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Living with Metastatic Breast Cancer: A Qualitative Analysis of Physical, Psychological, and Social Sequelae

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Abstract

Women with metastatic breast cancer face a wide range of medical, practical, and emotional challenges that impact their quality of life. Research to date, however, has not focused on the quality-of-life concerns of metastatic breast cancer patients with significant distress. The present study examined a range of concerns among distressed metastatic breast cancer patients, including physical and emotional distress, social functioning, and existential issues. Forty-four distressed women with metastatic breast cancer wrote their deepest thoughts and feelings regarding their illness. These essays were thematically analyzed for effects of the illness on quality of life. Three themes were identified in patients' essays. First, metastatic breast cancer and its treatment may result in a number of quality-of-life concerns, including physical symptom burden, emotional distress, body image disturbance, and disrupted daily activities. Second, social constraints on disclosure of cancer-related concerns may exacerbate patients' distress. Third, many women experience a heightened awareness of life's brevity and search for meaning in their cancer experience. Results highlight a range of quality-of-life concerns following a metastatic breast cancer diagnosis and suggest that addressing social constraints on cancer-related disclosure and the search for meaning may improve patients' psychological adjustment.

Keywords

distress; health; metastatic breast cancer; quality of life; social constraints

Metastatic breast cancer is an incurable illness with a median survival time of 2–4 years following diagnosis (1). Patients face a wide range of challenges, including frequent medical procedures (2), chronic side effects (e.g., occupational disability, pain, fatigue, cognitive impairment, sexual dysfunction) (3–6), and practical concerns (e.g., work and family role

disruption, financial strain) (7,8). Women with metastatic breast cancer are also at risk for emotional distress, including symptoms of depression and anxiety as well as existential distress and loneliness (9–11). Among women with breast cancer recurrence, most of whom had metastases, distress peaked around the time of diagnosis and then declined in the year thereafter (12). However, this trajectory does not characterize the experience of all metastatic breast cancer patients equally well, as many patients report distress even years after diagnosis (7,13). In cross-sectional studies, almost one-third of women with metastatic breast cancer met DSM-IV criteria for a depressive disorder and 6% met criteria for an anxiety disorder (10,14).

Demographic and medical correlates of distress among metastatic breast cancer patients have been identified. Younger age (10,14) and the progression of the disease toward a terminal stage (5) have been associated with worse psychological adjustment. Medical treatment variables have shown mixed associations with distress (10,14,15), whereas physical symptoms, such as pain, fatigue, insomnia, and gastro-intestinal symptoms, have been positively correlated with distress (10,16–18).

Limited evidence suggests that increased social support predicts better psychological adjustment to metastatic breast cancer and that many patients turn to their partners for support (19,20). According to social-cognitive processing theory, talking with others facilitates cognitive and emotional processing of the cancer experience, which, in turn, enhances psychological well-being (21). Consistent with this theory, open communication with family members has been associated with better psychological adjustment among metastatic breast cancer patients (20). Conversely, social constraints, or perceptions of inadequate social support that result in a reluctance to discuss personal stressors, have been consistently associated with distress in various cancer populations (22–24). Social constraints can stem from objective environmental factors (e.g., others' avoidance, denial, and criticism) or individuals' interpretations of their environment (21,25). Although social constraints have rarely been studied in the context of metastatic breast cancer, patients have reported that close others reacted with fear and discomfort when they attempted to discuss their illness (26).

To date, few qualitative studies have been conducted to characterize the quality of life of women with metastatic breast cancer (8,26–28), and none of these studies have focused on women with clinically significant distress. It is important to understand the quality-of-life concerns of distressed patients, as much of clinical care aims to reduce distress. Therefore, the goal of this research was to identify concerns among distressed women with metastatic breast cancer with an emphasis on their experience of physical and emotional distress, social constraints, and existential issues. We analyzed essays of women who were instructed to write their deepest thoughts and feelings about their illness in the context of a home-based expressive writing trial (29). Our analysis could serve to guide the development of future psychosocial interventions by clarifying the nature of their problems.

MATERIALS AND METHODS

Participants and Procedures

The trial design and methods were published previously (29). Following approval of study methods by the Memorial Sloan-Kettering Cancer Center (MSKCC) Institutional Review Board, participants were recruited from MSKCC for an expressive writing intervention trial. Letters inviting study participation and consent forms were mailed to patients approved for contact by their oncologists. Of the 405 patients who were potentially eligible for study participation, 173 (43%) completed a screening assessment via telephone, 183 declined to participate, and 36 could not be contacted. Thirteen participants were not screened because the study ended before they could be scheduled. As previously reported (29), patients who completed screening were significantly younger (58.1 ± 11.5 versus 61.4 ± 13.0 years, respectively, $p < .01$) and more proximal to diagnosis (4.0 ± 3.2 versus 5.0 ± 5.1 years, respectively, $p < .05$) than those who did not complete screening. Race and medical treatment history (i.e., receipt of chemotherapy, surgery, hormonal therapy, and radiation) did not significantly vary between respondents and nonrespondents. Eligibility criteria were: (a) English fluency, (b) at least 18 years of age, and (c) significant distress as indicated by scores exceeding the cutoff (> 4) on the Distress Thermometer (30). Patients were excluded from study participation if they: (a) had severe cognitive impairment assessed with the Short Portable Mental Status Questionnaire (31), or (b) engaged in expressive writing on a daily basis.

Of the 101 patients who were eligible for this study, 98 consented to participate and 90 (89%) completed the baseline assessment. Participants were then randomly assigned to complete four expressive writing or neutral writing sessions over 4–7 weeks. Patients received four sets of writing instructions, lined paper, and envelopes for returning materials by mail. A psychology research fellow called the patient to provide instructions and answer questions before and after each writing session. Patients were told to start writing immediately after hanging up the phone and to write continuously for 20 minutes. Instructions for both writing conditions did not vary across the four sessions. Expressive writing participants ($n = 45$) were instructed to write their deepest thoughts and feelings about their cancer, whereas neutral writing participants ($n = 42$) described yesterday's activities in a factual manner. Instructions were based on published work (22) and are available from the first author. Physical and psychological health outcomes of this expressive writing trial have been published (29).

Forty-four women completed the four expressive writing sessions and mailed all of their essays to the researchers. Thus, a total of 176 essays were analyzed in this study. The majority of participants were Caucasian, married, and well-educated (see Table 1). The average time since diagnosis of Stage IV breast cancer was 4 years, and most participants had received chemotherapy and hormonal therapy.

Data Analysis

Essay data were subjected to theoretical thematic analysis (32). Our goal was to describe the impact of metastatic breast cancer and its treatment on dimensions of quality of life (e.g.,

physical, emotional, social, existential well-being) to guide the development of future interventions. The first two authors generated initial codes after reading all essays. Using Atlas.ti, a software package that aids in qualitative research, the authors then independently coded the essays and met at regular intervals to review the codes and reconcile differences until complete agreement was reached. The authors then sorted the codes into broader themes and checked to ensure that data within themes were consistent, and that the themes were distinct from one another.

RESULTS

Quality-of-Life Concerns

Emotional Distress—Some participants described emotional reactions to the initial breast cancer diagnosis, including feelings of shock and isolation. One woman wrote that “the terror and fear that gripped me was unimaginable... I couldn’t move.” Another wrote that she was “completely devastated and numb” and thought that she was “having a terrible nightmare.” Another noted her “sense of desperation” at the time of diagnosis and wrote that it “alienates you from the vast majority of people you know” and “leaves you feeling abandoned in the truest sense of the word.”

Others reported even more pronounced emotional reactions to breast cancer recurrence. One woman wrote, “I can’t say how frightening it was because I thought I beat it. I felt lonely and terrified of what was to come.” Another described recurrence as “deeply shocking” and said that it was “much harder than the first time because then I had hope of a total recovery.” Another wrote that, since the recurrence, “I have never gained back the feeling of utter laugh-out-loud happiness and freedom I once enjoyed.”

Loss of a sense of control over their lives and fear of future disease progression and disability were common concerns. One woman wrote, “I am a person who lives in black and white and this disease has forced me into a gray area. This is torture at times. I am a planner. I want to know outcomes and it is impossible with this cancer.” Similarly, another wrote that “I have always been one who liked living in the ‘know.’ I just do not know anything anymore. These metastases could go to my brain, lungs, liver, anywhere.” Another stated, “I always have to worry about what comes next. How disabled will this make me? What are my new limitations?”

Physical Symptom Burden—Participants reported a wide range of physical symptoms and most frequently mentioned fatigue (55%) or pain (61%). Individual participants attributed their fatigue to cancer and its treatment, inadequate sleep, medications, the aging process, and increased activity. Some women expressed feelings of guilt or frustration because their fatigue interfered with routine activities. As one participant, a teacher, stated, “I’ve been terribly short-changing the two sections of my class this semester— often sitting semi-comatose with fatigue while they go about their work... I’m not bringing much, if anything, to the class these days.”

Pain was a more anxiety-provoking experience than fatigue and other symptoms, as many participants attributed their pain to disease progression. As one woman wrote, “I am

frightened every time I feel a small pain or sensation in my body that I do not recognize. When that happens, I can't help but think it is the insidious cancer trying to erode other parts of my body. I do not dwell on it, but it flashes across my mind."

Side effects of chemotherapy or hormonal therapy included infections, hot flashes, sexual dysfunction, anemia, neuropathy, nausea, vomiting, diarrhea, weight changes, and inability to taste certain foods. Other symptoms were related to lung metastases (e.g., breathing difficulties) or brain metastases (e.g., imbalance). Cognitive changes included difficulties with concentration, memory, and word retrieval. One woman noted "the big disproportion between how much I'm suffering from these side effects, and how little (so far) from the actual cancer." Another longterm survivor referred to her advanced cancer as a "chronic disease" and stated, "I'm likely to be over-whelmed by side effects... long before the disease kills or disables me."

Participants reported a range of functional limitations associated with pain, paralysis, and other symptoms. One woman described herself as "a cripple" and wrote that "Every joint in my body ached, my brain was fogged... I felt so terrible that I rarely left my bedroom." Several women were bothered by their new dependency on others to do simple tasks. One woman, whose left arm was not functional, wrote, "I have to learn to live with this disability no matter how much I hate it... now I have to depend on my family for little things like getting dressed, opening a jar, or buttering my toast."

Appearance Concerns—Almost half of the sample (44%) reported appearance concerns, which most often included hair loss and changes in breast appearance (i.e., scars, mastectomy, uneven breasts). Women described their hair loss as "devastating," "embarrassing," "more upsetting than I thought it would be," and their "biggest grief." One woman wrote, "When I started to shed like a dying cat I thought I would go mad." Referring to her mastectomy, one woman stated, "I no longer felt like a woman because I was missing one breast." Other appearance changes, such as scars, weight gain, lymphedema, and black nails, were sources of frustration and embarrassment for some participants. Accepting one's appearance was often characterized as a daily challenge. As one woman with lymphedema wrote, "How can I feel attractive when on many days I feel like a Picasso painting?"

Changes in Daily Activities—Many women noted the emotional strain associated with frequent medical appointments and disruption of daily activities. As one woman stated, "Tomorrow, I go to New York for treatment... 12–15 hours of thinking about this disease. That's a lot of time. Sitting in waiting room – isn't anyone else fiery mad! Why do we have no cure?" Another stated that "it's an awful way to live —weekly treatments, regular scans to see if the cancer spread." Tests to determine the extent of disease progression were particularly distressing for many women. One participant noted that "other people do not live their lives from scan to scan. My fears have never gotten easier." Similarly, another long-term survivor wrote, "even after all of these years of living with metastatic cancer, my emotions are so affected by tests results... I find the waiting to be the most difficult part."

In addition to frequent medical appointments, some participants characterized their inability to work as a major change in their daily routine. Whereas some women described feelings of

boredom associated with job loss, others noted a profound shift in their self-concept. One woman wrote, “My identity was always tied into my professional life... and now that’s been taken away from me.” Another described her former job as “contributing to people’s lives” and stated that “not working created a sense of valuelessness for me.”

Many participants worried about the impact of their illness and eventual death on family functioning and viewed their daily activities and conversations as efforts to reduce their family members’ burden. As one woman wrote, “it is very important that I do all I can for my family... like getting the laundry done, keeping the kitchen clean, helping my daughter with her homework... I don’t want to be a burden on my family.” Another wrote, “I worry a lot about my husband. If I should die how will he manage? I’m... teaching him how to do washes, clean, etc.” Other women regularly discussed their illness with family members. One woman wrote, “I now have realistic conversations with my husband. He doesn’t like these conversations but he is becoming more open to them. I now discuss my treatment and progress with all of my children. I hope to make them stronger and... better equipped to deal with life’s issues.”

Experiencing Social Constraints

Twenty-one women (48%) described social constraints on disclosure of cancer-related concerns. Specifically, participants stated that close others denied the severity of their illness and treatment, avoided discussing the illness, and showed discomfort when discussing the illness.

Denial—Participants stated that some family members and friends had difficulty accepting their diagnosis. One woman described her ex-husband as “great, but in denial, telling people that I was really stage three—when my initial diagnosis was stage four.” Another woman wrote, “I really think people believe I am exaggerating my deadly prognosis.” Another recounted an experience with a friend who asked her, “Do you really have cancer?”

Participants also reported that close others denied the severity of their cancer treatment. For example, after one woman told a friend about her upcoming chemotherapy treatments, the friend said, “Oh, you’ll be OK; you will just have mild chemotherapy!” Such statements of denial resulted in a loss of emotional intimacy in their relationships. As one woman stated, “I was looking for someone who would just listen to my fears and concerns and not offer quick solutions like: You’ll be OK.”

Avoidance—Some participants reported that close others, especially their husband, avoided discussing their illness and prognosis. For example, one woman wrote, “My husband will rarely discuss my cancer let alone my death.... He just doesn’t want to believe I am going to die.” Another woman described unsuccessful attempts to discuss her prognosis with her husband. She wrote, “I can’t bring up the subject with him, as he will cut me off and discuss something he plans to do for the day.” As one woman concluded, “people really do not want to hear about dying.”

Other participants restricted their illness-related disclosure in an effort to protect their loved ones from further emotional strain. As one woman wrote, “I do not want to upset my family

and friends, so I basically pretend (most of the time) that I am doing okay— when I'm often not." Regarding her children, another woman wrote, "I watch what I say to them as I don't want to burden them with my feelings or instill any sense of guilt that will emerge when I am gone." Another did not discuss her cancer recurrence with her young children for 1 year following the diagnosis.

Discomfort—Some women noted that family and friends were uncomfortable discussing their diagnosis and treatment. One woman wrote, "People are often fearful of me and really don't know what to say or do." Another stated, "I think the longer I survive with this disease the less friends I will have. They always ask about me and are encouraging but are uncomfortable hearing the 'real facts.'" Some women expressed frustration and loneliness following awkward conversations with family and friends regarding their illness.

Existential Issues

The most common existential issues were a heightened awareness of their eventual death and its impact on their family (43%) and the search for meaning in their suffering (25%). One woman described a change in her outlook on life: "We are all here for a limited amount of time, and cancer patients... got advanced notice of our timeline." Another woman noted her tendency to think of her life as "short spaces" with an awareness of "a limit on time."

Reflections on mortality often centered on the loss of time with family. As one woman wrote, "I want to be there to see my two daughters get married and have children. I want to hold my grandchildren some day. I want to retire some day with my husband and I am afraid that I may not be able to because I will die before that." Another woman wrote about her uncertain timeframe for raising her young children: "I just have so much to do with them... and to teach them. It feels so unfair that I probably will not be given ample time to do this. It's my job—how can God deny me this? Torture."

Other participants attempted to find a reason for their suffering. As one woman wrote, "There is always the 'why me' question - which I know intellectually has no answer - but emotionally - I keep on delving for an answer that sounds right." Another woman with young children referred to her family when asking this question: "From the day of diagnosis, the questions remains, 'Why me?' ... do we really need to torture this family with this disease?... why my children?"

DISCUSSION

This study provides an initial thematic analysis of various concerns among distressed women with metastatic breast cancer. Results underscore the detrimental impact of the disease and its treatment on physical, emotional, and social well-being, as found in prior research (7,10,17,18,20), and provide new information regarding women's daily experiences with this disease. First, our analysis revealed a number of inter-related losses (e.g., loss of professional identity, loss of relational intimacy, negative changes in appearance and functional status) that may contribute to reduced emotional well-being, whereas most studies have examined a subset of factors (e.g., medical variables) associated with patients' distress (10,14). Second, the present research expands the limited literature on social aspects of

metastatic breast cancer (19,20) by providing the first analysis of social constraints. Specifically, patients reported that close others denied the severity of their illness and treatment, avoided discussing the illness, and showed discomfort during these discussions. Finally, prior research has documented metastatic breast cancer patients' heightened awareness of life's brevity (26), but little is known regarding patients' efforts to cope with this awareness. Our analysis indicated that many women viewed their daily activities and conversations as efforts to reduce their family members' burden and prepare them for their eventual death, and other women searched for meaning in their cancer experience.

Results also revealed periods during which quality of life may be most affected by metastatic breast cancer. Specifically, women characterized the time of cancer diagnosis or recurrence as a period of heightened distress and loneliness, as found in prior research (6,12,33). Distress also peaked during follow-up evaluations to determine the extent of disease progression and recovery from acute treatment side effects. Perceptions contributing to women's distress included a reduced sense of control over their lives and a growing awareness of their own mortality. Perceived control has predicted adjustment to early-stage breast cancer (34), and our results suggest that it warrants further study in the context of advanced breast cancer.

In addition to highlighting stressful periods in the illness trajectory, our findings indicate that patients experience a variety of social constraints (e.g., denial, avoidance) that may hinder open communication about cancer. Such communication is critical for cognitive and emotional processing of the illness (21). For socially constrained patients, processing may take the form of distressing intrusions regarding the illness alternating with attempts to avoid reminders of it (35,36). Evidence supports theorized associations of social constraints, intrusions and avoidance, and distress among primarily early-stage cancer patients (22, 23, 37). Our findings suggest that advanced cancer patients also experience constraints on disclosure, which may differ from those experienced by early-stage patients. For example, in this study, social constraints often involved others' reluctance to discuss the patient's prognosis.

Limitations of this study should be noted. First, although this sample was relatively diverse in terms of age and medical variables (e.g., time since diagnosis, treatments received), the majority were Caucasian and well-educated. Future research should consider using purposeful sampling to explore quality-of-life concerns among patients with greater ethnic and socioeconomic diversity. Second, the sample was self-selected, as accrual efforts were linked to participation in an expressive writing trial, and only patients with significant distress were eligible for participation. Further research is needed to examine quality of life among patients with low levels of distress in order to better understand coping efforts and contextual factors that are associated with positive adjustment. Finally, this article was intended as an overview of metastatic breast cancer patients' concerns. The current methods did not allow for follow-up questions regarding the experiences described in patients' writings. Physical and psychological symptoms, social constraints, and existential issues identified in this analysis should be explored in greater detail by both qualitative and quantitative research.

CONCLUSIONS

Our findings carry several implications for future research and clinical practice. First, brief distress screening measures with clinical cutoffs, such as the Patient Health Questionnaire-Depression Scale (38) or the Distress Thermometer (39), may be used to identify patients who warrant further assessment and referral to psychosocial support services. Distress screening may be conducted during stressful periods in the illness trajectory, such as the time of diagnosis or follow-up evaluations to determine the extent of disease progression. Second, a preventative intervention offered to all patients, such as educational materials on coping with their emotions and physical side effects of the disease and treatment, may improve their treatment experience. Research is needed to assess whether preventative approaches result in better management of patients' quality-of-life concerns than other strategies (e.g., routine screening and referral to supportive services). Finally, providing outlets for patients to process their cancer experience, such as inperson and online support groups and psychotherapy, may help patients who feel constrained in discussing their disease. Metastatic breast cancer patients randomized to supportive-expressive group therapy have shown improved mood, reduced traumatic stress symptoms, and more adaptive emotion regulation strategies relative to controls (40–44); however, results of these intervention trials have been mixed (40,45,46). Although supportive-expressive group therapy has been theorized to promote adherence to anti-cancer therapies (47), it has not been found to prolong the survival of metastatic breast cancer patients (46,48,49). In addition, one Cochrane review concluded that trials of cognitive-behavioral and emotion-focused psychotherapy for metastatic breast cancer patients have only resulted in short-term psychological benefits (50). However, another Cochrane review of six studies found that psychotherapy reduced depressive symptoms among patients with advanced cancer (51). Given the limited literature to date on psychological interventions for advanced cancer patients, novel approaches to the management of distress in this population deserve investigation. For example, preliminary findings suggest that meaning-centered psychotherapy designed to enhance advanced cancer patients' sense of peace and purpose in life may improve their emotional and spiritual well-being (52). Given that discussion of mental health concerns with a health care provider is the most important predictor of whether advanced cancer patients will receive services (53), more of these discussions need to occur in oncology clinic settings.

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Table 1Sample Characteristics ($N = 44$)

Characteristic	No.	%
Age, years		
Mean	57.9	
SD	12.1	
Race		
Caucasian	38	86.4
African American	2	4.5
Asian	2	4.5
Other	2	4.5
Education		
12 years	5	11.4
Some college	9	20.5
College or graduate degree	30	68.2
Employment status		
Employed	14	31.8
Not employed	30	68.2
Marital status		
Married or marriage equivalent	30	68.2
Not married	14	31.8
No. of comorbid conditions		
Mean	1.3	
SD	1.4	
Time since diagnosis of Stage IV breast cancer, years		
Mean	4.1	
SD	3.1	
Chemotherapy		
Yes	43	97.7
No	1	2.3
Hormonal therapy		
Yes	34	77.3
No	10	22.7
Radiation		
Yes	29	65.9
No	15	34.1
Breast cancer-related surgery		
Yes	37	84.1
No	7	15.9
Type of surgery ($n = 37$)		
Mastectomy	20	54.1
Lumpectomy	11	29.7

Characteristic	No.	%
Both surgeries	4	10.8
Other	1	2.7
Missing	1	2.7

SD, standard deviation.