Supporting women with advanced breast cancer: The impact of altered functional status on their social roles

by Bai Qi Peggy Chen, Monica P. Parmar, and Kimberley Gartshore

Abstract
Despite early detection of breast cancer and the progress of treatment modalities, metastasis-specific symptoms continue to impact women’s functional status and daily living. The aim of this study was to explore the experience of altered functional status and social roles of women with advanced breast cancer. Using qualitative descriptive methodology, semi-structured interviews were conducted with 10 women diagnosed with advanced breast cancer and altered functional status attending a tertiary care cancer centre. Results illustrated the adaptive experience of women living with their illness as they reshaped their social roles to fit with their altered functional status and advanced disease. These findings highlight the opportunity for supportive care nursing interventions to facilitate the behavioural and cognitive transitions that are experienced by women with advanced breast cancer and altered functional status. These results may have implications for women with other advanced chronic diseases, though more research is required.

Introduction
Recent statistics estimate that 23,800 women have been diagnosed with breast cancer in Canada in 2013 (Canadian Cancer Society, 2013) and of these, 5% will be diagnosed with Advanced Breast Cancer (ABC) (National Cancer Institute, 2011b). ABC is defined as invasive breast cancer with metastasis past the ipsilateral axillary lymph nodes to other organs of the body (American Cancer Society, 2011). Due to earlier detection and improved treatment, the survival rates of this population have been steadily increasing (Braithwaite et al., 2010). Statistics indicate that the five-year survival rate for women diagnosed with ABC is currently 23% (National Cancer Institute, 2011b), so that it is increasingly approached as a chronic illness (Kagawa-Singer, 1993). Chronic illness has been defined as a condition that requires continual adaptation and long-term monitoring by health care professionals (Rolland, 1987). Within this context, the relevance of exploring the experience of women living with ABC, as well as the impact of this illness on their daily living becomes evident.

One factor greatly affecting women living with ABC and with a potential impact to their social roles (Patrick & Chiang, 2000) is altered function (Hurria et al., 2006), as measured by how well a patient is able to perform activities of daily living (Hurria et al., 2006). These activities of daily living may be physical, social, spiritual, psychological, or intellectual (Hurria et al., 2006). Given that 99% of breast cancer patients are women (Canadian Cancer Society, 2013) and that women hold multiple social roles including those of mother, wife, worker, and/or friend (Coty & Wallston, 2008), the exploration of the potential impact of altered functional status on the social roles of this patient population warrants investigation.

Literature review
Breast cancer and functional status
Treatment for ABC may involve hormonal therapy, biological therapy, chemotherapy, radiation therapy, and/or surgery, and is often associated to numerous side effects (National Cancer Institute, 2011a). In addition, metastasis to the bone, which occurs in 70% of ABC patients, often causes pain, fracture, bone weakening, or compression of the spinal cord (Tonkin et al., 2006). These complications can lead to decreased mobility and further comorbidity (Petrut, Trinkaus, Simmons, & Clemons, 2008). These data suggest that the treatment and disease progression of ABC may significantly affect physical, mental, and emotional functioning, which, in turn, may lead to the decreased ability to perform daily activities.

Most studies assessing functional status have focused on the impact of earlier-staged breast cancer, usually stage I and/or II (Ahles et al., 2005; Broeckel, Jacobsen, Balducci, Horton, & Lyman, 2000; Cimprich, Ronis, & Martínez-Ramos, 2002; Helgeson & Tomich, 2005; Montazeri et al., 2008); all report physical functioning in women with breast cancer to be decreased, as compared to healthy age-matched controls. Unfortunately, women with ABC have been largely excluded from these investigations. However, a study conducted by Luoma and Hakamies-Blomqvist (2004) examined the impact of ABC on quality of life, and demonstrated how limitations in physical functioning caused great distress. Additionally, participants were unable to perform most of their activities of daily living with an associated impact on their social roles.

Women’s social roles in illness
A social role is defined as any set of expectations or behaviours that a person is expected to fulfill based on what is guided by the norms of a society (Mead, 1967). Though a dearth of literature

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doi:10.5737/1181912x243194198
exists investigating the experience of social roles in women with ABC, the concept has been explored in women living with other chronic illnesses. Abraido-Lanza (1997) examined the effect of rheumatic disease on women’s roles as homemaker, parent, grandparent, spouse, worker, and/or friend. The women interviewed for the study reported that the illness intruded on their roles as homemaker, worker, and to a lesser extent, the roles of spouse and parent (Abraido-Lanza, 1997). More recently, researchers have described a loss of social interactions due to greater unemployment (Alavinia & Burdorph, 2008) or disability from rheumatic disease (Abraido-Lanza & Revenson, 2006). Although these results shed some light on how women’s social roles might be influenced by a chronic illness, the experience of living with rheumatoid arthritis differs greatly from that of living with ABC, due to differing symptoms and prognosis.

Purpose
The potential link between functional status and social roles is well supported, though not yet explicitly explored in women living with ABC. The general dearth of literature exploring the lived experience of this population, in addition to the complexity of physical symptoms caused by ABC on overall function and coping, implies the need for further exploration. The purpose of the present study is to explore the way(s) in which women living with ABC and altered functional status experience their social roles.

Methods

Design
A qualitative descriptive design was chosen to gain insight into the experiences of these women without any pre-existing notions or expectations and by providing the lowest amount of inference through the use of descriptions (Sandelowski, 2000).

Sample

Purposive sampling was used for recruitment from the Cancer Centre of a university-affiliated teaching hospital in Montreal, Quebec. Eligibility criteria included: 1) female gender; 2) a diagnosis of primary stage IV breast cancer; 3) Eastern Cooperative Oncology Group (ECOG) performance status score ≥ 1 (Oken, et al., 1982); 4) ≥ 18 years of age; 5) ability to speak, read, and write in English; 6) capacity to engage in a one hour face-to-face interview; and 7) a prognosis of ≥ 3 months. The oncology care team determined prognosis at the time of recruitment. Exclusion criteria included: 1) ECOG score ≥ 4, 2) a cognitive condition impeding the woman’s ability to participate in the interview as determined by the Clinical Nurse Specialists (CNSs) aiding in recruitment, 3) current hospitalization >1 month, and/or 4) a palliative prognosis with a life expectancy of < 3 months. Women with a prognosis of < 3 months were excluded from recruitment due to the potentially differing experience of the palliative phase of the ABC illness trajectory (Tuckett, 2004).

Procedures
Following ethical approval, participant recruitment occurred between July and December 2011. The CNSs introduced the study to potential participants, and permission was obtained for the student researcher (SR) to contact the patient. The SR met with potential participants to explain the study, and voluntary written consent was obtained according to patient interest.

Data were collected using semi-structured interviews conducted at a single time point. Open-ended questions and probes were used to encourage the women to provide an in-depth description of the impact of their altered functional status on their social roles. The audiotaped interviews were then transcribed verbatim. Field notes documenting non-verbal behaviour, such as crying or other signs of distress were used to inform data analysis (Morse & Field, 1995). Socio-demographic information was collected using a questionnaire and included: age, marital status, number of children, level of education, domicile status, date of diagnosis, type of metastases, type of cancer treatment, and number of hospital admissions.

Data analysis
Qualitative content analysis of the interview transcripts was conducted to identify and code salient excerpts addressing the women’s overall experience of their social roles, within the context of ABC and altered functional status (Polit & Beck, 2008). To maintain rigour, credibility, confirmability, dependability, and transferability were ensured (Lincoln & Guba, 1985). Preliminary analysis of the data began with a thorough reading of the transcripts, with the goal of understanding the phenomenon as a whole (Sandelowski, 1995). Open coding was then performed line by line to highlight data that were relevant to the women’s functioning and social roles (Berg, 2001). Newly collected data were compared and contrasted to previously analyzed data, and adjustments were made as new codes were identified (Burnard, 1991). The SR further reduced the data by clustering common codes into higher-order categories and verifying the category set with the research team (Burnard, 1991). Categories were then grouped into themes capturing the essence of the experience described by the women.

Results
Ten women were recruited for participation in this study with the average interview lasting 55 minutes. The women ranged from 31 to 69 years of age, with a mean age of 53.2 years. The women had been living with ABC for three months to four years, with an average time since diagnosis of two years. At the time of the interviews, eight of the ten women were living with bone metastases, and all were currently receiving treatment. The symptoms most commonly reported were fatigue, pain, nausea, and difficulty concentrating. Fear, stress, anxiety, irritability, and depression were also described. At the time of the interviews, three of the 10 women were employed, and all had had at least one hospital admission.

Women described the need to modify the way they engaged in self-care, rest, work, exercise, food preparation, housework, and family and leisure activities. They explained how they adapted to these changes, both behaviourally and cognitively. Two main themes emerged describing the strategies used to make these modifications including: Redefining Social Roles, (encompassing the behavioural adaptations made by the women) and Transforming Perceptions (describing the cognitive adaptations).

Redefining social roles
The first theme describes the ways in which women had to modify their social roles and responsibilities while living with an altered functional status through behavioural changes, and includes three categories: decreasing participation, adjusting to a new normal, and adapting existing relationships.

Decreasing participation. The women spoke about decreased functional status with reference to both the physical and emotional symptoms experienced with ABC. All of the women described a noticeable decrease in their ability to participate in activities. One woman discussed her fatigue and how it affected her role as a mother, “We would go up to the lookout on Mount-Royal and I’m just so tired I can’t get out of the car, so I just stay in the car and [participant’s daughter] goes out with [participant’s friend]” (Participant 004). Other women noted how increasing fatigue and pain meant they were less able to engage in activities or manage their usual responsibilities, such as household chores, working, and socializing.
In some cases emotional rather than physical symptoms posed a more significant barrier to participation in everyday activities. One participant explained, “It’s mentally that it kills...if you get sad you’re less productive. You’re not as happy, so you’re not going to work in the same way or concentrate in the same way. It does take something from you” (Participant 005). All the women shared how sadness, fear, and anxiety in some way prevented them from actively participating in their work, home, and social lives.

Adjusting to a new normal. In spite of the physical and emotional symptoms described above, all of the women spoke of the importance of keeping up with their usual activities. This was accomplished by pushing their own physical and mental limits in order to maintain usual participation, or by modifying their activities to fit their reduced stamina. One woman explained:

“I used to go shopping from 8 o’clock in the morning till 11 o’clock at night and I’d still be on the go, but now I have to take breaks and sometimes if I’m very tired I’ll take one of those electric carts to go around. I would never have done that before. It’s just changed my whole way of doing things (Participant 004).

Planning ahead and anticipating potential challenges was another strategy used by the women to manage the demands of the illness and adapt to their new normal. One woman stated: “I must call for transportation the day before. I must plan that I have a lunch or where I’m going to eat or where I’m going to sit to wait” (Participant 002). Along with an increased awareness of their physical environment, the women needed to be more aware of their emotional state. This involved being attentive to feelings of anxiety, fear, or frustration after a treatment or before a hospital appointment. This self-awareness enabled the women to prepare more successfully for their activities, and allowed them to develop new strategies for more effective communication with their loved ones.

Adapting existing relationships. As a result of the women’s altered functional status, transformations occurred in their existing relationships. Certain individuals in their network were drawn closer, whereas others were pushed away. Most participants acknowledged that the individuals kept at a distance were those who had been unable to adjust to the women’s changed circumstances. As stated by one woman:

“I’m more close-knit with a small group of friends who really try to keep up with what’s going on with me and checking in a lot, but a lot of friends I now hold at arms length… in a situation like this you really need supportive people around you (Participant 003).

Due to the women’s decreased ability to participate, relationships had to be adjusted to remain meaningful. Those who did not accommodate the women’s need for increased understanding and support eventually faded out of the women’s lives. For example, this occurred by the women either decreasing the priority of these relationships, or by eliminating them completely.

Individuals who were deemed supportive and responsive to the women’s changed circumstances became part of an “inner circle”, described by participants as a group of friends and family to whom they grew even closer over the course of their illness. The women reported engaging in more open, direct, and honest communication with these individuals, and placed more value on time spent with them. The women and members of the “inner circle” found ways of adapting respective roles within their relationships to accommodate the women’s altered level of physical functioning. Although the women still considered their role to be that of a wife, mother, daughter, or friend, responsibilities encompassed by these roles were redefined, and with the help of the “inner circle”, adjustments were made to maintain them.

Transforming perceptions

The second theme captures the women’s transforming perceptions, as their lives changed with ABC, and how these adaptations affected their perspective on life. Transforming perceptions highlights the cognitive adaptations made by the women and is composed of three categories: living with new challenges, learning to accept help, and relinquishing roles.

Living with new challenges. This category highlights the psychosocial challenges the women experienced as a result of altered functional status, including stigmatization, internalization of worries, and the stress of becoming the focus of loved ones. Many of the women expressed a feeling of going against their own expectations or those of society, particularly if they experienced physical and emotional symptoms generally unexpected for their developmental stage/age group. One woman remarked, “I’m in the accelerated aging program ‘cause a lot of the things that seem to bother me, bother other people who are aging, it’s just that they’re 10 or 15 years older than me” (Participant 010). Some women felt embarrassed by the changes in their physical appearance, as these seemed to reveal their illness to others, making them “look like a sick person”.

As a consequence of their illness, many women described becoming the centre of attention in social situations. They discussed having to adjust to the new ways in which people related to them. This proved to be a difficult transition, often making the women feel uncomfortable. As one woman observed, “I noticed that when we go out, they’re always attentive… I can feel their concentration is on me… they’re so worried…I could feel them all the time… feeling their fear” (Participant 009). These types of interactions highlighted the noticeable change in the dynamics of the women’s relationships, often contributing to increased stress.

Learning to accept help. Due to fluctuating functional ability, women were, at times, unable to uphold all aspects of their social roles by simply adapting their activities. This eventually led to a cognitive shift allowing the women to overcome self-imposed barriers to asking for and accepting help, thus enabling them to continue fulfilling their role responsibilities. As one woman explained:

“I used to count on myself, now I know I can accept help from others. I never asked for help in the past. Now my role is more [that] I’m here for them, but I can also say, “Ok, thank you. Could you do something for me?” (Participant 001).

This acceptance developed over time, as women realized their functional limitations.

Another strategy implemented was the delegation of tasks, which allowed them to focus on responsibilities most important to them, thus permitting continued fulfillment of priority social roles. Ultimately, this shift in thinking enabled the women to maintain their role responsibilities effectively, even in the context of altered functional status. As one woman described, “After my surgery, I didn’t have strength to do the whole thing… [just] keep work as my focus… if I could delegate the cooking…I could focus on my accounting” (Participant 005).

Relinquishing roles. Nine of the 10 women relinquished one or more roles they had previously held or hoped to fill in the future. Six women had to decrease their workload, leave their jobs, or retire.
early. These women had no choice but to abandon certain roles in order to respect the limits of their energy and stamina. As their functional status changed, the women's lives were restructured around the roles that were most important to them, while resigning from others. One woman explained:

"I can tell you the ones [social roles] that are gone. Worker, a productive member of society... the romantic relationship aspect is completely. Mother being completely out... if you have ABC, you don't start having kids. I think what's more difficult is all the stuff you aren't anymore (Participant 003)."

The relinquishing of these roles represented a true sacrifice for the women, contributing to a feeling of identity loss, as well as a modification of personal goals and expectations.

Discussion

The results of this study illustrate the impact of altered functional status in the context of ABC on women's social roles, and describe the use of both behavioural and cognitive strategies to cope with these changes.

Adaptation of social roles in illness

The findings demonstrate that women living with ABC and altered functional status redefined the social roles and relationships most important to them. This allowed for their continued participation in priority role responsibilities, in spite of the significant life disruptions caused by their disease. Many of the women's social roles involved relationships with others, thus an adjustment in these relationships was inherent to the women's social role adaptation. The women described the development of a highly valued "inner circle" of individuals able to provide support. This finding is in contrast to a study conducted by Rosendale (2009) exploring the experience of breast cancer survivors, showing that participants felt a sense of loneliness when support was not provided in the ways in which they expected, resulting in a feeling that their relationships were unreliable. Though the present study indicates that women with ABC also experience unmet needs in some relationships post-diagnosis, this feeling may be mitigated by a strengthening of the relationships in which the women felt supported, the "inner circle" of individuals prioritized by the women.

Thus, the findings of the present study suggest a coping process through which women living with ABC as a chronic disease redefine roles and relationships rather than relinquishing them completely, thereby maintaining a stable, though altered, social and self-identity. This finding is suggestive of a more effective coping pattern than previously thought to be experienced by women living with ABC.

Illness, social roles, and identity

The women in this study described an evolution in their social roles, as they made modifications to their activities and relationships; this was associated with a transformation of their overall perception, leading to a shift in their self-identity. Identity theory proposes identity to be based on the categorization of oneself as an occupant in a particular role, and incorporating the meanings and expectations associated with that role to guide behaviour (Burke & Tully, 1977). Through their narratives, the women described the espousal of a new unspoken "sick role", which seems to have emerged as part of the women's experience of living with ABC. Although none of the women explicitly identified this new role, all described new demands associated with frequent hospital visits, treatment side effects, and changes in their physical abilities leading to new responsibilities within the context of their disease. Associated with this new "sick role" was a relinquishing of some of the roles held pre-diagnosis; these were sacrificed to manage new commitments required of the disease, as well as to maintain other, more highly prioritized roles. Many women sacrificed roles that had previously shaped their sense of self in a significant and meaningful way. Inherent to this loss was a remodelling of the women's self-identity, as they adapted to the challenges associated to altered functional status, while assimilating the responsibilities associated to living with ABC.

Limitations

Despite the use of purposive sampling techniques, the results of this study may not fully represent the experience of all women living with ABC and altered functional status. For instance, women who consented to participate may have had more social support or resources available to them. Additionally, interviews were conducted at one point in time, and the results may not be reflective of their longitudinal experience.

Clinical implications

The unique findings of the present study suggest important nursing interventions to facilitate coping in women living with ABC. The significance of the "inner circle" underlines the need for routine exploration of this key support network in the assessment of women living with ABC, to facilitate mobilization of resources as appropriate. This may include incorporating appropriate health care resources (e.g., rehabilitative therapy, or catering food services, etc.) in order to promote the maintenance of priority roles. Furthermore, normalizing the process of adapting existing relationships, and the common evolution of an "inner circle", early on in the illness trajectory may serve to buffer the psychosocial impact associated with this adaptation.

Further research is warranted to study the type of support garnered from the different members of the "inner circle" (i.e., informational, emotional, practical, etc.), and the ways to best utilise them to facilitate coping. Results from this type of study may assist nurses to engage more effectively with women's support networks. Additionally, investigation into the unnamed "sick role" will help to elucidate the cognitive adaptations experienced by this population, particularly with regards to self-identity.

Conclusions

The findings reveal cognitive and behavioural adaptations employed by women living with ABC and altered functional status in order to maintain their self-identity, as defined by their priority social roles. Understanding these adaptations will enable nurses to intervene in a way that facilitates them, and protects the social roles most valued by women leading to the preservation of their self-identity in the context of a terminal illness.

Acknowledgements

I would like to thank my project supervisors, Monica Parmar and Kimberley Garthshore, for their continued guidance and encouragement. Thanks as well to Dr. Margaret Purden for her constructive feedback and assistance. I would also like to thank my family, friends, and classmates for their continued support. Thank you to the Segal Cancer Centre and the Jewish General Hospital for providing me with the opportunity to conduct this project.

Finally, I would like to thank each woman who participated in this study for opening up about their lived experience with advanced breast cancer, thus shedding light on the unique challenges faced by this population. Thank you for sharing your stories.

Conflict of interest

The authors have no funding or conflicts of interest to disclose.
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