

ONLINE INTERACTION. EFFECTS OF STORYTELLING IN AN INTERNET BREAST CANCER SUPPORT GROUP

METTE TERP HØYBYE^{a,*}, CHRISTOFFER JOHANSEN^a and TINE TJØRNHØJ-THOMSEN^b

^a *Department of Psychosocial Cancer Research, Institute of Cancer Epidemiology, Danish Cancer Society, Copenhagen, Denmark*

^b *Institute of Anthropology, University of Copenhagen, Copenhagen, Denmark*

SUMMARY

The internet provides new ways of forming social relationships among people with breast cancer and is increasingly used for this purpose. This qualitative study, using ethnographic case-study method, aimed to explore how support groups on the internet can break the social isolation that follows cancer and chronic pain, by analysing the storytelling emerging on the Scandinavian Breast Cancer Mailing list. Using participant observation and face-to-face or online interviews of participants, we investigated the motivations of 15 women who chose the internet to counteract social isolation after breast cancer. The results showed that the women were empowered by the exchanges of knowledge and experience within the support group. The internet was considered a means for finding ways of living with breast cancer.

Our study suggests that internet support groups have important potential for the rehabilitation of cancer patients. Copyright © 2004 John Wiley & Sons, Ltd.

INTRODUCTION

In the US, the internet has become one of the most commonly used sources of information on health and illness (Fox, 2003). To our knowledge, use of the internet by health consumers in Scandinavia has been addressed in only one study, which examined Norwegians' use of internet health services (Andreassen *et al.*, 2002). That study showed a significant increase in use of the internet for health information, from 19% in 2000 to 31% in 2001. Given that general access to the internet in Scandinavia has been growing over the past few years [<http://cyberatlas.internet.com>], we assumed that similar trends would exist in Denmark and Sweden. In 2003, a large proportion of the Danish population (77%) was found to have access to the internet from home and/or work (Statistics Denmark, 2003).

The internet is also increasingly used by cancer patients to find information about their disease. Fogel *et al.* (2002) interviewed 188 US women with breast cancer and found that 41.5% consulted the internet for breast health issues. Satterlund *et al.* (2003), in another study on US women with breast cancer, found that the internet was the second most frequently cited source 8 months after diagnosis and the most frequently cited source 16 months after diagnosis. Although these studies indicate a general trend among women with breast cancer, language is a barrier to extended internet use, as most of the information on the internet is in English (Mursch and Behnke-Mursch, 2003).

A diagnosis of cancer has been described in several personal accounts as a life-shattering experience (Broyard, 1992; Mayer, 1993; Franks, 1991). Various studies affirm that such a diagnosis increases a person's need for effective social and emotional support but may in fact increase their social isolation when family and friends cannot provide this support (Wortman and Dunkel-Schetter, 1979; Peters-Golden, 1982; Wortman, 1984; Gordon, 1990; Cope, 1995; Mathews, 2000).

*Correspondence to: Danish Cancer Society, Institute of Cancer Epidemiology, Strandboulevarden 49, DK-2100 Copenhagen, Denmark. E-mail: metteh@cancer.dk

During the past two decades, support groups and self-help groups have become central to psychosocial interventions for cancer patients and their families, and such groups have been found to improve their quality of life (Spigel *et al.*, 1989; Spiegel, 1997; Cella *et al.*, 1993; McLean, 1995; Gray *et al.*, 1997). The past decade has seen a growing number of cancer support groups on the internet, and some cancer patients find these communities crucial to living with cancer (Høybye, 2002). Previous studies have shown that use of health information and groups on the internet increases social support by reducing social isolation and increases the patients' personal empowerment and self-esteem (Weinberg *et al.*, 1996; Sharf, 1997; Klemm *et al.*, 1998; Fernsler and Manchester, 1997; Fogel *et al.*, 2002, 2003; Houston *et al.*, 2002; Lieberman *et al.*, 2003; Winzelberg *et al.*, 2003). Participation in internet-based support groups has also been suggested to reduce depression and cancer-related trauma (Houston *et al.*, 2002; Lieberman *et al.*, 2003; Winzelberg *et al.*, 2003).

This paper addresses the new theoretical and methodological challenges to health research posed by use of the internet in a Scandinavian non-English language context. Although there has been one non-English language study of internet use among brain tumour patients in Germany (Mursch and Behnke-Mursch, 2003), that study was a retrospective study. We conducted a prospective study through the use of ethnographic research methods in virtual and face-to-face contexts, we explored how the social isolation that follows breast cancer can be broken through support groups on the internet. We investigated the social interactions that occur in such support groups and investigated the social mechanisms and dynamics that make the groups useful in rehabilitating cancer patients. By focusing on the stories told on a breast cancer internet mailing list, we investigated how the overwhelming experience of breast cancer and the isolating and mentally debilitating effects of the disease can be counteracted. Although similar issues have been explored in studies on internet support groups for cancer patients (Weinberg *et al.*, 1996; Fernsler and Manchester, 1997; Sharf, 1997; Klemm *et al.*, 1998), we provide a theoretical and analytical framework for the relationship between social life in an internet-based group and the potential therapeutic effects.

MATERIAL AND METHODS

Previous research in medical anthropology by Kleinmann (1988), Good (1992) and Mattingly (1998, 2000) on the therapeutic potential of narratives of illness constituted the theoretical basis for this study. By telling and interpreting experience, narrative mediates between an inner world of thinking and feeling, and an outer world of observable actions and states of affairs (Mattingly and Garro, 2000). Narratives are a useful methodological and analytical tool for approaching the experience of illness and the active process of social transformation. In this paper, we use the terms 'story' and 'storytelling' rather than 'narrative' in order to accentuate the intersubjective encounter in storytelling, to emphasize the social process rather than the product of narration (Jackson, 2002). Storytelling is thus a methodological frame for accessing the social process and interactions on an internet mailing list.

Ethnographic setting

The empirical basis of the study was an ethnographic fieldwork conducted between 1 April and 15 December 2000 on the Scandinavian Breast Cancer Mailing list (SCAN-BC-LIST) hosted by the Association of Cancer On-line Resources (ACOR; <http://www.acor.org>). The mailing list represents an independently organized self-help group on the internet. The list was found by an internet search for support groups of Scandinavian origin related to cancer. One of the searches led to the ACOR web site, which at that time hosted 143 mailing lists. A single mailing list of Scandinavian origin was listed and was selected as the field of study. The SCAN-BC-LIST was founded in May 1999 on the private initiative of a Danish breast cancer survivor. It is a virtual meeting-place for people with breast cancer, their families and persons with a professional interest in breast cancer.

Participants

At the time this research was undertaken, the list had 39 members, who were mainly women with breast cancer speaking a Scandinavian language (Norwegian, Swedish or Danish, including women in the Faeroe Islands and Greenland

communicating in Danish and a Danish woman living in the USA). This study is based on the 15 women (100%) who were active in the mailing list from 27 April to 15 December 2000.

The women had all received a diagnosis of breast cancer stage I–IV and had all undergone breast surgery and received (or were receiving) chemotherapy. A majority (86%; $n = 13$) of the women had also been (or were) receiving radiation treatment, and most (60%; $n = 9$) were receiving treatment with tamoxifen or femar. The mean age of the 15 women at the time of diagnosis of breast cancer was 41 years (range, 28–49 years). In 2000, when this study was undertaken, the mean age of the women on the list was 45 years (range, 28–55 years). Most of the women (80%; $n = 12$) were married or living with a spouse, and 13 (86%) had children; five had (33%) children under the age of 18. The majority of the women (86%; $n = 13$) had university or college degrees. Two (14%) had completed basic vocational courses.

All the women on the list had been diagnosed with breast cancer, but the time since initial diagnosis differed greatly. At the time of our study, six women (40%) had received their diagnosis in 2000, when they joined the list. The cancers of five women (33%) had been diagnosed in 1998–1999, one to two years before our study. The cancers of the remaining four women (27%) were diagnosed in 1984–1998, but all these women had experienced one or more recurrences, new primary breast cancer or metastasis after their first breast cancer. Thus, all the women had encountered breast cancer within 5 years of 2000 and were either in treatment or were examined regularly. At the beginning of this study, the mailing list had existed for only 1 year, and the duration of membership on the list varied from 1 year (the founders of the list) to 2 months. By the end of the study, most of the women (86%; $n = 13$) had been on the list for more than 1 year.

Ethical considerations

The internet raises issues in research ethics, particularly with regard to privacy and informed consent (King, 1996; Sharf, 1999; Eysenbach and Till, 2001; Rhodes *et al.*, 2003) and the nature and prevention of harm in mediated communication (Waldron *et al.*, 2000).

The SCAN-BC-LIST was approached on 27 April 2000 by sending an email to the list

describing the purpose of the research project and its background and asking permission from the group to take part in their activities. The women on the list accepted this request and welcomed the study, expressing an interest in spreading knowledge about living with breast cancer. Not all of the 39 women on the mailing list agreed to participate in the research, but the 15 women who were included in the study gave consent and permission to use quotations from exchanges on the site. We were unable to approach the remaining 24 persons on the list; they were not communicating with the rest of the group at that time. According to information provided by the list owner, most of the inactive participants had contacted the list on at least one occasion.

We reintroduced the study to each new member who entered the group. We realized that this might pose an ethical dilemma, as new members might feel unable to refuse participation in a research project to which all existing members had agreed to participate.

Procedure

The study was designed as an ethnographic case study (Mitchell, 1984) involving detailed personal accounts over time of the transformation of women's lives after a diagnosis of breast cancer and the strategies they used to overcome the transformation, expressed in stories on the internet mailing list. The women on the list made daily contributions to the discussion through e-mails, although not all the women were equally active or active at the same time.

Data were derived from both participant observation and interviews. The study thus comprised 12 face-to-face interviews with seven participants and nine on-line interviews with four participants. The interviews were begun 4 months into the project. Four women did not wish to be interviewed, two because of their health. As the women were geographically scattered, it was not possible to interview all of them face-to-face. To extend and explore on-line methods with the women we could not meet face-to-face, we conducted interviews in a closed live chat room. We consider that the data obtained on-line are no different from those obtained face-to-face.

The interviews were semi-structured, covering the issues to be addressed but with no specific sample questions. The issues explored were

personal breast cancer story, use of the internet, involvement in the SCAN-BC-LIST, understanding of list conversations, personal social relations (family, friends), understanding of one's own present situation and assessing the future (hopes, risk). Most women were interviewed twice, giving us a chance to assess any change in how they saw their personal situation and their attachment to the mailing list. Unfortunately, we could not interview all the women twice, and one woman interviewed on-line was interviewed three times due to a technical malfunction.

Participants were observed on the basis of their daily involvement in the internet mailing list and in two physical meetings. The everyday life of the women on the list was observed by following the topics discussed, which included life with breast cancer and the coping strategies used. Like other members of the list, we read and responded to the daily messages, trying to take part in the fears and victories described. We also took part in scheduled Sunday chats.

Participant observation is a crucial method in ethnographic research for contextualizing stories and experiences presented verbally in the field. The interplay between the researcher and the object, the relations formed in the field, constitute the foundation for understanding the field and make it possible to analyse it.

Analytical perspectives

The philosopher Arendt emphasized the crucial role of being heard and seen by others for ensuring and maintaining 'humanness' (1958). This insight raises a key issue in our interpretation of value of an internet-based support group to its users, as being deprived of relationships with and recognition from others is, according to Arendt, being deprived of human existence. Stories are seen and heard by others and thereby constitute a common reality. Storytelling restores the viability of people's relationship with others (Jackson, 2002). We become visible to others through our stories and position ourselves in the world. In order to understand the link between the social group constituted by the internet mailing list and the therapeutic effects, we must understand how storytelling can mediate social transformation. Storytelling is a coping strategy, and words are a supplement to action, put to use when action is impossible or confounded (Jackson, 2002). For

people confronted with illness and pain, the existential loss is the inability to act (Scarry, 1985; Jackson, 1998). Storytelling is a way of moving from being acted upon to acting (Jackson, 2002). By telling her story in the field of interpersonal relations on an internet mailing list, the breast cancer patient is actively negotiating and preserving her identity. She is no longer being passively acted upon.

We therefore considered the breast cancer mailing list and the internet as strategies of empowerment for cancer patients, in which storytelling provided a passage from isolation to inclusion in a new social world. Thus, storytelling was considered a way of acting on experience and mediating social transformation.

RESULTS

Between 27 April and 15 December 2000, 1156 postings were made on the SCAN-BC-LIST, giving an average of 122 per month (range, 67–273). The frequency of postings varied widely, from 0 to 20, with an average of four per day. Not all the 15 women included in this study were active on the list all the time: five were core users and active throughout the study, while others were active at certain times or wrote when certain subjects were discussed. When a person was 'silent' for a time, the others would address her directly, asking her to let them know how she was doing.

By analysing participation on the mailing list during the 8-month period and categorizing all 1156 postings, we defined 14 distinct categories (Table 1) of storytelling. By analysing the social mechanisms and dynamics that made the mailing list useful in rehabilitation, we found that the categories could be summarized as four empowerment strategies.

Empowerment through knowledge

The women described how the breast cancer mailing list worked to empower them, by fostering a sense of control that linked them with resources and promoted well-being. 'I feel that via the internet I regained power over my body, because I know everything about my diagnosis, my possibilities and my risk,' one woman reported. Using the internet to find information or support gives

Table 1. Distribution of discussion of distinct categories in the Scandinavian Breast Cancer Mailing List project, Denmark, 27 April–15 December 2000

| Categories | Number of women | Percentage of all eligible participants ^a (N = 15) |
|---|-----------------|---|
| Experiencing social isolation/ loneliness | 15 | 100 |
| Implications of medical treatment | 15 | 100 |
| Social support/ encouragement | 15 | 100 |
| Positive posts about mailing list | 15 | 100 |
| Community | 15 | 100 |
| Information giving/ seeking | 14 | 93 |
| Physical implications of breast surgery | 13 | 87 |
| Living with risk | 12 | 80 |
| Humour/ laughing | 12 | 80 |
| Experience of mental exhaustion | 11 | 73 |
| Sexuality and breast cancer | 11 | 73 |
| Breast reconstruction | 8 | 53 |
| Getting back to work | 8 | 53 |
| Control check up | 7 | 47 |

^a Eligibility criteria for this study was a diagnosis of breast cancer and activity > 1 post in the Internet mailing list discussion from 27 April to 15 December 2000.

women the possibility to act when they had thought that impossible.

Another motive for turning to the mailing list was to find survivor stories and women to share the experience of breast cancer. Finding personal stories from women who had survived and found ways to live with breast cancer was described as a strong encouragement. 'You turn to the net to find women who have the same age, diagnosis and treatment as yourself—if they are alive it is good and gives encouragement—if they are dead you get sad', one woman explained. Turning to the internet broke down the social isolation created by the experience of breast cancer.

Tears and laughter

The mailing list provided a space in which experiences could be voiced and shared through storytelling. The personal stories told on the internet had several central and recurrent themes, including breast surgery, sexuality, physical and mental exhaustion, loneliness and fear.

The stories were not, however, always serious: humour and jokes played a large part in the stories on the list, and were often stressed by the women as being important aspects of survival. Postings on the list sometimes contained remarks that would elicit laughter, bringing relief to both the writer

and the reader. After her first visit to the chat room, one woman wrote: 'Time passed so quickly last night and I was on-line 1 hour and 10 minutes. [...] If a laugh is good medicine then the chat was something that can heal, maybe not our breast cancer but our souls.' We often found that humour was used in mailing list conversations to create distance from an event or situation. Seeking advice on 'Shampoo for bald-headed people' or joking about the forgetfulness of 'chemo brains' and about ill-fitting breast prostheses are examples of jokes shared on the mailing list with sympathetic understanding. Shared laughter also establishes a shared social world, and on several occasions women on the mailing list said that they enjoyed talking to each other '[...] because we can laugh at the same things'.

Entering a new social world

The users described the breast cancer mailing list as a support group and a virtual community, a group notion that exists through shared communicative practices and social experience. Strong bonds formed between the women who shared stories, surfacing through humour and powerful metaphors of kinship and through expressions of recognition and intimacy.

A subject brought up persistently in postings on the mailing list and in our interviews with the women was the inescapable experience of isolation. Some women described a diagnosis of breast cancer as 'being moved to' or 'entering' another side of life. They became isolated from their loved ones and from the social world they used to be a part of. The isolation experienced by these women was complex, at times being experienced as overwhelming. It appeared to be persistent and was a keynote to the stories. 'Nobody calls, nobody writes, do they think this is contagious? I am very disappointed—should I call? I can hardly be bothered now', one woman reported resignedly. Another woman wrote: '[...] It is the loneliness I find worst, and that is why it is good the list has started, so we have somebody to share it all with when we need it.' In response, another woman wrote: 'I see that xx writes about loneliness. I recognize my own situation very well in that, and I feel it even more strongly this time—the absence of people. I miss some of those who would normally get in touch with me. It hurts so badly. Even close friends have disappointed me, they stay away to some extent and I do not know how to tackle this'. We found that the community of the mailing list counteracted the experience of social isolation and incorporated the women into a new social world.

Women with a new diagnosis entered the list to seek the experience and advice of women who had already lived through surgery and various treatments, whereas women who had lived some years with breast cancer gratefully took the opportunity of telling their stories. Passing on stories about support and care was seen not only as reaching out to others but also as a way of dealing with one's own experience and making it meaningful, leading to maintenance of self-esteem. 'What you experience on the list is the opportunity to give, to give love to each other', one woman explained in an interview. The social nature of the breast cancer mailing list was expressed as genuine concern for others. The women stated in interviews and in their postings to each other that participation on the mailing list had greatly improved the quality of their life with breast cancer.

Social intimacy

The women used each other's experiences to learn how to live with illness. One example was the

difficult subject of sexuality after breast cancer. In response to a posting on the subject, one woman wrote: 'It is good that you write about this. So far I thought that I was the only one on the list that encountered problems of that kind. I could write tons of mails on that subject. I love my husband, but I happened to suggest that we got a divorce—that seemed easier than getting our sex life to work again [...]'. Several women encountered both physical and mental difficulties in engaging in the sexual act, and they learned from each other how to confront such problems. Recognition that sex was not what it used to be was central, but they also gave each other practical advice on how to deal with physical discomfort through exercise, various aids and pharmaceutical products.

Interviews with participants and observation of the daily storytelling indicated that participation promoted strong awareness of breast cancer and its implications. The women not only gave each other information about breast cancer but also encouraged each other to formulate expectations and questions for their personal consultations with physicians.

Many stressed that the absence of physical contact on the internet made it easier to start discussions on difficult and painful subjects, whereas the intimacy and trust formed on-line created the basis for discussions when the women met face-to-face. It was not the anonymity of the internet but rather the lack of physical contact at the time of writing that proved helpful to the women.

DISCUSSION

Our observations show how writing and sharing a story in an internet support group can lead to the articulation and transformation of the individual experience of illness by offering a mode of action. The illness is not just experienced submissively, as women progressed from isolation to active participation in a new social context. Internet-based support groups offer a space for recognition, a social level for sharing knowledge and experience and an individual level for finding ways to live with breast cancer.

The empowerment observed in this study can be broken down into three modes of action through which the women confronted their illness: *verbal acts* of writing and communicating experience; *imaginative acts*, embodied in metaphors,

re-imagining their experience of the world and regaining power over a life that was shattered by breast cancer; and, finally, *practical action*, for withstanding cancer treatment, nursing the body through diets and exercise and educating themselves about their disease (Høybye, 2002).

We found that taking part in a self-help group for breast cancer patients on the internet, through personal storytelling, could breach the social isolation experienced as a consequence of breast cancer, as reported elsewhere (Weinberg *et al.*, 1996; Klemm *et al.*, 1998; Houston *et al.*, 2002; Winzelberg *et al.*, 2003). To understand the therapeutic effects of internet-based support groups, we must see them as intersubjective storytelling. Effective stories can influence the subsequent actions of the teller and the audience (Mattingly and Garro, 2000), making internet groups a means of empowerment.

Our study enlarges the concept of empowerment used by Sharf (1997), as empowerment came not only by obtaining information but also by increasing personal strength through social support. Patients use the groups for information, support and sharing personal experience (Weinberg *et al.*, 1996; Sharf, 1997; Klemm *et al.*, 1998; Pereira *et al.* 2000; Klemm *et al.*, 2003). These are effects of action, but the essence of the concept 'empowerment' should be understood through the movement from being *acted upon* to be *acting* in intersubjective storytelling. We find that this theorizing is essential in order to convey from research to practice why internet-based support groups can prove to be important to cancer rehabilitation.

Writing is an inescapable part of on-line storytelling, and the therapeutic potential of storytelling is linked to the therapeutic aspects of writing. In a pilot study, Rosenberg *et al.* (2002) found only limited support for the hypothesis that a written emotional disclosure can positively affect health outcomes in cancer patients; however, they used a different method from ours. We found that writing contains the potential for transformation. In an existential perspective, there may be a relation between writing and healing: as we write our personal stories, we explore the features of our experience and name it, giving ourselves the possibility to obtain a sense of determining if not the course then the meaning of our lives (Jackson, 2002). The distancing associated with the process of writing offers a means for converting a loss into

a strength and testifying that life is precious and worth living. The women on the SCAN-BC-LIST found that writing represented a means for leverage out of social isolation and into a community of equals.

Labelling a chronic condition as hopeless can affect people's efforts to recover (Becker, 1997). A recent report of women with breast cancer using the internet showed that internet use was not related to psychological coping (Fogel, 2004). Our material suggests that an internet support group can change this labelling, providing hope, support, recognition and humour, reversing the picture and making women feel in charge of their own lives again. These positive psychological coping results may be specific to internet support groups and not to breast cancer patients who only use the internet for breast health information. Internet communities might therefore have clinical relevance in the rehabilitation of breast cancer patients. Providing facilities and education and helping patients to become 'internet-literate' might give them the means to counteract the isolation and medicalization of cancer. Another argument for clinical relevance is embodied in the characteristics of electronic communication. As has been argued by others (Weinberg *et al.*, 1996; Klemm *et al.*, 1998; Waldon *et al.*, 2000; Houston *et al.*, 2002; Fogel *et al.*, 2003), the internet opens new possibilities for people restrained by physical or mental disability to seek information and social support. Persons deprived of other forms of action have recourse to action on the internet. In contrast to other studies, which indicated that anonymity is an important factor in the posting of personal issues on-line (Weinberg *et al.*, 1996; Pereira *et al.*, 2000), we found that the lack of a physical presence was important in creating social intimacy, possibly by providing a space where difficult and painful subjects could more easily surface.

Our study suggests that internet communities should be viewed as complementary to other actions rather than opposing them. Thus, the therapeutic potential of storytelling applies to support groups both on and off the internet. It will nevertheless be essential to assess the therapeutic effects of on-line support communities further, comparing them with each other and with conventional face-to-face support groups, as also mentioned by Till (2003), to understand better how they can be used in rehabilitation. Klemm and Hardie (2002) compared face-to-face and internet support groups for cancer patients

in relation to the incidence of depression but did not arrive at a conclusion about therapeutic effectiveness. That study does provide some insight into who chose to participate in face-to-face groups and who chose to use the internet for support.

Most current research (Weinberg *et al.*, 1996; Sharf, 1997; Klemm *et al.*, 1998; Pereira *et al.*, 2000; Klemm *et al.*, 2003; Winzelberg *et al.*, 2003; Lieberman *et al.*, 2003) on on-line cancer support groups has been conducted in the USA. We found in our context that communication in one's native language is very important, as also noted by Mursch and Behnke-Mursch (2003) in their study of brain tumour patients in Germany. In our study, some participants were unable to communicate in English, and those who could communicate in English said that they preferred to communicate their personal experience of breast cancer in their native language. The experience of cancer is situated in specific cultural contexts (Gordon, 1990; Mathews, 2000), and being able to communicate within one's own cultural and linguistic context when faced with critical illness is important. More studies are needed on this topic in non-English-speaking regions.

Although the emotionally intense communication and the intimacy of the mailing list provided recognition and a sense of belonging, the absence of a physical dimension to a conversation can lead to misunderstandings and potentially harmful situations. Although this was not the focus of our study, it is important to reflect on all the social dynamics of internet support groups. Misunderstandings arose no more frequently than in any other group; however, in an internet-based group it is more difficult to negotiate differences, owing to the lack of face-to-face contact and the asynchronic communication, as also documented by Kiesler *et al.* (1984). The greater awareness of breast cancer and its implications that resulted from participation in the mailing list also caused greater insecurity and concern among some women. A particular difficulty was dealing with the fear that arose when one participant experienced a relapse. This issue was also discussed by Pereira *et al.* (2000) and Waldron *et al.* (2000), but the situations appeared to be equally difficult to deal with in face-to-face support groups (Gray *et al.*, 1997). We found that central, veteran members of the mailing list took on the role of mediators in conflicts and sought to resolve crises, working to counter harm, as also observed by Till

(2003), who stressed the emergence of 'tacit peer-navigators' in unmoderated mailing lists. He suggested that the navigator role should be investigated in future research, as it is central to preventing harm in electronically mediated communities.

This ethnographic case-study contributes important knowledge about the social process in an on-line support group. The study covered only a small group of participants because of the choice of setting and the qualitative research design. We are aware that this leaves a number of questions pending with regard to possible health improvements after on-line interaction. The use of ethnographic methods, in particular participant observation, provides insight into the personal transitions that occur with use of internet-based communication in sharing the experience of breast cancer. By contextualizing qualitative interview data through participant observation on-line and face-to-face, we investigated the rich web of intersubjective experiences. Medical anthropology has developed as a discipline within the social and cultural anthropological sciences during the past two decades. A number of studies similar to ours have been conducted (Kaufert, 1998; Gordon, 1990; Sered and Tabory, 1999), and a number of ethnographic studies have addressed the social dynamics and cultural consensus within cancer support groups (Cope, 1995; Mathews, 2000). To our knowledge, this is the first ethnographic study of an on-line breast cancer support group. We found that qualitative ethnographic methods were useful for studying the role of the internet in human interactions and social processes in the field. As traditional ethnographic methods of participant observation and interviews are applied in an internet context, new questions will arise about positions in the field, simultaneous or displaced communication, the importance of sensory experience in the field, ethics and other important issues. With increasing research on the internet, experience with data production on-line will also grow, which should enable greater methodological discussion of a variety of issues.

CONCLUSION

This study suggests that internet support communities can empower and this have a strong impact

on the well-being and rehabilitation of cancer patients. Further exploration of these strategies could indicate new practices in the rehabilitation of cancer patients.

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