

Activities of Daily Living in Women With Advanced Breast Cancer

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Purpose/Objectives: To detail the daily activities of women with advanced breast cancer.

Design: Descriptive, qualitative.

Setting: Six clinical sites in New England. Of the six sites, three were urban, one was suburban, and two were rural, with three sites being comprehensive cancer centers.

Sample: 84 women with a confirmed diagnosis of stage IV breast cancer with a life expectancy of four months or more.

Methods: A secondary analysis of an expressive writing intervention study control group. As part of the control writing group, participants kept handwritten activity logs for four consecutive days. Standard content analysis procedures were used to analyze the transcribed activity logs.

Main Research Variables: Activities of daily living in women with advanced breast cancer.

Findings: 22 codes were identified that depicted the daily activities of participants. Subsequent analysis merged the 22 codes into six themes.

Conclusions: Findings demonstrated that patients with advanced breast cancer are living very full, active lives despite numerous symptoms and cancer treatments.

Implications for Nursing: The study serves as a foundation for the development of interventions to enhance daily functioning. Oncology nurses should counsel women with advanced cancer regarding pacing and self-care activities.

Key Points . . .

- ▶ Women with advanced-stage breast cancer carry out usual family and professional roles while coping with physical challenges and cancer treatments.
- ▶ Napping and activity pacing are essential to the daily lives of patients with metastatic breast cancer to manage pervasive fatigue.
- ▶ Nurses can help women with advanced breast cancer maintain healthy and balanced lives through self-care and activity pacing education, counseling, and coaching.

et al., 2005) and focused on symptom-related changes (Gua-landi et al., 2003) and care activities and interventions aimed at improving women's quality of life (QOL) (Fowler, Rodney, Roberts, & Broadus, 2005; Golant, Altman, & Martin, 2003; Helgeson & Tomich, 2005). However, qualitative research that explores the extent to which women with metastatic breast cancer are able to carry out their daily activities is lacking. The current study was designed to describe, in detail, the daily activities of women with advanced breast cancer. Content analysis of activity logs completed for four consecutive days provided insight into the breadth of activities performed by women living with advanced-stage breast cancer.

Literature Review

Although an extensive amount of cancer research is dedicated to the psychological, social, and physical sequelae of breast cancer, research that specifically focuses on the effect of metastatic breast cancer on women's daily activities is limited. The majority of research has been quantitative, focusing on activities of daily living or functional status at a specific time point (i.e., diagnosis, treatment, or post-treatment or survivorship). Changes in functional status or daily activities after receiving the diagnosis of cancer (Kroenke et al., 2004), after initial treatment for cancer (Given, Given, & Azzouz, 2001), during

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Breast cancer is the most common cancer among women, with the exception of nonmelanoma skin cancers. An estimated 178,480 new cases of invasive breast cancer will be diagnosed in women in the United States in 2007 (American Cancer Society, 2007). The National Cancer Institute estimated that approximately 2.3 million women with a history of breast cancer were alive in January 2002 (Ries et al., 2007). Although some of the women no longer had cancer, many had evidence of advanced disease and continued to actively undergo treatments. The diagnosis of breast cancer, its symptoms, and, consequently, the side effects of treatments create multiple physical and psychological challenges and can have devastating effects on women's everyday lives (Ahlberg, Ekman, & Gaston-Johansson, 2005; Bourjolly, Kerson, & Nuamah, 1999; Kroenke et al., 2004). Many patients with breast cancer report changes in their physical activities, including basic self-care and engagement in work and leisure, during cancer treatment and in its aftermath (Ganz et al., 2003; Hann et al., 1999; Kroenke et al.). For some, post-treatment daily activities gradually return to pretreatment levels; however, others may not fully participate in life activities for many years (Flechtner & Bottomley, 2003) and, in some cases, may not regain a precancer level of activities (Ganz et al., 2003).

Prior research using quantitative methods has measured changes in activity levels of women with metastatic breast cancer (Hodgson & Given, 2004; Kroenke et al., 2004; Scheier

radiation treatment (Bourjolly et al., 1999), and in long-term postsurgery survivors (Polinsky, 1994) have been reported. Virtually absent from the literature is a description of the extent to which breast cancer affects daily activities and the lives of women with metastatic breast cancer over a period of time.

Research has demonstrated that a diagnosis of breast cancer and side effects of breast cancer treatments can have devastating effects on women's lives. Trends in the research literature suggest that breast cancer survivors are likely to be physically and socially impaired as a result of diagnosis and treatment. Given et al. (2001) examined the effects of initial treatment for cancer on older adult patients. The findings indicated that surgery, chemotherapy, and radiation therapy were significant indicators of compromised physical functioning. In a comparison study, Kroenke et al. (2004) found that young women may fare worse than middle-aged or older women in physical and psychosocial dimensions after a breast cancer diagnosis. Bourjolly et al. (1999) examined the role of race in social functioning for women undergoing radiation therapy as a treatment for breast cancer. The results revealed that differences in functioning between African American and Caucasian women do exist, with African American women demonstrating greater decreases in social functioning and performance of household activities.

Research suggests that physical activity and function may not improve with time. Chirikos, Russell-Jacobs, and Jacobsen (2002) demonstrated that breast cancer survivors were more likely than controls to be functionally impaired at a five-year benchmark. Impaired women, in turn, were more likely to reduce work effort and experience downturns in market earnings. Similarly, Helgeson and Tomich (2005) examined the long-term effect of breast cancer on QOL by comparing five-year disease-free women to age-matched controls. The study found that breast cancer survivors reported more difficulties with physical functioning and physical symptoms than controls. In addition, compared to disease-free survivors, survivors with recurrence experienced more general fatigue and intrusive and avoidant thoughts.

Research findings also indicate that women with breast cancer encounter a number of physical symptoms related to the disease and the effects of treatment (Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998; Gualandi et al., 2003; Nail, 2002). Pain, fatigue, and insomnia have been reported as significant and independent predictors of reduction in patients' functional status. The results contrast a study conducted by Polinsky (1994) that found high physical, psychological, and social functioning in breast cancer survivors. The purpose of the current study was to augment prior research by providing descriptions of daily activities of women with advanced breast cancer based on their accounts and directing attention to gender and social contexts of those activities.

Conceptual and Theoretical Framework

The current study was guided by feminist theory, with a core assumption that women's experiences are real and provide the foundation for knowledge (Osmond & Thorne, 1993). The assumption emphasizes that women think, act, and feel differently than men. Feminist theory provided the lens through which women's activities of daily living were viewed. The activity logs gave voice to women's daily activities and provided insight into gender and socially constructed principles that guide them. Presumed ideas about women's daily activities were dispelled

through the detailed descriptions of how the women allocated time and energy to their breast cancer diagnosis and treatment.

Methods

Qualitative description was used to analyze activity logs written by women with metastatic breast cancer. This was a secondary analysis; the activity logs originally were written and collected as part of the control group of a randomized trial of an expressive writing intervention (Bauer-Wu et al., 2003). In the primary study, participants were randomized to one of two groups: expressive writing or control writing. Participants in the expressive writing group wrote about deeply personal thoughts and feelings for 20–30 minutes for four consecutive days. Participants in the control writing group kept an activity log in which they documented the activities they carried out for four consecutive days. Only data from participants in the control writing group were included in the current analysis and report. Institutional review board approval was obtained from study sites for the primary study, and participants signed a written consent form stating that their writing would be reviewed by the researchers and kept anonymous and confidential.

Sample and Recruitment

Women with a confirmed diagnosis of stage IV breast cancer were recruited from six clinical sites in New England. Of the six sites, three were urban, one was suburban, and two were rural. In addition, three of the sites were National Cancer Institute–designated comprehensive cancer centers. Inclusion criteria included a life expectancy of four months or more and the ability to speak, read, and write in English. Women were excluded if medical or mental status precluded meaningful participation as determined by their oncology clinicians.

The convenience sample was recruited through referral by oncologists or oncology nurses or by self-referral in response to study brochures and flyers posted in clinic areas. A total of 112 women met the eligibility criteria, signed written consent forms, and agreed to keep an activity log. Of those, 28 did not return the activity logs and other study materials, resulting in a 25% attrition rate. The sociodemographic characteristics of women who dropped out were similar to those who stayed in the study. The final sample consisted of 84 participants.

Activity Logs

Participants kept handwritten activity logs for four consecutive days according to the following instructions.

- Track and record your activities and the approximate amount of time you spend on each.
- Include any activity breaks, such as naps or quiet reading, that you take.
- Write down how you have felt during the day.

Participants were provided with small writing pads, one for each of the four days, labeled with the study identification number and the day of writing (e.g., day 1). Participants mailed the completed activity logs to the researchers in preaddressed, stamped envelopes.

Each of the activity logs was transcribed by a study staff member and then reviewed and validated by a different staff member. Any identifiable information was removed in the transcription process. Transcribed activity logs were formatted according to guidelines for the qualitative software program NVivo (QSR International) and saved electronically.

Content Analysis

Standard content analysis procedures of identifying, coding, and categorizing patterns in the data (Patton, 1990) were used to analyze the transcribed activity logs. A team of three researchers began by randomly selecting three transcripts from the activity log dataset, which they collectively reviewed and hand coded. Copies of additional transcripts, three to five randomly selected transcripts at a time, were distributed to each team member for independent analysis. During regular meetings, the team discussed discrepancies in coding until they reached agreement. A detailed codebook was developed that defined and described inclusion and exclusion criteria and provided an example of each code (see Figure 1). The researchers analyzed and coded the same transcripts until no new codes were identified. The remaining transcripts were divided among the team and individually coded by hand, using the codebook as a guide. Randomly selected transcripts were reviewed and validated with the team to ensure reliability. After hand analyses, all transcripts and codes were imported into NVivo. Electronic coding mirrored hand coding. Subsequent analyses identified broader themes that revealed the reality of everyday life for women with advanced breast cancer.

Results

Participant Characteristics

Table 1 displays the sociodemographic characteristics of the 84 study participants. The sample was predominantly Caucasian, married, and college educated. The mean age was 52.2 years (SD = 10.6), ranging from 28–79 years. More than half of the sample were working in some capacity, and 91% reported that they were able to perform their daily activities (Eastern Cooperative Oncology Group performance status 1 or 2). Thirty-nine percent had children younger than 18 living at home.

Codes

A total of 22 codes depicting the different activities of the sample were identified. Of those, 12 predominant codes were noted in more than 100 passages (see Table 2).

- Cancer: activities related to cancer care
- Care of others: activities related to meeting the needs of others
- Diversion: activities intended to provide distraction or pleasure
- Household: daily activities that keep the home in order
- Hygiene: activities related to personal hygiene, grooming, and normal bodily functions
- Nap or rest: any resting, which may or may not include lying down or sleeping, performed during the hours of

Description: activities that are performed to enhance one's sense of well-being

Inclusion criteria: activities that are performed with the intention of enhancing one's sense of physical, mental, or spiritual well-being

Exclusion criteria: activities that are explicitly used to distract or serve another purpose other than enhancing one's sense of well-being

Examples: meditating, walking on a beach, getting a pedicure

Figure 1. Example of the Self-Care Code

Table 1. Sample Characteristics

| Characteristic | n | % |
|---|----|----|
| Race or ethnicity | | |
| Caucasian | 78 | 93 |
| Hispanic or Latino | 1 | 1 |
| Other or multiethnic | 4 | 5 |
| Missing data | 1 | 1 |
| Marital status | | |
| Single or never married | 9 | 11 |
| Married or partnered | 63 | 75 |
| Separated or divorced | 11 | 13 |
| Widowed | 1 | 1 |
| Educational preparation | | |
| High school | 14 | 17 |
| Some college | 16 | 19 |
| College graduate | 38 | 45 |
| Advanced degree | 15 | 18 |
| Missing data | 1 | 1 |
| Employment status | | |
| Full-time | 14 | 17 |
| Part-time | 16 | 19 |
| Homemaker | 18 | 21 |
| Retired | 11 | 13 |
| Student | 1 | 1 |
| Unemployed because of disability or illness | 24 | 29 |
| Annual household income (\$) | | |
| < 15,000 | 7 | 8 |
| 15,000–30,000 | 5 | 6 |
| 30,000–60,000 | 19 | 23 |
| 60,000–100,000 | 33 | 39 |
| > 100,000 | 15 | 18 |
| Missing data | 5 | 6 |

N = 84

8 am–8 pm, after waking for the day and before retiring for the night

- Nutrition: eating, drinking, or preparing meals for self or self and others
- Phone: activities reflecting using the telephone or cell phone
- Self-care: activities that imply the intention to enhance one's own sense of well-being
- Social visit: activities reflecting spending time or interacting with others
- Time with family: activities reflecting quality time, interactions, or activities shared with family members
- Work: occupational and professional activities

Themes

Subsequent analysis merged the 22 codes into six themes: impact of cancer, interactions with others, responsibilities, personal well-being and care, communication, and slowing down and pacing (see Table 3).

Impact of cancer reflects the varied activities related to participants' cancer care, such as going to clinics for chemotherapy, doctors' appointments, and picking up prescriptions. The following is an example of a participant's experience with cancer-related activities.

- 6:15 am Friend drove me to hospital for treatment
- 7:30 am Arrived at hospital to register for treatment
- 8:30 am Laboratory work done via implantable port; no problems

Table 2. Predominant Daily Activities of Women With Advanced Breast Cancer

| Code | Examples | Women Reporting Activity | Activities per Woman | |
|------------------|---|--------------------------|----------------------|-------|
| | | | \bar{X} | Range |
| Cancer | Travel to wig fitting, had wig fitting; pick up prescriptions | 61 | 3.34 | 1–18 |
| Care of others | Picked up kids from school, made snacks for kids, picked up my son from his friend's house, drove my other son to gymnastics, helped with homework | 55 | 7.38 | 1–42 |
| Diversion | We relaxed in the family room and watched T.V. until 10 pm. | 82 | 8.29 | 1–22 |
| Household | I spent the next two hours doing housework. While doing laundry, I used the opportunity to continue exchanging winter clothes from the cedar closet with the summer clothes in the upstairs closets. | 82 | 8.87 | 1–22 |
| Hygiene | Took shower, dried hair, dressed | 74 | 4.96 | 1–14 |
| Nap or rest | Tired, from 2–3 pm napped | 68 | 3.03 | 1–11 |
| Nutrition | Made breakfast for myself and daughter | 83 | 10.14 | 1–22 |
| Phone | 9:37 am, started making phone calls (repair, information, appointments) | 60 | 60.00 | 1–13 |
| Self-care | Being a novice gardener, I have discovered how peaceful and relaxing the inner self can get when you have your hand in the soil. Your mind just drifts through your problems, and after awhile, whatever was bothering you seems minimal. | 54 | 3.41 | 1–12 |
| Social visit | I left work at 6:10 pm and met some of my very best friends for dinner. They were taking me to dinner to celebrate my birthday. | 62 | 2.69 | 1–14 |
| Time with family | Walk on beach with husband approximately two hours. Very emotional. Trying to chart our course ahead. Do we need help? I don't want to give up; I want to live as long as I can. We both cried. | 71 | 4.80 | 1–17 |
| Work | Taught seven half-hour swimming classes from 12–3:30 pm. I was able to handle this number of hours well; the 90° heat, however, really knocked me. | 33 | 3.42 | 1–8 |

- 8:45 am Weight, vital signs, and appointment with doctor; talked about future tests. No problem
- 9:30 am Returned to [medical] floor for infusion of paclitaxel; finished at 11:20 am

Interactions with others reflects activities related to meeting people's needs, social visits, and quality time with family.

I get home and the gang's all here, my friends, my hubby, his mom. We perform some cooking feats, plan some dessert. Soon we're out on the patio overlooking the ocean and the newly grass-pulled garden, chewing on fish and corn and wax beans and salad, a quick cleanup.

Responsibilities include work, household chores, and personal business, as well as community service activities, such as volunteering.

Got ready for [work]. At the office I made some phone calls, left messages for people to return calls with info that I need. I'm in the middle of doing my mailings, sending out postcards to the different neighborhoods looking for new leads for new listings.

Personal well-being and care reflect the activities of mental health care, self-care, diversions, religious activities, nutrition, and hygiene.

Laid down on the floor to do my morning stretching exercise. They only take about 15 minutes, but they are a tremendous help in getting my stiff joints and sore muscles moving.

Communication includes activities related to e-mail, written correspondence with loved ones, and telephone calls.

Listen to telephone message. Two calls, both from college friends. Plans are to meet September 17th for reunion (four of us). Do Internet: Answer my e-mails, clean my "mail box" from two months of junk.

The final theme, **slowing down and pacing**, relates to challenges of keeping up with a normal level of daily activities while fighting cancer and striving to pace themselves so they did not overextend themselves on the days that they felt well.

I usually have a minimum of one day per week that I'm out of commission and I deal with it. Doing a lot of physical activity brings on pain and fatigue. I am having trouble keeping up with my housework. This was a very busy day for me, and I was very tired when I returned home. I won't be able to iron and hang up my curtains today, but I'll do it tomorrow. I'm having to take one day at a time. As I write this I am becoming aware of how active I still am even though I thought my activity had been curtailed significantly.

Dominant in the activity logs and emerging from the themes was the importance of **maintaining normalcy**. For the women, maintaining normalcy related to the high value placed on keeping activities as normal as possible, supporting a sense of independence, competency, and control. One woman captured how she felt to begin driving again on her own.

I'm going to drive myself today. Usually my husband has been doing the driving, not because of fatigue but since I lost sight in my left eye. It is great to feel independent and drive myself to [the ice cream store].

The ability to maintain a normal lifestyle amidst breast cancer fostered a positive attitude. A woman wrote,

Take dog for fast (4 mph) walk with girlfriend. (The more exercise the more strong and in charge I feel. I am convinced it is part of the reason I am doing as well as I am.)

Even though the women remained active, they were challenged to balance their activities and responsibilities with continuing to care for themselves. Although keeping up with activities was important for them mentally, physically it was necessary to pace themselves. Most participants (85%) wrote about feeling fatigued, which was the most commonly reported physical symptom. Fatigue also was reflected in the high frequency of naps and resting reported daily. Other notable symptoms that interfered with carrying out daily activities included pain, sleep disturbances, visual changes, and nausea.

Discussion

The activity logs of participants in the study offered an important and rarely seen glimpse of the effects of metastatic breast cancer on daily activities of women living with the disease. The data illustrate multiple responsibilities and demands that women continue to meet despite numerous symptoms, treatments, secondary complications, and cancer-related stressors, in addition to activities and stressors of everyday life. For women who participated in the study, daily activities included maintaining gender and socially constructed roles and responsibilities of being mothers, spouses, daughters, siblings, friends, and employees; managing households; continuing to work; participating in social and community activities; caring for themselves physically, psychologically, and spiritually; and managing cancer.

Although the women clearly were quite active, the study revealed changes in normal activities and evidence of pronounced limitations. The findings are consistent with previous research reporting that many patients with breast cancer experience decreases in physical functioning, including engagement in work and leisure activities (Kriegsman, Deeg, & Stalman, 2004; Kroenke et al., 2004). Although living full lives, the women in the current study did experience physical symptoms. To maintain active lifestyles and cope with the fatigue, the women took frequent rest periods and naps. Consistent with the literature, many women also experienced cancer-related pain, sleep disturbances, and nausea (Dodd, Miaskowski, & Paul, 2001; Nail, 2002). Despite changes in normal activities and increased fatigue and pain secondary to the breast cancer and its treatment, the women found ways to compensate for the limitations and continued to live full and active lives.

Limitations

Limitations exist in the generalizability of the study. Study participants were not chosen randomly, although they were assigned randomly to the control group of the primary study.

Most participants were Caucasian, middle to upper class, and well educated.

Ethnic, socioeconomic, and educational variations limit the extrapolation of the findings to other populations. The findings cannot be assumed to transfer across cultural contexts and types of cancer.

Implications

Research

The study results, as well as its limitations, point to future research directions. Replicating the study in ethnically and socioeconomically diverse populations of breast cancer survivors is warranted. Studies using a similar approach are needed to describe the daily activities of individuals with other types of advanced cancer and their treatments. Based on the findings of the current study and other similar research, interventional studies aimed at enhancing self-care practices, reducing cancer-related fatigue, and encouraging activity pacing across the cancer trajectory should be developed and tested.

Practice and Education

Nurses and other healthcare providers working with patients with breast cancer have roles to play in providing counseling and educating patients about activity pacing and self-care practices.

Although women in the current study continued to live active lives, they often were beset with fatigue. Cancer-related fatigue has been reported as a major obstacle to normal functioning and adequate QOL (Gualandi et al., 2003; Vogelzang et al., 1997). Therefore, oncology clinicians should assess for fatigue, monitor patients' activity levels, and develop personalized care plans to maximize patient functioning and QOL.

Changes in the fundamental understanding of breast cancer, advances in treatment, and enhanced rehabilitation

Table 3. Themes Identified From Activity Codes

| Theme | Code | Incidence (%) |
|------------------------------|--------------------------|---------------|
| Impact of cancer | Cancer | 4 |
| | Interactions with others | 20 |
| Responsibilities | Connection | |
| | Social visit | |
| | Time with family | |
| | Community service | 19 |
| Personal well-being and care | Household | |
| | Personal business | |
| | Work | |
| | Education | 45 |
| | Diversion | |
| | Mental health | |
| | Religion | |
| | Self-care | |
| | Hygiene | |
| | Nutrition | |
| Communication | Other medical | |
| | Computer or e-mail | 6 |
| Slowing down and pacing | Phone | |
| | Correspondence | |
| | Nap or rest | 6 |
| | Activity limitations | |

and support services have contributed to improvements in breast cancer survival rates for women with advanced breast cancer (American Cancer Society, 2007; Rowland, Aziz, Tesauro, & Feuer, 2001). The study illuminated the effects of metastatic breast cancer on the daily lives of women living with advanced disease. The findings challenge assumptions of healthcare providers and society related to capabilities of patients with advanced breast cancer and their ability to perform activities of daily living. Women in the study were balancing demands and expectations of daily life along with challenges and complexities associated with breast cancer. Support and education are critical to women's abilities to balance demands and expectations of career, family, and illness (Wilmoth, 2003). Support groups and self-care training programs can be particularly valuable. Based on strong connections with patients and high levels of trust, oncology nurses are in ideal positions to educate, counsel, and coach women with advanced cancer on activity pacing using patient-centered educational activity pacing protocols. An important goal is to foster strategies that assist women

with advanced breast cancer to maintain healthy and balanced lifestyles.

Conclusions

Women with metastatic breast cancer continue to participate actively in and pursue a multitude of daily activities. Despite numerous symptoms, cancer treatments, secondary complications, and cancer-related stressors, women with metastatic breast cancer are living full, active lives. This study serves as a foundation for the development of interventions that enhance daily functioning for women with breast cancer and their families. Oncology nurses should counsel women with advanced cancer regarding activity pacing and self-care activities to help them maintain physical and psychological well-being.

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