers participated for a significantly shorter period of time compared to the posters (Table 2). Lurkers visited the online support groups significantly less frequently than the posters did. Most of the posters (65%) indicated that they visited the support group daily, compared to 27% of the lurkers. There was no significant difference between the posters and the lurkers concerning the duration of the visit to the online support group.

Lurkers and posters differed significantly with regard to some of the reasons for visiting the online support groups. Posters indicated visiting the online support groups significantly more often for social reasons, such as curiosity about how other members were doing, to enjoy themselves, as a part of their daily routine, and because other members expected them to be there. Lurkers and posters did not differ with their information-related reasons to visit the online support group. In general, the lurkers were significantly less satisfied with the online support group compared to posters.

Table 1 Demographics and health characteristics of posters and lurkers

	Posters*		**Lurkers**		**χ^2 (df)†**	**Mann-Whitney‡**	***p*§**
	No.	%	No.	%			
Sex					0.000 (1)||		1.00
Female	392	94	102	94			
Male	27	6	7	6			
Age in years (posters: n=416, lurkers: n=109)						18291.50	0.002
Mean (SD)	43 (10.4)		47 (9.9)				
Minimum	17		19				
Maximum	73		75				
Marital/relationship status					0.094 (1)||		0.76
Single	88	21	25	23			
In a relationship	331	79	84	77			
Education					2.24 (2)		0.33
Low	129	32	42	39			
Middle	170	42	43	39			
High	111	27	24	22			
Employment status					1.33 (2)		0.51
Paid job (> 20 hours)	128	31	39	36			
Paid job (≤ 20 hours)	54	13	11	10			
No job	234	56	59	54			
Diagnosis					0.745 (3)		0.86
Breast cancer	166	40	48	44			
Fibromyalgia	95	23	22	20			
Arthritis	97	23	24	22			
More diagnoses	61	15	15	14			
Time in years since diagnosis (posters: n=385, lurkers: n=96)						14382.50	0.001
Mean (SD)	5.4 (6.1)		3.7 (4.6)				
Minimum	0		0				
Maximum	51		21				
Well-being (SF 12) (posters: n=355, lurkers: n=52)							
Physical well-being, mean (SD)	36.4 (11.6)		37.5 (9.9)			8294.50	0.24
Mental well-being, mean (SD)	40.5 (6.4)		37.7 (5.9)			6960.50	0.004

* No. is the number of respondents per item. Percentages are given with the total number of respondents per question as denominator (due to nonresponses, denominators may vary from question to question)

† Chi-square values are Pearson chi-square values with degrees of freedom in parentheses

‡ Mann-Whitney U value

§ *p* value for chi-square tests and Mann-Whitney U tests comparing posters and lurkers

|| Chi-square values are Pearson chi-square values with continuity correction

Table 2 Use of the online support group by posters and lurkers

	Posters*		**Lurkers**		**χ^2 (df)†**	**Mann-Whitney‡**	**p§**
	No.	%	No.	%			
Number of years participating in an online support group (posters: n=389, lurkers: n=94)						13456.00	<0.001
Mean (SD)	2.3 (2.1)		1.6 (2.1)				
Minimum	0		0				
Maximum	9		9				
Frequency of visits to online support group					75.756 (5)||		<0.001
More than once during a day	140	35	6	7			
About one time during a day	121	30	18	20			
More than once in a week	96	24	28	31			
About one time in a week	31	8	19	21			
More than once in a month	0	0	0	0			
About once in a month	6	2	7	8			
Less than once in a month	6	2	12	13			
Duration of visits to online support group					3.560 (3)		0.31
Less than 10 minutes	94	23	30	29			
10 minutes to 30 minutes	237	58	50	49			
30 minutes to 1 hour	57	14	18	18			
More than 1 hour	21	5	4	4			
Reasons for visiting the online support group							
Because I'm curious how other members are doing	244	58	34	31	24.298 (1)¶		<0.001
It's part of my daily routine	202	48	15	14	40.992 (1)¶		<0.001
When I have a question about my disease	180	43	36	33	3.131 (1)¶		0.08
To enjoy myself	157	38	15	14	21.070 (1)¶		<0.001
When I heard new information about my illness	125	30	25	23	1.698 (1)¶		0.19
When I have a lot of symptoms	92	22	20	18	0.475 (1)¶		0.49
When I feel lonely	92	22	15	14	3.106 (1)¶		0.08
When I get new symptoms	106	25	27	25	0.000 (1)¶		1.00
After visiting a doctor	61	15	6	6	5.609 (1)¶		0.02
Before visiting a doctor	43	10	3	3	5.226 (1)¶		0.02
Because other members expect me to be there	50	12	2	2	8.830 (1)¶		0.003
General satisfaction with the online support group (posters: n=375, lurkers: n=63), mean (SD)	4.3 (0.79)		4.0 (0.65)			8652.50	<0.001

* No. is the number of respondents per item. Percentages are given with the total number of respondents per question as denominator (due to nonresponses, denominators may vary from question to question)

† Chi-square values are Pearson chi-square values with degrees of freedom in parentheses

‡ Mann-Whitney U value

§ *p* value for chi-square tests and Mann-Whitney U tests comparing posters and lurkers

|| The assumption of chi-square concerning the minimum expected cell frequency (5 or greater) has been violated. Therefore the answer option "more times a month" has been left out of this analysis

¶ Chi-square values are Pearson chi-square values with continuity correction

Empowering processes

With regard to all empowering processes, lurkers scored significantly lower than the posters (Table 3). The processes that were reported most frequently in the online support groups by both lurkers and posters were "exchanging information" and "finding recognition."

Table 3 Mean scale scores processes for posters and lurkers

	Posters		**Lurkers**		**Mann-Whitney***	***p*†**
	No.	Mean (SD)	No.	Mean (SD)		
Exchanging information (1-4)	411	3.0 (0.54)	99	2.8 (0.59)	15560.00	<0.001
Finding recognition (1-4)	387	2.9 (0.54)	73	2.5 (0.67)	9720.50	<0.001
Sharing experiences (1-4)	387	2.8 (0.85)	73	1.9 (0.93)	6233.00	<0.001
Encountering emotional support (1-4)	405	2.3 (0.74)	86	1.5 (0.61)	6272.50	<0.001
Helping others (1-4)	387	2.3 (0.71)	73	1.6 (0.63)	6463.50	<0.001

* Mann-Whitney U value
† p value for Mann-Whitney U tests comparing posters and lurkers

Empowering outcomes

Table 4 shows that lurkers did not differ significantly from posters with regard to the empowering outcomes, with the exception of "enhanced social well-being."

The lurkers experienced the outcome of "enhanced social well-being" significantly less often compared to the posters. The empowering outcome that was experienced to the strongest degree by both posters and lurkers was "being better informed."

Table 4 Mean scale scores outcomes for posters and lurkers

	Posters		**Lurkers**		**Mann-Whitney***	***p*†**
	No.	Mean (SD)	No.	Mean (SD)		
Being better informed (1-5)	373	3.7 (0.76)	61	3.6 (0.66)	9403.50	0.03
Enhanced social well-being (1-5)	359	3.4 (0.96)	52	2.8 (0.76)	5603.50	<0.001
Feeling more confident in the relation with their physician (1-5)	369	3.4 (0.72)	58	3.3 (0.60)	10248.00	0.60
Improved acceptance of the disease (1-5)	365	3.3 (0.91)	56	3.1 (0.92)	9001.50	0.15
Feeling more confident about the treatment (1-5)	365	3.2 (0.79)	57	3.1 (0.79)	9112.50	0.13
Enhanced self-esteem (1-5)	359	3.2 (0.94)	52	3.0 (0.83)	7790.00	0.05
Increased optimism and control (1-5)	361	3.2 (0.59)	52	3.1 (0.64)	8268.00	0.16

* Mann-Whitney U value
† p value for Mann-Whitney U tests comparing posters and lurkers

Discussion

Principal results

To the best of our knowledge, this study is the first to empirically examine differences in perceived empowering outcomes between lurkers and posters. Our study revealed that, with the exception of the empowering outcome “enhanced social well-being,” participation in an online support group had the same profound effect on lurkers’ feelings of being empowered in several areas as it had on posters. Apparently, the mere reading of postings from others in online support groups can be beneficial for patients. Therefore, lurking in online support groups might be seen as a form of bibliotherapy. The idea of bibliotherapy is that well-being can be improved by reading self-help books or stories in which people can identify themselves with others [26]. Other studies have found evidence for online bibliotherapy; it has been shown to be effective in reducing depression [27], increasing self-management ability [26], and treating panic disorders [28].

Lurkers and posters did differ, however, with regard to the empowering outcome of “enhanced social well-being.” Fewer lurkers than posters reported that participating in an online support group led to a rise in their number of social contacts or to a decrease in loneliness. These results did not surprise us because it seems to be impossible to achieve new social contacts by lurking in an online support group.

In contrast to the empowering outcomes, we did find differences between lurkers and posters concerning the empowering processes executed in the online support groups. These differences not only appeared when focusing on processes that cannot be executed as a lurker, such as “helping others,” but also with processes such as “finding recognition.” These results are in line with the study results of Bane et al [29], who found indications in their study that lurkers in an online weight management group were less likely to see the group as a source of support and that it was less likely for them to find another group member with whom they could socially compare themselves.

An explanation for the significant difference between lurkers and posters with regard to the process “exchanging information” can, in our opinion, be linked to one of the frequently mentioned advantages of online support groups, namely that patients have the opportunity to request and receive informational support according to their personal needs and preferences [30]. Although lurkers have the option to read the information posted by others, they do not take advantage of the option to ask questions with specific concern for their own personal situation.

Our study indicated that lurkers were less satisfied than posters with the online support group. These results are in line with results of earlier studies that found that the majority of lurkers were significantly less enthusiastic than posters about the online group they participated in [13, 14]. Nonnecke et al [14] suggested that lurking might even be a result of dissatisfaction with the online group, although they did mention that it is not clear whether lurking behavior causes dissatisfaction or whether dissatisfaction with the online group results in lurking.

This study also provided some insight into the demographic characteristics of lurkers in Dutch online support groups. The demographic populations of lurkers and posters were similar in this study with the exception of age. Lurkers were somewhat older compared to those who post. These results might indicate a relationship between a lack of computer skills and lurking since elderly people are in general less familiar with computers. In addition, one of the respondents to our questionnaire illustrated this problem: "I gave up trying to contribute a posting to [name of online support group]. I just cannot find out how to…."

Finally, the results of our study showed that lurkers are active for a significantly shorter period of time in the online support groups compared to the posters. This might indicate that among the lurkers, there are indeed new users of the online support groups who first want to get to know the group before they start posting. This phenomenon is referred to in the literature as "de-lurking" [20, 31].

Several researchers have focused on methods to speed up the process of de-lurking, for example, by fostering receptive participation and by making the learning about the community and the first experiences as pleasant as possible [31] or by providing clear usability instructions [13]. The present study, however, indicates that for lurkers themselves it is not really necessary to de-lurk because they profit to the same extent from participating in online support groups as posters do. This does not mean that we encourage lurking. Lurking may be a problem for online patient support groups if there are few or no participants who contribute postings. According to Nonnecke et al [14], lurking is especially a problem for new online groups that do not yet have a sustainable group of active contributors. Silent online groups cannot survive because there is so much on offer on the Internet that people do not return to these groups [13].

In addition, this study showed that lurkers do not profit to the same extent as posters with regard to the outcome "enhanced social well-being" and that lurkers had a poorer mental well-being. These results might suggest that posting improves social or mental well-being. However, because we do not have baseline information about social and mental well-being at the time a patient joined an online support group, we cannot draw any conclusions about the causality of this relationship.

Limitations of the present study

The findings of this study are limited by the relative small percentage of lurkers (21%) included. Although a response percentage is not available, we presume that the percentage of lurkers active in the online support groups under study is higher than 21% when we consider the study results of Nonnecke and Preece [17], who reported an average rate of 45.5% of lurkers in health-related online support groups.

In addition, a considerable number of participants only partially completed the questionnaire. To examine whether there was selective attrition, we compared those respondents who completed the questionnaire with the respondents who did not complete the questionnaire on crucial aspects, such as whether they were posters or lurkers (data not shown). This analysis showed that lurkers did not complete the questionnaire significantly more often than posters. Since the questions on empowering outcomes were at the end of the questionnaire, this might mean that those lurkers who did not feel empowered simply did not respond to the respective questions. However, we can also think of other viable reasons. According to Preece et al [13], lurkers usually do not have the inclination to respond to questionnaires. Therefore, it can also be expected that lurkers more often than posters decide not to complete a questionnaire. This might especially be the case if a questionnaire is of considerable length, such as the one used in our study. Thus, the participants who chose to complete the online questionnaire are not necessarily representative of all lurkers and posters participating in online support groups for patients with breast cancer, fibromyalgia, and arthritis.

Finally, it should be taken into account that the results are self-perceived outcomes. Participants themselves estimated to what extent they profited from participation in online support groups. This does not prove that they truly profited from participation. Although this study provided us with relevant insights into the empowering outcomes as experienced by the posters and lurkers, a randomized controlled trial or a longitudinal study is required to evaluate whether posters and lurkers are truly empowered.

Conclusion

Earlier studies showed that patients can profit from participation in online patient support groups. Our current study suggests that this not only applies to those patients who actively participate by sending postings, but also to those patients who only lurk in online patient support groups. Apparently, the use of online support groups, even if it consists of merely reading postings by others, might be beneficial for patients. Physicians should therefore acquaint their patients with the existence of online patient support groups since these groups offer the surplus value of patient expert information compared to regular medical information.

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6

Health-related Internet use by patients with somatic diseases: frequency of use and characteristics of users

C.F. van Uden-Kraan
C.H.C. Drossaert
E. Taal
W.M. Smit
H.J. Bernelot Moens
S. Siesling
E.R. Seydel
M.A.F.J. van de Laar

Submitted

Abstract

Objective To explore the percentage of Dutch patients using the Internet to search for information about their illness. In addition, we studied patients' usage of health-related Internet applications, such as online patient support groups. The final objective of this study was to explore which demographic, health and psychological characteristics are related to patients' health-related Internet use.

Methods We sent a written questionnaire to a representative sample of patients with breast cancer, rheumatoid arthritis and fibromyalgia. The overall total response rate was 69% (N=679).

Results In total 52% of the patients used the Internet to search for information about their illness. However, only 15% of the respondents had ever read along with an online patient support group. An even smaller proportion of the patients (4%) had sent postings to such a group. Online communication with health professionals was not commonly practiced. A younger age, a higher education and employment appeared to be the only significant predictors of patients' health-related Internet use. Patients' health-related Internet use could not be predicted by health and psychological characteristics.

Conclusion Although about half of the patients made use of the Internet for health-related reasons, mostly their health-related Internet use was restricted to seeking information about their illness.

Introduction

The Internet can provide patients suffering from a chronic or life-threatening health condition with additional information about their illness, treatment options and health improvement strategies [1, 2]. Appealing attributes of the Internet as a source for health-related information are low costs, convenient and anonymous accessibility, 24-hour availability and the provision of updated, detailed information [3]. Patients who use the Internet feel empowered in managing their health, feel more involved in partnerships with their physicians, and in making decisions about their treatment [4, 5, 6]. However, health-related Internet use has also raised some concern. Patients may misinterpret information they find on the Internet [7] or they might come across misinformation which can result in a false sense of knowledge and control [8].

In the Netherlands, the percentage of persons with access to the Internet increased to 88% in 2007 [9]. During the past years, several studies focused on the percentage of patients using the Internet to search for information about their illness. Reported rates of health-related Internet use by patients vary between 24% and 59% in the case of cancer patients [10-16], and between 14% and 63% in the case of patients with rheumatic disorders [17-21]. Owing to the increasing availability and popularity of the Internet, it can be expected that more patients will use it for health-related reasons. There is hence a constant need for studies that explore the proportion of patients that use the Internet for these reasons [13]. The first objective of this study was to explore how many Dutch patients with breast cancer, fibromyalgia and rheumatoid arthritis use the Internet to search for information about their illness.

The Internet offers a variety of health-related Internet applications that can be divided into a) content (searching for health-related information), b) community (sharing concerns and experiences with peers online in patient communities), and c) communication (soliciting medical advice from online health professionals or contacting a physician via the email) [22]. Although information is available on the usage of these health-related Internet applications, few studies have specifically examined the usage of these applications among patient populations. Studies that have been carried out took place from the “service side”, e.g., they studied how often certain health-related websites or online patient support groups were visited and how often people sent postings to an online patient support group or solicited medical advice from an online health professional during a certain period [23-26]. Studies on the “demand side” are important to gain more insight into the number of patients who use these health-related Internet applications and the frequency with which they do so. The second objective of our study was thus to explore if - and if so, the frequency with which - patients make use of these health-related Internet applications.

Many studies have explored the relation between patients’ demographic characteristics and health-related Internet use. These studies showed that patients who use the Internet for health-related reasons were younger [e.g., 4, 10, 11, 13, 14, 16], were higher educated [e.g., 4, 11-13, 16, 27, 28], had a higher income [e.g., 4, 12, 13, 28], and were more often employed [4], compared to those patients who did not. Less is known about the relation between patients’ health-related and psychological characteristics and health-related Internet use. Although there are indications that health status is associated with health-related Internet use, the findings were contradictory. Some studies found that people who self-report fair or poor health [e.g. 2, 29] or who have 1 or more of 5 chronic conditions (diabetes, hypertension, cancer, heart problems, and depression) [3] use the Internet more often. In contrast, others found that health-related Internet use was not associated with worse pain [18], disease severity [14], length of time since diagnosis [10], or with the stage of breast cancer [10, 16]. Only a few studies have explored if psychological variables are related to health-related Internet use [4, 28, 30-32]. The final objective of this cross-sectional self-reported study was to explore which demographic, health and psychological characteristics are related to patients' health-related Internet use. Our aim was to determine these relations for the content function of the Internet as well as for the community and communication functions.

Methods

Sample and procedure

We focused the study on patients with breast cancer, fibromyalgia and rheumatoid arthritis. We chose to explore these three groups because of the contrast between the illnesses (life-threatening, unexplained and chronically disabling).

We selected a random sample of 400 patients from each patient population in the electronic database of two regional hospitals. Inclusion criteria were that the patients had to be younger than 75 and that they had to have sufficient knowledge of the Dutch language to be able to answer the questionnaire. Attending physicians (N=22) were asked to exclude those patients who did not meet the inclusion criteria and those who for other reasons were deemed unsuitable for participation in our study. Reasons mentioned for exclusion by the physicians were: deceased, aggravation of the illness, co-morbidity, mental health problems, wrong diagnosis or family circumstances. Two of the physicians did not respond, which meant that 30 breast cancer patients were not approached. After exclusion of in total 187 patients owing to the above mentioned reasons, 1013 patients could be included. The attending physicians invited the patients by mail and enclosed the questionnaire. If necessary, this was followed by one reminder. Of the total of 1013 patients approached, 28 were ineligible because they were deceased or had no valid address. The overall total response rate was 69% (N=679). Of these respondents, 272 patients had been diagnosed with rheumatoid arthritis (response rate: 78%), 212 patients with fibromyalgia (response rate: 64%) and 195 with breast cancer (response rate: 65%).

All patients were asked for their consent to check the actual date of diagnosis in their medical records.

Instrument

Demographic and health characteristics

The respondents were asked to provide information about the demographic characteristics sex, age, marital status, education and employment. Health-related quality of life was assessed with the SF 12, version 2. Standardized scores were calculated for the physical and mental well-being varying from 0 (poor wellbeing) to 100 (excellent wellbeing), with a mean of 50 and a standard deviation of 10 in the general population of the United States [33].

Psychological characteristics

For each psychological factor measured the internal consistency (Cronbach's alpha) was determined and mean total scores were calculated. *'Loneliness'* was measured by the short version of the loneliness scale [34], consisting of 6 items (alpha=0.88). Respondents could answer on a 5-point scale, ranging from 'no, completely disagree' (1) to 'yes, completely agree' (5). *'Social support'* was measured by the Social Support List–Interaction [35], consisting of 12 items (alpha=0.93). *'Extent of feeling informed'* was measured by a self-constructed scale [6], consisting of 4 items (alpha=0.90). The illness cognitions *'Acceptance'*, *'Helplessness'* and *'Perceived benefits'* were measured by the Illness Cognition Questionnaire [36]. *'Acceptance'* was measured by 6 items (alpha=0.93), *'Helplessness'* was measured by 6 items (alpha=0.93) and *'Perceived benefits'* was measured by 6 items (alpha=0.89). *'Perceived control'* was measured by 6 items (alpha=0.80) based on the revised illness perception questionnaire [37] and on the Dutch version of the Mastery Scale [38]. Respondents could answer on 4-point scales, ranging from 'seldom or never' (1) to 'often' (4).

Use of the Internet for health-related reasons

Respondents were asked to indicate how often they used the Internet in general. Respondents who did use the Internet were asked if they had ever used the Internet to search for information concerning their illness. In addition, these respondents were asked to indicate how often they had visited an online support group about their illness, if they ever contributed postings to these groups, and if so, how many postings they had contributed during the last four weeks. Respondents were also asked how often they had been in contact with peers in a chat box or via an email group, if they ever had visited a weblog of another patient and if they had a weblog themselves. Finally, they were asked to indicate if they ever posed questions about their illness to a health care professional or to their own physician via the Internet or email.

Data analysis

We defined health-related Internet users as "patients who had ever searched for information about their illness on the Internet". Differences in continuous variables between health-related Internet users and patients who had never used the Internet to search for information about their illness were tested by means of T-tests and differences in categorical variables by Chi-square tests. A hierarchical logistic regression analysis was performed to assess the relative importance of the variables that were correlated significantly ($p<0.05$) to health-related Internet use. In the first block of the regression analysis, the demographic characteristics that correlated significantly with health-related Internet use were entered, followed by health characteristics in the second block and psychological characteristics in the third. Statistical significance was assumed when alpha<0.05.

Results

Health-related Internet use

Of the respondents 71% made use of the Internet in general and 52% used it for health-related reasons (Table 1). For most of the respondents who did make use of the Internet to search for information about their illness, this was restricted to once (43%) or sometimes (37%) (data not in table).

Table 1 Health-related Internet use

	N	%
Frequency of general use of the Internet		
(Nearly) everyday	215	32%
4 to 5 days a week	47	7%
2 to 3 days a week	70	11%
About once a week	54	8%
Less often	84	13%
Never	196	29%
Health-related Internet use		
Never	323	48%
Yes, once	154	23%
Yes, sometimes	131	19%
Yes, often	71	11%

Demographic and health characteristics

Most of the respondents were women (84%) (Table 2). The average age of the respondents was 54 years. The majority of the respondents were married or living with a partner (81%). Most participants (60%) had a low level of education and were not employed (68%).

Patients who made use of the Internet for health-related reasons were significantly more often female, younger, higher educated and employed. No significant differences were found in marital status.

The mean duration of the participants' illness was 7 years, with a range of 0 to 59 years. The respondents had an average score of 38.6 on the physical component of the SF12 and an average score of 43.9 on the mental component of the SF12. This indicates that the respondents' physical and mental well-being was worse than the average of the general population.

Patients who made use of the Internet for health-related reasons were more often diagnosed with fibromyalgia and were more recently diagnosed, compared to patients who did not. No significant differences were found in physical and mental well-being.

Table 2 Demographic and health characteristics of Internet users versus non-Internet users

	Internet users#		**Non-Internet users**		**Total**	
	(328≤n≤356)		(274≤n≤323)		(602≤N≤679)	
Sex (n, %)*						
Female	312	88%	259	81%	571	84%
Male	44	12%	62	19%	106	16%
Age in years***						
Mean (SD)	48 (11.7)		61 (10.2)		54 (12.9)	
Minimum	18		23		18	
Maximum	74		75		75	
Marital status (n, %)						
Single	65	18%	63	21%	128	20%
Together	288	82%	242	79%	530	81%
Education (n, %)***						
Low	158	45%	246	77%	404	60%
Middle	130	37%	46	14%	176	26%
High	66	19%	28	9%	94	14%
Employment (n, %)***						
Employed	160	46%	52	17%	212	32%
Unemployed	190	54%	257	83%	447	68%
Diagnosis (n, %)***						
Breast cancer	83	23%	112	35%	195	29%
Fibromyalgia	159	45%	53	16%	212	31%
Arthritis	114	32%	158	49%	272	40%
Time passed since diagnosis (in years)***						
Mean (SD)	5.1 (5.8)		9.3 (9.0)		7.1 (7.8)	
Minimum	0		0		0	
Maximum	42		59		59	
Well-being (SF 12) (mean, SD)						
Physical well-being	37.7 (10.8)		39.5 (11.8)		38.6 (11.3)	
Mental well-being	43.5 (6.6)		44.4 (6.6)		43.9 (6.7)	

N is the number of respondents per item. Percentages are given with the total number of respondents per question as denominator (due to nonresponses, denominators may vary from question to question)

*p<0.05 **p<0.01 ***p<0.001 for Chi-square tests or T-tests comparing Internet users versus non-Internet users

Use of health-related Internet applications

In total 15% of the respondents had at some time read along with an online patient support group (Table 3). An even smaller share of the patients (4%) had actively participated in an online patient support group by sending postings. Only 8 patients had sent postings to online patient support groups during the last four weeks. In total 20 of the respondents had had some contact with peers via chat boxes and 7 respondents with peers via email groups. Of all the respondents 12% had at some time read along with a weblog and 4 respondents had a weblog themselves. Online communication with health professionals was not commonly practiced: 13 respondents had on occasion posed a question via the Internet or via the email to a health-professional and 8 respondents had at some time posed a question to their own physician via the email.

Table 3 Use of health-related Internet applications

	N	%
Use of online patient support groups		
Never	580	85%
Less than once a month	69	10%
About once a month	10	2%
More times a month	7	1%
About once a week	5	1%
More times a week	5	1%
About once a day	3	<1%
More times a day	0	-
Postings sent to an online patient support group		
Yes	28	29%
No	70	71%
Not applicable*	481	-
Number of postings sent to online patient support group		
No postings	20	71%
1 posting	3	11%
2 to 5 postings	2	7%
6 to 10 postings	2	7%
11 to 20 postings	0	-
More than 20 postings	1	4%
Not applicable**	551	-
Use of chat boxes for patients		
No, never	659	97%
Yes, once	16	2%
Yes, sometimes	3	<1%
Yes, often	1	<1%
Use of email groups for patients		
No, never	672	99%
Yes, once	2	<1%
Yes, sometimes	4	<1%
Yes, often	1	<1%
Visited weblog of other patients		
No, never	595	88%
Yes, once	70	10%
Yes, sometimes	11	2%
Yes, often	3	<1%
Having an own weblog		
Yes	4	<1%
No	675	99%
Posed a question about one's illness to a health-professional on the Internet		
No, never	666	98%
Yes, once	11	2%
Yes, sometimes	1	<1%
Yes, often	1	<1%
Posed a question about one's illness to one's own health-professional via the Internet or the email		
No, never	671	99%
Yes, once	6	<1%
Yes, sometimes	2	<1%
Yes, often	-	-

* Not applicable: this question was not applicable to patients who never visited an online patient support group

** Not applicable: this question was not applicable to patients who had never sent a posting

The relationship between the demographic, health and psychological characteristics of the patients and the use of the community and communication functions of the Internet could not be analyzed due to the small number of respondents that used the Internet to join a patient community or to communicate with health care professionals.

Psychological factors

Patients who used the Internet experienced more social support, felt less informed, accepted their illness to a lesser degree, felt more helpless, perceived less control and fewer benefits of their illness (Table 4). No significant differences were found concerning loneliness.

Table 4 Psychological factors of Internet users versus non-Internet users

	Internet Users	**Non- Internet Users**	**Total**
	(349≤n≤356) Mean (SD)	(314≤n≤322) Mean (SD)	(663≤N≤678) Mean (SD)
Social support (1-4)**	2.6 (0.64)	2.5 (0.66)	2.6 (0.66)
Loneliness (1-5)	2.2 (0.82)	2.2 (0.69)	2.2 (0.76)
Extent of feeling informed (1-4)***	2.8 (0.75)	3.1 (0.79)	2.9 (0.78)
Acceptance (1-4)***	2.6 (0.64)	2.9 (0.68)	2.8 (0.68)
Helplessness (1-4)**	2.0 (0.74)	1.9 (0.79)	2.0 (0.77)
Perceived benefits (1-4)***	2.5 (0.73)	2.7 (0.74)	2.6 (0.74)
Perceived control (1-4)*	2.3 (0.55)	2.4 (0.73)	2.4 (0.64)

*$p<0.05$ **$p<0.01$ ***$p<0.001$ for T-tests comparing Internet users versus non-Internet users

Associations between demographic, health and psychological characteristics and health-related Internet use

The regression analysis revealed that the variables together could explain 40% (Nagelkerke R^2) of the variance of Internet use (Table 5). The demographic characteristics (block 1) could explain 39%. Adding health characteristics (block 2) and psychological characteristics (block 3) did not indicate a significant improvement. The only significant predictors were age, education and employment. Patients who were younger, higher educated and employed used the Internet significantly more often for health-related reasons.

Discussion

About half of the patients questioned in our study used the Internet to search for information about their illness. Strikingly, the patients who indicated they sought health-related information on the Internet, mostly did so only once or occasionally. This is in contrast to our expectations, since we expected patients to seek online health-related information repeatedly during their illness process, i.e., when they noticed new symptoms or when a different type of treatment had been prescribed.

Table 5 Logistic regression analysis for health-related Internet use (N=597)

	Model 1 **Odds Ratio** (95% CI)	**Model 2** **Odds Ratio** (95% CI)	**Model 3** **Odds Ratio** (95% CI)	**Nagelkerke R^2**
Step 1 Demographic characteristics				0.39***
Sex	0.89 (0.53-1.51)	1.05 (0.58-1.89)	1.00 (0.55-1.82)	
Age	0.91 (0.89-0.93)***	0.91 (0.89-0.94)***	0.92 (0.89-0.94)***	
Education	1.68 (1.27-2.23)***	1.72 (1.29-2.29)***	1.67 (1.25-2.23)**	
Employment	0.60 (0.38-0.93)*	0.60 (0.38-0.95)*	0.61 (0.38-0.97)*	
Step 2 Health characteristics				0.39***
Time passed since diagnosis		0.97 (0.94-1.00)	0.98 (0.95-1.01)	
Arthritis versus breast cancer		0.69 (0.40-1.19)	0.79 (0.44-1.41)	
Arthritis versus fibromyalgia		0.85 (0.47-1.55)	0.92 (0.49-1.75)	
Step 3 Psychological characteristics				0.40***
Social support			1.15 (0.82-1.61)	
Extent of feeling informed			1.23 (0.86-1.75)	
Acceptance			0.78 (0.52-1.16)	
Helplessness			0.98 (0.70-1.36)	
Perceived benefits			0.78 (0.57-1.06)	
Perceived control			1.10 (0.74-1.62)	

*p<0.05 **p<0.01 ***p<0.001

Owing to the different patient populations studied, it is difficult to compare the estimate of health-related Internet users found in our study with estimates found by others studying health-related Internet use. In our study, the type of illness was not related to health-related Internet use. For example, in our study we found a lower percentage of health-related Internet use compared to not only the 59% found by van de Poll-Franse and van Eenbergen [13] among cancer patients but also the 63% found by Hay et al. [18] among rheumatology patients. They, however, respectively questioned a patient population younger than 65 [13] and still not diagnosed [18]. Owing to the increasing availability and popularity of the Internet, it can be expected that even more patients will use the Internet for health-related reasons. In our opinion, studies that explore the percentage of patients using the Internet for health-related reasons should thus be regularly repeated.

Our study revealed that for most patients their health-related Internet use was restricted to seeking information about their illness on the Internet. Only a very small number of patients made use of the 'community' and 'communication' functions. A disadvantage of merely using the Internet to search for (health-related) information is that patients can "get lost" in the wealth of information, because there is no intermediary (e.g., health professional) to help them find relevant and credible information [39]. Eysenbach [39] suggests that as a replacement for this intermediary, patients could use so-called 'apomediaries'. Apomediaries are agents (people or tools) that can guide a consumer to high quality information. One example of an apomediary is an online patient support group. Online patient support groups can, for example, be helpful when a patient wants to assess the quality of the information found on the Internet or when a patient needs guidance to obtain additional (credible) sources of health-related information [39]. Besides offering informational support, online patient support groups have several other functions, such as the provision of social support and the opportunity for social comparison and for sharing experiences [5]. It is thus suggested that online patient support groups might be the health-related Internet application with the biggest impact on health outcomes [40]. Owing to this (potential) empowering role of online patient support groups, it is a pity that our study showed only a small number of patients using these groups. Factors that impede participation in online patient support groups are misconceptions, such as the misconception that only severe, older and lonely patients or those unable to cope with their illness engage in support groups, and a lack of awareness of these groups [41]. More studies that focus on participation rates and reasons for non-participation in online patient support groups are, however, needed. We advise future studies to focus on ways in which participation in support groups can be facilitated.

Online communication with health professionals was not commonly practiced at all. These low numbers might result from the fact that there are still limited possibilities to electronically communicate with health professionals. Although other studies have shown that patients would like to have the possibility to pose questions to physicians via the Internet or email [13], physicians have been reluctant to adopt so-called e-consultation, because they fear an increase in workload and a decrease in the quality of care [42, 43]. In addition, physicians are of the opinion that they are inadequately rewarded for e-consults [43].

The final objective of our study was to explore which demographic, health and psychological characteristics are related to patients' health-related Internet use. Our study confirmed previous findings on the impact of age, education and employment on health-related Internet use. Although this is a confirmation of the results found by others studying the connection between demographic characteristics and health-related Internet use [4, 10-13, 27, 28], we had expected that these might have no longer applied because of the intensity of Internet penetration among the Dutch population [9]. However, having access to the Internet does not mean that people have the necessary skills to be able to use all health-related Internet applications [44]. In addition, some people might not be very keen to use the Internet for health-related reasons. This might especially be the case in this study since we questioned a somewhat older patient population. Elderly people mostly treat Internet with greater scepticism than younger people. Trust is of specific importance to health-related Internet use, because the topic of "an illness" in itself requires a high level thereof [45]. The current generation of patients still leans heavily on their physicians and considers them the most reliable source of information [13]. It will be interesting to follow future developments, especially because of the emergence of more advanced apomediaries, such as "PatientsLikeMe" [46] and "Revolution Health" [39].

Our study revealed that patients' health-related Internet use could not be predicted by health characteristics. This is in contrast to our expectations, because we had expected that those who had been diagnosed more recently would use the Internet more often, and because other studies showed that patients who indicated having a poorer physical or mental health used it more often for health-related reasons [2, 29].

In addition, our study revealed that patients' health-related Internet use could not be predicted by psychological characteristics. This is in contrast not only to the study of Fogel, Albert, Schnabel, Ditkoff, & Neugut [31] who found that patients' health-related Internet use was associated with greater social support and less loneliness, but also to the study of Kalichman et al. [30], who found that patients' health-related Internet use was associated with greater social support, disease knowledge, active coping and information-seeking coping. However, the associations found by Fogel et al. [31] and by Kalichman et al. [30] were only significant on $p<0.05$ level. Moreover, Fogel et al. [31] questioned a patient population younger than 65, whereas Kalichman et al. [30] questioned a patient population with a mean age of 41.

Limitations

The findings of this study are limited by the fact that we conducted a cross-sectional study. No causal relationships could be attributed. Although no cross-sectional relations were found between patients' psychological and health characteristics and patients' health-related Internet use, we do not know from this study what effect patients' health-related Internet use has on psychological and health status. A randomized controlled trial or a longitudinal study would be the best way to detect the outcomes of health-related Internet use on patients. To conduct a randomized trial or a longitudinal study with "the Internet" as intervention is a great yet arduous challenge because of the difficulty of composing a comparable control group [47].

The small number of respondents that used the Internet to join a patient community or to communicate with health care professionals made it impossible to assess the relationships between the usage of these health-related Internet applications and demographic, health and psychological characteristics.

Conclusion

Our study showed that about half of the patients questioned made use of the Internet to search for information about their illness. For most patients, their health-related Internet use was restricted to seeking information about their illness on the Internet. Only a very small number of patients participated in peer communities or communicated with health care professionals online.

A younger age, a higher education and employment appeared to be the only significant predictors of patients' health-related Internet use. Patients' health-related Internet use could not be predicted by health and psychological characteristics.

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Determinants of engagement in face-to-face and online patient support groups

C.F. van Uden-Kraan
C.H.C. Drossaert
E. Taal
W.M. Smit
H.J. Bernelot Moens
M.A.F.J. van de Laar

Submitted

Abstract

Despite patients' tendency to profit from their engagement in peer support, studies have shown that many face-to-face peer support groups only have few participants. Although it was anticipated that engagement would increase with the emergence of online peer support, recent studies have indicated that only few patients actually use it.

In this study we explored factors that facilitate or impede engagement in face-to-face and online peer support. To explain patients' participation behavior we employed the Theory of Planned Behavior (TPB). We explored to what extent TPB variables can predict patients' intention to engage in peer support.

To answer this research question, we applied a mixed methods strategy. A questionnaire was completed by 679 patients being treated for arthritis, breast cancer and fibromyalgia at two Dutch regional hospitals. In addition, we interviewed 19 patients with arthritis who did not engage in peer support.

Our study confirmed that only a relatively small percentage of the patients engaged in peer support. The respondents were more positive about face-to-face peer support, compared to online peer support. In accordance with the TPB, having a more positive attitude, feeling more supported by people in the social environment, and feeling more able to participate in peer support increased the intention to participate in both kinds of peer support. Nevertheless, the intention to engage in face-to-face and online peer support could only be modestly predicted by the TPB variables. Our study offers specific pointers for an intervention to increase participation rates in peer support.

Introduction

Over the past decades, considerable attention has been paid to the concept of peer support groups for patients. Several studies have shown that patients tend to profit from engagement in peer support. Such group participation can offer emotional support, confidence and strength [1], can foster hope [2], can lead to better coping styles [3], less distress [4], and an improvement of the participants' quality of life [5]. Despite these empowering outcomes of engagement in peer support, studies have shown that many face-to-face peer support groups only have small numbers of participants [6, 7]. When patients seek contact with peers, it is often restricted to contact with an acquaintance with the same disease [8].

Several studies have investigated why people engage in face-to-face peer support groups and results showed that participants of peer support groups were more often female, younger, higher educated and of a higher economic status compared to non-participants [9-11]. More often participants made use of other professional and voluntary support [9]. Contradictory findings appeared concerning social support: some studies found that those who participated experienced less social support in their social environment [9-11], while others found no effect [6, 12, 13]. In general, participants seem to be more anxious about their illness and had greater emotional problems compared to non-participants [10, 14].

With the availability of the Internet, so too has the opportunity to share concerns and experiences with peers online. The outcomes of participation in online support groups are in line with the outcomes of participation in face-to-face support groups [15-21]. It was anticipated that engagement in peer support would increase with the emergence of online support groups as these kinds of groups have specific advantages compared to face-to-face support groups, such as the absence of geographical barriers, 24-hour availability, reasonable costs and anonymity [22-24]. However, a recent study showed that only 6% of the patients make use of online peer support groups [25].

Little is known about determinants of participation in online support groups. We are only aware of two studies that provided some insight. Dutta & Feng [26] showed that participants are younger compared to non-participants. Shaw, Hawkins, Arora, McTavish, Pingree, & Gustafson [27] found that the only significant difference between active and inactive participants of an online peer support group was that active participants were more likely to consider themselves as actively participating in health care.

In this study we focused on determinants of engagement in online as well as face-to-face peer support. Considering the fact that several studies showed that engagement in face-to-face and online peer support can have a positive effect on participants, it is important to gain more insight into the factors that impede or facilitate engagement in these kinds of peer support. Possibly, more patients can benefit from engagement in face-to-face and online peer support when misconceptions and barriers of peer support are altered or removed.

As the theoretical basis for the present study, we took the Theory of Planned Behavior (TPB), a frequently used model to explain human behavior [28]. According to the TPB, intention to engage in peer support is determined by three considerations: (1) attitude, defined as thoughts and feelings regarding engagement in peer support (2) subjective norm, defined as patients' perceptions about whether significant others would like them to engage in peer support, and (3) perceived behavioral control, defined as the extent to which patients think that they are able to engage in peer support.

The TPB has been used to predict participation behavior in face-to-face support groups but has never been used in studies concerning online peer support. The primary purpose of this study was to explore to what extent TPB variables can predict patients' intention to engage in face-to-face and online peer support. In addition, we studied whether demographic characteristics, health-related quality of life (physical and mental) and social support factors are associated with intention to engage in face-to-face and online peer support. Finally, we explored if face-to-face and online peer support had the same or differing predictors.

To answer these research questions, we applied a mixed methods strategy: Creswell's [29] concurrent procedure. This means that we conducted both a survey and interviews simultaneously. The quantitative study was conducted among a broad patient population and focused on demographic, health, social support and TPB variables. The qualitative study was conducted among a sample of non-participants and was aimed at achieving a more in-depth understanding of patients' perceptions of engagement in support groups.

Quantitative Methodology: survey

Sample and procedure

We focused the quantitative study on patients with breast cancer, fibromyalgia and rheumatoid arthritis. We chose to explore these three groups because of the contrast between the illnesses (life-threatening, unexplained and chronic disabling respectively).

We selected a random sample of 400 patients from each patient population in the electronic database of two regional hospitals. Inclusion criteria were that the patients had to be younger than 75 and that they had to have sufficient knowledge of the Dutch language to be able to answer the questionnaire. We mailed attending physicians (N=22) with the request to exclude those patients who did not meet the inclusion criteria and those who for other reasons were deemed unsuitable for participation in our study. Reasons mentioned for exclusion by the physicians were: deceased, aggravation of the illness, co-morbidity, mental health problems, wrong diagnosis or family circumstances. Two of the physicians did not respond which meant that 30 breast cancer patients were not approached. After exclusion of in total 187 patients owing to the abovementioned reasons, we were left with a group of 1013 patients. The attending physicians invited the patients by mail and enclosed the questionnaire. If necessary, this was followed by one reminder. Of the total of 1013 patients approached, 28 were ineligible because they were deceased or had no valid address. The overall total response rate was 69% (N=679). Of these respondents, 272 patients had been diagnosed with rheumatoid arthritis (response rate: 78%), 212 patients with fibromyalgia (response rate: 64%) and 195 with breast cancer (response rate: 65%).

All patients were asked for their consent to check the actual date of diagnosis in their medical records.

Instrument

Demographic and health characteristics

The respondents were asked to provide information about the demographic characteristics sex, age, marital status, education and employment. Health-related quality of life was assessed with the SF 12, version 2. Standardized scores were calculated for the physical and mental well-being varying from 0 (poor well-being) to 100 (excellent well-being), with a mean of 50 and a standard deviation of 10 in the general population of the United States [30].

Social support factors

Social support factors were measured by the Social Support List – Interaction [31], consisting of 12 items. An example of a social support item is: "Does it ever happen that someone shows interest in you?" Respondents could answer on a 4-point scale that ranged from 'seldom to never' (1) to 'often' (4). The internal consistency (Cronbach's alpha) for this construct was alpha=0.93. A mean total score was calculated.

Current use of peer support

Respondents were asked to indicate whether they had had contact with peers at patient meetings, via the Internet, at patient organization venues, or whether they had had contact with an acquainted peer during the past year and, if so, how frequent this contact was. Respondents could answer on a 4-point scale that ranged from 'never' (1) to 'regularly' (4).

TPB variables were measured regarding both face-to-face and online peer contact. Items were derived from literature [e.g., 8, 10, 14], and our earlier studies on peer support [21, 32]. For each construct the internal consistency (Cronbach's alpha) was determined and a mean total score was calculated.

Intention to engagement in peer support

We asked the patients if they intended to have contact with peers face-to-face or via the Internet during the coming year. Respondents could answer on a 5-point scale that ranged from 'certainly yes' (1) to 'certainly no' (5).

Attitude towards peer support

Attitude towards face-to-face and online peer support was measured directly with two single items: "Face-to-face contact with peers is valuable" and "Contact with peers via the Internet is valuable". Attitude was also measured indirectly by assessing advantages and disadvantages. In total, 28 items were formulated that described the patients' advantages and disadvantages with regard to peer support (see table 4). The items had the format of a statement that began with 'Contact with peers…' or 'Through having contact with peers …'. Respondents could answer on a 5-point scale that ranged from 'totally disagree' (1) to 'totally agree' (5). 'Advantages of face-to-face peer support' was measured with 9 items (alpha=0.93). 'Disadvantages of face-to-face peer support' was measured with 5 items (alpha=0.74).

'Advantages of online peer support' was measured with 9 items (alpha=0.92). 'Disadvantages of online peer support' was measured with 5 items (alpha=0.65).

Subjective norm towards peer support

Subjective norm was measured with two items: "People who are important to me think that I certainly should be in contact with peers face-to-face" and "People who are important to me think that I certainly should be in contact with peers via the Internet". Respondents could answer on a 5-point scale that ranged from 'should not' (1) to 'should' (5).

Perceived behavioral control towards peer support

Perceived behavioral control was measured directly with two items: "I consider myself capable of having contact with peers face-to-face" and "I consider myself capable of having contact with peers via the Internet". Respondents could answer on a 5-point scale that ranged from 'totally disagree' (1) to 'totally agree' (5). Perceived behavioral control was also measured indirectly by assessing barriers. In total, 13 items were formulated that described the patients' perceived barriers in having contact with peers face-to-face or via the Internet (see table 5). The items had the format of a statement that began with "How difficult or how easy is it for you to…?". Respondents could answer on a 5-point scale that ranged from 'very easy' (1) to 'very difficult' (5). The barriers questioned for face-to-face and online peer support partially differed, as a result of the different characteristics of these kinds of peer support. 'Barriers of face-to-face peer support' was measured with 5 items (alpha=0.83). 'Barriers of online peer support' was measured with 8 items (alpha=0.90).

Data analysis

Differences in TPB variables concerning face-to-face and online peer support were tested by means of paired-sample t-tests. A hierarchical multiple regression analysis was used to determine to what extent intention to engage in face-to-face and online peer support could be predicted. The determinants of the TPB were entered in the first block of the regression analysis. In the second block social support factors, health related characteristics and the demographic characteristics that correlated significantly with intention were entered. Statistical significance was assumed when alpha<0.05.

Results of the quantitative study

Demographic and health characteristics of the participants

Most of the respondents were female (84%) (Table 1). The mean age of the respondents was 54 years. The majority of the respondents was married or living with a partner, had a low level of education and was unemployed. Patients had been diagnosed with rheumatoid arthritis (40%), fibromyalgia (31%) and breast cancer (29%). The mean duration of the participants' illness was 7 years, with a range from 0 to 59 years.

The respondents had an average score of 38.5 on the physical component and an average score of 43.9 on the mental component of the SF12. This indicates that the respondents' physical and mental well-being was worse than the average of the general population.

Table 1 Demographic and health characteristics of the participants and social support factors (602≤N≤679)

		n	%
Sex (n, %)			
	Female	571	84%
	Male	106	16%
Age in years			
	Mean (SD)		54 (12.9)
	Minimum		18
	Maximum		75
Marital status (n, %)			
	Single	128	20%
	Married/cohabiting	530	81%
Education (n, %)			
	Low	404	60%
	Middle	176	26%
	High	94	14%
Employment (n, %)			
	Employed	212	32%
	Unemployed	447	68%
Diagnosis (n, %)			
	Breast cancer	195	29%
	Fibromyalgia	212	31%
	Rheumatoid arthritis	272	40%
Disease duration (in years)			
	Mean (SD)		7.1 (7.8)
	Minimum		0
	Maximum		59
Well-being (SF 12) (mean, SD)			
	Physical well-being		38.6 (11.3)
	Mental well-being		43.9 (6.7)
Social support (mean, SD) (1-4)			2.6 (0.66)

Current use of face-to-face and online peer support

The majority of the respondents (n=396, 58%) had had contact with peers during the past year (data not in table). The most regular type of peer support was contact with an acquainted peer (52%) (Table 2). In total, 10% of the respondents had engaged in face-to-face meetings for patients in the past year. Only 4% of the respondents had had contact with peers via the Internet in the past year. Of the respondents, 5% indicated they had had contact in the past year with peers through patient organization venues.

Table 2 Current use of face-to-face and online support (N=679)

	Never		Once		Several times		Regularly	
	n	%	N	%	n	%	n	%
How often did you have contact with peers at patient meetings during the past year?	614	90%	26	4%	26	4%	13	2%
How often did you have contact with peers via the Internet during the past year?	649	96%	7	1%	17	3%	6	1%
How often did you have contact with (an) acquaintance(s) with the same disease during the past year?	326	48%	35	5%	216	32%	102	15%
How often did you have contact with peers at patient organization venues during the past year?	643	95%	15	2%	12	2%	9	1%

Determinants of the TPB concerning face-to-face and online peer support

The respondents' intention to engage in peer support in the future was slightly negative (Table 3). The majority of the respondents did (certainly) not intend to look for peers via the Internet (74%) or face-to-face (60%) in the coming year (data not in table).

Table 3 Mean scores for determinants of the TPB by diagnostic group for face-to-face and online peer support

	Face-to-face peer support (601≤N≤663) Mean (SD)	**Online peer support** (530≤N≤654) Mean (SD)
Intention* (1-5)	2.4 (1.2)	2.0 (0.95)
Attitude* (1-5)	3.7 (1.1)	3.2 (1.1)
Advantages* (1-5)	3.5 (0.85)	3.2 (0.86)
Disadvantages* (1-5)	2.9 (0.88)	3.2 (0.85)
Subjective norm* (1-5)	3.0 (0.69)	2.8 (0.67)
Perceived behavioral control* (1-5)	4.1 (1.2)	3.9 (1.4)
Barriers† (1-5)	2.8 (0.80)	2.8 (0.91)

* $p<0.001$ for paired-sample t-tests comparing face-to-face and online peer support

† No differences in amount of barriers between face-to-face and online peer support can be determined, because different barriers were questioned

Although the respondents had a slightly positive attitude towards both kinds of peer support, they were significantly more positive towards face-to-face support. Respondents experienced significantly greater advantages and fewer disadvantages of face-to-face support compared to online peer support. The scores on the separate items (Table 4) revealed that the most important advantages of both types of peer support were 'sharing experiences' and 'finding recognition'.

Table 4 Mean items scores on attitude towards face-to-face and online peer support

	Face-to-face peer support (601≤N≤616) Mean (SD)	**Online peer support** (526≤N≤546) Mean (SD)
Advantages		
Contact with peers offers a good opportunity to share your experiences (1-5)	3.8 (1.1)	3.6 (1.1)
Contact with peers provides recognition and understanding (1-5)	3.8 (1.1)	3.6 (1.0)
Contact with peers provides support (1-5)	3.7 (1.1)	3.4 (1.0)
Contact with peers is informative (1-5)	3.5 (1.1)	3.4 (1.0)
Contact with peers is comforting (1-5)	3.4 (1.0)	3.1 (1.0)
Through contact with peers you feel empowered as a patient (1-5)	3.4 (1.1)	3.1 (1.1)
Contact with peers provides reliable information (1-5)	3.3 (1.1)	3.1 (1.0)
Through contact with peers you can cope better with your illness (1-5)	3.2 (1.1)	3.0 (1.1)
Through contact with peers you can accept your illness more easily (1-5)	3.2 (1.1)	2.9 (1.1)
Disadvantages		
Through contact with peers you are occupied too much with your illness (1-5)	3.2 (1.4)	3.6 (1.3)
Contact with peers is too informal (1-5)	2.9 (1.1)	3.2 (1.0)
Contact with peers makes people more concerned about the consequences of their disease (1-5)	2.9 (1.2)	3.1 (1.2)
Contact with peers is too shallow (1-5)	2.7 (1.1)	3.2 (1.0)
Contact with peers takes too much time (1-5)	2.7 (1.3)	2.9 (1.3)

The most important disadvantage of both types of peer support was the ‘continual confrontation with their illness’. In general, respondents felt significantly more encouraged by people in their social environment to be in contact with peers face-to-face than via the Internet. The respondents considered themselves significantly more capable of having contact with peers face-to-face than via the Internet. The respondents indicated the same number of barriers to face-to-face support as towards online support. No differences in perceived barriers between face-to-face and online peer support could be determined, because different barriers were questioned. The scores on the separate barriers (Table 5) revealed that for both kinds of peer support the most important one was to find a suitable peer support group. For online peer support other important barriers were to discuss the illness on the Internet, to actually write about the illness on the Internet, and the difficulty (due to the illness) of having to type or sit behind the computer for a long period of time.

Table 5 Mean items scores for barriers of face-to-face and online peer support

	Mean (SD) (582≤N≤595
Barriers of face-to-face peer support	
How difficult or how easy is it for you…	
to find a suitable face-to-face peer support group? (1-5)	3.0 (1.0)
To find the time and the opportunity to contact peers face-to-face? (1-5)	2.9 (0.97)
considering your illness to visit face-to-face peer support groups? (1-5)	2.9 (1.0)
To afford the cost involved with face-to-face peer contact? (1-5)	2.8 (1.0)
to talk about your illness with peers face-to-face? (1-5)	2.7 (1.0)

	Mean (SD) (506≤N≤518)
Barriers of online peer support	
How difficult or how easy is it for you…	
to find a suitable online peer support group? (1-5)	3.1 (1.1)
to talk about your illness on the Internet? (1-5)	3.1 (1.1)
to verbally express your illness on the Internet? (1-5)	3.1 (1.1)
considering your illness to type or sit behind the computer for a long period of time? (1-5)	3.1 (1.2)
to find the time and the opportunity to contact peers via the Internet? (1-5)	3.0 (1.0)
to afford the costs involved with peer-to-peer contact via the Internet? (1-5)	2.6 (1.1)
to work with the Internet? (1-5)	2.3 (1.3)
to obtain access to the Internet? (1-5)	2.2 (1.2)

Prediction of intention

For face-to-face contact, the first block consisting of the TPB variables could explain 33%. Of the distal factors, physical and mental well-being could significantly improve the total amount of explained variance of intention to face-to-face support. The multiple regression analysis showed that attitude, perceived advantages, perceived disadvantages, subjective norm, barriers and poorer physical and mental well-being were significant independent predictors of intention to face-to-face peer support.

For online contact, the first block consisting of the TPB variables could explain 26%. Of the distal factors only mental health and age could significantly improve the total amount of explained variance of intention to online peer support. The multiple regression analysis showed that attitude, perceived advantages, perceived disadvantages, subjective norm, perceived behavioral control and poorer mental well-being appeared to be significant independent predictors of intention to online peer support.

The total amounts of explained variance were moderate for face-to-face contact (38%) and online contact (35%) (Table 6).

Table 6 The extent to which the intention to online peer support and face-to-face peer support can be predicted by determinants of the TPB

		Intention to face-to-face peer support (n=554)		Intention to online peer support (n=489)	
		β		**β**	
Step 1	Attitude	0.22***		0.19***	
	Advantages	0.17**		0.20***	
	Disadvantages	-0.19***		-0.11**	
	Subjective norm	0.22***		0.19***	
	Perceived behavioral control	n.s.		0.16**	
	Barriers	n.s.		0.12*	
		R²=0.33 F (6, 548)=45.1***		R²=0.26 F (6, 483)=28.7***	
		r	**β**	**r**	**β**
Step 2	Attitude	0.46**	0.21***	0.38**	0.16**
	Advantages	0.46**	0.17**	0.40**	0.18***
	Disadvantages	-0.33**	-0.20***	-0.19**	-0.10**
	Subjective norm	0.37**	0.19***	0.30**	0.17***
	Perceived behavioral control	0.19**	n.s.	0.24**	0.11*
	Barriers	-0.18**	-0.12**	n.s.	n.s.
	Social support factors	n.s.	n.s.	n.s.	n.s.
	Physical health	-0.14**	-0.09*	-0.23**	n.s.
	Mental health	-0.10**	-0.12**	-0.23**	-0.12**
	Time passed since diagnosis	n.s.	n.s.	-0.14*	n.s.
	Arthritis versus breast cancer	n.s.	n.s.	-0.21**	n.s.
	Arthritis versus fibromyalgia	0.13**	n.s.	0.30**	n.s.
	Sex	0.11**	n.s.	n.s.	n.s.
	Age	-0.15**	n.s.	-0.34**	-0.16**
	Marital status	n.s.	n.s.	0.09*	n.s.
		R²=0.38 F (15, 539)=21.8*** R² change=0.05***		R²=0.35 F (15, 474)=16.8*** R² change=0.09***	

*p<0.05 **p<0.01 ***p<0.001 n.s.=non-significant

Conclusions quantitative study

The results of the quantitative study showed that only a very small portion of the participants had engaged in organized kinds of peer support during the last year. In general, respondents were more positive about face-to-face compared to online peer support. TPB variables could only moderately explain intention. For both types of peer support, the regression analysis showed that attitude components and subjective norm contributed the greatest to the explained variance of intention to engage in peer support.

Qualitative Methodology: interviews

Sample

We focused the qualitative study on patients with rheumatoid arthritis who did not participate in peer support groups. We chose to explore this group of patients because the

Dutch online support groups for patients with rheumatoid arthritis were less active than support groups for breast cancer and fibromyalgia patients [33].

Three rheumatologists employed at a regional hospital recruited 20 patients. The patients were selected from those who visited their rheumatologist during a random week at the outpatient clinic. During the interviews, it appeared that one of these patients read along with an online peer support group. This patient was thus excluded from further participation in this study, leaving a group of 19 respondents.

Measures

We used a semi-structured interview schedule to allow flexibility, individual contextualization and probing of issues that arose [34]. Areas explored included current and intended use of face-to-face and online peer support, attitude, subjective norm and perceived behavioral control towards peer support. The patients were asked to provide information about their demographic characteristics, sex, age, marital status, education, employment and disease duration.

Procedure

The patients were interviewed at home (n=18) or at another place of preference (n=1). The interviews were audiotaped with prior consent of all participants and transcribed verbatim. The interviews lasted between 30 minutes and 1 hour.

Data analysis

Data were analyzed by two coders using inductive analysis per TPB determinant. According to Patton [35], inductive analysis means that the patterns, themes and categories of analysis come from the data: "They emerge out of the data rather than being imposed on them prior to data collection and analysis" (p. 390). Each coder read all transcripts through separately several times to familiarize him-/herself with the data, and to identify emerging themes by which the data could be examined. On the basis of these analyses, the coders developed a thematic framework which they used to independently code the transcripts. To reach general consensus, results were discussed with a third independent coder, after which themes were refined and sub-themes were identified [36].

All quotes provided in this article were translated from Dutch into English. To ensure anonymity we removed all identifying information from the quotes.

Results of the qualitative study

Demographic and health characteristics of the participants

The majority of the participants interviewed were female (n=12). The mean age of the participants was 55 years (SD 13.2 years) with a range of 35 to 77 years. Of the total group, 12 were either married or living with someone. In total, 9 participants had a low level of education, while 7 had a secondary and 3 a high level of education. Half of the participants (n=9) had either a full- or a part-time job. The median disease duration of the participants was 12 years (SD 10.4 years), with a range of 2 to 37 years.

Current engagement in face-to-face and online peer support

None of the respondents were in contact with peers in an organized group at the moment the interviews were conducted. In the past, one respondent had participated in such a group, however. Two other respondents had read along with a peer support group on the Internet, but did not do so at the moment. Over half of the respondents indicated that they knew a person who also had rheumatoid arthritis (e.g., a family member, acquaintance, colleague). Contact with these peers about the illness was irregular, varying from weekly to incidental meetings in which the illness was also discussed.

Attitude towards face-to-face and online peer support

In this section, we present the themes concerning the respondents' attitudes towards face-to-face and online peer support that emerged from the analysis of the transcripts. We distinguished between "attitude towards peer support in general", and "attitude towards online peer support".

Attitude towards peer support

All respondents mentioned that peer support could be valuable. Advantages of peer support mentioned by the respondents were e.g., exchanging information, finding recognition and encountering social support. The respondents, however, indicated that these were advantages for other people who were in need of peer support and not for themselves:

> Yes, I do not benefit from peer support. But I think that it could be an advantage for people who don't know how to cope with rheumatism. I think that is very important for many people. […] For instance if you are alone with your rheumatism.

For themselves, they saw mainly disadvantages of peer support. These disadvantages were thus discussed further.

1. Continual confrontation with (negative sides of) their illness

Most patients indicated that a disadvantage of engagement in peer support was the (continual) confrontation with their illness: "The moment you talk with people who have got it too, it is 'Okay you have got it', and then you have to face the facts again." Respondents especially shy away from the confrontation with the negative sides of their disease: "It is good that you do not know everything. I don't want to see the misery of other people. I have enough problems of my own." They indicated that they did not like to be confronted with patients with whom the disease had progressed further: "Then you see people who have used Prednison since childhood and who have stayed very small." Other respondents worried about receiving information about negative sides of their disease that they would rather not know about:

> The main disadvantage, I think, is that you might get information you don't want, for which you are not ready, and which is completely useless. Once I met a woman with the same medication and she told me: 'There are only a few people who use [name of medication] longer than a year.' And then you start worrying much more.

Some patients indicated that they were afraid that engagement in peer support would lead to feeling worse and more depressed: "I think it is a disadvantage that you end up in a pattern of illness, being ill, pain, these things. You are always 'ill' in the group. This can be very depressing, you know."

2. Peer support groups have a negative atmosphere

The majority of the respondents had a negative image of peer support groups. Many respondents believed that the focus in peer support groups would only be on negative aspects of the disease: "That you group together and that you start mentioning only negative things. 'Not this' and 'Not that' and 'This is hard'." Other respondents had the idea that patients engaging in peer support would constantly complain about their disease: "There will always be people who drone on about it or complain. Who each tell the same story time and again." Several respondents thought that some of the participants of peer support groups saw themselves as victims: "My problem with self-help groups is that the people who participate often see themselves in the role of victim. And I think that is very negative." Moreover, respondents indicated that they were of the opinion that peers could sometimes exaggerate their disease. According to these respondents, the peers considered their situation more negative and more pessimistic than it was in reality: "I know it's a bit of a cliché, some think the glass is half empty and some think the glass is half full. But it depends on the way you look at it!"

3. In peer support groups unwanted social support is provided

Other respondents believed that people participating in peer support groups would be very inquisitive: "A lot of people are terribly curious! They would like to know everything! Like: 'What time do you get up in the morning?' and 'Do you really rest on time?'" Some respondents mentioned that they had the feeling that they were constantly being checked on by other participants:

> Then they tell you something and then I think I will try it out. But already after a few days they ask: 'And? Have you tried it out already?' So you get the feeling that certain people keep an eye on you. That they check if you're really following their advice.

4. Stigma

Several respondents assumed that patients who engaged in peer support had not yet accepted their disease or did not know how to cope with it: "I think that they don't know how to cope with it, that they are looking for something. But I know how to cope with it."

Other respondents were of opinion that peers who engage in peer support would cope with their disease in a different way than they did.

Some respondents mentioned that peer support is intended for patients who are lonely, old and who are not supported by significant others in their coping process. Therefore respondents explicitly expressed that they have too much self-respect to engage in peer support:

> I really don't appeal for help to participate in such things, because I have too much self-respect. I do what I want to do and for as long as I can, then I feel it's good. The illness should not take precedence.

The majority of the respondents do not want to be associated with other people who have this illness, and want to be treated normally: "I would simply like to be treated as an ordinary human being. I don't want to be stigmatized as an invalid or handicapped person".

Several respondents mentioned that they do not want to be foisted by their peers, but they want to deal with their illness themselves: "I don't like to be cajoled into doing something. Others can tell you that those tablets gave them a headache, but I can really find this out myself."

5. No trust in the quality and value of the information exchanged

Almost half of the respondents mentioned the lack of insight into the quality of the information provided by peers. Several respondents did not trust the information provided by peers because they were no medical specialists: "Come on, look. Of course they are not all really specialized." Respondents believed that each individual experiences the illness differently, which makes it difficult to compare their situation with peers: "Look, for everybody it's also their own experience. What is perhaps really good for one person, may be very bad for me. We may be peers, but that doesn't make us identical!" Some respondents indicated that they did not think they would receive any new information in peer support groups, because they already know a lot about their illness.

6. Peer support does not help in coping with the disease

The majority of the respondents indicated that although peer support can be a source of support, they have to learn how to cope with their illness themselves: "You simply have to take it as it comes and try to deal with it as well as possible. Another person can support you, but you have to do it yourself."

Several participants indicated that they have other strategies to cope with their illness. They talk to their partners or other family members about what concerns them: "Yes, and of course I can turn to my husband if I have to get something off my chest." With questions about their illness they would rather go to their rheumatologists or nurse practitioners:

> I prefer a safer way, by obtaining information from my physician or my rheumatology nurse. The rheumatology nurse has booklets and everything, and if I have problems I simply turn to her. I am allowed to call her anytime.

7. Not being the suitable type of person for joining a peer support group

Finally, several respondents mentioned that they did not think they were the type of person to engage in face-to-face or online peer support: "Oh, I don't need that. I'm not the type. I will find it out for myself." Some patients indicated that they did not like participating in groups. They mentioned that they did not feel like being candid about their problems to strangers: "I would feel out of place there. I always have difficulties getting acquainted with people, especially when I go somewhere for the first time."

Attitude towards online peer support

Specific advantages of online peer support mentioned by the respondents were the absence of geographical barriers, 24-hour availability, and the fact that online peer support groups are perceived as more informal. The respondents also indicated specific disadvantages of online peer support. Several respondents emphasized negative sides of the Internet, such as impersonality: "I think it is very impersonal. I would prefer writing to someone, handwritten, then you have to think more. It's much more personal." Respondents indicated that they do not like the anonymity of online peer support. As they cannot see other participants, they cannot assess them.

Many respondents indicated that they did not trust the medium Internet:

> What could be a disadvantage is that of course just anyone can be on it. You often hear that nowadays. That there is a lot of scum between them. There are of course many people who do not really have good intentions.

Several respondents especially mentioned the lack of insight into the quality of information provided in online peer support groups: "There might be a troublemaker between them who will just give the wrong answers. Everybody can pull your leg on the Internet."

Subjective norm towards face-to-face and online peer support

All respondents indicated that they think that significant others (i.e. partners, family members) in their social environment have the same opinion about engagement in face-to-face and online peer support as they do. However, the majority of the respondents mentioned that they never discussed this topic: "I think that he [partner respondent] sees the same disadvantages as me. But we really never talk about it."

Most respondents mentioned that they assumed that people in their surroundings would support them if they decided to engage in face-to-face or online peer support: "If I say that I need this, and that I would like to go, then he [partner respondent] says: 'Then you have to do it.' I'm convinced of it. I have that support, yes!"

Perceived behavioral control towards face-to-face and online peer support

In this section, we present the themes concerning the barriers to face-to-face and online peer support that emerged from the analysis of the transcripts.

Perceived barriers to face-to-face support

Although all respondents considered themselves capable of engaging in face-to-face peer support, they did mention several barriers, the most frequent being a lack of time: "I do not allow myself the time for this. Come on! I work full-time, I'm very busy." Respondents indicated that they do not want to have more obligations.

Several patients indicated that a barrier to participation in a face-to-face support group was the geographical distance. As these patients were not so mobile anymore, due to their illness or age, they always had to ask someone for transportation: "If you go somewhere, you have to be taken, and when you return again, you have to be picked up. And then you cause problems for others. This I don't like."

In addition, some of the respondents mentioned that for some problems the frequency of meetings of face-to-face peer support groups was too low:

> If you do not know how to open a lid, another person can tell you: 'You should pick up a particular device from the domiciliary equipment service'. But with a conversation group, you have to wait till they meet again once a month.

Finally, one respondent mentioned that she did not know that there are groups for rheumatic patients: "To tell you the truth, I have not heard about this. I did not know it existed."

Younger respondents mentioned that they thought that it was often only elderly people in support groups: "Then there I am as a young woman among all those old ladies, so I thought: No, no!" and "If they set up a group for young people, then I really would participate."

Perceived barriers to online peer support

About half of the respondents (n=9) considered themselves able to engage in online peer support. The other half of the respondents did not have a computer with an Internet connection at their disposal or they did not have the skills to engage in online peer support.

Other respondents indicated that they already used a computer for their work all day and that, therefore, they did not feel like using the computer for contacting peers: "I am at my computer at work almost all day long, and to carry on doing this at home. No, I'm afraid not."

Several respondents indicated that they did not know that there is a possibility to engage in online peer support: "But there is not something like that, is there? On the rheumatism site I could not find peer support anywhere." Other respondents mentioned that they knew about this possibility, but that they were not able to find such a group on the Internet: "These things I simply can't find. When you leave later, I will turn on the computer and I will try to find it."

Future engagement in face-to-face and online peer support

About half of the respondents did not intend to ever engage in face-to-face and online peer support, whereas others did not exclude the possibility. Almost all of these participants mentioned that they will possibly engage in peer support when their disease progressed: "Look if I get in a rut or if I am going downhill, then I think I would sooner grab the opportunity." Other reasons mentioned to seek peer support were "loneliness", "old age", "new problems/questions". Two participants indicated that they did not have an opinion about whether or not they intended to ever engage in peer support.

In addition, all respondents were asked that if they participated in peer support, whether they would prefer face-to-face or online peer support. Half of the respondents would prefer to engage in online peer support, mainly because of the fact that online peer support is free of obligations: "At a group I have to be present and I have to listen. At the moment I think on the Internet 'I've had enough', I can turn it off." Most other respondents indicated to favor face-to-face support groups. Two respondents did not have a preference.

Conclusions qualitative study

The results of the qualitative study showed that although respondents thought that peer support could be valuable for other patients, for themselves they saw mainly disadvantages. Most of the respondents had a negative image of peer support groups: these were meant for people who could not cope with their illness, and who were old and lonely. Specific disadvantages of online peer support mentioned were anonymity, impersonality, lack of trust in the medium Internet, and in the information exchanged. Barriers mentioned about face-to-face peer support were lack of time and the geographical distance that had to be bridged to attend a group. The main barrier of online peer support was the lack of a computer or Internet connection or the lack of computer skills. For both kinds of peer support, lack of awareness of peer support groups also seemed to play a role.

Discussion

To the best of our knowledge, this study is the first to indicate which determinants predict patients' intention to engage in face-to-face and online peer support. Earlier studies focused only on determinants of patients' intention to engage in face-to-face peer support, and frequently suffered from a lack of a theoretical framework. A strength of our study is our use of Creswell's [29] concurrent procedure, i.e., we used both questionnaires and interviews to allow exploration of a wide range of relevant factors. This enabled us to find pointers for an intervention to increase participation rates in face-to-face and online peer support.

Our study confirmed that only a relatively small percentage of the patients engage in organized forms of peer support. The respondents were more positive about and more inclined to use face-to-face peer support, compared to online peer support. These results are in contrast to our expectations, because it was anticipated that engagement in peer support would increase with the emergence of online groups. An explanation might be found in the fact that we questioned a somewhat older patient population. Elderly people mostly treat Internet with greater skepticism than younger people. Since "trust" is of specific importance to patient support groups, because the topic of "an illness" in itself requires a high level thereof, this might have influenced patients' perceptions of online peer support [37].

The quantitative part of the study showed that the majority of the respondents did not intend to look for peers face-to-face or via the Internet during the coming year. The qualitative study showed that although some of the patients do not intend to ever engage in face-to-face and online peer support, others did not exclude the possibility that they might in the future. Several patients expect that they might engage in peer support when their disease progressed, or when they were old, lonely or confronted with new problems.

Our study revealed that in accordance with the TPB, having a more positive attitude, feeling more supported by people in the social environment, and feeling more able to participate in peer support increased the intention to participate in both face-to-face and online peer support. This is in line with Grande, Myers & Sutton [10], who found that a more positive attitude and a higher subjective norm increased engagement in peer support, and it is in line with Voerman et al. [11], who found that a more positive attitude and a higher perceived control increased intention to engage in peer support. For both kinds of peer support, attitude components and subjective norm contributed most to the explained variance of intention to engage in peer support.

Intention to engage in face-to-face and online peer support could only be modestly predicted by the TPB variables (face-to-face: 33%; online 26%). A meta-analysis has shown that TPB variables, on average, account for 35-50% of the variance in intention [38]. It is difficult to compare the amount of explained variance with others studying participation behavior in face-to-face peer support, because in these studies logistic regression analysis was used [10, 11]. An explanation for the relatively low amount of explained variance might be found in the results of our qualitative study. Although respondents were of opinion that peer support was valuable, they did not consider it valuable for themselves personally, but only for other patients. According to the TPB, people need to perceive benefits of engagement in peer support to be of personal importance for themselves, instead of only for others, if they intend to execute the behavior questioned [10, 28].

Those patients who indicated having a poorer mental well-being had a greater intention to participating in face-to-face and online peer support, and those who had a worse physical well-being were more inclined to participate in face-to-face peer support. These results are not surprising, considering the fact that health-related support groups have a health-promotional function. Therefore these groups are less appealing to those patients who perceive to already have a good mental and physical well-being despite their illness [39].

Of the demographic factors, only age could significantly improve the total amount of explained variance of intention to online peer support. Younger patients were more inclined to engage in online support groups. These results were in line with our expectations as it is still mainly younger people who use the Internet [25].

Pointers for an intervention

This study yielded several pointers for an intervention to increase participation rates in face-to-face and online peer support. However, before implementing such a strategy, it has to be considered to what extent patients should be recommended to participate in peer support groups. Studies have shown that not all patients profit from participation in peer support [40]. In addition, and in line with the results of Winefield et al. [14], our study shows that several patients cannot really bear the thought of participation in support groups because they do not continually want to be confronted with their illness.

Nevertheless, our study shows that not all patients were aware of possibilities for peer support, or that they perceived barriers to join such a group. Moreover, our study shows that it was unclear for many patients what a support group could offer them personally. In addition, we found that several patients have misconceptions about peer support groups. Consequently we deem an intervention necessary, so that patients can make well-informed decisions about whether or not they want to engage in peer support and so that they are able to trace a peer support group the moment they want to enroll.

First, we think that an intervention should make patients aware of the possibility of engaging in peer support groups. Awareness of peer support especially seemed to play a role considering online peer support. Indications for these results were already found in our earlier studies on peer support. Most participants of online peer support groups indicated that they had accidentally found the online group themselves while surfing the Internet looking for health-related information [21]. Since studies showed that not all people have the necessary Internet skills to be capable of finding the information and applications they are looking for on the Internet [41], it can be expected that not all patients manage to find online peer support groups by themselves.

Second, an intervention should inform potential participants about what the specific aim is of the peer support groups and how they operate [14]. Patients could, for example, be encouraged to read along with an online peer support group, i.e., so-called "lurking". By lurking, patients get a feeling for how such a group operates and what kind of people participate in it [42].

Third, attention should also be paid to removing misconceptions of peer support, e.g., the misconception that only patients who are severely ill, old, lonely or unable to cope with their illness engage in support groups. It should be emphasized that an increasing number of online peer support groups also offer the opportunity for "buddy matching". Buddy matching makes an optimal peer match possible for individuals, whereby personal needs and specifications are met by making use of automated matching functionalities [43]. An optimal match between peers can have a positive influence on interpersonal trust and this is an important basis for the exchange of experiences and empathy [44].

Finally, health care providers should broach the possibility of peer support several times during the illness process, and should inform and assist patients who are considering whether or not they want to engage in peer support [39, 45]. In addition, webmasters of online patient support groups must actively promote their groups among potential participants so that patients are able to trace a group the moment they want to enroll [46].

Limitations

The findings of this study are limited by the fact that we conducted a cross-sectional study. Therefore no causal relationships could be attributed.

A second limitation of this study is the high number of missing variables in the section of the questionnaire on TBP items concerning online peer support. A considerable number of people without computer skills did not respond to these items which might have led to unnatural high scores on perceived behavioral control and also might have led to an underestimation of the role of perceived behavioral control.

Finally, the results of this study are limited by the inclusion of mainly female patients. Since it is suggested that men use support groups in a different fashion [47], the extent to which these results are representative for male patients is not known.

Conclusions

Our data confirmed that only a relatively small percentage of the patients engaged in organized forms of face-to-face and online peer support. The respondents were, in general, more positive about face-to-face peer support, compared to online peer support. Our study revealed that in accordance with the TPB, having a more positive attitude, feeling more supported by people in the social environment and feeling more able to participate in peer support increased the intention to participate in both face-to-face and online peer support. Nevertheless, it has to be concluded that the intention to engage in face-to-face and online peer support could only be modestly predicted by the TPB variables. Finally, our study offers pointers for an intervention to increase participation rates in peer support.

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8

Patient-initiated online support groups: motives for initiation, extent of success and success factors

C.F. van Uden-Kraan
C.H.C. Drossaert
E. Taal
E.R. Seydel
M.A.F.J. van de Laar

Submitted

Abstract

With patient-initiated online support groups currently mushrooming, we decided to explore the motives and goals of those who took the initiative to start a group, the so-called webmasters. In addition, in our desire to learn more about how they define success and success factors, we interviewed 23 webmasters. The results revealed that webmasters have altruistic and intrinsic motives for initiating an online support group. They define success as the fulfillment of the goals they had in mind when they initiated their groups. To be able to make a group successful, decisions about its organization and management need to be coherent with these goals. The results of our study offer an overview of the pros and cons of differing decisions which may serve as handles when initiating online support groups. In addition, we draw attention to those factors that might contribute to their success as they evolve. Success of the group is important, since it can be expected that effects of participation in an online support group for patients may vary, depending on the group's success.

Introduction

Patients who participate in online support groups tend to profit in various ways [1-12]. Results of our earlier study showed that participation in online support groups had a profound effect on the participant's feelings of 'being empowered' in several ways, such as: being better informed, feeling confident with their physician, their treatment and their social environment, improved acceptance of the disease, increased optimism and control, and enhanced self-esteem and social well-being [12].

Nowadays, patients are able to choose between many online patient support groups. While some groups are initiated by professionals, such as health care providers, most groups are started by individual patients or patient organizations. The threshold to start an online support group is low: an increasing number of facilities are available online to initiate such a group without having to have sophisticated technical Internet skills, and the cost is limited. Most research has focused on professionally led online support groups [13]. With patient-initiated groups now mushrooming, a need for an increase in research on this type of online support group is warranted.

Little is known about the motives and goals of people who voluntarily take the initiative to start an online patient support group, the so-called webmasters, facilitators, operators, community founders, community leaders or web owners. We are only aware of one study in which webmasters' motives for starting an online group was examined. This study showed that webmasters experienced more altruistic benefits than participants from spending time on an online group, i.e., "help other people", "think about others instead of myself", "support this list community", and "promote the topic or issue of the group" [14]. The first objective of this study was to explore the motives and goals of webmasters who initiated their own online patient support groups.

Some webmasters succeed in initiating groups which develop into successful ones with a large number of participants. The online groups of other webmasters may never get off the ground, or bleed to death at a later stage. Although the success of groups is assumed to be related to the degree of activity of the support groups [15], it may also ensue from other factors. According to Lazar and Preece [16], different stakeholders, such as webmasters, initiators, moderators, and participants, also define the success of the online support groups differently. The second objective of our study was thus to learn more about how webmasters of online support groups define success, and if they were of opinion that their own groups were a success.

Success of the group is important, since it can be expected that effects of participation in an online support group for patients may vary, depending on the group's success. Therefore, it is deemed valuable to formulate strategic guidelines for webmasters aimed at successfully running an online group [17]. For managing an online support group, two phases are important: the initiation stage and the evolution stage. The initiation stage is the period before the patient support group goes online. During this stage, webmasters need to make decisions about such aspects as its access, embedding, design, and content. The evolution stage starts the moment the group goes online, and this stage is ongoing. The decisions webmasters need to make during this phase concern the management of processes and people in the online group. Webmasters have less influence over these aspects since they do not control the participants of the online group [16]. Preece [18], however, argued that webmasters can do much to set the tone of an online group, i.e. by making decisions concerning the extent of moderation. The final objective of this study was to explore the factors that according to the webmasters determine the success of online patient support groups.

Methods

To answer the research questions, we interviewed webmasters of online patient support groups. In this study we especially focused on webmasters of online patient support groups in which asynchronous communication occurs, i.e., discussion groups and forums. Groups in which synchronous communication occurs, such as chat boxes, were not included.

Sample

We focused our study on online support groups for patients with breast cancer, fibromyalgia and arthritis. We chose to explore these three groups because of the contrast between the illnesses (life-threatening, unexplained, and chronically disabling). We searched the Internet with the search engine Google™ to identify all Dutch online support groups for patients with breast cancer, fibromyalgia and arthritis. In total, we found 26 groups (9 breast cancer, 10 fibromyalgia, and 7 arthritis). After asking the webmasters of these groups to take part in the study, 25 responded positively. However, one of the webmasters withdrew from participation due to illness, and one webmaster did not respond to a follow-up email. We thus conducted interviews with a total of 23 webmasters (8 breast cancer, 8 fibromyalgia, and 7 arthritis).

Measures

We used a semi-structured interview schedule to allow flexibility, individual contextualization and probing of issues that arose [19]. Areas explored included the motives for starting an online support group, the goals of the group and the webmasters’ opinion about whether or not the group was a success. In addition, we asked them about the factors that contribute to the success of their groups, focusing on the webmasters’ decisions during the initiation stage (with regard to access, embedding, content and design), and the webmasters’ decisions during the evolution stage (concerning the management of the processes which took place and the people who participated in their online support groups).
The webmasters were also asked to provide information about their demographic characteristics sex, age, education and employment. In addition, they were asked to indicate when they had initiated their online support groups, and whether they had initiated the online support group themselves.

Procedure

The webmasters were interviewed either at home (n=19) or at another place of preference (n=4). The interviews were audio taped with prior consent of all participants and transcribed verbatim. The interviews lasted between 1 and 2.5 hours.

Data analysis

Data were analyzed by two coders using inductive analysis. According to Patton [20], inductive analysis means that the patterns, themes and categories of analysis come from the data: "They emerge out of the data rather than being imposed on them prior to data collection and analysis" (p. 390). Each coder read nine of the transcripts through separately several times to familiarize him-/herself with the data, and to identify emerging themes by which the data could be examined. Then the two coders met to discuss their findings in order to resolve differences. On the basis of these analyses, the coders developed a thematic framework together which they used to independently code the transcripts. Results were discussed to reach a general consensus, after which themes were refined and sub-themes were identified [12, 21]. All quotes provided in this article were translated from Dutch into English by a native speaker. To ensure anonymity we removed all identifying information from the quotes.

Results

Demographics of the participants and characteristics of the online support groups

The majority of the webmasters were women (n=20). The mean age of the participants was 46 years (SD 10.9 years) with a range from 24 to 65 years. In total, 4 participants had a lower level of education, while 10 had a secondary and 9 a higher level of education. In total, 6 participants had a full-time job, 9 had a part-time job, and 8 were unemployed or unable to work. Most webmasters were patients themselves (n=21). The other 2 webmasters had a spouse who was a patient.

Of the webmasters, 18 had initiated the online support group themselves. The other 5 support groups were embedded in official Dutch patient associations. The webmasters of these groups did not initiate the online support groups themselves, but 4 of them had been active as webmasters since the groups' initiation.

The online support groups were initiated between 1999 and 2007 and existed on average for a period of 3 years. The online support groups differed in their degree of activity. In the most active public support group under investigation, several hundreds of messages were exchanged daily, while in the least active support group only some messages had been exchanged for a couple of weeks. This is of course a random indication of the situation. These groups might have been more active before, or might have only recently been initiated. In addition, 13 support groups under investigation were private groups to which we as researchers had no access, i.e., we could not verify the number of exchanged messages.

Motives and goals

First we asked the webmasters for their motive to initiate an online support group. The webmasters who had initiated their group before 2004 mentioned that there were no other groups at the moment of initiation (or at least that they could not find any). The other webmasters had initiated an online support group because they were not satisfied with existing groups. Some did not like the atmosphere of other groups: "Other forums were so incredibly dramatic: 'Let's light a candle'. I like to be realistic, but I don't like all that drama and histrionics." Other factors mentioned were the activity (too busy or too quiet), the extent to which the group was moderated (too strict or not strict enough), or the content (off-topic not allowed or too much off-topic). Several webmasters wanted to have an online support group for themselves as a kind of hobby, or they initiated the support group as an extension of their already existing website. One webmaster indicated that she initiated the online support group as a kind of advertisement for her book about her disease.

The webmasters mentioned several goals they strove for when initiating their online support groups. Most of them wanted to create a meeting point where patients with the same disease could meet one another and exchange support and experience. Other webmasters put more emphasis on the exchange of information: "I had the idea that the wheel was being re-invented over and over again. Every woman seemed to be looking individually for articles on breast cancer." Several webmasters mentioned that by initiating an online support group they wanted to empower other patients in different ways. Some webmasters particularly mentioned the physician-patient relationship. Their goal was to educate their participants so that they were able to think along with their physicians about their medical treatment. Other webmasters emphasized aspects such as social well-being and increased optimism and control. They wanted to motivate patients to get something out of their lives despite the fact that they were ill: "To get people moving. To draw them out of their negative spiral and stimulate one another that there is more to life than sitting behind the geraniums!" Finally, a couple of webmasters also had a public goal. They wanted to make the disease their online support group focused on more known among the general public, and they wanted to create understanding for the problems and feelings of the patients living with it: "Because I really want cancer to play more of a role in society, so it will be understood better."

Defining success and the extent of success of online support groups

Almost all webmasters considered their online support groups a success. Webmasters indicated that they were of the opinion that their groups were a success because they fulfilled the goals they had had in mind when they initiated the online support group: "I wanted to create a meeting place for people with breast cancer. And in the hope that it will give people support and recognition, whatever. And it does!"

Webmasters inferred the success of their group from various signs. Some mentioned the fact that their group was well known, frequently visited and the message exchange rate very high. These webmasters were of opinion that having a large and active group increased the chance of finding recognition among the participants, which was what their goal was. Others mentioned the positive responses of the group participants: "I recently received an email from a woman who said 'I just wanted to let you know how really happy I am with your initiative'." Several webmasters mentioned the nature of the exchanged messages (warm and supporting), which was as they intended. Finally, several webmasters mentioned the intimacy and involvement of the participants in their small groups. According to these webmasters, patients could be supported quite personally in their groups because participants did not become overwhelmed by the exchange of too many messages.

Only five webmasters indicated that their online support group was no (or no longer a) success. The main reason mentioned was that the online support group had evolved in another direction then the webmaster had intended:

> It has become more of a social club than a place to really exchange information and experience. Not that you have to complain about rheumatism all the time, but it is our aim after all to be a source of information with lay experts.

In addition, some webmasters indicated that their group was not active enough: "It is not as if we are being inundated at the moment. […] The forum is rather quiet. There hasn't been much posting going on since February." Finally, several webmasters mentioned that it took them too much energy to keep the group alive. In their opinion, they had to take the initiative all the time to keep the discussion in the group going: "It would be nice if members also took the initiative from time to time. Not to wait until I have posted a message that they can react to. Broach a subject yourself!"

Success factors in the initiation stage

In this section we present the factors that according to the webmasters determine the success of online support groups in the initiation stage. Table 1 presents an overview of the pros and cons during this phase.

Decisions made concerning access

An important decision for the webmasters was whether or not their online support groups would only be accessible to participants (a private group) or also to people who wanted to read the postings but who would not contribute to the discussion (a public group). Over half of the webmasters had opted for a private group. The main reason for this decision, the webmasters indicated, was the protection of the participants' privacy: "You really need to be able to tell your story without somebody being able to read it who can use it against you later at a birthday party or something." Unique for a private group, according to these webmasters, was that all topics could be discussed: "The greatest taboo subject which is never talked about with breast cancer is sexuality, yet if you have a private forum then it is possible."

Table 1 Pros and cons in the initiation stage of online support groups

Options	Pros	Cons
Access **Public (versus private)**	- Low threshold for future participants: • Participants do not need to provide personal data before they can take part in the forum • Participants can become acquainted with the forum before actually taking part	- Less protection of the participants' privacy
	- Providing information to patients who only want to read along	- Not all topics can be discussed owing to a lack of anonymity
	- Informative function for the broad public (learning about and creating sympathy for the illness on which the forum focuses)	- More difficult to keep unwanted participants (fake patients, inquisitive family members, friends, etc.) out of the forum
	- Good for the forum's competitive position	- Greater problems with spam
Embedding **Stand-alone (versus embedded in an organization)**	- Freedom of expression for webmasters and participants because one does not have to consider the interests of the organization to which the forum is linked	- Chance of being taken less seriously by potential participants because there is no connection with a health care organization
	- Independence of the webmasters to define their forum's identity	- Unable to profit from the reputation of the health care organization
	- Low threshold for future participants because the forum is not tied to (embedded in) an official organization	- Having to seek funding for the group oneself
	- No inconvenience from the stuffy identity of patient organizations	- No support with the forum's technical problems
	- Potential participants do not have to be a member of a patient organization to take part in the forum	
Content **Chit-chat acceptable (versus chit-chat not acceptable)**	- Chit-chat puts the situation the participants find themselves in into perspective	- Chit-chat does not belong on an illness-related forum
	- Chit-chat creates warmth and a sense of connection within the group	- With chit-chat illness-related subjects are overlooked
	- By exchanging chit-chat the participants get to know one another better	- With chit-chat there's a greater chance of conflict between the participants
	- The participants can share anything they wish	

Table 1 Pros and cons in the initiation stage of online support groups (continued)

Options	Pros	Cons
Medical experts present (versus no medical expert)	- A medical expert can answer the participants' medically-related questions	- A medical expert can never assess the personal situation of a patient in such a way that he/she can give sound advice
	- A medical expert can prevent dangerous situations by reading along in online support groups	- A medical expert is incompatible with the goal of the contact between fellow sufferers
Design		
Structure into categories (versus bulletin board)	- The messages are clearly ordered on the forum	- A division into categories is never 100% clear
	- Postings can easily be found	- Too much has to be 'clicked through'
	- It is easy to search for specific topics	- A division into categories can lead to a fragmentation of discussions in the group
	- Categories can easily separate the 'chit chat' from the postings concerning the illness	- The most recent postings do not immediately stand out
Free software (versus paid software)	- No expenses need to be incurred when making use of free software	- Limited possibilities to adapt the design of the online support group (structure and lay-out)
	- Because of the frequent use of free software (potential) participants are often already familiar with this type of software	- Greater problems with spam
		- Dependent on the decisions of the supplier of the software

The main reason for webmasters to initiate a public online support group was the lower threshold of a public group: “The hurdle to join in is lower. You can read along for a few weeks to start with before thinking ‘Well, I feel quite at home here, so I’ll join up.’” Some webmasters indicated that their group also had an educational goal for patients, as well as for the general public who were interested in the illness: “I think that anyone who has just been diagnosed, or is about to be, is looking for information, and if you’ve got it you’ve got to make it available.”

Decisions made concerning the embedding

The webmasters of the independent online support groups were very satisfied with the fact that they were not embedded in an organization. The most often mentioned restricting aspect of embedding was the expected loss of freedom:

> I really treasure my independence. And because I also like it when people write a critical piece on [name patient association], about something they really disagree with. It wouldn’t be so easy to do that if you are a member of that organization.

Other disadvantages of embedding mentioned by the independent webmasters, were the higher threshold and the stuffy image of patient associations.

On the other hand, the webmasters did mention some advantages. First, some remarked on the evolving brand awareness of the organization: “Primarily of course the familiarity. When you’ve been to see the physician, you’re given a flyer of the [name patient association], and then you automatically end up here.” Some webmasters were of opinion that patients would take online support groups of organizations more “seriously”. Another advantage of embedding in an organization was its financial support.

Decisions made concerning the content

The webmasters differed in their opinion about whether it is acceptable to talk only about the illness in the online support group or whether it is also acceptable to talk about daily issues. The majority of the webmasters indicated that in their group daily issues, so-called “chit-chat”, could be discussed besides issues related to the disease. According to the webmasters, chit-chat provided a normalizing experience for the participants: “I think it is important that there is also room on a forum for cheerfulness. Breast cancer is serious and quite drastic, but it is not the case that it is always miserable.” Some webmasters indicated that “chit- chat” contributed to the establishment of trust, warmth and concern between participants of the online support group. By exchanging daily issues, participants really got to know one another.

A minority of the groups only allowed discussion on the disease and related topics. A reason for this decision, the webmasters said, was that chit-chat does not belong in an online patient support group:

> You can talk about anything as long as it has to do with cancer or the consequences thereof. Look, if it is about a holiday and how confronting it was due to cancer, then of course it belongs here. An amputated breast and a beach vacation, sure that's cancer. But idle chit-chat about having a meal out has got nothing to do with cancer.

Besides this, these webmasters were afraid that chit-chat would prevail in the online support group: "At some point you'd go onto the forum and see 10 Happy Birthday messages, but not the answer to a question that was troubling someone else."

Another decision that had to be made by the webmasters about the content was whether or not a medical expert should be present in an online support group. Most webmasters indicated that it was not necessary for their groups to have one present. They were of opinion that a medical expert was not in accordance with the group's objective:

> From the start we did not want to be a medical site. The aim for us was to share experience and contact between fellow sufferers. Certainly not medical. It would alter the character of our site tremendously. Now it is truly experience-oriented.

Other webmasters mentioned that this service was already offered on other websites and in other online support groups, which made it unnecessary for them to have a medical expert present as well. Finally, some webmasters thought that patients were better off visiting their own medical expert if they had a question: "I think if people need a physician, let them visit their own family doctor. You can't answer medical questions via messages."

Only in four online support groups under investigation were medical experts present (e.g., physicians, a pharmacist, a physiotherapist and a rehabilitation nurse). Some webmasters were of the opinion that the presence of a medical expert was or would be an asset to their online support groups: "I would really like it if there were a doctor who, shall we say, would tell his side of the story. A kind of question time. That every week a number of questions would be answered." A medical expert could also prevent dangerous situations in the group: "If people have certain complaints, then they usually turn to the forum first, does anybody know this, before they go to their family doctor. That is always a bit scary."

Decisions made concerning the design

Most webmasters indicated to have little influence on the design of their groups because they used free software. They were thus tied to the restrictions of this software concerning the structure and lay-out: "Well there's not much I can change about that. This forum is exactly how it was delivered. Sure you can choose a number of colors, but I don't have any influence at all on the scrolling or the lay-out."

Most webmasters thought that the lay-out of an online support group was not that important to become successful: "I don't think it is that important. It needs to look neat. But it mustn't look as if I knocked it up in my spare time. I think these days even a 12-year-old can build a good website." Only some webmasters were of opinion that the lay-out is the group's 'calling card': "Your lay-out is your calling card. If a lay-out is wrong, then the site looks

untidy. That's unprofessional, so you start to doubt what's behind it. Whether the information is right or not." Most webmasters mentioned that important aspects of the lay-out of online support groups were the readability of the text and a quiet lay-out (no flash, moving elements, etc.).
At the same time, however, most webmasters indicated that the structure of an online support group is much more important than the lay-out. From the interviews it appeared that when webmasters mentioned "structure", they mainly meant an arrangement of the postings into categories or no category arrangement (a bulletin board structure). Most webmasters preferred an arrangement into categories. Advantages mentioned were that postings could easily be found and that participants were able to search for specific topics:

> Look, if you're really busy with one thing, you're looking for other people's experiences with a certain subject, then all you have to do is click on the name of the category and hey presto! Post-cancer tiredness, for example. That of course is quite a specific subject, so it's ludicrous if you have to run through the thousands of stories.

Categories, in addition, could easily separate the 'chit-chat' from the postings concerning the illness: "People are inclined to go off- topic. They start with radiation and end up with the plants in the garden. That's when you have to intervene: 'Carry on chatting in the [name chit-chat category].'" Arranging in categories also had its disadvantages, however. Some webmasters indicated that too much had to be 'clicked through' to find a specific message. Moreover, they indicated that categories are never 100% clear and that some of them can also lead to a fragmentation of discussions in the group:

> At the beginning every kind of rheumatism was subdivided, the diagnosis, the paramedical care and medications, which also considerably fragmented any discussion. If someone at r.a. asked a question about a specific medicine, and someone asked the same at psoriatic arthritis, they would never actually 'meet' one another.

Some webmasters choose a bulletin board structure, whereby all topics are placed in the order as they come in. The most important reason to opt for this structure was, the webmasters said, that the most recent postings immediately stood out: "With me the last posts are at the top. You can see it right away."

Decision-making in the initiation stage

During the interviews it appeared that not all webmasters had clearly thought about all the decisions that had to be made at this stage: "We didn't really think about it. We just made it private and that was that. I think that certain parts, like the tips, should be public. Thinking about it now..." Some of the webmasters even regretted that some of the decisions taken during the initiation stage could no longer be undone:

> There have been times I thought why not make it public, and then we said no, it's too late because people have written in the understanding that it was private, so you can't really change that.

According to some of the webmasters, this resulted from the fact that initiating an online support group was so easy and without any risk: "Yes, the risk is that it fails. I mean that's not the end of the world. Then you just stop. But if it fails, the time and energy you've invested is wasted." Other reasons that made them change their minds about some of the decisions made during the initiation stage were "changing insight" and the "organic growth" of the community.

Success factors in the evolution stage

In this section we present factors that - according to the webmasters - determine the success of online support groups during this phase. These factors concern the management of the processes and people within the online support group. Table 2 presents the pointers of this stage.

Promoting and financing the online support group

Most webmasters indicated that they usually restricted the promotion of their groups to the Internet, with activities such as the posting of links on other online support groups and link pages: "Well, also on fibromyalgia websites. I'd say yes, I have fibromyalgia too, and I started a forum. Let them come together, your link to mine and vice versa." Other webmasters invested time in being easy to find with Google™.

A limited number of webmasters also used other channels to make their online support groups known, such as giving interviews about their groups to papers or magazines, distributing flyers at places patients often frequent (hospitals, wig shops, rehabilitation centers etc.), and by being present with a booth or giving a presentation at relevant events for patients. Word-of-mouth advertising was, according to some webmasters, also important for their group's promotion: "I am now in the revalidation centre and of course I let it slip that I have those forums." Most webmasters were mainly busy with the promotion of the online support group during the period just after the initiation of their groups. Some webmasters even indicated that they conducted no promotional activities at all at the moment, because they were of opinion that their online support groups already had enough participants or that they simply did not have the energy or time to do so.

Table 2 Pointers in the evolution stage of online support groups

Pointers	Options
Promoting the online support group	Ways of promoting an online support group: - Posting links to the online support group on websites such as link pages, online support groups etc. - Being easily found by Google™ - Giving interviews about the online support group in newspapers or magazines - Distributing flyers at places patients often frequent - Being present with a booth or giving a presentation at events for patients - Word-of-mouth advertisement (e.g., in the waiting room of a hospital)
Financing the online support group	Ways of financing the online support group: - Paying for the expenses as a webmaster yourself - Asking for a contribution from the participants of the online support group - Financial support by patient associations - Financial support by pharmaceutical industry - Financial support by public funds - Organizing sponsor events - Merchandising (t-shirts, teddy bears etc., with the name of the online support group)
Keeping the group alive	Advice when the group has just gone online: - Start with a small group of patients - Ask family and friends to contribute postings - Send postings to yourself under a "false" name Advice to keep a group alive: - Respond to questions of participants quickly - Start new topics frequently (e.g., send postings about media attention to the disease) - New participants should keep joining the group - Make new participants feel at home (e.g., by sending special welcome messages) - Providing new members promptly with an explanation of how the forum works (e.g., how do I post a personal message) - Pay adequate attention to the new participant's story - New participants should be supported by experienced participants: • Experienced participants can help new members find their way on the forum • Experienced participants can act as a role model to new members • Experienced participants can answer newcomers' questions - Experienced participants should be cherished for their role in the group
Extent of moderation	Tasks of the moderators: - Maintaining the rules of the online patient support group - Removing advertisements, spam and abusive postings - Moving topics which have been posted in the wrong position on the forum - Soothing arguments between participants - Supporting participants with technical questions - Acting as host(ess) to new participants

Table 2 Pointers in the evolution stage of online support groups (continued)

Pointers	Options
Extent of moderation	Advice for the extent of moderation: - Moderators must keep a low profile - Moderators must read along as much as possible on the forum - If there are several moderators, they must work together as a team - On selecting new moderators, attention must be paid to the following: • Moderators must be active participants of the forum • Moderators must be capable of being able to operate from various perspectives on the forum (as both patient and moderator) • Part of the team of moderators must have experience in moderation • Webmasters must consider training moderators
Organizing meetings and creating rituals	Pointers when organizing meetings: - Organizing meetings can be conducive to a stronger bond within the support group - Meetings enable patients who have lost their social contacts due to their illness to make new friends - Organizing meetings increases the chances of 'clique formation' in the support group - Organizing meetings can sabotage unique elements of online support groups, such as "anonymity" and the "non-committal aspect" Pointers when creating rituals: - Rituals reinforce the bond within the online support group - Rituals are an effective way of showing you sympathize with other participants - Rituals are usually off-topic and hence do not belong on a forum which only permits discussing one's illness - Rituals soon tend to be over-the-top, cloying, and hysterical
Input of the participants	- Members are the forum's cement, and so it is important to listen to their input and to consult them when changes are made.

The majority of the webmasters indicated that they financed the online support group themselves, whether or not with support of the participants: "Generally we pay for it ourselves but sometimes we do make an appeal. Usually that boils down to 50 cents or a euro from 30 users and then you will be home and dry again." Some other independent webmasters were financially supported by commercial organizations, such as the pharmaceutical industry, by public funds or individual supporters. The embedded groups were financed by the patient associations. Some webmasters mentioned that their groups were financed through organizing or participating in sponsor events or through selling merchandise of the online support group. According to the webmasters, the cost for the online support group was limited. The extra funds were used for complementary activities, such as a chat box, trips for the participants or for promotional activities for the online support group.

Keeping the group alive

All webmasters indicated that it was important for an online support group to be dynamic: "People look to see what's changed. They have soon read what's there, but what's new draws more attention." According to several webmasters, this was especially a challenge when the group had just gone online. Some webmasters were convinced that it was essential to start with a small group of participants, e.g., together with patients from other online support groups:

> People shouldn’t only know that it exists, but they should also see that something’s happening there. You really need to be with a group of preferably different kinds of people. […] You can start a forum like a café that may look inviting, but if nothing happens there people won’t come.

Other webmasters indicated that they asked family and friends to send postings or that they “faked” a group of participants:

> And what I did right at the beginning is that I sometimes sent a posting under a false name. To get things going. There have been times I posted four, five messages, one after the other. So that something was there. And then slowly but surely reactions started to appear, to which you reply. So, to get the ball rolling, I did cheat a bit.

The webmasters mentioned that also at a later stage it was sometimes important to blow life into the community, e.g., by starting a new topic: “If things have been quiet for a while then I look to see if there’s something I can post. […] Something that’s been on the news about rheumatism.” In addition, most webmasters indicated the importance of questions being responded to as quickly as possible.

Almost all webmasters indicated how crucial it was for their online support groups that new participants kept on joining: “It’s good if new people keep coming. You need a constant intake. Otherwise I think it will become like a knitting club.” Webmasters mentioned that new participants should feel that they are welcome in the group with special welcome messages and by paying adequate attention to the new participant’s story: “It’s important that each newcomer is greeted properly, even if it’s the 200th who says oh, I’ve got rheumatism. Otherwise no more new people will come.” New participants should also be looked after by the experienced participants: “After six months you see people offering advice more often than they ask for it. And that happens more and more frequently.” Several webmasters mentioned that the experienced participants should be cherished for their role in the group: “When there’s a newcomer, it’s those people who welcome them and say nice that you’ve joined us. You need people like that. They are the cement. […] You have to show them how grateful you are.”

The extent of moderation

All webmasters indicated that to manage the processes in an online support group, moderators were of immense value. In most online support groups several participants were active as moderators besides the webmasters. In the other groups the webmasters themselves were the sole moderator. The webmasters defined the following tasks of the moderators: maintaining the rules of the online support group, removing advertisements, spam and abusive postings, moving wrongly placed postings or topics on the forum, soothing arguments between participants, supporting participants with technical questions (e.g., with logging in), and being a host(ess) to new participants.

Most webmasters stressed that moderators had to stay in the background. Some compared the role of a moderator to the role of a referee:

> It's comparable to a referee. Do you whistle to stop play or do you let them play and only intervene when someone's really fouled? The users are the forum's guests, and guests also have to behave in a certain way. But you mustn't prescribe exactly what they can or cannot say. That way there will never be a discussion.

Others compared the role of the moderator to the role of a mother in the family: "It might sound a weird comparison but it is similar to the mother's role in a family. That you look and make sure that everything's going okay." Several webmasters indicated that the selection of new moderators is a crucial process with not all participants being suitable for the role, because as a moderator you have to look at certain aspects from a different perspective: "You can't let just anyone do it. As a moderator you start to view and write things differently. I always note the following: 'At the moment I'm [name webmaster] the patient.'" The webmasters indicated that moderators had to be active participants, because they had to read along as much as possible. Some webmasters indicated that it was useful if moderators were experienced: "When you've been doing it for a while you have an idea where it can go wrong. Hormone therapy, wanting children and alternative therapy are just examples of where it can go wrong really easily." Two webmasters of the groups that were embedded in Dutch patient associations indicated that to become a moderator in their groups it required training.

All webmasters mentioned that in their online support groups behavioral rules were applied, which were maintained by the moderators. Most webmasters indicated that they explicitly listed the rules in the online support group, although not all webmasters thought that that was necessary: "I think it's normal to behave in a decent and civil fashion. I don't think you need to stipulate that in a regulation or something."

Organizing meetings and creating rituals

The webmasters differed in their opinion about the value of offline meetings, although almost all of them indicated that only a limited number of the participants have a need for such a venue. Aspects such as a lack of time or the impact of the illness were frequently mentioned obstacles that led to a limited attendance: "Imagine you all go sailing on the lake, but if you have to travel a long way to get there, well…And if you're not steady on your legs you soon think, oh I won't go." An advantage of such meetings is that it strengthens the bonds of the online support group: "You're no longer that unknown face with a nickname. The meetings do create a special bond." The webmasters mentioned that patients who had lost their social contacts in their own environment can make new friends at the meetings. A disadvantage is that the meetings reinforce 'clique formation' in the online support group:

"When we've had such a gathering, I always say at the end remember that on the forum we're not the same group we were today but we must also include the others. " Several webmasters thought that meetings sabotaged the unique features of online support groups, such as "anonymity" and "the non-committal aspect": "I think that the power of the Internet is that one is anonymous and that people don't feel obliged to participate in certain activities when they visit a site. I think you need to keep that reasonably non-committal." Many webmasters said that they created or stimulated some kinds of ritual in their online support groups (e.g., birthday calendar, weekly virtual flowers, virtual Santa Claus). In the case of these webmasters, they were the same as those who permitted 'chit chat'. This was one of the reasons for the other webmasters not to initiate rituals: "Christmas as a topic is alright, as is a Christmas tree, but to me it's off-topic, and has nothing to do with the subject." Some webmasters considered rituals to be an effective way of showing that you sympathized with other participants: "Yes, people really like it when they receive the bouquet of the week. It might be virtual, but it really does offer them support." Other pros and cons of rituals mentioned were identical to those of the meetings.

Following the wishes of the participants

According to most webmasters, it was not up to them alone to make a success out of the online support group but it had to be a joint effort of them and the participants. Most webmasters indicated that it was very important to listen to their input:

> It is after all the users who ultimately decide what the forum is going to look like. I sometimes draw the comparison with the catering industry: you can design the interior as a cosy pub but if the users want something more lounge-like, you adapt. You're there for the users, so you facilitate. You do things behind the scenes so that it offers them what they want.

Some webmasters, however, indicated that there were restrictions to the extent of participants' input:

> Maybe people miss it [the virtual burning of a candle] but at the same time I think they will look for it elsewhere. It has to appeal to me too. I am open to lots of things, but those things: terrible!

Several webmasters felt this could lead to difficult situations, especially when the wishes of the participants did not correspond with the goal the webmaster had in mind for the online group:

> I think that's a shame. Not sharing the normal things of life, but only sharing the illness. We had a period when we did but you continually had to take the initiative yourself. So, if you stop moderating, then it's gone. I'm slowly cutting down on the forum now, because I can't really stand it anymore. Stand the whining, shall we say.

Webmasters indicated that because of these differing wishes, it was positive that there were so many Dutch patient support groups, which gave each patient the opportunity to join a group that suited him/her: “It’s not a bad thing that there are so many forums in the Netherlands. Because one person wants this, and the other that. Each person should be able to find his/her own forum.”

Obstacles for effective management of the group

During the interviews it appeared that the management of the processes and people within the online support groups took up much of the webmasters’ time and energy. On average they were occupied with the group for 10-15 hours a week: “I think that many people who start up a forum underestimate what tasks it entails. It’s just a lot of work.” Some webmasters indicated that they sometimes had the feeling that it had become too much: “I sometimes arrive at a point where I think do I go on with this or not? Yes, what with your work and other things, you’re just so busy.” The reason for this, according to some, was the responsibility they constantly felt due to their leading role in the online support groups: “Yes, you’re the one who has to keep things moving, and well, after a while you’re at it almost all day long. Yes, how about you take over. I can’t continue to carry the load.“ Others mentioned this resulted from the continual confrontation with their own illness: “Sometimes I think I can’t stand the word cancer anymore.”

Discussion

Motives for initiation, and extent of success

Our study showed that webmasters had several motives and goals when they initiated their own online patient support groups. Most of them had an altruistic motive for initiating a group, such as providing information to patients and/or the general public, providing support, or empowering patients. However, several webmasters also mentioned intrinsic motives, like a hobby, or even as a kind of advertisement for a book. In addition, almost all webmasters indicated that they had initiated an online support group because they were looking for a (suitable) support group that they themselves could participate in. These results are consistent with studies on volunteers in offline groups, communities or organizations. People expect to derive benefits from volunteering, either through the benefits they provide to others (altruistic motives) or directly (intrinsic motives) [14, 22].

Webmasters’ differing motives for initiating an online support group yielded a wide range of online groups focusing on diverse goals. According to several of the webmasters, it provides an opportunity for Dutch patients to join a support group that matches their needs. It should, however, also be taken into account that only a relatively small percentage of patients are interested in participation in online support groups (unpublished data on file). To keep a community going, a critical mass of participants is needed [23, 24]. Too many support groups can lead to unwanted competition for participants between the groups. Patients who decide to start a group should thus verify whether there is room for a new online patient support group.

According to the advice provided in the literature, an online group needs to have a clearly formulated goal because people need a reason to become active in an online group [18, 25]. Preece et al. [26] state that formulating a clear goal involves understanding the needs of the potential participants. Since the majority of the webmasters were part of the target group themselves, it was to be expected that they were abreast of the participants' needs. However, the results of our study show that the goals of the webmasters do sometimes clash with the wishes of the participants. These situations may be intercepted if webmasters clearly list the goals they have in mind, e.g., on the entrance screen of the online group [16, 18, 25].

Most webmasters were of opinion that their online support groups were a success since they fulfilled the goals they had in mind when they initiated their groups. That they consider their groups a success does not mean that participants are of the same opinion. Participants usually define success as whether they got what they were looking for when they joined the online group [16]. Therefore it was interesting to see that the goals of the webmasters were in line with the empowering outcomes of participation mentioned by participants of online patient support groups [12].

Success factors in the initiation stage

Our study showed that success factors are closely connected to the goals of the groups. To be able to make a success of an online support group, decisions made during this stage should be in accordance with these. Our study revealed that not all webmasters have paid enough attention to these considerations. Since it became apparent that not all decisions taken during the initiation stage can be reversed, it seems of paramount importance that webmasters are informed about the pros and cons of the different options at hand. The results of our study offer an overview of pros and cons which may serve as handles when initiating successful online patient support groups (see Table 1).

Some interesting results were found in our study concerning the decisions taken during the initiation stage. First, webmasters disagreed whether or not their support groups should be publicly accessible. Even in the literature on online groups, no unambiguous stance can be found. Lazar and Preece [16] advised that there needs to be some form of registration to be able to keep troublemakers out of the group. On the other hand, online groups need to be as public as possible to give those people who only want to read along, the so-called lurkers, the opportunity to inform themselves [18, 27]. According to our study, the level of registration should be in line with the goal of the group. If the group's goal is to provide information, the group should be open to lurkers. However, for groups that seek support and the exchange of personal experience, it might be better to be accessible to members only.

Webmasters had either initiated their own online support groups or managed a group that was embedded in a Dutch patient association. Embedding may be valuable because patients regard specialized health care organizations as reliable. Online patient support groups embedded in Dutch patient associations profit from the long track record of these organizations in supporting patients via other communication channels such as “telephone support lines”. (Potential) participants thus have greater trust in these online groups [16, 23]. According to Leimeister et al. [28], “trust” is of specific importance to online patient support groups since their members are mostly elderly people who treat Internet with more skepticism than younger people. In addition, the topic of “an illness” in itself requires a high level of trust [28].

Webmasters disagreed whether or not chit-chat should be allowed in their groups. By exchanging chit-chat, interpersonal impressions are exchanged which leads to participants getting to know each other better [29]. It is assumed that participants need to “know” each other, to be able to compare themselves with other participants. Upward social comparison is considered to be a source of inspiration and advice [30], while lateral social comparison makes participants feel less alone in coping with their disease [12]. For webmasters who strive to empower their participants by making use of positive role models in the groups, allowing chit-chat may be a pro for the fulfillment of this goal.

Our study showed that webmasters have little influence on the design of their groups because they are tied to the restrictions of the free software they use. As webmasters have no opportunity to change certain elements, such as the type of structure (categories or a bulletin board) in the evolution stage, potential webmasters need to be abreast of all the pros and cons the moment they choose the software.

Success factors in the evolution stage

Our study showed that there are several points that webmasters should heed during this stage in order to be able to make a success of an online support group (see Table 2). Most of all potential webmasters need to consider that managing an online support group will occupy much of their time and energy. The majority of the webmasters underestimated the amount of work an online support group involves, and for some the group even became a burden. Most webmasters interviewed were the sole persons responsible for the group. This is of course a risk for continuation, especially when one considers that most of the webmasters are patients themselves. Another important point of interest is that webmasters should (constantly) monitor the participants’ wishes [23, 17]. Although it is not always possible or easy to concede to the wishes of all participants, webmasters should keep in mind that without participants there is no group.

Some interesting results of our study concerned the pointers in the evolution stage (see Table 2). First, webmasters differed in the level of promotional activities conducted. Some of them indicated that they had only promoted the group when it had just gone online. Studies show that promotion is needed for online groups, especially for private groups where interactions are invisible to non-participants. Conducting no promotional activities is something that webmasters cannot afford since the drop-out rates of online groups have proven to be high [14].

All webmasters indicated that it was of paramount importance to keep an online group alive. One of the conditions for this was a constant influx of new participants. This is in line with

Kim's [25] advice who stressed that webmasters should foster the membership life cycle. An online group should be open to new members who should be supported by experienced participants. Webmasters should show appreciation for the contributions of the experienced participants and in this way encourage reciprocity [25]. The concept of reciprocity, "whatever is given ought to be repaid", is considered to constitute an online community [15, 18]. As participants can be online anonymously, it is easy to take from a group, without repaying [18]. However, we found that cancer survivors are often active in online support groups for years after their recovery by helping other participants as a way of repayment [12]. According to the webmasters, reciprocity can be ensured by constantly offering new postings.

In contrast to advice offered in the literature, not all webmasters greatly valued explicitly listed behavior codes in their online patient support groups [25, 17, 31]. They indicated that this was unnecessary for their groups because no incidents had yet happened and they expected participants to behave properly. This contrast might be explained by the fact that online patients support groups are ones with a narrow focus. Groups that focus on more general topics are more sensitive to so-called flame wars [32] and therefore have a greater need of explicit behavioral rules.

Webmasters disagreed whether or not offline meetings should be organized. In line with Kim [25], several webmasters stressed their importance because they strengthen an online group. However, solely communicating online also has advantages. The knowledge that you will never meet a person can encourage people to disclose more about themselves. In addition, when exchanged postings only focus on the disease, a false sense of similarity can develop [15]. When peers meet each other offline, it can cause disillusionment. These meetings cannot, however, be intercepted. Especially participants of Dutch online patient support groups always live at distances that can usually be covered.

Limitations

The findings of this study are limited by the fact that we conducted a retrospective study. Webmasters themselves reported which factors contributed to the success of their online patient support groups.

A second limitation of this study is the small sample size, which limits our ability to generalize the findings. Although we interviewed nearly all the webmasters of Dutch online support groups for patients with breast cancer, arthritis and fibromyalgia, we do not know to what extent these results are representative for groups aimed at patients with either a mental illness or dominated by male participants.

Conclusions

Our data show that webmasters have differing altruistic and intrinsic motives for initiating an online patient support group. Webmasters define success as the fulfillment of the goals they had in mind when they initiated their groups. To be able to make a success of an online support group, decisions taken need to be in coherence with the goals of the group. The results of our study offer an overview of the pros and cons of decisions in the initiation stage which may serve as handles when setting up a successful online patient support group. In addition, pointers are presented that might contribute to the success of online patient support groups in the evolution stage.

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9

Experiences and attitudes of Dutch rheumatologists and oncologists with regard to their patients' health-related Internet use

C.F. van Uden-Kraan
C.H.C. Drossaert
E. Taal
C.B. Peek
W.M. Smit
E.R. Seydel
M.A.F.J. van de Laar

Submitted

Abstract

Objective To explore the experiences and attitudes of rheumatologists and oncologists with regard to their patients' health-related Internet use. In addition, we explored how often physicians referred their patients to health-related Internet sites.

Methods We sent a questionnaire to all the rheumatologists and oncologists in the Netherlands. The questionnaire included questions concerning demographics, experiences with patients' health-related Internet use, referral behavior and attitudes to the consequences of patients' health-related Internet use (for patients themselves, the physician-patient relationship and the health care). The response rate was 46% (N=238). Of these respondents, 134 practiced as a rheumatologist and 104 as an oncologist.

Results Almost all physicians encountered their patients raising information from the Internet during a consultation. They were not, however, confronted with their patients' health-related Internet use on a daily basis. Physicians had a moderately positive attitude towards the consequences of patients' health-related Internet use, the physician-patient relationship and the health care. Oncologists were significantly less positive than rheumatologists about the consequences of health-related Internet use. Most of the physicians had never (32%) or only sometimes (42%) referred a patient to a health-related Internet site. Most physicians (53%) found it difficult to stay up to date with reliable Internet sites for patients.

Conclusion Physicians are moderately positive about their patients' health-related Internet use but only seldom refer them to relevant sites. Offering an up-to-date site with accredited websites for patients might help physicians refer their patients.

Introduction

An increasing number of patients are using the Internet to search for health-related information. Reported rates of health-related Internet use by patients with rheumatic disorders vary from 14% to 28% [1-4]. Since mainly younger patients search online for health-related information, it can be expected that in the future this portion of patients will even further increase [1]. A recent study among new rheumatology patients attending rheumatology clinics showed that 62.5% of them searched the Internet to look up their symptoms or suspected condition prior to their first appointment [5].

Patients who use the Internet feel empowered in managing their health, feel more involved in partnerships with their physicians and in making decisions about their treatment [6]. However, Internet use for health-related information has also raised some concerns. Patients may misinterpret information they find on the Internet or they might come across misinformation which can result in a false sense of knowledge and control [7, 8].

Increased Internet use is noticeable in the physicians' daily practice with patients increasingly broaching health-related information from the Internet [9, 10]. Recently, it is shown, that only 20% of the patients who search for health-related information on the Internet discuss their information with their physicians. The main reason mentioned by patients to not discuss health-related Internet use is the fear of being perceived as challenging their physician [5]. Therefore it is important to know more about physicians' attitudes with regard to their patients' health-related Internet use [5, 11, 12].

The primary purpose of this study was to explore the experiences of rheumatologists and oncologists with their patients' health-related Internet use and their attitudes towards the consequences thereof (for patients themselves, for the physician-patient relationship and for the health care). We were also interested if and how often physicians referred their patients to health-related Internet sites. In addition, we were interested if the physicians' age, sex and profession (rheumatologist or oncologist) are related to their experiences, attitudes and referral behavior. We chose these two professional groups because of the contrast between the illnesses they treat (chronic disabling versus life threatening).

Methods

Sample and procedure

A questionnaire was mailed to all Dutch rheumatologists and oncologists, followed by one reminder. Of the total of 539 physicians approached (255 rheumatologists and 284 oncologists), 23 (9 rheumatologists and 14 oncologists) were ineligible because they had retired, were no longer in practice or had no valid address.

Instrument

A draft version of the questionnaire was pre-tested among 5 medical specialists. Based on their reactions some textual indistinctness and response options were adapted. The final questionnaire contained questions on the topics written below.

Experiences with patients' Internet use

The physicians were asked to estimate how many of their patients used the Internet to search for health information. Respondents could choose between the following response options: 0-20%, 21-40%, 41-60%, 61-80%, 81-100%, or 'I have no idea'. In addition, the physicians were asked how many times during the past month patients had discussed their health-related Internet use with them, and how many times during the past month patients had asked them for referrals to health-related Internet sites. Respondents could answer on a 5-point scale that ranged from 'never' to 'almost daily'.

Referral behavior

The physicians were asked how many times during the past month they had referred patients to health-related Internet sites and to online support groups. Respondents could answer on a 5-point scale that ranged from 'never' to 'almost daily'. The physicians were also asked how many times during the past month they had visited health-related Internet sites and online support groups. Respondents could answer on a 5-point scale that ranged from 'never' to 'almost daily'.

Attitudes towards patients' Internet use

In total, 20 items were formulated that described the perceived consequences of patients' health-related Internet use. The items had the format of a statement that began with 'Patients who use the Internet in relation to their health…' or 'Through patients' seeking health-related information on the Internet…'. Respondents could answer on a 5-point scale, that ranged from 'almost never' (1) to 'nearly always' (5). For each construct the internal consistency (Cronbach's alpha) was determined [13]. 'Consequences for patients' was measured with 7 items (alpha=0.71). 'Consequences for the physician-patient relationship' was measured with 7 items (alpha=0.66). 'Consequences for the health care' was measured with 6 items (alpha=0.68). For each scale an average score was computed. Scores could range from 1 'negative consequences' to 5 'positive consequences'.

Perceived difficulties with patients' Internet use

Physicians' perceived difficulties in coping with their patients' health-related Internet use were measured with 6 items. The items had the format of a statement that began with 'How difficult or how easy is it for you to…'. Respondents could answer on a 5-point scale, that ranged from 'very difficult' (1) to 'very easy' (5). The internal consistency for this construct was alpha=0.77.

Demographic and job characteristics

The respondents were asked to provide information about age, sex, their profession, and the number of years they had been in practice or in training as a medical specialist.

Finally, the respondents were invited to describe by means of a free-text response their positive or negative experiences with their patients' health-related Internet use.

Data analysis

Differences in continuous variables between rheumatologists and oncologists, male and female physicians and older and younger physicians (split at the median) were tested by means of T-tests and differences in categorical variables by Chi-square tests. Statistical significance was assumed when alpha<0.05. Free-text responses were used as illustrations for the quantitative data.

Results

The total response rate was 46% (N=238). Of these respondents 134 (response rate: 54%) were in practice or in training as a rheumatologist and 104 (response rate: 39%) were in practice or in training as an oncologist. Demographic and job characteristics are reported in Table 1.

Table 1 Demographic and job characteristics of rheumatologists and oncologists

	Rheumatologists[†] (131≤n≤134)		**Oncologists** (n=104)		**Total** (235≤N≤238)	
Sex (n, %)						
Female	71	53%	44	42%	115	48%
Male	63	47%	60	58%	123	52%
Age in years						
Mean (SD)	47 (9.0)		46 (10.0)		46 (9.5)	
Minimum	30		28		28	
Maximum	63		64		64	
Medical specialist in practice or in training (n, %)						
Medical specialist in practice	112	84%	86	83%	198	83%
Medical specialist in training	22	16%	18	17%	40	17%
Period in practice (in years)						
Mean (SD)	12 (8.5)		12 (10.2)		12 (9.3)	
Minimum	0		0		0	
Maximum	30		32		32	

[†] n = number of respondents per item. Percentages are given for the number of respondents per item

Experiences with patients' Internet use

In total, 80 physicians estimated that 41-60% of their patients sought health-related information on the Internet. A further 58 physicians estimated that 21-40% of their patients used the Internet for health-related reasons, whereas 51 physicians estimated that 61-80% of their patients did so (data not in table). Almost all physicians experienced patients raising information from the Internet during a consultation (Table 2) but less often that patients asked for referrals to health-related Internet sites. More than half of the physicians (57%) indicated that this never happened.

Female physicians experienced more often than male physicians (p<0.01) that patients raised information from the Internet during a consultation (data not in table). No relation was found regarding age or profession.

Physicians' referral behavior

Physicians themselves seldom visited health-related Internet sites and online support groups (Table 2). Most of the physicians had never (32%) or only a couple of times (42%) referred a patient to a health-related Internet site. Most oncologists and rheumatologists had never (69%) or only a couple of times (24%) referred a patient to an online support group. Some of the physicians added in a free-text response that it was not they who referred their patients: "At our centre, it's the rheumatology nurse who takes care of the referrals to relevant websites."

Rheumatologists referred their patients more often to Internet sites than oncologists (p<0.01). Female physicians referred their patients more often to Internet sites than male physicians (p<0.05) (data not in table). No relation was found regarding age.

Attitudes towards patients' Internet use

Consequences for patients

The physicians indicated that although patients are often better informed about both their illness (54%) and treatment options (51%) as a result of searching the Internet for health-related information (Table 3), a negative consequence is that patients are more often (32%) or sometimes (53%) unnecessarily concerned. Some of the physicians added in a free-text response that Internet use is only positive for those patients who want to inform themselves after being diagnosed. They were less positive about other goals such as self-diagnosis:

> Recently, I saw a woman with fibromyalgia and her partner who didn't want to accept it. He found information on the Internet stating that the symptoms of FM can be the same as with a vitamin B12 deficiency. They refused to see that a vitamin B12 deficiency was out of the question here. So in this case the information from the Internet was used to prove that it is something other than FM, and that's when it becomes difficult.

No relation was found regarding sex, age and profession.

Consequences for the physician-patient relationship

According to the physicians, Internet use by patients can sometimes (48%) or often (30%) lead to patients being more able to participate in the decision making process concerning their treatment (Table 3). The physicians indicated that sometimes (41%) Internet use can even lead to better treatment decisions. Although most of the physicians indicated that patients often (57%) become more assertive as a result of health-related Internet use, they are of the opinion that it rarely has negative consequences for the physician-patient relationship. Most of the physicians indicated that Internet use seldom (46%) or almost never (23%) undermines the physicians' authority. In addition, the physicians indicated that the bond of confidence between the physicians and the patient is seldom (43%) or almost never (33%) compromised by health-related Internet use. A small majority of the physicians felt that patients raised more unreasonable demands (59%) and that Internet use led to more unnecessary discussion between physicians and patients (51%).

Table 2 Experiences with patients' health-related Internet use and physicians' referral behavior (236≤N≤238)

	Never	**A couple of times**	**Multiple times**	**A couple of times a week**	**Almost daily**	**Rheumatologists** (133≤n≤134)	**Oncologists** (103≤n≤104)
	%	%	%	%	%	Mean (Sd.)	Mean (Sd.)
How many times during the past month did patients…							
…discuss health-related information from the Internet with you during a consultation?	1%	46%	32%	17%	5%	2.7 (0.92)	2.9 (0.86)
…ask you for referrals to health-related Internet sites?	57%	36%	4%	2%	0%	1.5 (0.75)	1.5 (0.62)
How many times during the past month did you…							
…visit health-related Internet sites for patients?	35%	45%	18%	1%	1%	1.9 (0.83)	1.9 (0.83)
…visit online support groups for patients?	79%	17%	4%	0%	0%	1.2 (0.47)	1.3 (0.56)
…refer patients to health-related Internet sites?**	32%	42%	20%	4%	2%	2.2 (1.05)	1.8 (0.74)
…refer patients to online support groups?	69%	24%	6%	0%	0%	1.4 (0.61)	1.4 (0.59)

**p<0.01 for T-tests comparing rheumatologists and oncologists

In a free-text response, one physician commented on how the consequences of health-related Internet use for the patient-physician relationship differed between patients: "If the relationship is good, Internet use is not a problem. The biggest problem is with new patients with whom no relationship has yet been forged and who arrive with a certain assertivity or suspicion."

Oncologists were less positive about the consequences of Internet use for the physician-patient relationship than rheumatologists ($p<0.001$). No relation was found regarding sex and age.

Consequences for the health care

The physicians indicated that unnecessary diagnostics and treatments are seldom given as a result of patients' Internet use (Table 3). Besides indicating that Internet use by patients seldom (36%) or almost never (48%) compromises their reputation, the physicians also commented that the duration of a medical consultation sometimes (39%) or often (36%) increases due to their patients' Internet use. However, in free-text responses some of the physicians added that the opposite was also the case: "Using the Internet also yields a shorter duration of the consultation because patients are better informed about their illness and need less explanation."

Oncologists were less positive about the consequences of Internet use for the health care than rheumatologists ($p<0.01$). No relation was found regarding sex and age.

Perceived difficulties in coping with patients' Internet use

Most physicians indicated that they find it quite easy to deal with their patients' increasing health-related Internet use (61%), to clear up misunderstandings it caused (59%), and to address the information that patients had found on the Internet (68%) (Table 4). Physicians experienced greater difficulties in referring their patients to trustworthy Internet sites or online support groups. Most physicians (53%) found it (very) difficult to stay up to date with reliable health-related Internet sites for patients. One of the physicians illustrated this: "It is imperative that doctors are trained in Internet usage. I rarely know which website to recommend to patients." Other physicians suggested that an up-to-date list with accredited websites for patients would help them.

Younger physicians (≤ 46 years) scored significantly lower on the perceived difficulties scale ($p<0.001$) than older physicians (data not in table). No relation was found regarding sex or profession.

Discussion

Physicians' experiences with patients' health-related Internet use

Physicians are increasingly aware of their patients' Internet use. The physicians' estimations corresponded with the degree of health-related Internet use found in our recent study among Dutch patients.

Table 3 Attitudes towards patients' health-related Internet use by patients (224≤N≤237)

	Almost never	**Seldom**	**Sometimes**	**Often**	**Nearly always**	**Rheumatologists** (125≤n≤133)	**Oncologists** (99≤n≤104)
	%	%	%	%	%	Mean (Sd.)	Mean (Sd.)
Patients who use the Internet in relation to their health…							
…are better informed about their illness	1%	6%	37%	54%	3%	3.5 (0.61)	3.5 (0.78)
…are better informed about their treatment options	1%	5%	41%	51%	3%	3.5 (0.59)	3.5 (0.77)
…are better informed about their rights as a patient	6%	23%	46%	22%	2%	2.9 (0.83)	2.9 (0.95)
…are more satisfied about their treatment	2%	25%	56%	16%	1%	2.9 (0.69)	2.8 (0.76)
…can cope better with their illness	2%	23%	50%	25%	0%	3.0 (0.69)	2.9 (0.82)
…are more often unnecessarily concerned	1%	12%	53%	32%	2%	3.2 (0.65)	3.3 (0.82)
…draw wrong conclusions about their illness*	0%	11%	70%	17%	2%	3.0 (0.51)	3.2 (0.68)
Scale score "Consequences for patients"						3.1 (0.39)	3.0 (0.50)
Through patients' seeking health-related information on the Internet…							
…patients become more assertive	2%	3%	35%	57%	3%	3.6 (0.65)	3.6 (0.75)
…patients become more able to participate in the decision making process about their treatment*	1%	21%	48%	30%	0%	3.2 (0.71)	3.0 (0.77)
…better treatment decisions are being taken*	12%	33%	41%	14%	0%	2.7 (0.79)	2.4 (0.96)
…patients make more unreasonable demands	8%	25%	59%	8%	0%	2.6 (0.69)	2.8 (0.82)
…more unwanted debate between the physician and the patient takes place*	7%	24%	51%	16%	3%	2.7 (0.81)	3.0 (0.92)
…the physician's authority is undermined*	23%	46%	22%	6%	3%	2.1 (0.86)	2.4 (1.09)
…the bond of confidence between the physician and the patient is compromised**	33%	43%	14%	6%	3%	1.9 (0.81)	2.3 (1.19)
Scale score "Consequences for the physician-patient relationship"***						3.5 (0.44)	3.2 (0.54)

*p<0.05 **p<0.01 ***p<0.001 for T-tests comparing rheumatologists and oncologists

Table 3 Attitudes towards patients' health-related Internet use by patients (224≤N≤237) (continued)

	Almost never	**Seldom**	**Sometimes**	**Often**	**Nearly always**	**Rheumatologists** (125≤n≤133)	**Oncologists** (99≤n≤104)
	%	%	%	%	%	Mean (Sd.)	Mean (Sd.)
Through patients' seeking health-related information on the Internet…							
…the duration of a medical consultation increases**	3%	17%	39%	36%	4%	3.1 (0.90)	3.4 (0.85)
…the number of medical consultations increases	11%	36%	38%	13%	1%	2.5 (0.83)	2.7 (0.97)
…unnecessary diagnostics are given	10%	41%	39%	9%	2%	2.5 (0.73)	2.6 (1.01)
…unnecessary treatments are given	25%	49%	15%	7%	4%	2.0 (0.81)	2.3 (1.20)
…the physician is given new suggestions	27%	39%	34%	0%	0%	2.1 (0.81)	2.0 (0.74)
… the physician's reputation is compromised*	48%	36%	5%	5%	6%	1.7 (0.95)	2.1 (1.30)
Scale score "Consequences for the health care"**						3.4 (0.54)	3.2 (0.61)

*p<0.05 **p<0.01 ***p<0.001 for T-tests comparing rheumatologists and oncologists

Table 4 Perceived difficulties with patients' health-related Internet use (232≤N≤238)

	Very difficult	**Quite difficult**	**Neutral**	**Quite easy**	**Very easy**	**Rheumatologists** (130≤n≤134)	**Oncologists** (101≤n≤104)
	%	%	%	%	%	Mean (Sd.)	Mean (Sd.)
How difficult or easy is it for you to…							
…deal properly with patients' increasing health-related Internet use?	0%	2%	28%	61%	9%	3.8 (0.59)	3.7 (0.69)
…to clear up misunderstandings caused by patients' health-related Internet use?	0%	16%	23%	59%	3%	3.5 (0.76)	3.4 (0.81)
…to address the information that patients found on the Internet?	0%	5%	23%	68%	4%	3.7 (0.61)	3.7 (0.62)
…to refer patients to reliable health-related Internet sites?	3%	20%	41%	32%	3%	3.2 (0.87)	3.0 (0.90)
…to refer patients to good online support groups for patients?	8%	33%	45%	12%	1%	2.6 (0.90)	2.7 (0.77)
…to stay up to date with reliable health-related Internet sites for patients?	11%	42%	40%	6%	0%	2.5 (0.78)	2.4 (0.77)
Scale score "Physicians' experienced difficulties"						3.2 (0.55)	3.2 (0.50)

This study showed that 42% of the patients with rheumatoid arthritis, 43% of the patients with breast cancer and 75% of the patients with fibromyalgia had used the Internet to seek health-related information (unpublished data on file). This is in contrast to Potts and Wyatt [11], who found that physicians in the United Kingdom probably underestimate the percentage of patients who used the Internet for health-related reasons. Most of them indicated that only a very small proportion (1%-2%) of their patients did so.

Almost all physicians indicated that patients raised information from the Internet during a consultation. This indicates an increase, since Murray et al. [12] found in their 2003 study that only 58% of the physicians had experienced an incident when a patient brought information from the Internet to a consultation. For most of these physicians this was still a relatively rare event [12], whereas in our study we found that over the past month most physicians had been confronted with health-related Internet use regularly. Nevertheless, our study did show that this was still not a daily occurrence.

Physicians' attitude towards patients' health-related Internet use

Physicians were moderately positive about the consequences of health-related Internet use for their patients. In the physicians' opinion a negative consequence of Internet use is that patients are more often unnecessarily concerned. These results are in line with the findings of a study among patients who participate in online support groups. These patients indicated that they found it stressful to be confronted with the negative sides of their illness in the group, such as metastases or consequential disabilities [14].

The physicians indicated that in general the consequence of their patients' health-related Internet use is also moderately positive for the physician-patient relationship. This is in line with Murray et al. [12] who reported that most physicians indicated that Internet use by patients had a positive (38%) or neutral (54%) effect on the physician-patient relationship. Most Korean rheumatologists were less positive, indicating that health-related Internet use by patients had a neutral (64%) or negative (21%) effect on the physician-patient relationship [2].

Physicians seldom reported negative consequences for the physician-patient relationship. Murray et al. [12] also found that only 17% of the physicians indicated that their authority was challenged by patients who made use of the Internet for health-related reasons. The physicians felt especially challenged when patients tested their knowledge or when patients used the information to diagnose themselves or make their own treatment plan [15]. This feeling of being challenged might also be related to their personal insecurity with regard to using the Internet [16].

Finally, physicians also indicated that they were moderately positive about the consequences of health-related Internet use for the health care in general. Physicians did, however, indicate that the duration of a consultation increases. This is a confirmation of the results of past studies, revealing that physicians considered patients' health-related Internet use as time consuming [11, 12, 15].

Since our study showed that physicians in general have a moderately positive attitude towards health-related Internet use, patients should not fear to discuss their health-related Internet use during consultations. Discussing health-related information might be of added value because physicians can clarify the information found online and they have the opportunity to adjust information that is misinterpreted by patients. A recent study suggests that discussing health-related information during consultations is related to a higher patient and physician satisfaction [5]. Physicians should therefore consider strategies for enabling communication about health-related Internet use [5].

Physicians’ referral behavior

Physicians seldom referred their patients to health-related Internet sites and online support groups. Although we do see an increase in the physicians’ referral behavior compared to the results of Murray et al. [12], who found that only 35% of the physicians had ever referred patients to websites, it is still not common practice. It is, however, advised that patients be assisted by their physicians in their Internet use for health-related reasons in order for it to be of added value [9, 17-19]. Health professionals need to be able to direct patients to high quality health-related websites [18]. In a study among patients it was found that 62% of the patients agreed that physicians should recommend websites where patients can learn more about their health care [9]. This is in line with the recommendations made by Gerber and Eiser [17], who introduced the idea of what they called an “Internet prescription”. Physicians should ‘prescribe’ their patients addresses of websites with reliable, evidence based data.

An explanation for the lack of referrals might be that most of the physicians found it difficult to stay up to date with reliable health-related Internet sites. Some physicians indicated that an up-to-date list with accredited websites for patients would help them with referrals.

Physicians hardly ever visited health-related Internet sites for patients or online patient support groups. This can be seen as a missed opportunity, because one of the benefits of physicians visiting these sites is that they gain increased insight into their patients’ issues. A better understanding might well lead to an improvement of the physician-patient relationship.

Relations found with physicians’ sex, age and profession

Oncologists were significantly less positive about the consequences of patients’ health-related Internet use for the physician-patient relationship and the health care compared to rheumatologists. This might result from the fact that rheumatologists in general have built a bond of confidence with their patients over many years, in contrast to oncologists who have intensive contact with a patient but for a relatively short period of time. Oncologists referred their patients less often to health-related Internet sites than rheumatologists. However, since cancer is a life-threatening illness, it might even be more important for cancer patients to receive guidance, because for them self-treatment through health-related Internet use has a more destructive consequence.

Female physicians indicated significantly more often that their patients raised information from the Internet during a consultation. This might result from the fact that female physicians tend to show more affiliative behavior towards their patients [20]. Female physicians are more sensitive to the physician-patient relationship, more accepting of the patient's feeling and more open to psychosocial factors in health care [21]. Patients might thus consider female physicians more approachable and expect fewer reservations from them about health-related Internet use.

Younger physicians (≤ 46 years) were less confident about their ability to cope with perceived difficulties of health-related Internet use. This might result from the fact that they have had less experience with patient care. Older physicians have experienced many years of patients bringing information from other media, such as the television or the newspaper, to consultations. Paying attention to patients' health-related Internet use during the physicians' training might be worthwhile.

Limitations of the present study

Although the response rate of our study was comparable to the response rate of 53% in a study among U.S. physicians [12], it might be the case that the physicians who chose to complete our questionnaire are not representative for all Dutch rheumatologists and oncologists.

In addition, it should be considered that we made use of self-perceived measures. It might have been difficult for physicians to estimate the amount of patients using the Internet.

Conclusion

Almost all physicians experienced their patients raising information from the Internet during a consultation. However, this was still not a daily occurrence. Physicians were moderately positive about the consequences of health-related Internet use for their patients, the physician-patient relation and the health care. The physicians indicated that they can cope with the perceived difficulties of health-related Internet use. However, despite the literature advising physicians to assist their patients in their Internet use, physicians only seldom refer them to health-related Internet sites. Maybe offering an up-to-date list with accredited websites for patients would help and stimulate physicians to refer their patients.

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10

Summary and general discussion

With the availability of the Internet, so has the opportunity arisen to share concerns and experiences with peers online. Owing to not only the ease of online peer support but also the ever increasing number of Internet users in the Netherlands [1], it can be expected that more and more people will seek contact with peers through this medium. On the one hand, a growth in online peer support seems to be a promising development because of the potentially positive functions of peer support, such as an increase in quality of life and knowledge [2-8]. On the other hand, however, participating in online peer support groups can also have negative consequences, such as an increase in fear, uncertainty or depressive feelings [3, 9]. The studies described in this thesis were conducted to gain further understanding of the meaning of participation in online patient support groups from the viewpoint of various stakeholders (participants, arthritis, breast cancer and fibromyalgia patients, webmasters and health care providers). To this end we employed various methods (content analysis, interviews and surveys).

In this final chapter the results of the studies conducted will be integrated, whereby we will focus on the following topics: the meaning of online peer support for patients with somatic diseases, and the embedding of online support groups in health care. We will also focus on the differences between the patient groups studied, the limitations of the studies conducted, and the recommendations for future studies. Finally, we will draw an overall conclusion.

The meaning of online peer support for patients with somatic diseases

In order to examine the meaning of online peer support for patients with somatic diseases, we conducted several studies as described in chapters 2, 3, 4, and 5. In the study described in chapter 2, we focused specifically (by means of a content analysis) on negative consequences of participation by investigating to what extent potential disadvantages of online support groups actually occurred. In the studies described in chapters 3, 4 and 5, we questioned participants of online patient support groups both qualitatively and quantitatively to explore the empowering and disempowering processes that take place in these groups and the empowering outcomes of participation in online support groups as experienced by them. We explored empowering processes and outcomes for both active users, who contribute by sending postings, and passive users, the so-called lurkers, of online support groups (chapter 5).

Positive functions of participation in online patient support groups

Ever since the onset of online support groups, much has been expected of the potentially empowering effect for patients who take part in these groups [10-12]. However, up until now there was no direct evidence for the effects of participation in online support groups on patient empowerment [13, 14]. In line with the expectations posited in literature, the results of the studies conducted showed that taking part in online support groups indeed endorses patient empowerment. The results of the qualitative study among participants of online support groups showed that patients experienced various empowering processes in using online peer support groups: patients not only find information but also feel supported in these groups. In addition, online patient support groups gave them an opportunity to open up and to compare themselves with other fellow sufferers. For some participants a positive function of an online support group was the ability to help other members, i.e., by 'providing information and advice', 'providing support' and 'sharing their own experiences' (chapter 3). The quantitative study among participants of online patient support groups (chapter 4) confirmed the findings of the qualitative study and showed that the process that took place most frequently in the online support groups was 'exchanging information', followed by 'finding recognition'. Despite the fact that 'exchanging information' was pointed out as the most important process, the content analysis of postings sent to online patient support groups (chapter 2) showed that these groups should not solely be seen as a source of medical information. When information is exchanged in online support groups, it is more likely to be about personal experiences than be medically factual (only 11% of the postings coded in the content analysis contained medical information).

With regard to the empowering outcomes, participation in online patient support groups resulted in participants feeling empowered in several ways, such as being better informed, feeling confident with their physician, their treatment, and their social environment, improved acceptance of the disease, increased optimism and control, and enhanced self-esteem and social well-being (chapter 3). The quantitative study among participants of online patient support groups (chapter 4) confirmed the findings of the qualitative study and showed that the empowering outcomes they experienced strongest were 'feeling better informed', followed by 'enhanced social well-being' (chapter 4).

Interestingly, the empowering processes and outcomes of participation mentioned by participants of online patient support groups were in line with the goals striven for by the webmasters of these groups, as described in the study reported in chapter 8.

Besides investigating the kinds of empowering processes that take place and the outcomes of participation as experienced by patients, we also examined which empowering processes, occurring in online support groups, were related to the empowering outcomes (chapter 4). The findings of our study revealed that the empowering outcomes could only be predicted partially on the basis of the processes that took place in the online support groups. The outcomes that could be predicted best were 'enhanced social well-being' and 'being better informed'. The most important predictors of the outcome 'enhanced social well-being' appeared to be 'encountering emotional support' and 'sharing'. The most important predictors of the outcome 'being better informed' appeared to be 'exchanging information' and 'finding recognition' (chapter 4).

The study described in chapter 5 indicated that the empowering outcomes not only apply to those patients who actively participate by sending postings, but also to those patients who only lurk in online patient support groups. Apparently, the use of online patient support groups, even if it consists of merely reading postings by others, might be beneficial to patients.

All in all, the studies conducted in this thesis revealed the positive functions of online peer support and indicated that patients can profit from active and passive participation in online support groups. Interestingly, the positive functions of participation in online support groups are in line with the positive functions of participation in face-to-face support groups [2, 3, 6-8].

Negative consequences of participation in online patient support groups

Despite the empowering outcomes of participation in online patients support groups, these groups are not without potential problems. One concern that is often expressed is the lack of control of the quality of the information exchanged in online support groups. Members may receive misinformation or be referred to false health information [15-17]. In addition, there is the concern that the exchange within the group might include socially inappropriate remarks (flaming) since there are no formalized guidelines for online support groups [15, 18]. In contrast to the concerns raised in literature, the content analysis described in chapter 2 showed that only in a minor proportion of the postings sent to online patient support groups potential disadvantages were present. An important result concerning the disadvantages of online patient support groups was that medical experts concluded that most postings containing medical information were classified as conventional (79%). According to these experts, none of the postings contained medical information that was dangerous for other participants. Also flaming was infrequent in the postings analyzed. The results of the qualitative study among webmasters (chapter 8) confirmed the results of the content analysis. The majority of the webmasters indicated that no incidents, so- called ‘flame wars’, had yet happened in their groups.

The results of the qualitative study among participants of online patient support groups (chapter 3) were also in line with the results of the content analysis. Negative consequences of participation were mentioned far less often during the interviews, compared to positive functions of participation. The concern mentioned most often by the participants was the lack of control on the quality and validity of the information and the possibility of receiving bad advice. Other participants, however, pointed to the so-called ‘self-cleansing capacity’ of online patient support groups, by which they meant that there was always someone who intervened when misinformation was posted. A disadvantage, uttered mostly by participants in the breast cancer support groups, was the fact that they were confronted in online support groups with the negative sides of the disease, such as metastases. This disadvantage of health-related Internet use by patients was also mentioned by the physicians questioned in the study described in chapter 9. These physicians were of the opinion that patients who used the Internet for health-related reasons were sometimes unnecessarily concerned. However, for none of the interviewed participants of online patient support groups was this a reason to leave the group (chapter 3). Finally, some of the participants were irritated by people who constantly complained or talked about themselves too much. Others put this into perspective, by realizing that they had been dealing with the disease for a longer period of time than the ‘complainers’.

In conclusion, the various studies conducted in this thesis showed that the disadvantages of online patient support groups that have been identified in literature turned out to be only present to a limited degree.

Embedding of online patient support groups in health care

To examine which place online patient support groups occupy in Dutch health care, we conducted several studies from the viewpoint of different stakeholders as described in chapters 6, 7, 8 and 9. In the study described in chapters 6 and 7 we quantitatively studied a representative sample of patients with breast cancer, arthritis and fibromyalgia from two regional hospitals, with regard to their health-related Internet use. We studied if, how often and how patients used the Internet in relation to their disease. Moreover, we studied in detail the reasons for (not) using online patient support groups. In the study described in chapter 8 we interviewed 23 individuals who voluntarily took the initiative to start an online patient support group, the so-called webmasters. We explored which goals they strove for when initiating their online support groups, and how these webmasters defined success and success factors. Finally, we studied patients' health-related Internet use in general and online peer support specifically from the viewpoint of Dutch rheumatologists and oncologists. We examined physicians' experiences with their patients' health-related Internet use and their attitudes towards the consequences thereof (for patients themselves, for the physician-patient relationship and for the health care). We were also interested if and how often physicians referred their patients to health-related Internet sites.

Extent of patients' health-related Internet use in general and use of online patient support groups in particular

Owing to the increasing availability and popularity of the Internet, it can be expected that a growing number of patients will use it for health-related reasons. The study described in chapter 6 revealed that 52% of the patients studied used the Internet to search for health-related reasons. In this study we also explored which demographic, health and psychological characteristics are related to patients' health-related Internet use. The findings of our study revealed that in line with others studying health-related Internet use [19-21], younger age, higher education and employment were the only significant predictors. Patients' health-related Internet use could not be predicted by health and psychological characteristics.

Our study among patients also revealed that communication with health professionals was not commonly practiced: only few patients had ever asked a health professional or their own physician a question via the Internet or via the email. In addition, online peer support was only used by a small number of patients. In total 15% of the respondents had ever read along with an online patient support group. An even smaller share of the patients (4%) had actively participated in an online patient support group by sending postings (chapter 6). These results are in contrast to the expectations posited in literature, namely that engagement in peer support would increase by the emergence of online support groups.

All in all, we can conclude that for most patients their health-related Internet use was restricted to seeking information about their illness. A disadvantage of merely using the

Internet to search for (health-related) information is that patients can ‘get lost’ in the wealth of information. Participation in online patient support groups can help in these situations, i.e., when a patient wants to assess the quality of the information found on the Internet, or when (s)he needs guidance to obtain additional (credible) sources of health-related information [22]. Owing to this (potential) empowering role of online patient support groups, it is a pity that our study showed only a small number of patients using these groups.

Determinants of engagement in face-to-face and online patient support groups

As engagement in face-to-face and online peer support can have a positive effect on participants, it is important to gain more insight into the factors that impede or facilitate such engagement. Whereas more patients could benefit from engaging in face-to-face and online peer support, our study showed that the respondents’ intention to engage was slightly negative. The majority of patients did not intend to look for peers face-to-face (60%) or via the Internet (74%). Our study revealed that in accordance with the Theory of Planned Behavior (TPB) [23], having a more positive attitude, feeling more supported by people in the social environment and feeling more able to participate in peer support increased the intention to participate in peer support. Nevertheless, it must be concluded that the intention to engage in face-to-face and online peer support could only be modestly predicted by the TPB variables (explained variance respectively 33% and 26%). Physical and mental well-being, and mental well-being and age respectively could significantly improve the total amount of explained variance of intention towards peer support: 38% face-to-face support and 35% online peer support. The results of the qualitative study among non-participants showed that although respondents thought that peer support could be valuable to other patients, for themselves they saw mainly disadvantages. Most of the respondents had a negative conception of peer support groups. Many thought that these were meant for people who could not cope with their illness, and who were old and lonely. Lack of awareness of peer support groups also played a role.

Summarizing, the study described in chapter 7 showed that participation in peer support groups is impeded by misconceptions and a lack of awareness. Owing to the potentially positive outcomes for patients of participation in online patient support groups, we think it might be helpful to develop an intervention to increase participation rates.

Characteristics of patients using online patient support groups

Up until now, little was known about the characteristics of patients who engage in online peer support groups. On the basis of several studies conducted in this thesis (chapters 2, 3, 4, 5, 6, and 7), we were able to provide some insight into the demographic characteristics of patients who use Dutch online support groups. First, it can be concluded that the online support groups under study are mainly used by female patients. We have to take into account, however, that the illnesses included in our study are dominated by female patients. The mean age of the participants differed between 38 (chapter 2) and 44 years (chapter 4). This is relatively young compared to the mean age of these patient groups in the

Netherlands [24, 25]. These results are, however, in line with our expectations as the study among patients described in chapter 6 showed, namely that it is still predominantly younger people who use the Internet. In addition, although it was expected that participants in online support groups were mainly people who had been recently diagnosed, we have to conclude that the participants were patients in different stages of their illness (chapters 2, 3 and 4).

When comparing passive users (lurkers) and active users (posters), those patients who indicated they only lurked in online patient support groups appeared to be somewhat older and had been more recently diagnosed, compared to the patients who actively participated (chapter 5). This is in line with the expectations raised in literature, namely that lurkers are predominantly new users of the online support groups who first want to get to know the group before they start posting [26].

In conclusion, the studies conducted in this thesis showed that participants of Dutch online support groups are mainly younger patients in different stages of their illness. However, because the availability and popularity of the Internet is still increasing, it can be expected that ever more people with varying characteristics will seek contact with peers via the Internet. In order to keep track of the characteristics of patients who participate in online patient support groups over time, it is relevant to continue this type of research at regular intervals.

The rise and fall of online patient support groups

Nowadays, patients are able to choose between many online patient support groups. Most of these groups are spontaneously initiated by individual patients on the Internet. As the threshold to start an online support group is low, online patient support groups are currently mushrooming. The online patient support groups that were involved in our studies were initiated between 1999 and 2007 (chapter 8). While some of these groups developed into successful ones, other groups never got off the ground or bled to death at a later stage. Success of the group is important since it can be expected that effects of participation in an online support group for patients may vary according to the group's success. Our study revealed that despite the large differences in the number of participants and activity on the forum, most webmasters questioned were of opinion that their groups were a success because they succeeded in fulfilling the goals they had in mind when they initiated their groups. These goals were mostly altruistic, such as providing information to patients and/or the general public, providing support, or empowering patients. However, several webmasters also mentioned intrinsic motives for initiating an online patient support group, like a hobby.

For managing an online support group, two phases are important: the initiation stage and the evolution stage. The initiation stage is the period before the patient support group goes online. The evolution stage starts the moment the group goes online, and this stage is ongoing. Our findings revealed that in the initiation stage several decisions have to be taken about access, embedding, design, and content of the online group. The webmasters mentioned a number of pros and cons of the differing options, and stressed that the decisions need to be in coherence with the goals of the online patient support groups. For example, if the group's goal is to provide information, the group should be open to lurkers. However, for groups that focus on the exchange of support and personal experiences, it might be better to be accessible to members only. When the group is online (the evolution stage), the success is dependent on the webmaster's success in managing the processes and people in the online group. Although they have less influence over these aspects, since they do not control the participants of the online group, the webmasters mentioned pointers concerning the ways to promote and finance the group, how to keep the group alive, the extent of moderation, the organization of meetings and rituals, and the extent to which the wishes of the participants should be followed. For example, the webmasters felt that online support groups should give heed to a steady influx of new participants by paying constant attention to the group's promotion.

The webmasters interviewed were of opinion that it was positive that there were so many different Dutch online patient support groups, because this gave each patient the opportunity to join a group that suited him/her. The study among a sample of patients with breast cancer, fibromyalgia and arthritis (chapter 6), however, revealed that only a relatively small percentage of patients are interested in participation in online support groups. In addition, a critical mass of participants is needed to keep a community going [27, 28]. Therefore, people who decide to start a group should verify whether there is room for a new online patient support group. Too many support groups can lead to unwanted competition.

Summarizing, the qualitative study among webmasters described in chapter 8 offered an overview of the pros and cons of differing decisions which may serve as handles when initiating online support groups and it drew attention to those factors that might contribute to their success as they evolve. Potential webmasters should, however, first make sure that a new online peer support group is needed.

Physicians' attitudes and behavior towards patients' health-related Internet use

Increased Internet use is noticeable in the physicians' daily practice with patients increasingly broaching retrieved health-related information. This may have a profound effect on the physician-patient relationship. Our study among physicians showed that almost all physicians have indeed experienced patients raising information from the Internet during a consultation. Although this was an increase compared to an earlier study among physicians [29], our study did show that this confrontation was still not a daily occurrence. In addition, our study revealed that physicians were moderately positive about the consequences of health-related Internet use for their patients, the physician-patient relation and the health care. Despite the physicians' moderately positive attitude towards patients' health-related Internet use and despite the literature [30-32] advising physicians to assist their patients in their Internet use, the study among rheumatologists and oncologists showed that physicians only seldom refer patients to health-related Internet sites. The lack of physicians' referrals to health-related Internet sites in general, and online patient support groups specifically, might be one of the causes for the awareness problems that online patient support groups struggle with (chapter 7). An explanation for the lack of referrals can be sought in the fact that most of the physicians found it difficult to stay up to date with reliable health-related Internet sites. All in all, we therefore suggest offering physicians an up-to-date list with accredited websites for patients. Such a list might help and stimulate physicians to refer their patients. Future studies should explore possibilities to compile this list and keep it up to date and they should investigate whether or not the introduction of such a list influences physicians' referral behavior.

Differences between the patient groups studied

The studies described in this thesis are unique due to the fact that we involved several patients groups instead of focusing on only one online group for patients with a life-threatening disease. We explored the concept of online patient support groups for three groups of patients: a) people with a chronic but not life-threatening disease (rheumatoid arthritis), b) people with a life-threatening but treatable disease (breast cancer), and c) people with an unexplained disease (fibromyalgia). It was expected that the meaning of support patients gain from engagement in online peer support would be different for patients suffering from diverse diseases [33]. However, contradictory findings appeared in the studies described in this thesis. While we did find indications for differences between patients suffering from either arthritis, breast cancer or fibromyalgia in the studies described in chapter 2, 3 and 4, we found no differences between patient groups in the studies described in chapter 6 and 7. The content analysis described in chapter 2 showed that the relative frequency with which the participants contributed from each illness group differed significantly. Most of the postings downloaded were sent by participants of the support groups for breast cancer and fibromyalgia, whereas the participants of the arthritis groups only contributed 3%. In addition, the results of the content analysis showed that participants of the arthritis groups used relatively less chit-chat but mostly sent 'on-topic postings'. The postings of the arthritis groups contained by far the most medical information. The quantitative study among participants of online patient support groups described in chapter 4 showed that there were no differences between the diagnostic groups with regard to the empowering outcomes. However, we did find differences between the patient groups concerning the frequency with which the processes took place in the online support groups. The processes 'exchanging information' and 'finding recognition' occurred significantly less often in the online support groups for arthritis patients. The quantitative study among patients with breast cancer, fibromyalgia and rheumatoid arthritis described in chapters 6 and 7 showed that 'type of illness' had no influence on their using the Internet for health-related reasons or on their intention to participate in (online) peer support. According to Davison & Pennebaker [33], the explanation for the differences between the patient groups must be sought in the characteristics of the illnesses such as cause and consequences. The high number of postings exchanged and the relatively high frequency with which the empowering processes took place in the online support groups for breast cancer patients might be due to the fact that breast cancer is a life-threatening illness, whereas the high number of postings exchanged and the relatively high frequency with which the empowering processes took place in the online support groups for fibromyalgia patients might be due to the ambiguity of this illness [33]. We must conclude, however, that we are unable to draw any conclusions on associations with type of illness because we only included one patient group of each type of illness (chronic, life-threatening, vague) in our studies. We suggest that future studies should include more patient groups of each type of illness (e.g., chronic illnesses, such as diabetes and asthma, versus life-threatening illnesses, such as other types of cancer and heart conditions, versus vague illnesses, such as chronic fatigue syndrome).

Limitations and recommendations for future studies

The surplus value of the studies conducted in this thesis is our focus on the concept of online patient support groups from the viewpoint of various stakeholders (participants, arthritis, breast cancer and fibromyalgia patients, webmasters and health care providers), and with various methods (content analysis, interviews and surveys). However, it is important to also be aware of the limitations of these studies. First, the participants of online patient support groups questioned were all highly active users of online support groups. In future studies, our advice would be to also question patients who have decided to no longer participate in online patient support groups. This might provide new insights into negative consequences of participation.

Second, future studies should pay attention to the associations between patients' characteristics and the outcomes of participation in online patient support groups. It is interesting to gain more insight into the characteristics of patients who do or do not profit from participation and the extent to which this does happen. For example, it would be interesting to know if those patients who join an online patient support group after just being diagnosed profit more than those who join later.

Third, the studies in this thesis only focused on online patient support groups for somatic illnesses that mainly affect women. Therefore we do not know to what extent these results are representative for online support groups for other patient groups. Future studies should also focus on online support groups aimed at patients with a mental illness and online support groups dominated by male participants.

Moreover, because the studies conducted showed that only a small proportion of Dutch patients with breast cancer, arthritis and fibromyalgia participated in online patient support groups, we do advise future studies to focus on ways in which participation in support groups can be facilitated.

In addition, future studies should also pay attention to the differing characteristics of the various online patient support groups and the effect these might have on the outcomes of participation. More research is, also needed on other forms of online peer support, such as chat groups and email groups and on so-called Web 2.0 applications, like 'PatientsLikeMe' [34].

Finally, although the studies conducted in this thesis provided us with relevant insight into the concept of online patient support groups, the studies are limited because we only used cross-sectional studies. Therefore we were not able to detect any causal relationships. A randomized controlled trial would be the best way to evaluate whether participation in online patient support groups is truly effective. To conduct a randomized trial with 'online peer support' as intervention is a great but arduous challenge, however, because of several reasons: the inherently self-selecting nature of peer support [35], the challenge of initiating a 'real' support group in an experimental setting, and the difficulty of composing a comparable control group [36]. It might be better to conduct a longitudinal study among participants who decide for themselves whether to engage in already established online patient support groups. However, also in the case of a longitudinal study, it is hard to compose a comparable control group.

Conclusion

In this thesis we have seen that patients who use online support groups benefit in various ways. Results of the studies conducted indicated that participation in online patient support groups had a profound effect on the participants' feelings of 'being empowered' in several areas. We have also seen that the disadvantages of online patient support groups identified in earlier literature appeared to be present to only a limited degree. Despite these favorable outcomes, this thesis showed that only a small proportion of Dutch patients with breast cancer, arthritis and fibromyalgia participated in online patient support groups. Online patient support groups seem to struggle with misconceptions and have an awareness problem. Due to the potentially positive outcomes for patients with regard to their participation, we think it might be helpful to develop an intervention to increase participation rates of online support groups. However, before implementing such an intervention, it has to be considered to what extent patients should be recommended to participate in peer support groups because not all patients inevitably profit from such peer support. Nevertheless, developing an intervention is necessary, because not only should patients be able to make well-informed decisions about whether or not they want to engage in peer support but they should also be able to find a peer support group the moment they want to enroll.

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Appendices

Appendix 'Constructs empowering processes'

Answer categories: 'seldom to never'; 'sometimes'; 'regularly'; 'often'.

Exchanging information (alpha=0.88):

The information and tips exchanged in this online support group are…

- … understandable
- … valuable
- … usable
- … new
- … applicable to my present situation
- … reliable
- … correct
- … of added value to the information I receive from my care providers
- … in line with the information I receive from my care providers

Encountering emotional support (alpha=0.95):

Does it ever happen in this online support group…

- … that someone in this online support group invites you to have (personal) contact outside this online support group?
- … that someone in this online support group starts a private conversation with you?
- … that someone in this online support group is empathic?
- … that someone in this online support group consoles you?
- … that someone in this online support group pays you a compliment?
- … that someone in this online support group is interested in you?
- … that someone in this online support group pays particular attention to you in special cases, such as during illness or moving house?
- … that someone in this online support group reassures you?
- … that someone in this online support group offers you sound advice?
- … that someone in this online support group points out your strengths?
- … that someone in this online support group confides in you?
- … that someone in this online support group asks you for your help or advice?

Finding recognition (alpha=0.70):

Does it ever happen in this online support group that…

- … you recognize yourself in the stories of other online support group members?
- … you experience the sense of 'not being the only one'?
- … others are an example to you?
- … you realize that you are not so bad off after all?

Helping others (alpha=0.82):

Does it ever happen in this online support group that…

- … you can be an example to other participants?
- … you can offer advice and support to others?

Sharing experiences (alpha=0.87):

Does it ever happen in this online support group that you can share …

- … your experiences with your illness with others?
- … your everyday experiences with others?

Appendix 'Constructs empowering outcomes'

Answer categories: 'completely disagree'; 'disagree'; 'neither agree nor disagree'; 'agree'; 'completely agree'.

Being better informed (alpha=0.85):

Through my participation in online support groups…

- … I feel better informed as a patient.
- … I understand my illness better.
- … I have a clearer picture about my illness.
- … I feel like I have more (correct) knowledge at my disposal to deal better with my illness.

Feeling more confident in the relationship with their physician (alpha=0.91):

Through my participation in online support groups…

- … I feel better prepared for a doctor's appointment.
- … I am more knowledgeable about which questions to ask my physician.
- … I can explain my needs to my physician better.
- … I have more courage to raise matters with my physician.
- … I am more able to oppose my physician.
- … I understand the information provided by my physician better.
- … the relationship with my physician has improved.
- … the relationship with my physician has deteriorated.
- … I am more able to judge when I really need the help of my physician.
- … I feel less dependent on my physician.
- … I am more able to think along with my physician about my treatment.

Improved acceptance of the illness (alpha=0.90):

Through my participation in online support groups…

- … I am able to be more open about my own illness.
- … I can tell others more easily when I am no longer able to do something.
- … I can ask others for help more quickly.
- … I can give in to my illness better.
- … I can accept my illness better.

Feeling more confident about the treatment (alpha=0.89):

Through my participation in online support groups…

- … I can stick to my treatment regime better.
- … I am more able to follow the medical guidelines and advice of my physician.
- … I know where to go with questions about my illness.
- … I feel I am more skilled at dealing well with my illness.
- … I feel able to make the right decisions with regard to my illness.

Increased optimism and control over the future (alpha=0.76):

Through my participation in online support groups…

- … I feel more in charge of the course of my illness.
- … I feel I can influence my illness myself.
- … I feel more in control over what is happening to me.
- … I feel less in control over what is happening to me.
- … I feel that what happens to me in the future is to a large degree dependent on myself.
- … I have learned to be more positive.
- … I have more faith in the future.
- … I have less faith in the future.

Enhanced self-esteem (alpha=0.93):

Through my participation in online support groups…

- … I have a greater sense of worth.
- … I have a more positive attitude towards myself.
- … I am in general more content with myself.

Enhanced social well-being (alpha=0.70):

Through my participation in online support groups…

- … I feel less lonely.
- … I have made new social contacts.

Samenvatting
(Dutch summary)

Wanneer mensen te maken krijgen met ernstige ziektes of aandoeningen zoeken zij vaak contact met lotgenoten. Lotgenotencontact kan voorzien in behoefte aan sociale steun, sociale vergelijking en ervaringskennis. Het kan leiden tot een toename van kennis en welbevinden en tot versterking van de positie van de patiënt in het zorgproces. Met de komst van internet zijn mogelijkheden ontstaan om ook online met lotgenoten in contact te komen. Gezien de voordelen van online contact zoals anonimiteit, ontbreken van geografische barrières, het op alle tijden toegankelijk zijn, en daarnaast het sterk toenemend aantal internetgebruikers in Nederland, kan verwacht worden dat steeds meer patiënten via internet contact zullen zoeken met lotgenoten. Echter, aan online lotgenotencontact kleven mogelijk ook nadelen zoals de uitsluiting van bepaalde groepen, gemis aan non-verbale communicatie en het ontbreken van toezicht op kwaliteit en betrouwbaarheid van informatie.

De onderzoeken die besproken zijn in dit proefschrift, zijn uitgevoerd om een beter begrip te krijgen van de betekenis van deelname aan online lotgenotencontact vanuit het gezichtspunt van verschillende stakeholders (participanten, patiënten, webmasters en zorgverleners). Wij hebben bij deze onderzoeken gebruik gemaakt van verschillende onderzoeksmethoden (inhoudsanalyse, interviews en vragenlijsten). In dit onderzoek hebben wij ons gericht op drie groepen patiënten, a) mensen met een chronische, maar niet levensbedreigende aandoening (reumatoïde artritis), b) mensen met een levensbedreigende, maar behandelbare aandoening (borstkanker), c) mensen met een vage, onbegrepen aandoening (fibromyalgie). In dit onderzoek hebben wij ons beperkt tot online lotgenotencontact via internetdiscussiegroepen. Andere vormen van online lotgenotencontact zoals emailgroepen en chatgroepen hebben wij buiten beschouwing gelaten. Tot slot, hebben wij ons alleen gericht op internetdiscussiegroepen die zijn opgezet door Nederlandse patiënten of patiëntenorganisaties.

In het onderstaande wordt elk hoofdstuk uit dit proefschrift kort besproken.

Hoofdstuk 2: Inhoudsanalyse van berichten geplaatst in online lotgenotengroepen

In de literatuur worden door verscheidene auteurs potentiële nadelen genoemd van online lotgenotencontact. Een nadeel dat vaak genoemd wordt, is het gebrek aan controle op de kwaliteit van de informatie die wordt uitgewisseld. Deelnemers kunnen hierdoor verkeerd worden geïnformeerd of worden verwezen naar onjuiste gezondheidsinformatie. Daarnaast bestaat de bezorgdheid dat er mogelijk sociaal ongepaste opmerkingen (zogenoemde ‘flaming’) worden geuit in online lotgenotengroepen, omdat er geen formele gedragsregels bestaan voor deze groepen. Het doel van het onderzoek beschreven in hoofdstuk 2 was om te onderzoeken in hoeverre de in de literatuur genoemde nadelen van online lotgenotencontact daadwerkelijk voorkomen. Deze onderzoeksvraag is beantwoord door middel van het uitvoeren van een inhoudsanalyse van berichten die geplaatst waren op internetdiscussiegroepen voor patiënten met reumatoïde artritis, borstkanker en fibromyalgie. Gedurende een periode van 3 maanden zijn alle nieuwe berichten van 8 publieke internetdiscussiegroepen gedownload. Dit leverde in totaal 27.341 berichten op. Een random steekproef van 1500 van deze berichten is onderworpen aan een inhoudsanalyse. De berichten in deze steekproef zijn gecodeerd door twee onafhankelijke codeurs. Berichten met medische informatie zijn beoordeeld door medische experts (reumatoloog en oncoloog). Uit dit onderzoek is naar voren gekomen dat de in de literatuur genoemde nadelen slechts in zeer beperkte mate voorkomen. Een belangrijke uitkomst van dit onderzoek was dat medische experts concludeerden dat de medische informatie die wordt uitgewisseld meestal conventioneel (79%) was en nooit schadelijk voor medegebruikers. Ook bleken deelnemers elkaar onderling te respecteren. In slechts 20 van de 1500 berichten was er sprake van het uiten van onbegrip, kritiek of het gebruik van scheldwoorden, gericht aan medegebruikers. Omdat niet alle potentiële nadelen kunnen worden onderzocht met behulp van een inhoudsanalyse, is er onderzoek uitgevoerd onder deelnemers van internetdiscussiegroepen (zie hoofdstuk 3 t/m 5).

Hoofdstuk 3: Kwalitatief onderzoek onder deelnemers aan online lotgenotencontact

Al sinds de opkomst van online lotgenotencontact wordt er veel verwacht van het potentiële empowering effect van deelname aan een online lotgenotengroep. Tot nu toe was er echter weinig bewijs voor de effecten van deelname aan online lotgenotencontact op patiënten empowerment. Het doel van het onderzoek beschreven in hoofdstuk 3 was om een inventarisatie te maken van welke empowering en welke disempowering processen zich volgens de deelnemers in internetdiscussiegroepen afspeelden. Daarnaast wilden we achterhalen welke empowering uitkomsten werden ervaren door de deelnemers aan internetdiscussiegroepen. Deze onderzoeksvragen zijn beantwoord door middel van het houden van interviews met 32 deelnemers van 9 publieke internetdiscussiegroepen voor patiënten met reumatoïde artritis, fibromyalgie en borstkanker. Empowering processen die genoemd werden door de deelnemers waren: het uitwisselen van informatie en steun, begrip en herkenning, het delen van ervaringen, het helpen van andere deelnemers en de amuserende functie. Disempowering processen die genoemd werden door de deelnemers waren: onzekerheid over de kwaliteit van de informatie en confrontatie met negatieve kanten van de ziekte en met 'klagers'.

Voor wat betreft de empowering uitkomsten bleek dat de ondervraagden zich op verschillende manieren gesterkt voelden door hun deelname. Allereerst voelden de deelnemers zich beter geïnformeerd. Daarnaast voelde een aantal zich gesterkt in hun relatie met hun arts. Zo durfden zij bijvoorbeeld dankzij hun deelname aan het forum, vragen aan hun arts te stellen die zij eerder niet durfden te stellen. Veel respondenten waren nu meer overtuigd van de aan hen voorgeschreven therapie en hadden het gevoel dat ze zelf beter beslissingen konden maken ten aanzien van hun therapie. Ook vertelden de meeste respondenten dat ze hun ziekte makkelijker en sneller konden accepteren dankzij hun deelname. Tenslotte hielp deelname sommige respondenten om 'opener' te worden over hun ziekte. Ze durfden nu bijvoorbeeld makkelijker aan te geven 'dat het niet meer ging' aan mensen in hun sociale omgeving. Op basis van dit onderzoek kunnen we concluderen dat patiënten die deelnemen aan de internetdiscussiegroepen zich gesterkt kunnen voelen door hun deelname. Een beperking van dit onderzoek is, dat het een kwalitatief onderzoek betrof met een klein aantal respondenten. Vandaar dat er gekozen is voor een kwantitatief vervolgonderzoek onder deelnemers aan online lotgenotengroepen (hoofdstuk 4).

Hoofdstuk 4: Kwantitatief onderzoek onder deelnemers aan online lotgenotencontact

Het onderzoek beschreven in hoofdstuk 4 betreft een vervolgonderzoek van het kwalitatieve onderzoek beschreven in hoofdstuk 3. Ondanks het feit dat dit onderzoek ons relevante informatie heeft opgeleverd over empowering processen en uitkomsten van online lotgenotencontact, heeft een kwalitatief onderzoek zijn beperkingen. Zo konden wij bijvoorbeeld geen conclusies trekken over de mate waarin de empowering processen en uitkomsten voorkwamen. Daarom hebben we een kwantitatief onderzoek uitgevoerd onder deelnemers aan online lotgenotengroepen. In dit onderzoek is gebruik gemaakt van een online vragenlijst, die ingevuld is door 528 deelnemers van online lotgenotengroepen voor patiënten met reumatische aandoeningen, borstkanker en fibromyalgie. Wij hebben ons gericht op de volgende onderzoeksvragen: 1) In welke mate komen de empowering processen en empowering uitkomsten voor? 2) In hoeverre kunnen de empowering uitkomsten worden voorspeld door de processen die zich afspelen in de internetdiscussiegroepen? Daarnaast hebben we ook gekeken naar verschillen tussen de ziektegroepen. Uit dit onderzoek kwam naar voren dat de processen die zich het meest frequent afspeelden in internetdiscussiegroepen 'het uitwisselen van informatie' en 'het vergelijken met anderen' zijn. Voor deze beide processen gold dat reumapatiënten aangaven dat deze processen zich significant minder vaak afspeelden in de internetdiscussiegroepen waar aan zij deelnemen, vergeleken met borstkanker- en fibromyalgiepatiënten. Ook bleek er, zij het in mindere mate, sprake te zijn van 'het uitwisselen van sociale steun', het 'uitwisselen van ervaringen' en van 'het helpen van andere forumgenoten'. De empowering uitkomst die in de sterkste mate werd ervaren door de respondenten was het 'zich beter geïnformeerd voelen'. De empowering uitkomsten 'toegenomen sociaal welbevinden', 'zich zekerder voelen over de relatie met hun arts', 'toegenomen acceptatie van de ziekte', 'zich zeker voelen over hun behandeling' en 'herwonnen optimisme en controle' bleken allemaal in ongeveer dezelfde mate te worden ervaren door de respondenten. 'Toegenomen zelfvertrouwen' naar aanleiding van deelname in de internetdiscussiegroep werd van de uitkomsten in de minste mate ervaren door de respondenten. Er bleken geen significante verschillen te zijn tussen de patiëntengroepen. De uitkomsten bleken slechts gedeeltelijk te kunnen worden voorspeld door de processen die zich afspeelden in de internetdiscussiegroepen. De uitkomsten die het best te voorspellen waren, zijn 'toegenomen sociaal welbevinden' en 'zich beter geïnformeerd voelen'. De belangrijkste voorspellers voor de uitkomst 'zich beter geïnformeerd voelen' bleek de mate te zijn waarin informatie wordt uitgewisseld, de mate waarin men sociale steun uitwisselt en de mate waarin men zich vergelijkt met anderen. In totaal kon 31% van de variantie worden verklaard. De belangrijkste voorspellers voor de uitkomst 'toegenomen sociaal welbevinden' bleek de mate te zijn waarin men sociale steun uitwisselt en de mate waarin men ervaringen uitwisselt. In totaal kon 30% van de variantie worden verklaard. Op basis van dit onderzoek kunnen we concluderen dat deelname aan een internetdiscussiegroep voor patiënten kan bijdragen aan patiënten 'empowerment'. Een belangrijke bevinding was, dat er geen significante verschillen werden gevonden voor wat betreft de empowering uitkomsten tussen de patiëntengroepen.

Hoofdstuk 5: Vergelijking tussen meelezers en posters in online lotgenotengroepen

Er wordt aangenomen dat een aanzienlijk aantal patiënten passief gebruik maken van online lotgenotengroepen. Deze patiënten lezen mee met een online lotgenotengroep, maar nemen niet actief deel door middel van het posten van berichten. Omdat het meeste onderzoek naar online lotgenotencontact zich richt op deelnemers die berichten posten, is het niet bekend of meelezers in dezelfde mate profiteren van deelname aan online lotgenotencontact als posters. Vandaar dat wij ons gericht hebben op deze onderzoeksvraag in het onderzoek beschreven in hoofdstuk 5. Daarnaast hebben we in dit onderzoek gekeken in hoeverre meelezers verschilden van posters met betrekking tot demografische karakteristieken en met betrekking tot gebruik van en tevredenheid met de online lotgenotengroep. Om deze onderzoeksvragen te kunnen beantwoorden hebben we dezelfde online vragenlijst gebruikt als in het onderzoek beschreven in hoofdstuk 4. We hebben de respondenten die aangaven alleen mee te lezen in een online lotgenotengroep (n=109) vergeleken met respondenten die aangaven dat zij actieve deelnemers waren (n=419). De meelezers bleken gemiddeld iets ouder te zijn dan de actieve deelnemers en waren korter geleden gediagnosticeerd. Er werden geen andere verschillen gevonden voor wat betreft de demografische karakteristieken. Meelezers bezochten de internetdiscussiegroep minder vaak dan dat de posters dat deden. Ook bleken meelezers significant minder tevreden met hun deelname aan online lotgenotencontact in vergelijking tot posters. Met betrekking tot de empowering processen bleken de meelezers significant lager te scoren met betrekking tot alle empowering processen. Dit hield in dat meelezers processen zoals 'het uitwisselen van sociale steun' en 'het vergelijken met andere forumgenoten' in mindere mate ervoeren in de online lotgenotengroepen. De meelezers bleken echter niet significant te verschillen van de posters met betrekking tot de empowering uitkomsten. Dit hield in dat de meelezers zich bijvoorbeeld eveneens beter geïnformeerd voelden naar aanleiding van hun deelname aan de online lotgenotengroep. De enige uitzondering hierop betrof 'toegenomen sociaal welbevinden' waarop de meelezers significant lager scoorden dan posters. Op basis van dit onderzoek kunnen we concluderen dat meelezers in even hoge mate profiteren van deelname aan internetdiscussiegroepen voor patiënten, met uitzondering van de 'empowering' uitkomst 'toegenomen sociaal welbevinden'. Schijnbaar is het lezen van berichten op zich voldoende om te profiteren van online lotgenotencontact.

Hoofdstuk 6: Kwantitatief onderzoek onder patiënten met borstkanker, fibromyalgie en reumatoïde artritis

Gezien de sterke toename van het aantal Nederlanders dat thuis toegang heeft tot het internet, kan verwacht worden dat steeds meer patiënten gebruik zullen maken van het internet voor ziektegerelateerde redenen. Daarom is er een constante behoefte aan onderzoeken die het aandeel patiënten die gebruik maken van het internet voor ziektegerelateerde redenen in kaart brengen. Het doel van het onderzoek beschreven in hoofdstuk 6 was om te onderzoeken hoe veel Nederlandse patiënten met reumatoïde artritis, borstkanker en fibromyalgie gebruik maken van het internet om te zoeken naar informatie over hun ziekte. Daarnaast hebben we onderzocht welke demografische, gezondheids en psychologische karakteristieken samenhangen met ziektegerelateerd internetgebruik van patiënten. Tot slot onderzochten we het gebruik van ziektegerelateerde internet applicaties, zoals online lotgenotengroepen. Het onderzoek is uitgevoerd middels vragenlijsten. De vragenlijst is verstuurd naar 985 patiënten met reumatoïde artritis, fibromyalgie en borstkanker die onder behandeling stonden in twee Nederlandse ziekenhuizen. Het totale responspercentage bedroeg 69% (N=679). Uit het onderzoek, dat is beschreven in hoofdstuk 6, is naar voren gekomen dat de helft van de patiënten (52%) wel eens gebruik maakt van het internet om informatie op te zoeken over zijn of haar ziekte. De resultaten van dit onderzoek lieten zien dat een jongere leeftijd, een hogere opleiding en het hebben van werk de enige significante voorspellers van ziektegerelateerd internetgebruik zijn. Ziektegerelateerd internetgebruik van patiënten blijkt niet te kunnen worden voorspeld door gezondheids of psychologische factoren. Bij de meeste patiënten bleek hun ziektegerelateerde internetgebruik beperkt tot het zoeken van informatie over hun ziekte op het internet. De resultaten van ons onderzoek lieten zien dat er niet vaak met zorgverleners via het internet werd gecommuniceerd: slechts enkele patiënten hebben via het internet of de email contact gehad met een medisch specialist of hun eigen arts. Een relatief klein percentage patiënten (15%) heeft wel eens een internetdiscussiegroep over zijn of haar ziekte bezocht. Voor de meeste van de patiënten die wel eens een internetdiscussiegroep bezocht hebben, bleef het bij meelezen. Slechts 4% van de patiënten hebben wel eens een berichtje op een internetdiscussiegroep geplaatst. In het onderzoek beschreven in het hierop volgende hoofdstuk is dieper ingegaan op de redenen van patiënten om al dan niet deel te nemen aan (online) lotgenotencontact.

Hoofdstuk 7: 'Mixed methods' onderzoek onder deelnemers en niet deelnemers aan lotgenotencontact

Hoewel werd verwacht dat deelname aan lotgenotencontact zou toenemen door de opkomst van online lotgenotencontact, is uit het onderzoek beschreven in hoofdstuk 6 gebleken dat slechts een klein aandeel van de patiënten daadwerkelijk deelneemt aan online lotgenotengroepen. In dit onderzoek hebben we factoren die deelname aan lotgenotencontact in levende lijve en via het internet faciliteren of hinderen onderzocht. Om deelnamegedrag van patiënten te kunnen verklaren hebben we gebruik gemaakt van de 'Theory of Planned Behavior' (TPB). Deze theorie gaat uit van de aanname dat gedrag van mensen bepaald wordt door intenties. De intentie om deel te nemen aan lotgenotencontact wordt bepaald door patiënten hun attitude, subjectieve norm en de mate van ervaren zelfeffectiviteit. In het onderzoek beschreven in hoofdstuk 7 hebben we gekeken in hoeverre TPB variabelen de intentie van patiënten om deel te nemen aan lotgenotencontact kunnen voorspellen. Om deze onderzoeksvraag te kunnen beantwoorden hebben we een ‘mixed methods’ onderzoek uitgevoerd. Voor het kwantitatieve gedeelte van het onderzoek hebben we gebruik gemaakt van dezelfde vragenlijst als in hoofdstuk 6. Deze vragenlijst was ingevuld door 679 patiënten die werden behandeld voor reumatoïde artritis, borstkanker en fibromyalgie in twee Nederlandse ziekenhuizen. Daarnaast hebben we 19 patiënten met reumatoïde artritis die niet deelnamen aan lotgenotencontact geïnterviewd. De resultaten van ons onderzoek hebben bevestigd dat slechts een relatief klein percentage van de patiënten participeert in lotgenotengroepen. De respondenten waren over het algemeen positiever over lotgenotencontact in levende lijve, dan over online lotgenotencontact. In overeenstemming met de TPB bleek het hebben van een positievere attitude, het ondervinden van meer steun door mensen in de omgeving en het meer in staat voelen om deel te nemen aan lotgenotencontact, de intentie om te participeren in beide vormen van lotgenotencontact te verhogen. Desondanks kon de intentie om te participeren in lotgenotencontact in levende lijve en in lotgenotencontact via het internet slechts gedeeltelijk worden voorspeld door TPB variabelen (respectievelijk 33% en 26%). Respectievelijk een verslechterd fysiek en mentaal welbevinden en een verslechterd mentaal welbevinden en lagere leeftijd konden het totale aandeel verklaarde variantie significant verhogen (lotgenotencontact in levende lijve: 38% en online lotgenotencontact: 35%). De resultaten van het kwalitatieve onderzoek lieten zien dat ondanks dat patiënten van mening waren dat lotgenotencontact waardevol was voor andere patiënten, zij voor zichzelf met name nadelen zagen. De meeste respondenten hadden een negatief beeld van lotgenotencontact. Lotgenotencontact was bedoeld voor mensen die niet om konden gaan met hun ziekte en die oud en eenzaam waren. Voor beide vormen van lotgenotencontact gold dat een aantal van de respondenten niet op de hoogte bleek te zijn van de mogelijkheid om deel te nemen aan lotgenotencontact. Uit de resultaten van het onderzoek beschreven in hoofdstuk 7 is naar voren gekomen dat het wellicht een goed idee is om een interventiestrategie te ontwikkelen, gericht op het verhogen van het aantal patiënten dat deelneemt aan lotgenotengroepen. Aandachtspunten voor deze interventiestrategie zijn het wegnemen van vooroordelen over lotgenotengroepen en het creëren van bewustzijn over het bestaan van dergelijke groepen.

Hoofdstuk 8: Kwalitatief onderzoek onder webmasters van online lotgenotengroepen

Inmiddels zijn er op het internet veel lotgenotengroepen te vinden met betrekking tot uiteenlopende ziekten en aandoeningen. Het merendeel van deze groepen is vrijwillig geïnitieerd door patiënten. Opvallend is dat sommige online lotgenotengroepen uitgroeien tot succesvolle groepen, met een groot aantal deelnemers, maar dat andere groepen nooit van de grond komen of in een later stadium ‘doodbloeden’. In het onderzoek beschreven in hoofdstuk 8 zijn wij op zoek gegaan naar de doelen en motieven van mensen, zogenaamde webmasters, om vrijwillig een online lotgenotengroep te initiëren. Tevens hebben wij gekeken naar hoe webmasters succes definiëren en welke factoren volgens hen van invloed zijn op het al dan niet slagen van online lotgenotengroepen. Hierbij hebben wij onderscheid gemaakt tussen factoren die van belang zijn op het moment dat de groep wordt gestart (de initiëringfase) en factoren die van belang zijn op het moment dat de groep online is (de evolutie fase). Om deze onderzoeksvragen te kunnen beantwoorden hebben wij interviews gehouden met 23 webmasters van online lotgenotengroepen voor patiënten met borstkanker, reumatoïde artritis en fibromyalgie. De analyse van de interviews liet zien dat de meeste webmasters altruïstische motieven hebben om een online lotgenotengroep te starten, zoals het verschaffen van informatie of steun of empowerment van patiënten. Andere webmasters noemden echter ook intrinsieke motieven zoals een hobby. Webmasters definieerden succes als het bereiken van de doelen die zij in hun hoofd hadden op het moment dat zij de groep initieerden. Webmasters vonden hun eigen groep veelal een succes. Ons onderzoek liet zien dat voordat een lotgenotengroep online gaat (de initiëringsfase), verschillende beslissingen moeten worden genomen zoals over de toegankelijkheid, het gelieerd zijn aan een (patiënten)organisatie, het ontwerp en de inhoud van de online lotgenotengroep. De webmasters noemden een aantal ‘voors’ en ‘tegens’ van de verschillende opties en benadrukten dat de beslissingen in overeenstemming met de doelen van de groep moeten worden genomen. Wanneer de groep online gaat (de evolutiefase), wordt het succes afhankelijk van de mate waarin de webmaster er in slaagt om de processen en deelnemers van de online groep succesvol te managen. Ondanks het feit dat webmasters minder invloed hebben op deze aspecten, omdat zij geen controle hebben over de deelnemers van de online lotgenotengroepen, hebben de webmasters aandachtspunten genoemd met betrekking tot de promotie en financiering van de groep, hoe de groep levendig te houden, de mate van modereren, het organiseren van bijeenkomsten of rituelen en de mate waarin de wensen van de deelnemers zouden moeten worden opgevolgd. Webmasters zouden bijvoorbeeld zorg moeten dragen voor een constante aanwas van nieuwe deelnemers, door blijvend aandacht te besteden aan de promotie van de groep. De aandachtspunten die naar voren zijn gekomen uit het onderzoek, kunnen worden gezien als richtlijnen voor (toekomstige) webmasters, die wellicht kunnen leiden tot succesvolle online lotgenotengroepen. Succes van een groep is belangrijk omdat er verwacht kan worden dat het effect van deelname aan een online lotgenotengroep kan variëren afhankelijk van het succes van de groep.

Hoofdstuk 9: Kwantitatief onderzoek onder Nederlandse reumatologen en oncologen

Artsen krijgen in hun dagelijkse praktijk steeds vaker te maken met patiënten die hen confronteren met gezondheidsinformatie van het internet. Er is echter weinig bekend over de attitude van artsen met betrekking tot ziektegerelateerd internetgebruik door hun patiënten. Het doel van het onderzoek beschreven in hoofdstuk 9 was om de ervaringen van reumatologen en oncologen met ziektegerelateerd internetgebruik door hun patiënten en de attitude ten aanzien van gevolgen hiervan (voor de patiënten, voor de arts-patiënt relatie en voor henzelf en de gezondheidszorg) in kaart te brengen. Daarnaast waren we geïnteresseerd in of en hoe vaak artsen hun patiënten doorverwezen naar ziektegerelateerde websites. Om deze onderzoeksvragen te kunnen beantwoorden hebben we een vragenlijst verstuurd naar alle Nederlandse reumatologen en oncologen. De respons bedroeg 46%

(N=238; 134 reumatologen en 104 oncologen). Uit het onderzoek is naar voren gekomen dat vrijwel alle artsen weleens hebben meegemaakt dat patiënten informatie van internet ter sprake brachten tijdens het consult. Dit is echter nog steeds niet de praktijk van alle dag. De artsen bleken gematigd positief te zijn over de gevolgen van het ziektegerelateerde internetgebruik van hun patiënten. De meest positieve gevolgen van ziektegerelateerd internetgebruik voor de patiënten zijn volgens de artsen dat de patiënten beter geïnformeerd zijn over hun ziekte en over de behandelingsmogelijkheden. Een negatief gevolg van internetgebruik door patiënten is, volgens de artsen, dat patiënten vaker onnodig ongerust worden. De artsen geven aan dat de gevolgen van ziektegerelateerd internetgebruik door hun patiënten overwegend goed is voor de arts-patiënt relatie. Zo kan internetgebruik er volgens de artsen toe leiden dat patiënten beter kunnen meebeslissen over hun behandeling. Negatieve gevolgen voor de arts-patiënt relatie komen volgens de artsen minder vaak voor. Zo geeft het merendeel van de artsen aan dat de autoriteit van de artsen niet wordt ondermijnd en dat de vertrouwensband tussen de arts en patiënt niet wordt geschaad naar aanleiding van ziektegerelateerd internetgebruik door patiënten. De meeste artsen geven aan dat er geen sprake is van onnodige diagnostiek en onnodige behandelingen ten gevolge van ziektegerelateerd internetgebruik door patiënten. Wel geven artsen aan dat de duur van het consult soms toeneemt ten gevolge van ziektegerelateerd internetgebruik door patiënten. Hoewel artsen dus overwegend positief zijn over de gevolgen van ziektegerelateerd internetgebruik voor hun patiënten, voor de arts-patiënt relatie en voor de gezondheidszorg, blijkt uit dit onderzoek ook dat artsen hun patiënten zelf weinig doorverwijzen naar patiëntenwebsites. Wellicht dat het (online) aanbieden van een up-to-date lijst van betrouwbare patiëntenwebsites artsen zou kunnen ondersteunen bij en stimuleren tot het doorverwijzen van hun patiënten.

Beperkingen onderzoek en suggesties voor vervolgonderzoek

De toegevoegde waarde van de onderzoeken die besproken zijn in dit proefschrift, is dat we ons gericht hebben op de betekenis van deelname aan online lotgenotencontact vanuit het gezichtspunt van verschillende stakeholders (participanten, patiënten, webmasters en zorgverleners) met behulp van verschillende onderzoeksmethoden (inhoudsanalyse, interviews en vragenlijsten). Het is echter belangrijk om ons ook bewust te zijn van de beperkingen van de onderzoeken die we hebben uitgevoerd. De voornaamste beperking van onze onderzoeken is dat we alleen gebruik hebben gemaakt van cross-sectionele onderzoeken. Daarom konden we geen causale verbanden aantonen. Een gerandomiseerd gecontroleerd onderzoek is de beste manier om te evalueren of deelname aan online lotgenotencontact echt effectief is. Om een gerandomiseerd gecontroleerd onderzoek met lotgenotencontact als interventie uit te voeren is echter een grote uitdaging en moeilijk haalbaar vanwege verschillende redenen: de zelf-selectie die inherent is aan deelname aan lotgenotencontact, de uitdaging om een ‘echte’ lotgenotengroep op te zetten in een experimentele setting en de moeilijkheid om een vergelijkbare controlegroep samen te stellen. Het is daarom waarschijnlijk beter om een longitudinaal onderzoek onder patiënten uit te voeren die voor zichzelf bepalen om deel te nemen aan al bestaande online lotgenotengroepen. Echter ook in het geval van een longitudinaal onderzoek is het moeilijk om een vergelijkbare controlegroep samen te stellen.

Conclusie

In dit proefschrift is gebleken dat patiënten die gebruik maken van online lotgenotencontact hier op meerdere manieren van profiteren. Resultaten van de onderzoeken laten zien dat patiënten die deelnemen aan online lotgenotencontact zich gesterkt kunnen voelen door hun deelname. Daarnaast is uit ons onderzoek gebleken dat de in de literatuur genoemde nadelen van online lotgenotencontact slechts in zeer beperkte mate voorkomen. Ondanks deze gunstige uitkomsten, laat dit proefschrift zien dat slechts een klein aantal van de Nederlandse patiënten met reumatoïde artritis, borstkanker en fibromyalgie deelneemt aan online lotgenotengroepen. Online lotgenotengroepen lijken te worstelen met vooroordelen en niet alle patiënten lijken zich bewust van het bestaan van dergelijke groepen. Vanwege de potentieel positieve uitkomsten van deelname aan online lotgenotengroepen voor patiënten, zijn we van mening dat er wellicht een interventie zou moeten worden ontwikkeld om het aantal patiënten die deelnemen aan online lotgenotencontact te verhogen. Echter, voordat een dergelijke interventie wordt geïmplementeerd, moet worden overwogen of patiënten zou moeten worden aangeraden om deel te nemen aan lotgenotencontact, omdat niet alle patiënten behoeven te profiteren van deelname. Desondanks is het ontwikkelen van een interventie gewenst, omdat patiënten met behulp van deze interventie in staat worden gesteld om een weloverwogen beslissing te nemen over deelname aan online lotgenotencontact. Daarnaast zouden patiënten door middel van een dergelijke interventie in staat moeten worden gesteld om een online lotgenotengroep te vinden op het moment dat zij zich willen aansluiten.

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Het schrijven van een proefschrift kan naar mijn mening worden vergeleken met het maken van een omvangrijk werkstuk. Als je het op deze manier beschouwt, is het niet zo verrassend dat ik er vier jaar geleden voor heb gekozen om aan een promotieonderzoek te gaan beginnen. In de vroegere klasgenotenboekjes vulde ik bij mijn lievelingsvak standaard "het maken van werkstukken" in. Mijn allereerste werkstuk als 8 jarige ging over de ijsbeer. Het gehele werkstuk was gebaseerd op één bron, een boekje uit de bibliotheek van mijn basisschool: de Menso Altingschool. Niet echt wetenschappelijk verantwoord te noemen dus! Mijn eerste echt empirische onderzoek was voor mijn schoolonderzoek biologie op het VWO en richtte zich op het volggedrag van kuikens zonder moeder. Mijn ouders en zus waren erg blij dat dit experiment na enige weken kon worden afgesloten vanwege de toenemende penetrante geur in ons huis. Voor dit proefschrift ben ik een heel andere richting ingeslagen. Er zijn echter wel degelijk parallellen met het schrijven van mijn werkstukken. Zoals ik destijds werd begeleid door en leerde van mijn juffen en meesters, ben ik ook nu begeleid en heb ik veel geleerd van de nodige anderen. Een aantal van deze mensen zou ik hier graag in het bijzonder willen noemen.

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Nelly van Uden-Kraan
Oktober 2008

Curriculum Vitae

Nelly van Uden-Kraan werd op 28 december 1979 geboren te Grijpskerk. In 1998 behaalde zij het eindexamen VWO aan het Augustinus College te Groningen. In hetzelfde jaar begon zij haar studie Toegepaste Communicatiewetenschap aan de Universiteit Twente in Enschede. In april 2004 rondde zij haar studie af met een evaluatieonderzoek van een HIV/Aids peer education programma in Lesotho en Zuid-Afrika. De master these getiteld "Understanding Peer Education in Practice" werd genomineerd voor de "Africa Thesis Award". Direct na haar afstuderen trad Nelly in dienst van de Universiteit Twente als onderzoeksmedewerker. In november 2004 ging zij van start met haar promotieonderzoek naar de betekenis van deelname aan lotgenotencontact via internetdiscussiegroepen voor patiënten met reumatoïde artritis, fibromyalgie en borstkanker. Op 1 december 2008 treedt Nelly in dienst van de Geneeskundige en Gezondheidsdienst (GGD) Amsterdam als gezondheidsbevorderaar.

Nelly van Uden-Kraan was born in Grijpskerk, the Netherlands on 28th December 1979. In 1998 she completed her secondary education at Augustinus College in Groningen. In the same year she started to study Communication Studies at the University of Twente in Enschede. In April 2004 she finished her studies with an evaluation study of a HIV/Aids peer education program in Lesotho and South-Africa. The master thesis titled "Understanding Peer Education in Practice" was nominated for the "Africa Thesis Award". Straight after finishing her studies Nelly started working at the University of Twente as a research assistant. In November 2004 she started her PhD study on the meaning of participation in online peer support groups for patients with rheumatoid arthritis, fibromyalgia and breast cancer. On the 1st of December 2008 Nelly will start working for the Public Health Service of Amsterdam as a health promoter.