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Breast and Prostate Cancer Online Discussion Boards

A Thematic Analysis of Gender Differences and Similarities

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Abstract

Online discussion boards are being used increasingly by cancer survivors, highlighting the need for understanding this potentially supportive communication process. Two online discussion boards, a prostate group and a breast cancer group, were studied using mixed methodology of both Grounded Theory and a quasi-numerative approach. Both men’s and women’s dialogues fell under two themes, information support and emotional support. Information support accounted for 60 per cent of communications in women and 64 per cent in men and emotional support 40 per cent in women and 36 per cent in men. However, there were gender differences in the language styles of these communications. Further research is recommended to understand adequately the emotional content within women’s and men’s dialogues in the context of breast and prostate cancer discussion boards.

Keywords

- breast cancer
- computer-mediated communication
- gender
- prostate cancer
- social supports
The modern era has brought with it advances in technological methods of communication, including Internet discussion rooms. From a psychological perspective, the Internet offers different modes of online healthcare, including email counselling, education websites, bulletin boards and self-help groups (Lieberman & Goldstein, 2005; Rice & Katz, 2001; Winefield, Coventry, & Lambert, 2004). Discussion boards (DB) have emerged online as a source of information and support for individuals seeking community (White & Dorman, 2001). This medium allows those with Internet access to engage in asynchronous written communication with others interested in the designated topic. For people who suffer from medical conditions such developments provide new opportunities to exchange experiences and views about illness (Sullivan, 2003) and are an important alternative to family and professional support (Winefield, Coventry, Pradhan, Harvey, & Lambert, 2000). Among the advantages are the choice to remain anonymous, log on and off at any time of day or night and receive support in the comfort of one's own home (Finfgeld, 2000). On the other hand information provided by participants might have negative effects on patient's well-being with identifying details being hidden, or misinformation and medical opinion being resisted (Rice & Katz, 2001). This new medium is important to investigate and evaluate for both online users and clinicians. The present research focused on the communication in online DBs of people who are experiencing cancer of the breast (BC) and the prostate (PC). Our focus here is not the medium itself, but how it may facilitate the provision and receiving of social support among those coping with serious illness. Because social support is recognized as a valuable source of both information and understanding, which aids and encourages people facing stressful situations, and because social support is delivered through interpersonal interactions, health psychologists need to understand the possible role of new communication media in making it accessible. At the same time there is intense interest among communication theorists in matters such as the personal relationships that may develop without face-to-face interaction (Berger, 2005; Walther, Gay, & Hancock, 2005).

Breast and prostate cancer

In Australia there are over 85,000 new cases of cancer diagnosed each year. Cancer is the leading cause of death, with an average of 35,000 people dying from the disease annually (Australian Institute of Health and Welfare, 2000). These two forms of cancer have similar morbidity and mortality rates and are generally sex-specific (Kiss & Meryn, 2001). The average age of first diagnosis for BC is 60 years and for PC it is 71. BC and PC are among the most common forms of cancer-causing deaths. Of all persons with cancer in Australia in the year 2000, 11,314 were BC and 10,512 were PC. In the year 2000 there were 2521 BC and 2665 PC deaths (Australian Institute of Health and Welfare, 2000). Thirty per cent of women treated by lumpectomy said that their sex lives had been negatively affected, while 80 per cent of men were impotent following radical prostatectomy or external beam radiation (Kiss & Meryn, 2001).

Support groups

When comparing men and women with cancer Zakowski et al. (2003) found a trend towards greater emotional expressivity in women compared with men. They concluded that men may be vulnerable to social barriers to expression, however differing social context is also suggested to affect expressivity. Gray, Fitch, Davis and Phillips (1996) studied BC and PC face-to-face self-help groups and reflected upon their differences. Men emphasized the importance of information and advocacy and are well served by large meetings, expert speakers and efficient organization. In contrast, women emphasize the importance of intimacy and peer knowledge and are well served by smaller group discussions, focusing on emotional support and friendship. In another investigation by Gray, Fitch, Davis and Phillips (1998) the perspectives of women in BC self-help groups were assessed. Women described appreciating sharing experiences, being understood, providing hope and sharing laughter. Samarel, Tulman and Fawcett (2002) found that for BC patients, group support and telephone counselling led to less mood disturbance, less loneliness and higher quality relationships than in non-participants. Poole et al. (2001) noted that those men with PC who attended a support group cited fellow patients as the most helpful source of information support. However McGovern, Hayman and Resnick (2002) reported no significant improvement in quality of life for attendees of a PC support group when compared with non-attendees.
Online support, gender and cancer

Finfgeld (2000) summarized that there are both advantages and disadvantages of online support groups. The positive features include anonymity, the opportunity to lurk and being free from the social constraints associated with face-to-face interaction. Also, people can communicate with each other without leaving home and this can be advantageous in the case of those minding children, or for people limited by illness. Among the disadvantages, the lack of non-verbal cues may preclude detecting nuances of relating and lead to misinterpretation of others’ meaning. This is sometimes overcome through users communicating cues symbolically, by, for example, using :) for a smile, or LOL for ‘laugh out loud’. A concern is that computer ownership is closely linked to education and income, which limit access for some to this support. Another drawback is that these groups may foster social isolation whereby the only interaction people have is in cyberspace. Of mixed effect, the lack of visual cues may help or hinder connection as gender, race, age and socio-economic status may be ‘neutralized’. People may also use DBs and chat rooms for reasons other than that stated by the group agenda. However theorists have been struck by how quickly users share intimate disclosures within what is experienced as a community of peers with agreed mutual expectations and knowledge (Walther et al., 2005).

Gender differences in online communication have been investigated. Herring (1993) analysed academic online discussion lists and determined distinct gendered modes of relating. Men used put-downs, assertions, lengthy postings, self-promotion and sarcasm. In contrast, women’s dialogue included supportiveness, appreciation, community building and making suggestions. In a mixed-gender online group there were equal contributions made by men and women (Davidson-Shivers, Morris, & Sriwongkol, 2003).

In research conducted by Davison, Pennebaker and Dickerson (2000), support seeking from online discussion groups was found to be highest for diseases viewed as most stigmatizing. Among those mentioned were BC and PC. Rozmovits and Ziebland (2004) investigated what patients want from BC or PC websites. They found that patients were highly interested in accessing practical and experiential information from fellow patients. Owen, Klapow, Roth, Nabell and Tucker (2004) suggested Web-based treatment formats could improve the effectiveness of psychosocial treatments because of their increased availability and accessibility.

Hoybye, Johansen and Tjomhoj-Tomsen (2004) suggest that the Internet is becoming increasingly a context for forming social relationships among people with BC. In a study of online communications between women with BC, Sharf (1997) found the group offered members enhanced decision making and preparation for illness experiences. Women were empowered by sharing knowledge and experiences and were helped in finding ways to live with cancer. Pitts (2004) proposed that the Internet provides the potential for women to step outside traditional roles of femininity and negotiate new ways of relating.

Davison and Pennebaker (1997) analysed a selection of online communications about illnesses including BC and PC sites. BC participants were nurturing and also had by far the highest percentage of positive emotion words. BC and PC board users expressed the least number of negative emotion words of all illness categories. In this regard they observe that both BC and PC members endured hardships and emotional duress with a loving and patient attitude and provided much encouragement to one another. PC patients used a low rate of self-references and distanced themselves more than other DB users.

Sullivan (2003) in her research of online ‘listservs’ for men with PC and women with ovarian cancer found distinct gender differences in online communication. Men were found to speak with an instrumental orientation, whereas women were more emotionally sensitive and expressive. Men provided each other with information, whereas women shared feelings and talked about their pain and frustrations. Using a phenomenological analysis, Sullivan found five main themes emerging in women’s communications and three main themes in men’s communications. Women spoke with the sentiment ‘I send my good vibes’ in which they used inclusive language and spoke about their love for group members. Another theme was ‘At this cyber tea party’ which involved messages displaying an understanding that only others with a similar experience could effectively convey. The third theme, ‘Feel free to rant’, described the way in which women vented their feelings and frustrations to one another. The fourth theme ‘Put a face w/a cyber-name’ encompassed the way in which women sought to engage in face-to-face get-togethers with
fellow listserv members. The fifth theme, ‘May we all be blessed with the ability to contribute to the lives of others’, involved members giving one another advice about how to become more active in their own healthcare. In Sullivan’s prostate problem mailing list, men primarily shared medical information. The first theme ‘As we all know’ describes how men give highly technical replies to requests for information. The second theme, ‘I do not respond to messages without a PC digest’, outlined the way in which participants were expected to provide case histories in digest form in order to conform to standards established on the list. The third theme, ‘If you want to be a partner in your own healing’, described how patients ought to arm themselves with the most up-to-date medical information in order to understand their case thoroughly.

Aims

The current research sought to build upon previous findings, to compare and contrast the ways in which the genders share issues with each other online. BC and PC have comparable age of onset, morbidity and mortality rates, hence in DBs designed for people with BC and PC these factors are relatively constant, providing an opportunity for understanding the potential influence that gender has upon discussion in online chat rooms for BC and PC patients. As has been observed in previous research, it is predicted that there may be differences in the ways in which gender impacts upon the supportive practices with which men and women engage, specifically in the form of greater emotional expressivity in women and greater informational engagement in men. A new approach to the qualitative analysis of gendered communication on the Internet was tested, using a second rater to establish the reliability of themes emerging from the observed communications, and providing some basic quantitative data (St Leger & Walsworth-Bell, 1999). It was predicted that women in the breast cancer discussion board (BCDB) would cater to emotional needs, while men in the prostate cancer discussion board (PCDB) would mostly cater to information needs.

Method

Participants

In the BCDB there were 79 participants, 69 women and two males who had BC and eight men were spouses or widowers of BC sufferers. In the PCDB there were 85 participants, 77 men with PC, six women and two men who were spouses or relatives of PC sufferers. In the BCDB there were 344 postings and 695 in the PCDB. In the BCDB 272 postings were from women who had BC, six postings were from men who were spouses or widowers and 12 postings were Spam. In the PCDB there were 591 postings from men who had PC, 95 from women who were spouses or relatives and 9 were Spam. No checks were possible on the gender or identity of messages-posters.

The participants came from several countries. Those identified were, Australia, America, Canada, England, India and Israel. Although two men had BC and other postings included Spam, relatives and spouses, this research looks only at the communications between women who had BC (n = 69) and between men who had PC (n = 77).

Materials

Internet DBs occur through the medium of writing and result in records that can be downloaded for analysis. Texts from two DBs were obtained from two websites, one for BC and one for PC. Unfortunately it was not possible to obtain specific background information about the site, such as who the initiators were, however the groups were not connected to any professional body and appeared to be generally open and accommodating to all persons whose lives were affected by cancer in some way. Data were collected for a period of one month in 2004. To protect participants’ privacy, specific dates and website addresses are not included in this article.

Procedure

Ethics approval was given by the relevant committee at the University of Adelaide. A mixed methodology was chosen (Creswell, 2003; St Leger & Walsworth-Bell, 1999) to gain understanding of the different ways in which the sites were being used. To enable identification of the core themes discussed, this study analysed men and women’s conversations using a thematic qualitative method of inquiry, that of Grounded Theory. Strauss and Corbin (1990) suggest that data be examined repeatedly in order to discern patterns and themes in subjects’ dialogue. The procedure involves three main stages, open coding, axial coding and selective coding (Rice & Ezzy, 1999), summarized as follows:
Stage 1: Open coding. The researcher notes general patterns, themes and metaphors that encapsulate the ideas conveyed in participants’ conversations. Codes are recorded. Paragraphs may contain one or several open codes.

Stage 2: Axial coding. Revision and regrouping of the open coding into more definitive themes takes place. The researcher amalgamates codes, making connections between different categories that seem related.

Stage 3: Selective coding. The final stage of analysis involves a description of the central phenomenon that emerges from the axial coding data. The different categories are unified around a core-code or theme.

The recording of codes was independent of the length of the DB posting, for example, a three-page message, or a three-line item could each qualify as one instance of a particular code. Likewise, a one-paragraph posting might contain several codes depending upon its content.

Two readers, both with four-year Psychology degrees and familiarity with qualitative analytic techniques, independently categorized the data to ensure inter-rater reliability (Boyatzis, 1998; St Leger & Walsworth-Bell, 1999). Discussion usually brought concurrence in categories, but those items about which there were remaining discrepancies, when it was not possible to ascertain the intent of a poster’s comment, were discarded. This included four communications from the BCDB and 10 from the PCDB. The number of instances of each open code was also recorded, then percentages were used to describe the different ways in which men and women communicate. To provide context, information is provided about the average number of codes per message, and the frequency with which individual members posted.

Results

Two selective codes, ‘information support’ and ‘emotional support’, were identified after conducting the three stages of analysis. Within ‘information support’ two axial codes were identified, ‘facts about the disease’ and ‘dealing with the effects of the disease’. Similarly within ‘emotional support’ another two axial codes were identified namely ‘coping philosophies’ and ‘nurturing and expressing’. Table 1 outlines the open codes that were identified under these headings.

In the BCDB there was a total of 582 instances of open codes and for the PCDB there were 971 instances of open codes. The percentage incidence of codes in each DB was calculated and Table 2 outlines the proportion of information support and emotional support, including all the axial and open codes as outlined in Table 1, within the BCDB and PCDB. For women information constituted 60 per cent of the communication and for men 64 per cent, while 40 per cent of communications for women incorporated emotional content and 36 per cent for men.

Table 1. Three levels of codes identified in messages to BCDBs and PCDBs

<table>
<thead>
<tr>
<th>Codes</th>
<th>INFORMATION SUPPORT</th>
<th>EMOTIONAL SUPPORT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Selective</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Axial</td>
<td>Facts about the disease</td>
<td>Coping philosophy</td>
</tr>
<tr>
<td>Open</td>
<td>Requesting information</td>
<td>Offering wisdoms</td>
</tr>
<tr>
<td></td>
<td>Providing own knowledge</td>
<td>Humour</td>
</tr>
<tr>
<td></td>
<td>Quoting own experience</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Quoting literature</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Evidence-based practice</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Alternatives</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Promoting choice</td>
<td></td>
</tr>
<tr>
<td>Selective</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Axial</td>
<td>Dealing with effects of disease</td>
<td>Nurturing and expressing</td>
</tr>
<tr>
<td>Open</td>
<td>My progress</td>
<td>Sharing the distress</td>
</tr>
<tr>
<td></td>
<td>Disease site-related concerns</td>
<td>Encouragement and valuing</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Challenging</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The group</td>
</tr>
</tbody>
</table>
Table 2. Proportions of information and emotional support within the BCDB and the PCDB

<table>
<thead>
<tr>
<th>Support</th>
<th>Women%</th>
<th>Men%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>INFORMATION SUPPORT</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Facts about the disease</td>
<td>46</td>
<td>49</td>
</tr>
<tr>
<td>Requesting information</td>
<td>11</td>
<td>5</td>
</tr>
<tr>
<td>Providing own knowledge</td>
<td>13</td>
<td>19</td>
</tr>
<tr>
<td>Quoting own experience</td>
<td>13</td>
<td>16</td>
</tr>
<tr>
<td>Quoting literature</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Evidence-based practice</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Alternatives</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Promoting choice</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td><strong>Dealing with effects of disease</strong></td>
<td>14</td>
<td>15</td>
</tr>
<tr>
<td>My progress</td>
<td>12</td>
<td>11</td>
</tr>
<tr>
<td>Disease site-related concerns</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td><strong>Grand total (Information)</strong></td>
<td>60</td>
<td>64</td>
</tr>
<tr>
<td><strong>EMOTIONAL SUPPORT</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coping philosophy</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Offering wisdoms</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Humour</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td><strong>Nurturing and expressing</strong></td>
<td>35</td>
<td>27</td>
</tr>
<tr>
<td>Sharing the distress</td>
<td>10</td>
<td>7</td>
</tr>
<tr>
<td>Encouraging and valuing</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>Challenging</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>The group</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Grand total (Emotional)</td>
<td>40</td>
<td>36</td>
</tr>
</tbody>
</table>

Table 3. Number of open codes in each posting within the BCDB and PCDB

<table>
<thead>
<tr>
<th>Number of open codes</th>
<th>Women</th>
<th>Men</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 code</td>
<td>131</td>
<td>348</td>
</tr>
<tr>
<td>2 codes</td>
<td>81</td>
<td>133</td>
</tr>
<tr>
<td>3 codes</td>
<td>29</td>
<td>71</td>
</tr>
<tr>
<td>4 codes</td>
<td>19</td>
<td>23</td>
</tr>
<tr>
<td>5 or more</td>
<td>12</td>
<td>16</td>
</tr>
<tr>
<td>Total postings</td>
<td>272</td>
<td>591</td>
</tr>
</tbody>
</table>

The number of open codes varied from one to five or more in each posting, as shown in Table 3. The majority of postings contained either one or two open codes. Sometimes a posting that was lengthy qualified for only one open code, for example when ‘quoting literature’. On other occasions short paragraphs dealing with a number of issues included several open codes.

Some participants posted frequently and others posted either once or rarely, as shown in Table 4. Most of the postings were from individuals who posted between one and five times. However, there were three men and one woman who posted over 40 times each.

Examples of communications from which open codes and their related axial and selective codes were derived, are provided in an appendix available on request from the first author. In the following sections we summarize the content of each coding category and the main differences between the communication styles of men and women.

**Information support**

**Facts about the disease** Requesting information took the form of seeking medical information and how to deal with the physical effects of the disease...
and/or treatment. Such requests were answered quickly and usually several responses came from those who had shared a similar experience. Sometimes people used the board for clarification of issues raised in conversation with their practitioners. Concerns about medications and requests about how to discuss this with the practitioner were run past the group. Some women wrote in to request information having recently been diagnosed with BC. On occasions some people were unaware of exactly what questions they needed to ask, or what information they needed to access. Therefore, incidental information from postings can prompt others to discover questions that would be helpful for them to ask in order to clarify their own position.

Providing own knowledge was an approach members used for informing others about BC and PC, and vigorous debates at times ensued surrounding a topic. Information usually involved an account that came from the general knowledge of the person offering it. However, sometimes the individual would quote, ‘my oncologist said . . . ’ or give another source. In the BC discussion board (BCDB) and PC discussion board (PCDB) members were quick to offer knowledge pertaining to questions about cancer. Some of the issues that were covered included the uses, actions and side-effects of drugs and the hormonal alterations occurring within the disease. They also spoke of the meaning of various test results and the physical aspects of the disease, operations, radiotherapy and other experiences.

When it came to sharing medical advice both men and women were clear in stating that their opinions had not come from a health practitioner. Professional opinion took precedence over lay-advice, or cancer-survivor experiences. The perspective was emphasized repeatedly throughout the transcripts. Members challenged those people who provided so-called answers on grounds that they were not experts and were quick to remind them of their layperson status.

Quoting own experience involved the BCDB and PCDB members giving detailed accounts of their own cancer experience and sometimes description of procedures. In the BCDB, for example, there were discussions about the injection of dye for identifying sentinel nodes and communications about surgery for removal of the breast. In the PCDB experiences of radiation treatment or surgery for the removal of the prostate was similarly detailed.

Quoting literature was one way of sharing information among BCDB and PCDB members. To assist understanding they recommended books, websites and posted studies of interesting findings. Users contributed conference summaries and relevant websites for recent medical developments. Women tended to provide short references, however men’s quoting of literature often took the form of lengthy summaries of research and studies, a number of which were several pages long.

Evidence-based practice was a primary approach users advised for choosing treatments and for understanding their cancer. Users were dedicated to learning about medical research outcomes and share this with other board users. They advocated that individuals look at the ‘hard evidence’. Scientific rigour was enforced. Without proof, members were reticent to accept solutions as valid treatment. Some BC members also adopted the ‘evidence-based’ argument to promote the use of alternatives.

Alternatives were explored within the BCDB. Women were interested to explore the use and the veracity of alternative treatments. There were active requests about how effective others had found them to be and different options were provided. At times, caution was expressed about alternative treatments, but these were also spoken about as acceptable. There was an open-minded view. Not all women agreed with accepting such treatments. In the PCDB there were no ongoing conversations about alternative practices. On occasions when people mentioned them, they were referred on to ‘alternative’ PC sites. Following conventional treatments seemed to be assumed.

Promoting choice was advised in both groups as the sensible approach to cancer management. Within this view, online participants encouraged people to seek out a range of opinions in order to ensure that their treatments were well researched. Also, they were encouraged to cross-reference information in order to check its accuracy and ensure they were receiving the best possible treatment. Sometimes recommendations were made for how health care could be conducted differently, so they had more choices. People used the site to lay down their expectations as a consumer. Men’s communication emphasized this theme, encouraging each other to make autonomous yet informed decisions about their own treatment. They were determined to respect individual choice: they wished others well with the choices they made and expressed interest in hearing about the results, advocating that people find the treatments that best suit them.
Dealing with the effects of the disease  

My progress involved members discussing their own cancer development. While BCDB members tended to report a summary of these facts, PCDB members were more likely to report in full test results and pathology reports. Men were explicit in their descriptions of the physical impact of their disease on functions such as urination, erection, abdominal problems such as gas, constipation and fatigue. The ongoing progress of prostate-level results, biopsy results, radiation treatments, while medications and their effects were regularly discussed. They also spoke about the impact that cancer had on their capacity to engage in sporting activities and primarily on sex.

Disease site-related concerns describe how men and women talked about the impact of the loss of function or appearance of the affected region. The tactics for re-gaining or replacing these were shared among members. Women’s concerns about breasts related to achieving the ‘right look’, however they tended to be short and hassle-free communications. Women tried to achieve a normal breast shape either through implants or inserts. One ongoing conversation detailed how to secure inserts into swimsuits. Another member expressed concern about attractiveness after mastectomy. Still others chose to re-define their understandings of prettiness. Most women, however, seemed interested to know about options for restoring their former look.

When men mentioned disease site-related concerns the postings provided great detail about the impact of deficits caused by cancer and its management and methods for getting the ‘hydraulics’ back in order. Men differed from the women’s surgical site-related concern in that they clearly articulated frustrations and expressed a strong need and hope to restore former function. Conversation involved frank expressions relating to the body as though it were a machine requiring restoration.

Emotional support  

Coping philosophy  

Offering wisdoms—both men and women shared soul philosophies or wisdoms. 

Humour within the BCDB was usually brief and incidental. While women’s engagements with humour tended to be short and unrelated to the disease, that is being part of general ‘chit-chat’, men’s lengthy series of jokes and humorous exchanges appeared to be a way to cope with various ramifications of the disease. A playful approach was adopted to deal with some of the difficulties men faced with PC. There was often creativity in participants’ wording. Men put a great deal of effort into witty communication exchange. There was a repartee between several members creating ditties to be sung to a familiar tune. Sometimes humour was used to address sadness. Men used humour to address embarrassment and frustration: there was an appreciation of light heartedness.

Nurturing and expressing  

Sharing the distress was a feature of the supportive nature of the online environment. Women clearly expressed the emotions they were experiencing. Through the messages in the PCDB there were occasions where distress and anxiety, though not named explicitly, was in fact being implied. Sometimes men seemed to ‘intellectualize’ to be able to express some sense of fear.

Encouragement and valuing was provided by women through expressions of affection and a nurturing style of support. Women were gently encouraging. They offered kisses and hugs and warm dialogue about caring and supporting one another with embracing terminology. Men gave encouragement in the form of promoting strength, encouraging each other to ‘keep their chin’s up’. They spoke with an attitude that indicated they would address the difficulties as they arise and in the mean time continue with life as usual. Although they did acknowledge their concern, they were quick to address it with an attitude of perseverance. One man mentioned that is was men’s duty to protect their wives from the difficulties associated with the illness. He said it was important men did not ‘burden’ their wives with any worries and instead should support each other online.

Battle-like terminology was a unique feature of the PCDB. Men spoke about addressing their cancer as though they were fighting the disease and talked about ‘beating the bastard’, the enemy being cancer. One participant wrote of the long-time cancer patients as ‘battle scarred vets’. Others talk of the effects of cancer, as though being punched or struck. Men’s valuing of each other took the form of camaraderie.

Challenging the claims and proposals made by others was a central feature of the BCDB and the PCDB. This was used equally by men and women. They challenged each other vigorously in debates about claims that each other made. Women sometimes chided each other, questioning the veracity of their claims. At other times they set firm boundaries regarding what the group should and should not talk
about, and told people when they had enough. Sometimes complaints were made about the medical care they had received, or the health system generally. Neither men nor women were consistently polite, but rather, they spoke freely about irritations. Women were just as forthright as men in expressing anger in the DBs.

The group reflects the idea of the strong sense of connection members felt with each other. Both BC and PC users spoke in ways that affirmed the group. They talked about the group as being the best one available for people with either BC or PC. Several people even proposed telephone communication to discuss issues further. Some people felt that the DB was the only place they could be properly understood. The group proved helpful for one member who wanted to keep her problems from others. They supported and welcomed new people and created a sense of belonging and unity among them, as though they were a community. A new member expressed that he felt welcomed. The DB also appears to provide an environment of support for those who prefer to lurk.

Discussion

Within the new research field of computer-mediated communication in health care, we examined the expressive content of postings to Internet discussion boards for cancer sufferers. In particular, postings by women and men were analysed to explore gender differences in communication style. The two primary reasons for which people used the DB were to gain information and emotional support about the experience of BC or PC.

In both DBs, participants used the forum as an information-gaining environment, in which they shared their understanding of the cancer. Both BC and PC DBs involved communications about facts regarding the disease and dealing with the effects of the disease. Pertaining to facts there were requests for information, provision of own knowledge, quoting own experience, quoting literature and promotion of evidence-based practice and choice. Dealing with the effects of the disease involved discussions about own progress and disease site-related concerns. The emotional support included coping philosophies where members offered wisdoms and humour. Nurturing and expressing involved sharing the distress, encouragement, challenging and validating the group. The extent to which women and men employed information or emotional styles of communicating about their disease did not confirm previous findings. Instead of men having a greater information focus and women having a marked preference for emotional support, the genders seemed to engage with them fairly equally. The similarities suggest that users of online DBs who seek support for addressing cancer are informed by similar needs and expectations, regardless of gender. Perhaps this is because the research controlled for variables of age of onset, morbidity and mortality that may influence their dealing with the impact of the disease.

On the other hand, differences were found highlighting gendered communication tendencies on BCDB and PCDB. There were differences in ‘quoting literature’, as men provided more lengthy accounts of findings of research than did women. Within ‘my progress’ men cited more medical reports than women. Regarding disease site-related concerns women gave less time to these matters, whereas men engaged in detailed postings to discuss ways of overcoming sexual dysfunction. Women’s engagements with humour were short and incidental to the disease, whereas men used lengthy series of jokes and humorous exchanges as a way to cope with the various ramifications of the disease. Regarding sharing the distress, women clearly expressed emotions, whereas men tended to imply their emotions. When providing encouragement, women offered expressions of affection and nurturing, whereas men promoted strength and used battle-like terminology, as though they were at war against cancer.

Unlike Sullivan (2003) who found that men engaged more with information and women with emotion, the current study found that both men and women appeared predominantly to engage in information support. This result may be a result of Sullivan using only one unit of coding per message, whereas this study allowed for more than one code per message. Men and women appeared to engage in the two styles of support, information and emotional, to a similar extent. Both the information and the emotional codes included instances of seeking and providing support for the BCDB and the PCDB. However, there was some variation between men and women in the language used to express emotion.

What constitutes emotional expressions and engagements in DB communications is complex. Researchers need to be alert to instances of talk that represent strong emotional content, but which do not employ emotion words. Comments such as, ‘If this one [PSA] is in the 30s again, I’ll get myself a
nice bottle of Scotch and find a nice gutter...’ arguably has strong emotional content, but has no emotion words. Identification of the range of ways in which emotional sentiments are conveyed needs further investigation.

Another matter to consider in understanding emotional support is that material that may appear to be information support may in fact function to help individuals on an emotional level. Sullivan also described this ambiguity: ‘The functional line between emotional support and information support becomes blurred...[for] It is evident that sharing information was [an act which] communicated to members that they were esteemed, valued and accepted’ (2003, p. 100). Therefore, to polarize the two forms of support into either ‘emotional’ or ‘information’ may hide the emotional support that people derive from having a source of well-informed and balanced information about a life-threatening disease. Future research could further explore this idea.

The present findings supported aspects of other past research. Boehmer and Babayan’s (2004) finding, that men seek both information support and emotion support for PC, was confirmed in this study. Analogous to Sharf’s (1997) investigation into BC members online, the group was reported by BCDB members to fulfil the function of a community (BCDB = 4%). PCDB members in 2 per cent of total communications spoke about ‘the group’ and welcomed new people. Consistent with the findings by Weinberg, Schmale, Uken and Wessel (1996) in their study of online communications for women with BC, conversations surrounded the sharing of information about their medical condition, in ‘quoting own experience’ (13%), personal concerns, in ‘sharing the distress’ (10%) and offering support to each other, in ‘encouraging and valuing’ (15%). These findings also support Davison and Pennebaker’s (1997) findings that women provide expressions of affection and nurturing. In line with Langelleir and Sullivan (1998) it was found that women were less body image focused than might be expected, with only 2 per cent of postings falling under ‘disease site-related concerns’.

In the present study women also appeared to speak freely about the use or potential use of alternatives, with 2 per cent of conversations surrounding this theme. Differing from Steginga et al. (2001) who found 55 per cent of men in their research used alternative cancer treatments, in the present study PCDB members spoke rarely about alternatives, not even enough to register as a percentage within total communications. Men spoke at length about ‘keeping the hydraulics in order’ within ‘disease site-related concerns’ with 4 per cent of postings relating to restoring sexual ability. This supports Arrington’s (2000) finding of the prevalence of talk about sex in survivors’ conversations.

Unlike Herring’s (1993) observation that male dialogue was characterized by put-downs, assertions, lengthy postings, self-promotion and sarcasm, the men in the PCDB were generally respectful towards each other. It should be noted that Herring was studying academics’ online communications. It is suggested that the serious and personal nature of PC may influence the way in which men speak in DBs, so that they are more valuing of each other.

The results of this study cannot necessarily be generalized to all cancer patients. The quality of writing of members in this research indicated that DB members were reasonably well educated and articulate. This may mean that some people would feel uneasy about presenting their ideas. Also, as noted by Finfgeld (2000) some populations may have little or no access to the DBs due to lack of equipment and skills. Another observation was that conversations about partners appeared to be limited to heterosexual references, which may have led to exclusion of others who did not identify with this norm. A final limitation is that online it is difficult to determine posters’ sentiments, which in the spoken word would be conveyed through verbal cues. This made interpreting data at times difficult and sometimes an irresolvable process, although not as often as might be expected.

The research has several implications for the provision of health-related information and support. Members appeared to be highly interested in accessing practical and experiential information from fellow members of the DB. According to Rozmovits and Ziebland (2004) cancer survivors prefer non-commercial sites and health information sites that are attached to ‘centres of excellence’, such as universities or reputable medical centres. Setting up a DB within such a context may carry the potential benefit of postings being monitored by trained health practitioners to ensure cancer patients’ emotional and information requirements are adequately met. For patients this would carry the advantage of greater assurance that they are receiving accurate and up-to-date knowledge when they enter the DB. This initiative could operate in conjunction with the help they receive from their healthcare providers.

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A disadvantage of professional presence in DBs is that members may feel inhibited in sharing their own expertise.

From a medical point of view, it would be interesting to investigate the accuracy of the information members provided each other, whether there is a place for discreet professional assessment of postings and indeed the extent to which involvement correlates with compliance to treatment. It is recommended that in future research online group members be questioned with regards to their experience of DBs and the impact it has on their psychological well-being and coping styles. Further, it would be interesting to investigate the extent to which lurking provides support to people, and to test the hypothesis that online mutual help provides a form of support for those who are less likely to engage with traditional forms of helping (Salem, Bogat, & Reid, 1997). DBs carry the potential to improve the productivity of psychosocial treatments.

Theoretical considerations include thinking about the outcomes of gendered forms of relating (Eckert & McConnell-Ginet, 2003). Health practitioners could benefit from contemplating the effects of gender-styles of relating, and whether they aid and/or hinder coping with the illness. Consideration of interventions to help establish adaptive and functional methods of coping would be useful. On a methodological note, other approaches to the analysis of observed communicative interactions could include discourse analysis, narrative analysis or participant observations, in addition to follow-up personal interviews. The approach used here, of a thematic analysis with checked reliability, is congruent with recommended mixed methods for health research (Boyatzis, 1998; St Leger & Walsworth-Bell, 1999).

In conclusion, discussion boards provide women and men with BC and PC an opportunity to communicate with fellow sufferers to gain a better understanding of their illness. They are able to share information about the physical aspects of the disease and how to manage its effects. There is also a rich emotional support provided by the DB. Advantages of DBs include their anonymity, accessibility and immediacy of access. Through this medium a sense of community exists, which appears to help members cope. While men and women both shared information and emotional support on these sites in a similar manner, there are qualitative differences in their ways of seeking and posting support to each other that quantitative methods do not capture. It is suggested that further research is required to conceptualize more adequately gender emotional differences and similarities within the context of BC and PC DBs.

References


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