

Computer-mediated and face-to-face communication in metastatic cancer support groups

RUVANEE P. VILHAUER, PH.D.

Psychology Department, Felician College, Lodi, New Jersey

(RECEIVED May 21, 2012; ACCEPTED December 2, 2012)

ABSTRACT

Objective: To compare the experiences of women with metastatic breast cancer (MBC) in computer-mediated and face-to-face support groups.

Method: Interviews from 18 women with MBC, who were currently in computer-mediated support groups (CMSGs), were examined using interpretative phenomenological analysis. The CMSGs were in an asynchronous mailing list format; women communicated exclusively via email. All the women were also, or had previously been, in a face-to-face support group (FTFG).

Results: CMSGs had both advantages and drawbacks, relative to face-to-face groups (FTFGs), for this population. Themes examined included convenience, level of support, intimacy, ease of expression, range of information, and dealing with debilitation and dying. CMSGs may provide a sense of control and a greater level of support. Intimacy may take longer to develop in a CMSG, but women may have more opportunities to get to know each other. CMSGs may be helpful while adjusting to a diagnosis of MBC, because women can receive support without being overwhelmed by physical evidence of disability in others or exposure to discussions about dying before they are ready. However, the absence of nonverbal cues in CMSGs also led to avoidance of topics related to death and dying when women were ready to face them. Agendas for discussion, the presence of a facilitator or more time in CMSGs may attenuate this problem.

Significance of results: The findings were discussed in light of prevailing research and theories about computer-mediated communication. They have implications for designing CMSGs for this population.

KEYWORDS: Computer-mediated communication, Online support, Breast cancer, Metastatic, Support group, Face-to-face

INTRODUCTION

Online support is sought by people who have many different conditions and concerns, including depression (Griffiths, Calear & Banfield, 2009), eating disorders (Eichhorn, 2008), addiction (Cunningham, van Mierlo & Fournier, 2008), HIV (Bar-Lev, 2008), disabilities (Smedema & McKenzie, 2010), diabetes (Chen, 2011), caregiving for dementia patients (Yoo, Jang & Choi, 2010), and cancer (Vilhauer, 2010; Hoybye, Johansen & Tjornhoj-Thomsen, 2005; Shaw et al., 2006; Sharf, 1997), to name but a few.

Much research has been done on the perceived benefits of online support groups or computer-mediated support groups (CMSGs) for various populations (Andersson et al., 2005; 2006; Devineni & Blanchard, 2005; Winzelberg et al., 2003; Vilhauer, 2009) and on communication patterns within them (Coulson, 2005; Coulson, Buchanan & Aubeeluck, 2007; Rimer et al., 2005; Winefield, 2006) but few studies have examined the differences between face-to-face (FTF) and online or computer-mediated communication (CMC) in support groups. Many studies have found that online groups are more convenient, because access is possible despite temporal and geographical barriers (e.g., Coulson, Buchanan & Aubeeluck, 2007; Rice & Katz, 2001; White & Dorman, 2001). Writers have suggested that interaction in online groups may be more deliberate

Address correspondence and reprint requests to: Ruvanee P. Vilhauer, Psychology Department Felician College, 262 South Main Street, Lodi, New Jersey 07644. E-mail: vilhauer@felician.edu

because group members are more able to reflect before communicating (Coulson, Buchanan & Aubeeluck, 2007), and that CMC is associated with more self-disclosure, probably because users feel an increased sense of anonymity (Wright & Bell, 2003; Coulson, Buchanan & Aubeeluck, 2007; Coulson & Knibb, 2007; Mallen, Day & Green, 2003). Some have reported (Rains & Young, 2009) that even stigmatized topics are easily discussed by members of computer-mediated groups because of the reduced social cues in these groups.

Discussing stigmatized topics is critical in support groups for women with metastatic breast cancer (MBC), for whom death and dying are primary concerns. MBC is a cancer that originates in the breast and spreads to distant sites. Women with the condition are at risk for psychological difficulties and social isolation because of disease symptoms, treatment side effects, and anticipation of impending disability and death (Vilhauer, 2008). Qualitative research suggests that women with metastatic disease perceive MBC-specific groups to be more helpful than mixed-stage groups (Vilhauer, 2011), but lack of programmatic funding and other resources may make it difficult to provide FTF groups (FTFGs) dedicated to women in this advanced stage of disease. It may be easier to provide computer-mediated groups. Therefore, finding out whether CMSGs compare favorably to FTFGs for this population is important.

This study was carried out to gain an understanding of how experiences of women with MBC might differ in CMSGs and FTFGs. The analysis of women's accounts will be examined in light of prior research and prevailing theories of computer-mediated communication.

METHOD

Participants

The participants were 18 women with MBC who participated in a larger mixed-method study of CMSG use (Vilhauer, McClintock & Matthews, 2010), and were also currently, or had been previously, in a FTFG. The larger study had a sample size of 30. Women were eligible to participate in the larger study if they reported having a MBC diagnosis, no concurrent chronic illness or medical condition likely to affect quality of life and no diagnosis of psychiatric illness before being diagnosed with MBC. Women were also required to have access to a computer and e-mail, familiarity with using e-mail, and to not be regular users of other MBC CMSGs.

Recruitment

The study was conducted from 1999 to 2000. Recruitment for the larger study was through letters to on-

cologists and staff at community support centers, BC clinics and organizations nationwide, and through flyers posted at cancer clinics. Women who contacted the investigator were interviewed by phone to determine eligibility before being enrolled in the study.

All participants gave written informed consent for participation in the study protocol, which was approved by the Institutional Review Board (IRB) at the University of Chicago, where the initial study was carried out. The protocol for the present analysis of interview data was also approved by the IRB at Felician College.

Groups

Each participant in the larger study was placed in one of three unmoderated CMSGs created specifically for the study. Ten to 11 women were in each group. An asynchronous listserv format was used for the CMSGs. (This format was deemed appropriate given the state of technology at the time of the study.) Women could send messages to all group members simultaneously, but did not have access to individual members' e-mail addresses. At the outset, each woman was e-mailed a welcome message that explained how to access the group via e-mail, and requested that women try to maintain a supportive, caring environment. Women were encouraged to communicate freely, expressing not only positive but also negative feelings. All messages sent to the groups were recorded. At the end of the study, women who wished to remain in touch with other consenting members of their groups were given the e-mail addresses of those members.

Interviews

Phone interviews were conducted after participants had been in their CMSGs for four months, or at the time they withdrew from the study.

Eighteen interviewees were selected for the current analysis from the 20 for whom interviews were available. (All 22 of the participants who completed the larger study were interviewed except for three who either could not be reached or whose illness severity had increased. Two study dropouts were also interviewed to maximize the diversity of opinions expressed; resulting in a total of 21 interviews, but one interview could not be transcribed due to an audiotape malfunction.)

The 18 interviewees were selected because they were currently, or had been previously, in a FTFG. One of the 18 interviewees selected for the current analysis, although not in a formal FTFG, interacted frequently with a group of women who were receiving chemotherapy along with her; because she considered this group to be an informal support group,

she was included in the sample. At the time of the interview, all 18 women were in an unmoderated CMSG set-up for the study.

Interviews were open-ended, with a view to gathering information about the participants' experiences in the CMSGs. Women were also asked about their experiences in FTFGs. Questions, such as "Was the group helpful to you? What was most helpful? How did you feel about being in the group?" were asked to begin the conversation, but women were encouraged to talk about anything they wished to broach. Questions were asked as needed to probe the women's views about how CMSGs compared to FTFGs. Interviews lasted between 30 and 90 minutes. All interviews were audiotaped with the participants' permission, and professionally transcribed. Transcripts were compared to audiotapes to ensure accuracy.

Interviewees were mostly middle-aged (mean 54.9 years; maximum 70 years; minimum 43 years). All identified themselves as White. Fifteen (83%) were married and lived with a spouse. Annual household income ranged from \$300,000 to \$35,000 (median \$58,500). Eleven (61%) were college-educated and five (28%) had graduate degrees. Time since diagnosis of metastasis ranged from 68 to 1 months (mean 22.3 months).

Data Analysis

Interpretative phenomenological analysis (IPA; Smith, 1996; Smith, Flowers & Osborn, 1997; Smith, Jarman & Osborn, 1999) was used to analyze interviews. The goal of IPA is to achieve an in-depth, insider's view of participants' experiences. IPA recognizes that the participants' accounts of their experiences are filtered through the researcher's interpretative lens. I was a silent observer of the e-mail interactions between CMSG participants on a daily basis over the course of many months. The understanding developed through these observations helped me to interpret the interview data.

The process used was similar to that used in a previous analysis of interview transcripts (Vilhauer, 2011). Interview transcripts were analyzed sequentially, and in detail. Interviews were read several times to get a picture of each interviewee's experience as a whole. Notes were made to summarize each woman's experience in her group(s). Themes that related specifically to the use of online versus face-to-face communication were noted in the margins. Some themes were combined as the process went on, or subsumed under superordinate headings. Portions of interviews that illustrated each theme were copied and pasted into a table and evaluated for similarities and differences between accounts. Interviewees' statements

were kept in context by constantly reviewing the interviews in their entirety. The themes emerging from the transcripts were then grouped into clusters. Clusters were rearranged to take into account interconnections between themes.

An assistant who was familiar with the study and the topic also independently analyzed a subset of the interview transcripts using the initial themes. The two sets of analyses were compared to increase the credibility of analysis. Smith (1996) suggested that the credibility of qualitative research could also be evaluated on the basis of internal coherence and presentation of evidence. Internal coherence is the extent to which the argument presented is consistent and supported by data. The presentation of evidence can increase credibility, because readers can evaluate whether interviewees' accounts support the interpretations made. Quotes are provided below to illustrate themes. Pseudonyms are used to protect the participants' identities.

RESULTS

Themes arising from the interviews related to convenience, level of support, intimacy, range of information, dealing with debilitation and dying, having an agenda and having a facilitator.

Convenience: "On Your Own Terms" Vs. "I Just Didn't Have the Time"

Five interviewees commented on the convenience of their CMSGs. Women who lived in rural areas without easy access to FTFGs, and women who had difficulty attending FTFGs because of illness symptoms or treatment side effects found CMSGs particularly helpful. Sally (48 years), said:

"And it was really helpful to me because, I think I've told you that I live so far away from everything that it's very difficult for me to join a support group . . . It was extremely difficult, and then the thing is, is that right now with the lymphodema, I'm going every day to [another town], and that's like an hour and 10 minute drive. And I mean, you're not going to feel like going to a support group. And what I do is, I come home and you know, I'll turn the computer on, and I'll read the e-mail."

Paula (53 years) had been in FTFG groups previously, but had decided not to join one after she was diagnosed with a metastasis. Explaining why she liked her CMSG she said:

"... It doesn't have to be locked into an hour on a Tuesday night. You know what I mean? It can be

a responsive thing that can take place on your own terms, when you have the energy, and the strength.”

This flexibility may have given women a greater sense of control, which is important because the illness, and treatment regimens and side effects, can leave women feeling that they have little control over their lives. Elizabeth (50 years) said:

“I think it was great having a support network, you know, in my computer room. Not having to get into the car and get someplace, put something on the calendar. It was really great having it totally available at my convenience. When I wanted to interact with people and when I didn’t, it was totally under my control.”

An opposing view was held by one woman, Olivia (45 years), who was less connected than most to her CMSG. She found reading the messages from other members time-consuming. She reported that the busy nature of her life and her lack of computer literacy contributed to her difficulties with her CMSG.

“... So I just didn’t have the time, and I would find out when I would get home and sit down, it took me so long to read the mail, that by the time it came for me to write, I was too tired to write.”

Level of Support: “You Could Find Somebody at 2 and 3 in the Morning”

Five interviewees suggested that the level of support was greater in a CMSG than in a FTFG, because of the constant presence of fellow-members, archiving of support messages and/or the greater possibility of getting their concerns heard.

Four of the five mentioned that they appreciated the constant presence of the fellow-members of their CMSGs. Such constant support is particularly useful for women with metastatic disease, who are often troubled by anxiety and fear related to their illness. Interviewees appreciated being able to communicate with others without having to wait for a weekly meeting, whenever they needed support or reassurance. Maddie (58 years) said:

“And I do think that online, the wonderful thing about online support, when I was first diagnosed, this was, I had so much to absorb of this that I wasn’t sleeping well and everything. And with online support, there’s chances that you could find somebody at 2 and 3 in the morning that you can talk to.”

A fifth interviewee, Elizabeth, pointed out that messages could be read long after they had been sent.

“And the one thing that is really great about email is that unless people empty their email boxes all the time, that information is still there ... So in that respect it’s a treasure trove.”

This fact may also have allowed women to feel that support was constantly available. Three of the five women said that the CMSGs also provided more opportunity for getting their concerns heard. Since time is limited in a FTFG that meets weekly or bi-weekly, not all members have a chance to broach issues that are troubling them. Time tends to be allotted to supporting those whose disease is progressing most aggressively, or to those who have recently received disturbing test results. In a CMSG, on the other hand, members can write as much as needed to convey their concerns, however mundane or trivial they might seem.

“... if somebody comes in with major bad news, like you know, they got really bad scan results, and their disease is progressing aggressively, then there is a sense that the group time is going to be devoted to that person. And other people feel then, oh well, what I have to talk about is irrelevant or not as important. And there wasn’t that feeling with being online, and that’s kind of what I wanted to explore, can we bring up any concern that we have regardless of how minor they might seem to somebody else. And that was really nice.” (Audrey, 51 years)

Intimacy: “A Different Kind of Knowing”

Four interviewees suggested that, for this particular population, a CMSG affords more opportunity for getting to know others intimately than does a FTFG. Mae (59 years), contrasting her FTFG to her CMSG, said:

“I think it is, I don’t know if it’s closer, it’s just different by virtue of the face-to-face versus you know, not seeing, not having a picture of these ladies in the e-mail group. And yet, we do maybe, probably know them more intimately. The e-mail support group people more intimately ... It’s just a different kind of knowing.”

Women attributed the greater intimacy not only to having more frequent communication in CMSGs, but also the opportunity to discuss more details about each other’s lives. In a FTFG, because of the limited time available, there is less opportunity for members to discuss non-illness related aspects of their lives.

Talking about her FTFG, Audrey said:

“... I had been part of a [face-to-face] support group for metastatic cancers here, and I felt that everybody was focused on the disease. And how horrible it was to have metastatic cancer, and how terrible the doctors and the medical system was, and all of that. And I would leave the group feeling worse than when I arrived. And I finally you know, resigned from the group after about 3 months. And I didn't feel that way about this group at all. It's like people were expressing their concerns and anxieties but there was also this sense of, well, I'm going to continue to live my life, and I'm going to garden, and I'm going to go on vacation, and I'm going to be there for my family, and it seemed more balanced to me.”

Three interviewees, Ginny (56 years), Edith (43 years), and Lucy (70 years) held the opposite view, suggesting that intimacy was low in their CMSGs. (Their experiences could not have been simply a function of their particular CMSGs, since they were in three different CMSGs and the women who expressed opposing views were in the same CMSGs.) The three women attributed the reduced intimacy to lack of physical presence. Ginny, a hairdresser, said she was used to interacting with people more directly.

“Probably just because I am a people person, coming in contact with them directly rather than just typing, you know. And not knowing who you're seeing, you know. I mean, I'm not saying there's no attachment. I'm just saying that there's much more when I have physical contact with the person.”

Edith, who had previously dropped out of many FTFGs as well, thought there was insufficient emotional content in her CMSG. Unlike several of the other interviewees, she wished the focus of her CMSG had been limited to cancer. Her criticism of her CMSG appears related to the group's reluctance to discuss death and dying, which is described later in this data analysis.

“It was very, almost mundane to me, the level on which they were supporting each other ... and there was just, I don't know whether it was a hesitancy or a fear, or just, it's just not done. But none of them put much emotional content into anything.”

Six interviewees, including two who had mentioned having more intimacy in the CMSGs, said that it took longer for intimacy to develop in their CMSGs. Lucy, who had said that she had felt closer to her FTFG than her CMSG, said:

“I think the personal contact [in the FTFG] makes you feel closer and more like a family. But I also think that if you're in the Internet group longer you would get that feeling. Because I have a different feeling now than I had in the beginning. You know, I feel more like I know them. But I didn't correspond enough to get to know them as well as I would have liked to.”

The slower development of intimacy in a CMSG seemed to be largely due to the absence of visual cues that are present in FTFGs. Elizabeth said,

“... Well, I think it was much slower getting started than a face to face group would be. I know that when I was writing to people, and I still feel this is true, even now, that in a face to face group, when you meet somebody you can receive their body language. The nodding of the head, you can sort of scope them out, well, this person looks like she might be feeling tired today. She looks like she might be really excited about something. She looks, you can sort of check out where they are in time and space, and judge your comments that way, or inquire a little bit more into what may be going on for them so that in a sense we can be more responsive to one another.”

Three interviewees suggested that occasional meetings or reunions might have accelerated the development of intimacy in the CMSGs, and one suggested that swapping of photographs might have done so.

Ease of Expression: “You Kind of Just Flow” Vs. “You Don't Have That Give and Take”

Four interviewees indicated that they were able to express themselves better in a CMSG. Mae's comments suggested that email gave her a sense of anonymity.

“... Email allows us all to hide out, so to speak, for lack of a better explanation.”

Members could express their thoughts more clearly and with fewer concerns about saying the wrong thing because they had time to consider and revise what they had written.

“Although the benefit of e-mailing is that you can stop and think about what you want to say next, or let the thoughts and feelings come in, you know and then you type it out. So you don't necessarily have to be as spontaneous, or if something did occur to you later. You know, a couple of minutes later, back up to it, or something. So I like that, being

able to sit and think about whatever you're saying, or think about what I just read, and read it over a couple of times, before I would respond to it" (Sara, 61 years).

Another factor that facilitated communication was the absence of an interlocutor who might interrupt the flow of thought.

"And I just, I think, as in writing anytime, whether it be in a diary or journalizing, or whatever, I just think you kind of just flow, you know, with speaking. Probably because you don't have that immediate interaction . . . So you stay focused, momentarily, on wherever you are" (Mae).

However, two interviewees, Lucy and Elizabeth, mentioned that the absence of immediate interaction can impede communication by diffusing focus.

" . . . When you're writing, you can't say as much as when you're sitting there going back and forth, responding immediately to one another . . . Well, you know, somebody says something and then comes back to you and by the time you respond, you know, you don't have that give and take immediately . . . Well, I think, yeah, and a lot of things get not responded to because by the time you respond other things have happened. And you bring those things up, instead" (Lucy).

In addition, Elizabeth found e-mail hampering because of her high attention to detail.

"I'm not one of those people who is really good at writing those terse little concise emails that go out with misspelled words and hardly legible but you get the gist of the message, it got out quick. You know, I like to write in complete sentences and spell correctly and phrase my thoughts exactly the way I want to . . . So it ended up being so long . . . so a few times there were things that I just couldn't, I just couldn't get the energy to get them down on paper, so to speak. And other times . . . I wasn't sure whether it took me a while to really be confident that people would actually read the email."

Range of Information: "People All Across the Country"

Information is at a premium for most women with metastatic breast cancer, since in order to explore all avenues for prolonging life, they must know about new drugs and treatments available at any given time and about on-going clinical trials. It is through

networking with other women with the disease that most of this information is acquired. One interviewee mentioned that a CMSG can allow women from many geographical areas to correspond about these matters.

"But the people all across the country getting involved in different trials, different treatments, different philosophies about how to handle this . . . And I know one time I mentioned a trial that I had researched in the beginning, but I decided against these because they were so far from home, there was one in LA and one in Portland, and she actually knew people that were in both of those trials . . . And she could tell how this person was reacting to the drug. You know, because they communicated about that over the Internet" (Lucy).

Dealing with Debilitation and Dying: "Stepping Back" Vs. "They Just Don't Have To Answer"

Four interviewees mentioned that CMSGs, unlike FTFGs, allowed them to receive support without being overwhelmed by exposure to the prospect of debilitation and dying.

Hilary, age 56 years, said that she had contemplated suicide when she began going to a FTFG after she was diagnosed with MBC.

"That can be, you know, to see what people are going to go through, what you might have to go through down the line, what people are going through. And people breathing through tubes in their throat, and just looking very sick. And I think you could talk to people on an e-mail basis and not have that, I mean, it's not that I didn't have sympathy for them, but, you know, it's frightening when you see people you think, oh no, am I going to be like that? That's not the way I want to go. I mean, to begin with I had thoughts of suicide, I thought well, I just really would perhaps take my chances, just go without chemotherapy and, you know, if it gets too bad just save up some pills and take them, and have it all over with rather than go through all of this."

What was helpful to women in a CMSG was not being able to see physical evidence of deterioration. Geri (63 years) said:

"I think it's somewhat easier when it's on the Internet than when you see a person and you see them as a, you see what they look like . . . You don't see the physical disability that the person is going

through, even though you hear about it. It doesn't quite register."

Similarly, women can participate in a CMSG and still not engage in some discussions, and so it may offer a less threatening alternative to a FTFG, in which women might be compelled to face realities they are not ready to face. Mae (aged 59) said that she had felt hesitant about discussing death and dying in her FTFG.

"This question came up in our face-to-face group yesterday. One of the ladies said, she asked the group about talking about final, you know, wills, and death and dying, and whatever, and my comment back to that was, I don't know that we want to do that only because everybody is at a different place with that . . . We're all at different places at different times, whereas in the e-mail group, you know, we've talked about it to some degree and you have the choice, you know, of kind of stepping back and saying, I don't feel like talking about this right now, you say to yourself, so you just don't comment. On the other hand, if you do want to comment, you know, that's good, too. So maybe two people can swap some stories, or some ideas, and the others if they don't want to be involved, just don't get involved."

However, CMSGs may also prevent women from addressing fears when they are ready to do so. Women who have come to terms with the possibility of dying from the disease need a venue to talk about this subject, which often weighs heavily upon their minds. Sara, who had accepted the likelihood that she will die from the disease, had this to say:

"I feel like I know that I want to, and I need to, talk about that. Because that's part of this . . . And, of course, I started really thinking about, wow, what's going to happen? What's ahead? What's it going to be like? For me, it helps to talk about it. Maybe not for everybody, but for me, it does. It's something, it's like if I could play it over in my mind, then it's not — it takes some of the scariness away because it's not as unknown, you know."

It is noteworthy that this topic was avoided for the most part in all three of the CMSGs in this study, even though many other anxieties and fears were often discussed. Sara said:

" . . . the only thing that I felt like was kind of lacking was, we really never got into deep, serious conversations about our dying. About having the whole situation go really bad on us, and to be facing

what appeared to be the end of our life. And a couple of times, different little things came up, and I felt like I had kind of put it out there, but nobody ever responded or picked up on it."

Paula felt that this subject was one that was difficult to discuss because of its very nature, and that its failure to emerge as an important topic of discussion in the CMSGs was not due to the type of communication possible via e-mail per se. Talking about dying provokes fear both in the speaker and the listener.

" . . . Fear . . . It would have been the same, regardless [of whether it was an on-line or face-to-face group]."

But the comments of four interviewees suggested that the absence of body language cues exacerbated the difficulty of communicating in CMSGs about an issue as sensitive as the possibility of imminent death.

"I think you have the body language in a face-to-face support group. I think you can, you can, you know, you ask somebody a question and, you know, how they sit in their seat, or the look on their face or the way they move their hands, or avert their eyes, or whatever. I think that you have a pretty, a better sense of, you know, are they comfortable with the question. And generally, when you're there you're kind of more confronting and they'll probably answer you in some way, whereas on the e-mail maybe a day has gone by, or they just don't have to answer" (Hilary).

As mentioned above, several women felt that the passage of time was an important element of increasing intimacy within the CMSGs. Some were hopeful that even subjects like dying could be discussed if they continued to interact by e-mail with each other often after the study ended. Sara re-introduced the subject of dying to her CMSG at the very end of the study; because recording of online conversations for the study ceased shortly after this action on her part, it is unknown whether a satisfying discussion of this topic emerged between the women after that point.

Agenda: "Something to Start Out with"

Two interviewees suggested that having an agenda may have allowed specific topics to get addressed.

" . . . I just thought a topic would give us, you know . . . it's kind of like we would have something to start out with, you know, on a weekly basis, or whatever, a particular subject if we wanted to address it. Things that we had learned that we could pass

on. Some people, you know, will bring things up and talk about them and others don't" (Mae).

Facilitator: "Could Zero in"

Having a facilitator may also promote honest communication in CMSGs. When painful topics are introduced into CMSG discussions, these can remain unaddressed because of the nature of e-mail interaction.

"And generally, when you're there [in a FTFG], you're kind of more confronting and they'll probably answer you in some way, whereas on email maybe a day has gone by, or they just don't have to answer" (Hilary).

Six interviewees mentioned that questions asked sometimes did not get answered in the groups. Five interviewees suggested that the presence of a facilitator might have addressed this problem and promoted healthier communication among group members.

"... Because a facilitator could zero in, you know and bring it out in the group a little more" (Sara).

The presence of a facilitator might have helped to alleviate any discomfort experienced by those who were unsure, because of the absence of nonverbal cues, about the appropriateness of broaching difficult subjects.

A facilitator might also have helped to alleviate the anxiety that can arise when members stop writing to a CMSG. Silence is interpreted differently in a CMSG than in a FTFG, particularly in this population. It can mean that someone has become very ill or possibly died.

"Say I formed a fondness for one of the women, and I don't hear from her for four weeks, and I can't get in contact and say, what's wrong, are you OK, I'm worried about you. That increases an anxiety level, you know" (Beth, 50 years).

Four interviewees mentioned having had concerns about silence from fellow members. The anxiety resulting from the assumption that a member has sickened or died can make people withdraw from the group. Declining participation in an un-moderated CMSG has the potential for snowballing because members, not knowing why others are writing less to the group, might attribute motives of disinterest or lack of attachment to them.

DISCUSSION

This analysis of interviewee comments suggests that, for this population, CMSGs compare favorably to

FTFGs in some ways, and unfavorably in other ways. Some findings are in line with the findings of other researchers on different populations, but other findings are novel. One idea that has not been previously discussed in the research literature is the notion that CMSGs could help more with early adjustment to a diagnosis of a progressive illness than a FTFG. Women who are not yet ready to face the reality of prospective debilitation and death, and especially those who are recently diagnosed with a metastasis, may be more willing to join a CMSG than a FTFG because a CMSG could give them needed support while shielding them from acute distress during a vulnerable period. The online medium allows them to regulate the rate at which they are exposed to the reality of their diagnosis. Acceptance is the most common coping strategy adopted by women with MBC (Heim et al., 1993; Kershaw et al., 2004; Svensson et al., 2009), but to my knowledge, no research has explored the process by which women come to accept a diagnosis of metastasis. The process model of coping suggests that coping styles are likely to change over time in individuals diagnosed with life-threatening illness (Lazarus, 1999). The model of grief proposed by Kubler-Ross (1969), suggests that people with terminal illness go through five stages from denial to acceptance. In the short term, denial may serve a protective function for those diagnosed with chronic illness (Kubler-Ross, 1987). Because support group use has not been studied much in women with MBC, we do not know whether fear of having to deal with physical evidence of disability is a significant barrier to their joining face-to-face support groups. A previous analysis of interviews from women in this study suggested that communicating in CMSGs made it easier for some women to communicate in FTFGs (Vilhauer, 2009), which supports the idea that joining a CMSG may be a valuable first step after diagnosis of MBC. This topic warrants further study, since other researchers have reported that women with MBC often have unmet needs for support (Aranda et al., 2005).

Although the lack of physical presence can be an advantage of CMSGs for women during their struggle for acceptance of their diagnosis, the absence of visual cues can also be a disadvantage, especially for those who are ready to discuss death and dying. The finding that the absence of visual cues may hinder communication about death and dying runs counter to much previous research on computer-mediated communication. Previous research suggests that discussion of stigmatized topics is more frequent in CMSGs because social cues are attenuated (Rains & Young, 2009). One might also expect that fears of dying would be freely discussed in CMSGs, given that many writers have noted that there is more self-disclosure in computer-mediated

communication than in face-to-face situations (Owen, Bantum & Golant, 2008; Coulson, Buchanan & Aubeeluck, 2007; Coulson & Knibb, 2007; Wright & Bell, 2003; Mallen, Day & Green, 2003; Henderson & Gilding, 2004), because of the sense of anonymity felt in online communication. Suler (2004) suggests that the asynchronicity of online communication, in addition to the invisibility and anonymity experienced during online communication, results in what he calls an “online disinhibition effect.” One interviewee in the present study mentioned that she could “hide out” while e-mailing, which may have increased her ability to let go more when expressing herself. Some interviewees also reported that the asynchronicity of e-mail communication allowed them to let go in writing. However, none of the women interviewed reported being able to let go enough in the CMSGs to freely discuss death and dying.

According to Suler (2004), the absence of visual cues ought to increase disclosure. But according to the women in the present study, the absence of visual cues increased reluctance to bring up difficult topics. Because they could not see other members’ reactions to comments they made, they held back, unwilling to risk causing offense or distress.

Some experimental studies have demonstrated that individuals engaging in FTF and computer-mediated communication did not differ in their ability to accurately gauge the feelings and reactions of their interactional partners, despite the lack of affective information in the computer-mediated situation (Boucher, Hancock & Dunham, 2008). The present study suggests, however, that there are non-experimental situations in which interpersonal interaction about sensitive issues is impeded by the absence of such cues in computer-mediated communication. Some interviewees suggested that a facilitator may circumvent this shortcoming of CMSGs for the MBC population. Owen, Bantum, and Golant (2009) have noted that the difficulty of interpreting emotional tone without visual cues poses a significant challenge to facilitating CMSGs for cancer survivors. No previous research has been published on communication patterns in moderated CMSGs for individuals with terminal illness, so there is no empirical data on whether discussions of death and dying can be effectively facilitated via computer-mediated communication.

Some interviewees indicated that intimacy was slower to develop in their CMSGs than in FTFGs. It is possible that given enough time, women may have adapted to the online communication medium and become comfortable enough to discuss concerns relating to death and dying. This possibility is in line with the social information processing theory of computer-mediated communication (Walther, 1992), which proposes that relationships develop more

slowly in computer-mediated contexts, but are likely to develop to a similar level as face-to-face relationships if given enough time.

Some interviewees suggested that more intimacy could be achieved in CMSGs than in FTFGs. Because members do not need to compete for speaking time in the parallel communicative environment of a CMSG, and because there is no set meeting time, they have the capacity to exchange much more information about their lives than is possible in a FTFG. This is particularly important for this population, because hearing about non-illness related aspects of other members’ lives can inspire hope of coping effectively and living well despite the illness (Vilhauer, 2009).

Interviewees’ comments about the convenience of CMSGs and the constant availability of support through them echo the findings of previous studies of CMSGs (e.g., Coulson, Buchanan & Aubeeluck, 2007; Rice & Katz, 2001; White & Dorman, 2001). Women with MBC often suffer anxiety when they experience new symptoms or are about to undergo tests (Vilhauer, 2009). Having access to support when they need it rather than having to wait for a specific meeting time can therefore be particularly helpful to them. The CMSGs in the present study were set up via mailing lists, and so members were only able to communicate asynchronously. Although asynchronicity has special advantages, such as giving members the ability to reflect on messages and edit their own responses, support may be even more available to members in CMSGs using more current technology that allows for synchronous communication (e.g., instant messaging). Having access to both asynchronous and synchronous channels of communication within a CMSG may have added benefits for members (Rains & Young, 2009).

One limitation of the present study is the length of time that has elapsed since data was collected. However, although technology has evolved considerably since 2000, and CMSGs can now be offered in many different formats, the study findings can still provide useful information. No other studies that examine communication within CMSGs for metastatic cancer have yet been published. Bender, Jimenez-Marroquin, and Jadad (2011) who conducted a study of Facebook-based breast cancer support groups, cite studies conducted as far back as 1997 (Sharf, 1997) that suggested that Internet breast cancer groups facilitate the discussion of stigmatized subjects. The present study suggests, however, that critical discussions of death and dying may be suppressed in the subpopulation of breast cancer CMSGs that serve those with metastatic disease, although the CMSGs have many other benefits. The study can inform the design of CMSGs that might be offered via today’s technology, such as

through online social networks; it suggests that the presence of a professionally-trained facilitator, and possibly discussion agendas, may be needed to offset the absence of visual cues in CMSGs for this population.

Despite the drawbacks of CMSGs described by interviewees, questionnaires and previously analyzed interview data showed that satisfaction with the groups was high. All but one of the participants who completed the study reported having benefited from the groups and wanted to stay in touch with group members after the study ended (Vilhauer, McClintock & Matthews, 2010). This suggests that communication in CMSGs warrants further study, so that such groups can be made maximally effective for this population.

It is important to note that the findings of the present study do not necessarily represent the views of all women with MBC who use CMSGs and/or FTFGs. The interviewees all volunteered for a study in which they had the opportunity to participate in CMSGs, and so may have had more favorable attitudes towards CMSGs than women who did not volunteer for the study. Although efforts were made to recruit a demographically diverse sample for the larger study, the women in the sample were all White and mostly well-educated. This was also a limitation of the study. However, IPA seeks to give an insider's view of a phenomenon, rather than to ensure maximum generalizability (Smith, Flowers & Osborn, 1997). The findings can, despite the limitations of the sample, give healthcare practitioners a better understanding of how to best provide support for this population.

CONCLUSION

The objective of this study was to examine the experiences of women with MBC in CMSGs versus FTFGs. Interviewee reports indicated that CMSGs had both advantages and drawbacks for this population, including many that have been previously reported in other types of CMSGs. One finding that has not been reported in other studies was that CMSGs allowed some interviewees with this progressive illness to receive support before they had fully accepted the reality of their diagnosis. They reported having been reluctant to attend a FTFG, for fear of being overwhelmed by evidence of disability in others or by discussion of topics they were unwilling to face. The features of computer-mediated communication that make this possible, namely the absence of visual cues and the lack of physical presence, however, also led to difficulties in discussing important concerns about death and dying. More time in the CMSG or professional facilitation may mitigate this

disadvantage. Further research, using facilitated CMSGs, is needed to resolve this question.

ACKNOWLEDGMENTS

This research was supported by grant no. RO3 HS10565 from the U.S. Agency for Healthcare Research and Quality.

REFERENCES

- Andersson, G., Bergstrom, J., Hollandare, F., et al. (2005). Internet-based self-help for depression: randomized controlled clinical trial. *British Journal of Psychiatry*, *187*, 456–461.
- Andersson, G., Carlbring, P., Holmstrom, A., et al. (2006). Internet-based self-help with therapist feedback and in vivo group exposure for social phobia: A randomized controlled trial. *Journal of Consulting and Clinical Psychology*, *74*, 677–686.
- Aranda, S., Schofield, P., Weih, L., et al. (2005). Mapping the quality of life and unmet needs of urban women with metastatic breast cancer. *European Journal of Cancer Care*, *14*, 211–222.
- Bar-Lev, S. (2008). We are here to give you emotional support: Performing emotions in an online HIV/AIDS support group. *Qualitative Health Research*, *18*, 509–521.
- Bender, J.L., Jimenez-Marroquin, M. & Jadad, A.R. (2011). Seeking support on Facebook: A content analysis of breast cancer groups. *Journal of Medical Internet Research*, *13*: e16.
- Boucher, E.M., Hancock, J.T. & Dunham, P.J. (2008). Interpersonal sensitivity in computer-mediated and face-to-face conversations. *Media Psychology*, *11*, 235–258.
- Chen, A.T. (2011). Exploring online support spaces: Using cluster analysis to examine breast cancer, diabetes and fibromyalgia support groups. *Patient Education and Counseling*, doi:10.1016/j.pec.2011.08.017.
- Coulson, N.S. (2005). Receiving social support online: An analysis of a computer-mediated support group for individuals living with irritable bowel syndrome. *Cyberpsychology & Behavior*, *8*, 580–584.
- Coulson, N.S. & Knibb, R.C. (2007). Coping with food allergy: Exploring the role of the online support group. *CyberPsychology & Behavior*, *10*, 147–150.
- Coulson, N.S., Buchanan, H. & Aubeeluck, A. (2007). Social support in cyberspace: A content analysis of communication within a Huntington's disease online support group. *Patient Education & Counseling*, *68*, 173–178.
- Cunningham, J.A., van Mierlo, T. & Fournier, R. (2008). An online support group for problem drinkers: AlcoholHelpCenter.net. *Patient Education and Counseling*, *70*, 193–198.
- Devineni, T. & Blanchard, E.B. (2005). A randomized controlled trial of an internet-based treatment for chronic headache. *Behaviour Research and Therapy*, *43*, 277–292.
- Eichhorn, K. (2008). Soliciting and providing social support over the Internet: An investigation of online eating disorder support groups. *Journal of Computer-Mediated Communication*, *14*, 67–78.
- Griffiths, K.M., Calear, A.L. & Banfield, M. (2009). Systematic review on Internet Support Groups (ISGs) and depression (1): Do ISGs reduce depressive symptoms?. *Journal of Medical Internet Research*, *11*, 1–20.

- Heim, E., Augustiny, K.F., Schaffner, L., et al. (1993). Coping with breast cancer over time and situation. *Journal of Psychosomatic Research*, 37, 523–542.
- Henderson, S. & Gilding, M. (2004). I've Never Clicked this Much with Anyone in My Life: Trust and Hyperpersonal Communication in Online Friendships. *New Media Society*, 6, 487.
- Hoybye, M.T., Johansen, C. & Tjørnhøj-Thomsen, T. (2005). Online interaction. Effects of storytelling in an internet breast cancer support group. *Psycho-Oncology*, 14, 211–220.
- Kershaw, T., Northouse, L., Kritpracha, C., et al. (2004). Coping strategies and quality of life in women with advanced breast cancer and their family caregivers. *Psychology & Health*, 19, 139–155.
- Kubler-Ross, E. (1969). *On Death and Dying*. New York: Springer.
- Kubler-Ross, E. (1987). *AIDS: The Ultimate Challenge*. New York: Macmillan.
- Lazarus, R.S. (1999). *Stress and Emotion. A New Synthesis*. New York: Springer.
- Mallen, M.J., Day, S.X. & Green, M.A. (2003). Online versus face-to-face conversations: An examination of relational and discourse variables. *Psychotherapy: Theory, Research, Practice, Training*, 40, 155–163.
- Owen, J.E., Bantum, E. & Golant, M. (2009). Benefits and challenges experienced by professional facilitators of online support groups for cancer survivors. *Psycho-Oncology*, 18, 144–155.
- Rains, S.A. & Young, V. (2009). A meta-analysis of research on formal computer-mediated support groups: examining group characteristics and health outcomes. *Human Communication Research*, 35, 309–336.
- Rice, R.E. & Katz, J.E. (2001). *The Internet and Health Communication: Experiences and Expectations*. Thousand Oaks: Sage.
- Rimer, B.K., Lyons, E.J., Ribisl, K.M., et al. (2005). How new subscribers use cancer-related online mailing lists. *Journal of Medical Internet Research*, 7, e32.
- Sharf, B.F. (1997). Communicating breast cancer online: Support and empowerment on the Internet. *Women & Health*, 26, 65–84.
- Shaw, B., Hawkins, R.P., McTavish, F., et al. (2006). Effects of insightful disclosure within computer-mediated support groups on women with breast cancer. *Health Communication*, 19, 133–142.
- Smedema, S. & McKenzie, A.R. (2010). The relationship among frequency and type of internet use, perceived social support, and sense of well-being in individuals with visual impairments. *Disability and Rehabilitation: An International, Multidisciplinary Journal*, 32, 317–325.
- Smith, J.A. (1996). Beyond the divide between cognition and discourse: using interpretative phenomenological analysis in health psychology. *Psychology & Health*, 11, 261–271.
- Smith, J.A., Flowers, P. & Osborn, M. (1997). Interpretative phenomenological analysis and the psychology of health and illness. In L. Yardley (Ed.) *Material Discourses of Health and Illness*. New York: Routledge.
- Smith, J.A., Jarman, M. & Osborn, M. (1999). Doing interpretative phenomenological analysis. In *Qualitative Health Psychology: Theories and Methods*. London: Sage.
- Suler, J. (2004). The online disinhibition effect. *Cyberpsychology & Behavior*, 7, 321–326.
- Svensson, H., Brandberg, Y., Einbeig, Z., et al. (2009). Psychological reactions to progression of metastatic breast cancer: An interview study. *Cancer Nursing*, 32, 55–63.
- Vilhauer, R. (2008). A qualitative study of the experiences of women with metastatic breast cancer. *Palliative & Supportive Care*, 6, 249–258.
- Vilhauer, R.P. (2009). Perceived benefits of online support groups for women with metastatic breast cancer. *Women & Health*, 49, 381–404.
- Vilhauer, R.P., McClintock, M.K. & Matthews, A.K. (2010). Online support groups for women with metastatic breast cancer: A feasibility pilot study. *Journal of Psychosocial Oncology*, 28, 560–586.
- Vilhauer, R.P. (2011). 'Them' and 'us': The experiences of women with metastatic disease in mixed-stage versus stage-specific breast cancer support groups. *Psychology & Health*, 26, 781–797.
- Walther, J.B. (1992). Interpersonal effects in computer-mediated interaction: A relational perspective. *Communication Research*, 19, 52–90.
- White, M.H. & Dorman, S.M. (2001). Receiving social support online: Implications for health education. *Health Education Research*, 16, 693–707.
- Winefield, H.R. (2006). Support provision and emotional work in an Internet support group for cancer patients. *Patient Education and Counseling*, 62, 193–197.
- Winkelberg, A.J., Classen, C., Alpers, G.W., et al. (2003). Evaluation of an Internet support group for women with primary breast cancer. *Cancer*, 97, 1164–1173.
- Wright, K.B. & Bell, S.B. (2003). Health-related support groups on the Internet: Linking empirical findings to social support and computer-mediated communication theory. *Journal of Health Psychology*, 8, 39–54.
- Yoo, J.H., Jang, S. & Choi, T. (2010). Sociocultural determinants of negative emotions among dementia caregivers in the United States and in Korea: A content analysis of online support groups. *Howard Journal of Communications*, 21, 1–19.