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Self-Management and Transitions in Women With Advanced Breast Cancer

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Abstract

Context—Self-management involves behaviors that individuals perform to handle health conditions. Self-management may be particularly challenging during transitions—shifts from one life phase or status to another, for example, from cure- to noncure-oriented cared—because they can be disruptive and stressful. Little is known about individuals' experiences with self-management, especially during transitions.

Objectives—Our purpose was to describe experiences of self-management in the context of transitions among women with advanced breast cancer.

Methods—We interviewed a purposive sample of 15 women with metastatic breast cancer about their self-management preferences, practices, and experiences, including how they managed transitions. Interviews were recorded and transcribed. The qualitative method of interpretive description was used to code and analyze the data.

Results—Participants' mean age was 52 years (range 37–91 years); most were White (80%), married (80%), and college educated (60%). Self-management practices related to womens' health and to communication with loved ones and providers. Participants expressed a range of preferences for participation in self-management. Self-management included developing skills, becoming empowered, and creating supportive networks. Barriers to self-management included symptom distress, difficulty obtaining information, and lack of knowledge about the cancer trajectory. Women identified transitions as shifts in physical, emotional, and social well-being, as when their cancer progressed and there was a need to change therapy. Transitions often prompted changes in how actively women self-managed and were experienced as positive, negative, and neutral.

Conclusion—Self-management preferences can vary. Providers should explore and revisit patients' preferences and ability to self-manage over time, particularly during transitions.

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Keywords

Breast cancer; self-management; transitions; qualitative; exploratory; oncology; metastatic

Introduction

Self-management involves daily behaviors that individuals perform to handle a health condition.[1] Such behaviors pertain to illness management, for example, learning about the health condition; role management, for example, reorganizing routines; and emotional management, for example, reevaluating life.[2] Self-management includes the skills of problem solving, goal setting, decision making, using resources, forming patient-provider partnerships, action planning, and self-tailoring.[3] Self-management can be particularly challenging during times of transition—processes of passage from one life phase, condition, or status to another[4]—for example, from cure- to noncure-oriented care. Challenges arise because transitions necessitate change in identity, roles, relationships, and patterns of behavior.[4] Subsequently, transitions can be stressful because they disrupt expectations and routines; however, transitions also present opportunities for individuals to reevaluate their health, find meaning, and gain a sense of control.[5] Several conditions may affect how a transition is experienced, including the meaning attached to the transition, expectations of the transition, level of knowledge and skill to manage the transition, environmental resources, level of planning before and during a transition, and emotional and physical well-being during and after a transition.[4] Self-management skills can be used to negotiate transitions as they arise.

Although many women with breast cancer want to self-manage,[6-9] few studies have explored individuals’ experiences with self-management, and no research was found on self-management in the context of transitions. Research on transitions among women with breast cancer largely focuses on the transition to survivorship after diagnosis and primary treatment.[10-12] However, effective self-management is critical throughout the course of care so that individuals can work toward their health and life goals, and little is known about how transitions affect self-management in the advanced cancer trajectory. The purpose of this exploratory study was to describe self-management (preferences, practices, and experiences) among women with advanced breast cancer, particularly during transitions. Findings from this study may inform the development of interventions to help individuals self-manage over the course of illness.

Methods

Sample and Interviews

Because there are few data on self-management and transitions, we used the qualitative method of interpretive description to describe how women with breast cancer manage their care, especially during times of transition. Interpretive description uses principles for analytic frameworks, sample selection, data analysis, and rigor to conduct inquiries into human health and illness experiences for the purpose of developing nursing knowledge.[13] We purposively sampled women aged 18 years or older who had a diagnosis of metastatic breast cancer, had failed first-line therapy for metastatic disease, were undergoing any type of treatment, and who spoke English, using physician referrals from the cancer center at the participating hospital. Semistructured interviews of approximately 45 minutes each (range 30–67 minutes) were conducted in a private setting of the participant’s choice, usually the participant’s home. Participants were asked, “How do you generally manage your care?” Additional interview questions elicited information on participants’ self-management preferences and practices, and how they experienced and managed care transitions.

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Demographic information also was collected. Specialized interview techniques, including acknowledging the participant's situation, assessing and accepting the participant's willingness and time to share their story, and debriefing were used to ensure sensitivity to participants and obtain trustworthy data.[14] We continued interviewing until we achieved saturation, that is, until no new themes emerged from successive interviews.[15] Interviews were digitally recorded and professionally transcribed. This study was approved by the Human Subjects Research Review Committee at the Yale School of Nursing.

Data Analysis

Initially, two members of the research team independently read the first three transcripts and assigned a descriptive phrase, or code, to key concepts. These authors then compared codes in joint session until agreement on codes and their meanings was reached[15,16] and a basic coding scheme emerged. As new concepts were identified, codes were expanded and/or consolidated into different conceptual categories. The final code key, which consisted of six codes and 34 subcodes, was applied to all transcripts. Codes were then summarized into themes that characterized the data. Atlas.ti qualitative software (Scientific Software, Berlin, Germany) was used to organize data. We then analyzed and integrated codes to discover themes that described self-management preferences, practices, and experiences, as well as participants' experience and management of transitions.

Results

Participant Characteristics

Participants (*n* = 15) ranged in age from 37 to 91 years (mean = 52 years). Most (80%) were White (*n* = 12), with the remainder (20%) including one Asian, one Latina, and one African-American participant. Participants were well educated, with 60% having received at least a college degree. Eighty percent were married, and most were Catholic. Although small, this sample size is adequate for an exploratory study seeking to describe participants' experiences. The sample is described in Table 1.

Themes

Analysis revealed three main themes around self-management and transitions. These included self-management practices related to health and communication with family, friends and providers; varying preferences for participation in self-management; and facilitators and barriers to self-management in the advanced cancer trajectory. Different types of transitions were described. Themes are summarized in Table 2.

Self-Management Practices—Reported self-management practices included caring for one's health and communication with family, friends, and providers. Behaviors associated with caring for one's health included managing symptoms, engaging in exercise and/or nutrition regimens, adhering to the treatment regimen, making treatment decisions, learning about cancer, and maintaining quality of life. Communication with family members and friends included evaluating and ensuring support in the home (e.g., housekeeping), keeping home life as normal as possible, and managing financial resources. Communication with health care providers included coordinating medical services, searching for cancer resources, and advance care planning.

Preferences for Participation—Women reported varying preferences about participation in self-management. Some women wanted to play a very active role:

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> I am the #1 advocate in my health care… everything that has been done or that has been discussed with me, I have researched. I have come up with suggestions for my own treatment.

Others preferred a passive role:

> I just kind of roll with the punches. Whatever they tell me to do, I know that the only way you're going to get better is to listen to the doctor and do what the doctor says, so that's what I do. …I try to keep a low profile…I'm assuming that everything's gone well with my treatment. I haven't heard otherwise.

Although she wanted little involvement, this participant self-managed by delegating some aspects of her care to her daughter:

> My daughter is on the [cancer phone] hot line every day and she's forever reading and giving [information] to me to give to [my doctor], which I don't even read, so I feel as though other people have taken care of it for me.

Facilitators and Barriers to Self-Management—The experience of self-management was often described positively in that it entailed learning new skills, becoming empowered, and creating a supportive network, all of which facilitated self-management:

> I'm giving myself two injections a day now, but I think after being around oncology for a couple of years, you almost get immune to that. If somebody had told me five years ago that someday I'd have to give myself two shots a day, I'd say I'd never be able to do it, they're going to have to have a nurse do it, and when the time came, it really wasn't a problem at all.

Participants reported several barriers to self-management. Often mentioned were symptom distress, limited time and energy to acquire information, and competing priorities:

> I used to be one of those Internet junkies, trying to diagnose my own case and get my own stuff. You get tired of that after years of doing it [and] kind of just start to give in, and that's where I'm at now…it's just not worth my time, and the pain that it causes to try to sit at the computer to try to research stuff… The pain-free time is spent doing things with my kids and not getting on a computer.

Self-management was described as frustrating and emotionally challenging because of fear and uncertainty around treatment options and making the "right" decisions:

> [Managing my care is] difficult and frustrating, and something I never thought I'd have to do… the fact that there's—at the beginning anyway—that there is so much out there, and now the fact that there's so little out there. It's frightening whenever you make your decisions because you don't know what's going to happen if you make the wrong ones.

Another barrier was lack of understanding of cancer and its trajectory. For example, a participant's misunderstanding of cancer staging affected her understanding of her prognosis and potentially how she would manage her care:

> …they said, "You have Grade 4," and I said, "Well, how many grades are there?" [The nurse said] "There is no more." [sic]… [So I said] "So you're telling me I have the highest grade cancer there is." She said, "Yes," so I said, "So, is this a correct assumption? It can only go down, because you can't go to 5—there is none, so I can go to 3, I can go to 2, I can go to 1 and I can go home."

Others were unclear about the definitions of curative, palliative, and hospice care, as well as which of these types of care they were receiving. Despite receiving palliative care, some did

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not understand the meaning of palliative care, that is, that their disease could be treated but not cured. A participant said: "I have a sister-in-law [who is a nurse] that I know does palliative care. I've never really quite asked her exactly what it involves. I know that I've heard it." Some equated palliative and hospice care: "When you say 'palliative care' to me, I think of no more treatment, just giving up and being comfortable until the end." Lack of knowledge about these types of care could affect self-management goals and decisions.

Types of Transitions—Participants' experiences reflected two main types of transitions: personal and care transitions (Table 3). Personal transitions included physical, emotional, and social changes that occurred over time. Physical transitions included hair loss, symptom distress, decreased energy, or change in ability to function. A participant spoke about getting through a phase of physical limitation:

> Knowing what I want to do and knowing what I can't do are very frustrating. I just want to do things all the time, and I can look around here and see 5 million things that have to be done and I don't do them because I can't move. Sometimes, I can't move from this side to this side… I'm sure [that] once this treatment is over, I won't have that anymore. We'll get through it.

Emotional transitions were times of psychological and emotional upheaval and adjustment. For example, a participant described shifts in her emotional state:

> Up 'til then, I was pretty easy going… they always said, "You take things so well," and I did. I always said to myself, "That's what you have to do anyway." There's nothing you can do about it, so you do the best you can, but I became angry after that—a little more so than I probably should, and even now I cry where I never cried before, like right now, because I get emotional more.

Social transitions were shifts in family functioning, routines, or roles played, including changes in family members' responsibilities and level of formal and informal support used, for example, a home health aide or housekeeper. A participant described the social transitions discussed among her family:

> I think the major transition point was when we hit the brain lesions. I think that was the key thing and as a family we sat down one morning and just said, "What does this mean? Is our life going to change further?" Because if it is we just didn't want it and… as a family how do we deal with it? …Do we have enough care in the house to help us?…[These were] issues that we just hadn't addressed, and we realized we had to address them.

Reported care transitions included shifts in cancer status, treatment, or approach to care, that is, transitions reflecting progression of the cancer and the need to change therapy. Transitions related to cancer status included initial diagnosis, recurrence, or being told of a limited prognosis. Speaking about her recurrence, a participant said, "The first most significant, worse than hearing it first diagnosed, is hearing 'Stage IV metastatic cancer.'" Treatment-related transitions included having surgery, procedures such as having a port placed, and starting or stopping chemotherapy or radiation; these transitions were significant because they followed diagnosis, indicated disease progression and increased symptom burden, affected daily functioning and routines, and/or were emotionally charged. One woman expressed how resuming radiation was a significant transition for her despite brief appointments because it affected her daily life:

> I would say that starting up with radiation again was more of a transition because that's every day… they call me down there and I go in there for 30 seconds on each side [of my head] and I'm out of there and I say, "That's it," but that's probably the biggest thing.

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Transitions in approach to care were shifts between curative, palliative, and hospice care as related to the progression of disease and the intent of treatment. A participant's contemplation of her status illustrated such a transition:

> I'm not on any chemos right now. Right now, it's just the hope that someday there will be a chemo out there that I can do… it kind of says that it's getting close to the end, because you're not fighting it, so it's just going to take over and spread… I guess there is hospice home care… I don't think I'm at that point yet though. I will eventually, but not right now.

Experience of Transitions—Participants described transitions in neutral, negative, and positive ways depending on the particular transition. Neutral descriptions reflected the intensity and unexpectedness of the transition. Examples of negative descriptors were "traumatic," "hard," and "scary." Uncertainty and vulnerability were often mentioned. Transitions were sometimes experienced as distressful in that the transition prompted recognition of an earlier, better time or circumstances. Positive transitions were described as inspiring, facilitating personal growth, a time to rally resources or emotions, and bringing family and community together. Transitions also were described as times when reliance on other people increased and as times to address issues that had previously been in the background. Transitions were perceived as happening actively, as when a decision was made for care to proceed differently, or passively, as when disease progression necessitated a change in goals and in the care plan.

Influence of Transitions on Self-Management

Participants' experiences showed how transitions could influence both the self-management plan and level of participation in self-management. For example, transitions were reported as prompting shifts in participants' priorities and goals. One woman described how being diagnosed with a brain metastasis prompted a significant shift in her mindset and plan:

> …when I had that brain tumor, that was scary—to realize that I was really lucky because [the cancer] could have gone to another part of the brain and I might not have even woken up, and that did change a lot of things. I owned a store and up until then I thought I could hold onto it, and I realized… I had to start taking care of things and one of those things was selling the store, so that really was a decision-making happening for me. Not a good one, but one where I had to just accept that something could have happened very quickly. Up until then, I just had sort of figured, whatever was going to happen, I'd have time to prepare, and all of a sudden, I realized that I might not.

Transitions also prompted changes in the level of participation in self-management wherein participants became more active or passive self-managers. Participation could become less active when participants were physically or emotionally overwhelmed but could also become more active as treatment options became limited and they contemplated their options. A participant described how the transition of becoming more ill forced her to become a less active self-manager:

> For me, a care transition [is when] I get too sick and I can't participate as actively as I want to participate because I'm not capable… I'm laying there in my little fog, thinking… "I wanted to know something." [So a] transition from not participating as clearly and as fully as I wish I could participate.

For another participant, the transition of a new diagnosis related to prior cancer treatment prompted her to become a more active self-manager:

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> [The doctor] called me back on that Monday when he came into work…and said, "To be honest with you, we're not out of the woods. I need to see you right away." So I went in… and I was told that I had Stage IV metastatic breast cancer… he gave us the news that it was not curable, but it was treatable. So I had to mobilize my fight once again and decide that, it's treatable. As long as I can keep getting treatment, they're going to keep coming up with better drugs and I had to just do this… So we, again, talked about my treatment options.

Thus, transitions could prompt voluntary changes or could impose changes in self-management preferences. A woman who was an active self-manager described a transition that forced her to delegate care management to her health care team:

> At that point in the treatment, all I kept saying was, "I want to live." I wasn't really making the decisions. "Whatever you think you have to do, get me through this." All along, I had had enough wits about me to ask questions and weigh out my options and I ultimately made the decision with counseling from [my doctors]. At that point, I just had no control over it. I just said, "Do what you have to do."

Experiencing more than one transition at a time also influenced self-management. Participants reported overlap of personal and care transitions that affected each other; for example, a transition in cancer status, such as progression of disease, would prompt an emotional transition of adjusting to the news. Having to cope with multiple transitions simultaneously could trigger changes in self-management preferences and behaviors and made self-management stressful for participants.

Participants described coping with transitions in a number of ways. One way was to anticipate the transition and "try on" how it felt as a step toward adjustment. A woman spoke about predicting the results of her initial biopsy and how her life would change:

> I remember walking up the stairs to my surgeon's office to get the results from the biopsy and stopping on the stairs and going, "I don't want to go in there because these are my last moments being a cancer-free person," and I just didn't want to walk into that doctor's office because I knew my life, as I knew it, was over at that point, and now, I'll never forget walking up those stairs to that doctor's office. Those were my last minutes. I knew that it was about to change—not for the better.

Another way of coping with transitions was reframing what was happening in a positive way. A participant described reframing her cancer, its physical effects on her, and her treatment:

> I can't control this disease, but I don't want it to control me… I try to always refocus my attention on where I need to be. When I first found out that I could lose vision, and now it's actually happening, I had two very, very, very blue days, and now I've totally changed my thinking and I'm saying, "I will learn to cope with this. This is not a big deal." The radiation is going to get the tumor. The tumor is little. Radiation works. I will learn now to cope. I like to read books. I'll get large print. I'll get books on tape… that's how I've always tried to redefine to myself… I want to control [the cancer], but I can't, so I have to control myself and get myself in working order to be normal at home and have a normal family life.

Modifying one's hopes was another method of coping. A woman spoke about her change in goal from cure to treatment of her cancer:

> Back then, I still had hope that I could walk away cancer-free, and I don't have that hope anymore, so I don't think without that hope that I could go through the process again. [My hope now is] that I can hang on and have as high a quality of life as possible…

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Although transitions were challenging, some participants described them as less overwhelming with time and experience:

> Once you're told once that you have cancer, I can't say it gets easier, but it's not so mind-blowing… you're always waiting for that shoe to drop again, no matter what they tell you—that it's gone—you're always kind of expecting it to come back. So once you've been told once, the other times aren't quite as shocking, or aren't as hard to deal with.

Discussion

Understanding transitions from the patient's viewpoint substantially contributes to what is known about individuals' experiences of transitions. To our knowledge, only two other studies have examined patients' experiences with transitions over the care trajectory. One study presents a composite case study as a framework for discussion of nursing support.[17] The other study compared perspectives on "sentinel events" during the care trajectory among patients with chronic obstructive pulmonary disease or cancer, their family members, and their clinicians.[18] Neither of these studies discuss the interaction between self-management and transitions.

In addition to providing the patient perspective, our work expands on earlier descriptions of transitions. Schumacher and Meleis[4] identified four broad types of transitions: developmental, situational, health illness, and organizational. Our data elaborate on health-illness transitions by describing personal and care transitions within the chronic illness of cancer and by capturing a broader range of health-illness transitions in more detail than previously described.[19,20] Identifying the breadth of transitions is important to enable patients, their families, and health care providers to understand various dimensions of a patient's situation at a given point in the course of care.

Our findings have implications for health care providers working with patients with serious illness. Acknowledging the personal and care transitions a patient is experiencing or is likely to experience fosters a shared patient and provider understanding of the salient issues and offers a starting point for care planning. In addition, our data suggest that transitions signal that some or all aspects of care are shifting and perhaps need to be managed differently. Providers should help patients to recognize when shifts are occurring because individuals with serious chronic illness experience many transitions and may have difficulty distinguishing if a particular transition is relatively minor or a critical shift. Meleis and colleagues[4,5] note that individuals must be aware of the meaning of a transition to understand and manage their experience of the transition and health consequences. Our findings indicate that patients may negotiate transitions more smoothly if given the opportunity to anticipate the transition, if possible, and integrate it into their lives.

Our findings also suggest that transitions can prompt changes in individuals' attitudes and ability to engage in self-management. Because self-management preferences vary, it is important for providers to revisit patients' preferences and ability to engage in self-management over time, particularly at times of transition. Self-management and transitions seem to have a reciprocal relationship: transitions can prompt individuals to self-manage either more or less effectively depending on the transition, and the level of effectiveness in self-management may affect how well individuals cope with transitions. Future research should explore this relationship.

We chose to interview women with advanced breast cancer because of the responsiveness of this disease to a multitude of treatment options that results in a longer course of care compared with many other patients with advanced cancer; this allowed us to hear about

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women's experiences over time. Although the focus on a single cancer diagnosis and small sample size is appropriate in qualitative research, additional research is needed to determine how self-management and transitions are handled and experienced in different populations with cancer, in populations without cancer, and in men. Additional work can help inform how individuals can best learn to manage the challenges that accompany serious illness.

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Table 1

Sample Description ($n = 15$)[a]

Characteristic	***n* (%)**
Gender	
Female	15 (100)
Male	0 (0)
Race	
White	12 (80.0)
Black	1 (6.7)
Asian	1 (6.7)
Latina	1 (6.7)
Education	
Less than high school	1 (6.7)
High school graduate	1 (6.7)
Trade or technical school	2 (13.3)
Some college	2 (13.3)
College graduate	4 (26.7)
Graduate school	5 (33.3)
Marital status	
Single	2 (13.3)
Married	12 (80.0)
Widowed	1 (6.7)
Religion	
Catholic	7 (46.7)
Protestant	1 (6.7)
Jewish	1 (6.7)
Other	6 (40.0)
Age (years)	
Mean	52.3
Median	50
Range	37–91

[a] Numbers may not total 100% because of rounding.

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Table 2

Themes Related to Self-Management and Transitions

Theme	Subtheme(s)	Description
Self-management practices	Caring for health	•Practices pertaining to physical health, for example, following regimens, learning about one's cancer, and making decisions
	Communication with family and friends	•Practices pertaining to communication with friends and family, for example, social and financial support and maintaining normalcy
	Communication with health care providers	•Practices pertaining to communication and coordination with health care providers, for example, obtaining resources and health-related documents
Varying preference for participation in self-management		•Range from active to passive
Facilitators and barriers to self-management	Facilitators of self-management	•Learning new skills •Becoming empowered •Creating a supportive network
	Barriers to self-management	•Can be frustrating and emotionally difficult •Symptom distress •Information-seeking burdens •Competing priorities •Limited understanding of cancer and cancer trajectory (curative/palliative/hospice care)
	Experience and management of transitions	•Described in neutral, negative, and positive terms •Reliance on others may increase •Time to address issues that had been in the background •Perceived as happening actively or passively •May overlap •May instigate changes in participation in self-management, priorities, goals, and self-management plan
	Coping with transitions	•Anticipating the transition and "trying it on" •Reframing events •Modifying hopes •Less overwhelming with time and experience

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Table 3

Types of Transitions

Domain	Dimensions	Example
Personal transition	Physical	Decreasing energy
	Emotional	Increasing anxiety
	Social	Stopping work
Care transition	Cancer status Treatment	Cancer recurs
		Starting a new chemotherapy
	Approach to care (e.g., curative/palliative/hospice)	Shifting exclusively to palliative care