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ScienceDirect

Computers in Human Behavior 24 (2008) 309–324

Computers in Human Behavior

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

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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.

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doi:10.1016/j.chb.2007.01.014

Keywords: Support groups; Internet; Breast cancer; Fibromyalgia; Arthritis; Content analysis

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1. 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 (Helgeson & Gottlieb, 2000). These groups may also provide the opportunity for social comparison with peers (Campbell, Phaneuf, & Deane, 2004). 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 (Riessman, 1997).

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 (Finfgeld, 2000; Finn, 1999; Salem, Bogat, & Reid, 1997; Winzelberg, 1997). 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 (Preece, Nonnecke, & Andrews, 2004).

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 (Finfgeld, 2000). 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 (Finfgeld, 2000). Another aspect is the possible time lag between the time an individual poses a question and receives a response (Lamerichs, 2003). Finally, it has also been suggested that many forums are so active that it can be very hard to keep up with all postings (Han & Belcher, 2001).

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 (Finn, 1999; Klemm, Reppert, & Visich, 1998; Wright, 2002).

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 (Finn, 1995; Mursch & Benke-Mursch, 2003).

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 (Pennebaker & Francis, 1996). However, if other participants reinforce such feelings, a negative, so called destructive thread, may arise (Johnsen, Rosenvinge, & Gammon, 2002). 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* (Finfgeld, 2000; Finn, 1999).

2. Present study

Although, several disadvantages of online support have thus been identified in literature, data are scarce (Finfgeld, 2000; Finn, 1999; Klemm et al., 2003). 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 (Bjornsdottir, 1999; Neuendorf, 2002).

3. Method

3.1. 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 (Finn, 1999; Lamerichs, 2003). 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.

3.2. Measures

3.2.1. 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.

3.2.2. Topics

We isolated 12 unique coding categories for topics. Several of these were adopted from a coding system developed by Perron (2002), 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 (Finn, 1999).

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…"*

3.2.3. Self-help mechanisms

Eight coding categories were derived from Perron (2002) and included: providing information, requesting information, sharing personal experiences, providing empathy or support, gratitude, friendship and creative expression.

3.2.4. 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 par-

ticipants 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 (1997) 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 (Mursch & Benke-Mursch, 2003). 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 (Salem et al., 1997).

3.3. Procedure

The first author and an independent coder separately coded a random half of the postings. As advised by Finn (1999) the coders did not code each posting on its own merits, but in relation to the thread as a whole. According to Finn (1999), 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.

4. Results

4.1. 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 ($N = 347$)

	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%	10	3%
Family member	1	1%	–	–	3	2%	4	1%
Acquaintance	2	3%	–	–	2	1%	5	2%
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	–

4.2. 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. As 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…"*

4.3. 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

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	4
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 χ^2-tests comparing the three illness 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 χ^2-tests comparing the three illness groups.

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.

4.4. Potential disadvantages of online support groups

4.4.1. 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.

Table 4
Disadvantages due to online asynchronous communication

	Breast cancer ($n = 500$)		Fibromyalgia ($n = 500$)		Arthritis ($n = 500$)		Total ($N = 1500$)	
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(SD)		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 χ^2-tests comparing the three illness groups.

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 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	49

$^{*}p < 0.05$, $^{**}p < 0.01$, $^{***}p < 0.001$ for χ^2 comparing the three illness groups.

4.4.2. 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.

4.4.3. 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

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 χ^2-tests comparing the three illness groups.

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!"*

4.4.4. 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.

5. Discussion

5.1. 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

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

$^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$ for χ^2-tests comparing the three illness groups.

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 (1997) in their study of online support groups. According to Davison and Pennebaker (1997) 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 (Dickerson, Flaig, & Kennedy, 2000; Jones & Lewis, 2001; Weinberg, Schmale, Uken, & Wessel, 1996; Winzelberg, 1997). 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. (1998), 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 (Culver et al., 1997; Dickerson et al., 2000; Miller & Gergen, 1998; Perron, 2002; Winzelberg, 1997). On the basis of these results 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 (Preece et al., 2004). 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.

5.2. 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 (1999), no other studies coded for chit chat. It is difficult to compare our results, because Finn (1999) 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 (Finn, 1999). 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 (Perron, 2002). 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 (2002) in his study among caregivers of mentally ill.

5.3. 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.

5.3.1. 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, Ravid, and Rafaeli (2004) 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.

5.3.2. 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 (Preece, 1999). Preece (1999) 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 (Potts, 2006). 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.

5.3.3. 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 (Mursch & Benke-Mursch, 2003). 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.

5.3.4. 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 (Finfgeld, 2000). In accordance with the study of Finn (1999) 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.

5.4. 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 (2006) 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 hormonal 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.

6. 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.

Acknowledgements

This study was supported by grants from the Netherlands Organization for Health Research and Development (ZonMw), the Dutch Arthritis Association, and Comprehensive Cancer Centre Stedendriehoek Twente (IKST).

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