

Qualitative Health Research

<http://qhr.sagepub.com>

Empowering Processes and Outcomes of Participation in Online Support Groups for Patients With Breast Cancer, Arthritis, or Fibromyalgia

Cornelia F. van Uden-Kraan, Constance H. C. Drossaert, Erik Taal, Bret R. Shaw, Erwin R. Seydel and Mart A. F. J. van de Laar

Qual Health Res 2008; 18; 405
DOI: 10.1177/1049732307313429

The online version of this article can be found at:
<http://qhr.sagepub.com/cgi/content/abstract/18/3/405>

Published by:



<http://www.sagepublications.com>

Additional services and information for *Qualitative Health Research* can be found at:

Email Alerts: <http://qhr.sagepub.com/cgi/alerts>

Subscriptions: <http://qhr.sagepub.com/subscriptions>

Reprints: <http://www.sagepub.com/journalsReprints.nav>

Permissions: <http://www.sagepub.com/journalsPermissions.nav>

Citations <http://qhr.sagepub.com/cgi/content/refs/18/3/405>

Empowering Processes and Outcomes of Participation in Online Support Groups for Patients With Breast Cancer, Arthritis, or Fibromyalgia

Cornelia F. van Uden-Kraan

Constance H. C. Drossaert

Erik Taal

University of Twente, Enschede, The Netherlands

Bret R. Shaw

University of Wisconsin–Madison, Madison, Wisconsin, USA

Erwin R. Seydel

Mart A. F. J. van de Laar

University of Twente, Enschede, The Netherlands

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 occur as a result of taking part 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.

Keywords: *online support groups; empowerment; breast cancer; fibromyalgia; arthritis*

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 (Finfgeld, 2000; Finn, 1999; Salem, Bogat, & Reid, 1997; Winzelberg, 1997), 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 (e.g., Eysenbach, 2003; Ferguson, 1992; Hoch & Ferguson, 2005; Winkelman & Choo, 2003). However, thus far there is no direct evidence of the effects of participation in online support groups on patient empowerment (Demiris, 2006; Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004).

Empowerment reflects the belief in patient autonomy, and the right and responsibility of patients to

Authors' Note: 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). Correspondence concerning this article should be sent to: C. F. van Uden-Kraan, Institute for Behavioral Research, Faculty of Behavioral Sciences, University of Twente, P O Box 217, 7500 AE Enschede, The Netherlands; e-mail: c.f.vanuden-kraan@gw.utwente.nl.

access health information and to make their own health-related decisions (Feste & Anderson, 1995; Funnell & Anderson, 2003). 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 (Hibbard, Stockard, Mahoney, & Tusler, 2004). According to Roberts (1999), 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 (Mitcheson & Cowley, 2003). Although patient empowerment is considered to be one of the key principles in the field of public health (Gutschoven & van den Bulck, 2006; Masi, Suarez-Balcazar, Cassey, Kinney, & Piotrowski, 2003), the concept is inconsistently defined (Aujolat, d'Hoore, & Deccache, 2007; Menon, 2002).

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 (Demiris, 2006). This makes it difficult to think of empowerment consistently (Gibson, 1991). Therefore, Gibson (1991) 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 (Menon, 2002; Roberts, 1999). 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 (Roberts, 1999; Schulz, Israel, Zimmerman, & Checkoway, 1995). 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 (Roberts, 1999). 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 (Feste & Anderson, 1995; Roberts,

1999). Finally, patients themselves also have different ideas about what it means to be empowered. According to Broom (2005), empowerment is unique to the individual patient. The experience of empowerment can fluctuate over time, depending on the context (Menon, 2002; Rappaport, 1987).

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 (e.g., Finn, 1999; Klemm et al., 2003; Perron, 2002; Salem et al., 1997; Sharf, 1997). 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 (e.g., Leiberich, Nedoschill, Nickel, Loew, & Tritt, 2004; Rimer et al., 2005; Shaw, Mctavish, Hawkins, Gustafson, & Pingree, 2000). 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 (e.g., Broom, 2005; Hill, Weiner, & Cudney, 2006; Høybye, Johansen, & Thornhoj-Thomsen, 2005; Powell, McCarthy, & Eysenbach, 2003). 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 above-mentioned 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 (Faulkner, 2001).

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?

Method

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 (Smith, 1995). 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 (1990), 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 subthemes were identified (O'Cathain et al., 2005). The final step consisted of revisiting the literature and seeking conceptual tools that could be used to make sense of the themes and subthemes that emerged from the data (Broom, 2005).

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.

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

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 (Helgeson & Gottlieb, 2000) and are in line with previous studies on online support groups (e.g., Finn, 1999; Klemm et al., 2003; Perron, 2002; Rimer et al., 2005; Salem, Bogat, & Reid, 1997; Sharf, 1997; Shaw et al., 2000).

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 (e.g., Sharf, 1997; Shaw et al., 2000; Preece, 1999). 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 (Høybye et al., 2005).

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 (1993), 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, Haymaker, and Zinchuk (2005) 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 (Preece, Nonnecke, & Andrews, 2004).

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 (2001), Cummings, Sproull, and Kiesler (2002), and Walstrom (2000) 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 (Van Uden-Kraan et al., 2007).

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 well-being, 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 (2005) 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 (Salmon & Hall, 2003) 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 (1997), 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 (Kraut et al., 1998; Morahan-Martin & Schumacher, 2003), 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 (2006), 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 (Roberts, 1999; Schulz et al., 1995).

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 in 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. (2005) and Preece et al. (2004), 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.

References

- Aujoulat, I., d'Hoore, W., & Deccache, A. (2007). Patient empowerment in theory and practice: Polysemy or cacophony? *Patient Education and Counseling*, *66*(1): 13-20.
- Bane, C. M. H., Haymaker, C. M. B., & Zinchuk, J. (2005). Social support as a moderator of the big-fish-in-a-little-pond effect in online self-help support groups. *Journal of Applied Biobehavioral Research*, *10*(4): 239-261.
- Broom, A. (2005). Virtually healthy: The impact of Internet use on disease experience and the doctor-patient relationship. *Qualitative Health Research*, *15*(3): 325-345.
- Cummings, J. N., Sproull, L., & Kiesler, S. B. (2002). Beyond hearing: Where real-world and online support meet. *Group Dynamics*, *6*: 78-88.
- Demiris, G. (2006). The diffusion of virtual communities in health care: Concepts and challenges. *Patient Education and Counseling*, *62*(2): 178-188.
- Eysenbach, G. (2003). The impact of the Internet on cancer outcomes. *CA Cancer Journal for Clinicians*, *53*(6): 356-371.
- Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., & Stern, A. (2004). Health-related virtual communities and electronic support groups: Systematic review of the effects of online peer-to-peer interactions. *British Medical Journal*, *328*: 1166-1170.
- Faulkner, M. (2001). A measure of patient empowerment in hospital environments catering for older people. *Journal of Advanced Nursing*, *34*(5): 676-686.
- Ferguson, T. (1992). Patient, heal thyself: Health in the information age. *The Futurist*, *26*(1): 9-14.
- Feste, C., & Anderson, R. M. (1995). Empowerment: From philosophy to practice. *Patient Education and Counseling*, *26*: 139-144.
- Finfgeld, D. L. (2000). Therapeutic groups online: The good, the bad, and the unknown. *Issues in Mental Health Nursing*, *21*(3): 241-255.
- Finn, J. (1999). An exploration of helping processes in an online self-help group focusing on issues of disability. *Health and Social Work*, *24*(3): 220-231.
- Funnell, M. M., & Anderson, R. M. (2003). Patient empowerment: A look back, a look ahead. *Diabetes Education*, *29*: 454-462.
- Gibson, C. H. (1991). A concept analysis of empowerment. *Journal of Advanced Nursing*, *16*(3): 354-361.
- Gutschoven, K., & Bulck, van den J. (2006). Towards the measurement of psychological health empowerment in the general public. Paper presented at the annual meeting of the International Communication Association, Dresden International Congress Centre, Dresden, Germany, June 16, 2006.
- Helgeson, V. S., & Gottlieb, B. H. (2000). Support groups. In S. Cohen, L. G. Underwood, & B. H. Gottlieb (Eds.), *Social support measurement and intervention: A handbook for health and social scientists*. Oxford: Oxford University Press.
- Helgeson, V. S., & Taylor, S. E. (1993). Social comparisons and adjustment among cardiac patients. *Journal of Applied Social Psychology*, *23*: 1171-1195.
- Hibbard, J. H., Stockard, J., Mahoney, E. R., & Tusler, M. (2004). Development of the Patient Activation Measure (PAM): Conceptualizing and measuring activation in patients and consumers. *Health Services Research*, *39*(4, Part 1): 1005-1026.
- Hill, W., Weiner, C. & Cudney, S. (2006). Influence of a computer intervention on the psychological status of chronically ill rural women: Preliminary results. *Nursing Research*, *55*(1): 34-42.
- Hoch, D., & Ferguson, T. (2005). What I've learned from e-patients. *PLoS Medicine* *2*(8):e206.
- Høybye, M. T., Johansen, C., Tjørnhøj-Thomsen, T. (2005). Online interaction: Effects of storytelling in an Internet breast cancer support group. *Psycho-Oncology*, *14*(3): 211-220.
- Klemm, P., Bunnell, D., Cullen, M., Soneji, R., Gibbons, P., & Holecek, A. (2003). Online cancer support groups. A review of the research literature. *Computers in Nursing*, *21*(3): 136-142.
- Kraut, R., Patterson, M., Lundmarck, M., Kiesler, S., Mukopadhyay, T., & Scherlis, W. (1998). Internet paradox. A social technology that reduces social involvement and psychological well-being? *American Psychologist*, *53*(9): 1017-1031.
- Leiberich, P., Nedoschill, J., Nickel, M., Loew, T., & Tritt, K. (2004). Selbsthilfe und Beratung im Internet: Mündige Benutzer können die Arzt-Patienten-Beziehung neu gestalten [Self-help and consultation via the Internet: Self-responsible users redefine the physician-patient relationship]. *Medizinische Klinik*, *99*(5): 263-268.
- Masi, C. M., Suarez-Balcazar, Y., Cassey, M. Z., Kinney, L., & Piotrowski, H. (2003). Internet access and empowerment: A community-based health initiative. *Journal of General Internal Medicine*, *18*: 525-530.
- Menon, S. T. (2002). Toward a model of psychological health empowerment: Implications for health care in multicultural communities. *Nurse Education Today*, *22*(1): 28-39.
- Mitcheson, J., & Cowley, S. (2003). Empowerment or control? An analysis of the extent to which client participation is enabled during health visitor/client interactions using a structured health needs assessment tool. *International Journal of Nursing Studies*, *40*(4): 413-426.
- Morahan-Martin, J., & Schumacher, P. (2003). Loneliness and social uses of the Internet. *Computers in Human Behavior*, *19*(6): 659-671.
- O'Cathain, A., Goode, J., Luff, D., Strangleman, T., Hanlon, G., & Greatbatch, D. (2005). Does NHS Direct empower patients? *Social Science & Medicine*, *61*(8): 1761-1771.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Newbury Park, CA: Sage.
- Perron, B. (2002). Online support for caregivers of people with a mental illness. *Psychiatric Rehabilitation Journal*, *26*(1): 70-77.
- Powell, J., McCarthy, N., & Eysenbach, G. (2003). Cross-sectional survey of users of Internet depression communities. *BMC Psychiatry*, *10*(3):19.
- Preece, J. (1999). Empathic communities: Balancing emotional and factual communication. *Interacting with Computers*, *12*(1): 63-77.
- Preece, J., Nonnecke, B., & Andrews, D. (2004). The top five reasons for lurking: Improving community experiences for everyone. *Computers in Human Behavior*, *20*(2): 201-223.

- Radin, P. (2006). "To me, it's my life": Medical communication, trust, and activism in cyberspace. *Social Science & Medicine*, 62(3): 591-601.
- Rappaport, J. (1987). Terms of empowerment/exemplars of prevention: Toward a theory for community psychology. *American Journal of Community Psychology*, 15(2): 121-148.
- Reeves, P. M. (2001). How individuals coping with HIV/AIDS use the Internet. *Health Education Research*, 16: 709-19.
- Riessman, F. (1997). Ten self-help principles. *Social Policy*, 27(3):6-11.
- Rimer, B. K., Lyons, E. J., Ribisl, K. M., Bowling, J. M., Golin, C. E., Forlenza, M. J., & Meier, A. (2005). How new subscribers use cancer-related online mailing lists. *Journal of Medical Internet Research*, 7(3):e32.
- Roberts, K. J. (1999). Patient empowerment in the United States: A critical commentary. *Health Expectations*, 2(2), 82-92.
- Salem, D. A., Bogat, G. A., & Reid, C. (1997). Mutual help goes on-line. *Journal of Community Psychology*, 25(2): 189-207.
- Salmon, P., & Hall, G. M. (2003). Patient empowerment and control: A psychological discourse in the service of medicine. *Social Science & Medicine*, 57(10), 1969-1980.
- Schulz, A. J., Israel, B. A., Zimmerman, M. A., & Checkoway, B. N. (1995). Empowerment as a multi-level construct: Perceived control at the individual, organisational and community levels. *Health Education Research*, 10(3): 309-327.
- Sharf, B. F. (1997). Communicating breast cancer on-line: Support and empowerment on the Internet. *Women & Health*, 26(1): 65-84.
- Shaw, B., McTavish, F., Hawkins, R. P., Gustafson, D., & Pingree, S. (2000). Experiences of women with breast cancer: Exchanging social support over the CHESS computer network. *Journal of Health Communication*, 5(2): 135-149.
- Smith, J. A. (1995). Semi-structured interviewing and qualitative analysis. In J. A. Smith, R. Harre, & L. V. Langenhove (Eds), *Rethinking Methods in Psychology*. London: Sage.
- Van Uden-Kraan, C. F., Drossaert, C. H. C., Taal, E., Lebrun, C., Drossaers-Bakker, W., Smit, W., Seydel, E., & van de Laar, M. (2007). Coping with somatic illnesses in online support groups: Do the feared disadvantages actually occur? *Computers in Human Behavior*. Epub ahead of print: doi:10.1016/j.chb.2007.01.014.
- Walstrom, M. K. (2000). "You know, who's the thinnest?": Combating surveillance and creating safety in coping with eating disorders online. *CyberPsychology and Behaviour*, 3(5): 761-83.
- Winkelman, W. J., & Choo, C. W. (2003). Provider-sponsored virtual communities for chronic patients: Improving health outcomes through organizational patient-centred knowledge management. *Health Expectations*, 6(4): 352-358.
- Winzelberg, A. (1997). The analysis of an electronic support group for individuals with eating disorders. *Computers in Human Services*, 13(3): 393-407.
- Cornelia F. van Uden-Kraan**, MSc., is a PhD candidate at the University of Twente Institute for Behavioral Research, Faculty of Behavioral Sciences, in Enschede, The Netherlands.
- Constance H. C. Drossaert**, PhD, is an assistant professor at the University of Twente Institute for Behavioral Research, Faculty of Behavioral Sciences, in Enschede, The Netherlands.
- Erik Taal**, PhD, is an associate professor at the University of Twente Institute for Behavioral Research, Faculty of Behavioral Sciences, in Enschede, The Netherlands.
- Bret R. Shaw**, PhD, is an assistant professor at the University of Wisconsin-Madison Department of Life Sciences Communication, Center of Excellence in Cancer Communications Research in Madison, Wisconsin, USA.
- Erwin R. Seydel**, PhD, is a professor at the University of Twente Institute for Behavioral Research, Faculty of Behavioral Sciences, in Enschede, The Netherlands.
- Mart A. F. J. van de Laar**, MD, PhD, is a professor of rheumatology at the University of Twente Institute for Behavioral Research, Faculty of Behavioral Sciences, & rheumatologist at the Medisch Spectrum Twente, in Enschede, The Netherlands.