

A Double Whammy: Health Promotion Among Cancer Survivors With Preexisting Functional Limitations

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More than 47 million Americans have one or more disabilities, a number projected to increase in the next 20 years (Brault, 2008). The incidence of cancer in the United States also will continue to rise, resulting in an 81% increase in the number of cancer survivors by 2020 (Levit, Smith, Benz, & Ferrell, 2010). The intersection of multiple comorbidities in that aging population will require a healthcare workforce well versed in managing complex-care needs and health-promotion strategies that maximize quality of life.

As an underserved population, people with disabilities experience health disparities. They are more likely than nondisabled people to experience delays in obtaining health care, receive fewer cancer screening examinations and tests, use tobacco, be overweight, and experience psychological distress (U.S. Department of Health and Human Services, 2011). In addition, that group may be less likely to receive standard cancer care, such as breast-conserving surgery or radiation for breast cancer, and, therefore, experience higher cancer-related rates of mortality (Chirikos, Roetzheim, McCarthy, & Iezzoni, 2008; Iezzoni et al., 2008a, 2008b; McCarthy et al., 2007). Reasons for those disparate outcomes are complex and may include problems with physical access to care, poor quality of cancer screening services, delays in treatment, and other medical considerations that impact treatment choices (Drainoni et al., 2006; Iezzoni et al., 2008a; Liu & Clark, 2008).

Cancer survivorship studies reveal challenges faced by short- and long-term survivors. Although many long-term survivors indicate that they are in good health, others live with numerous sequelae of the disease and treatment: pain, fatigue, peripheral neuropathies, lymphedema, gastrointestinal problems, sleep disturbances, bladder dysfunction, and menopause (Brearley et al., 2011; Harrison et al., 2011). At one year postdiagnosis, patients with one or more comorbid conditions have a higher symptom burden than those with

Purpose/Objectives: To explore the experience of living with a preexisting functional disability and a cancer diagnosis and to identify strategies that promote health in the growing population of cancer survivors.

Research Approach: Qualitative, descriptive.

Setting: Four sites in the United States.

Participants: 19 female cancer survivors with preexisting disabling conditions.

Methodologic Approach: Four focus groups were conducted. The group discussions were audio recorded and transcribed and analyzed using content analysis techniques.

Findings: Analytic categories included living with a cancer diagnosis, health-promotion strategies, and wellness program development for survivors with preexisting functional limitations. Participants described many challenges associated with managing a cancer diagnosis on top of living with a chronic disabling functional limitation. They identified strategies to maintain health and topics in health-promotion programs tailored for this unique group of cancer survivors.

Conclusions: The “double whammy” of a cancer diagnosis for people with preexisting functional limitations requires modification of health-promotion strategies and programs to promote wellness in this group of cancer survivors.

Interpretation: Nurses and other healthcare providers must attend to patients’ preexisting conditions as well as the challenges of the physical, emotional, social, and economic sequelae of a cancer diagnosis.

Knowledge Translation: Cancer survivors with preexisting functional disabilities had difficulties finding cancer care providers who could manage their unique needs. That may be because some cancer-care providers are inadequately prepared to care for patients with cancer who have complex preexisting conditions. Cancer survivors with preexisting conditions may benefit from health-promotion programs that emphasize self-advocacy strategies, management of the economic impact of multiple diagnoses, and wellness activities adapted to their unique functional limitations.

none (Shi et al., 2011). Some survivors experience psychosocial concerns: fear of recurrence, sexual problems, depression, problems with social relationships, and loneliness (Foster, Wright, Hill, Hopkinson, & Roffe,

2009; Harrison et al., 2011; Rosedale, 2009). Survivors also are more likely to experience work disability than individuals without a cancer history (Short, Vasey, & Belue, 2008), and may face diminished employment opportunities, difficulty obtaining health and life insurance, and high out-of-pocket costs for health care (Hewitt & Ganz, 2006).

Although some knowledge of health issues among cancer survivors and people with disabilities exists, little is known about the needs of someone who has a preexisting functional disability and then develops a cancer diagnosis and undergoes treatment. Those survivors seem to be absent from cancer survivor studies because demographic profiles typically do not specify functional disability as a preexisting condition. Studies suggest that the challenges associated with living with a functional disability could uniquely impact their cancer experience and subsequent health-promotion needs and services. For example, women with mobility impairments who are breast cancer survivors may experience physical access barriers to care, such as difficulties with imaging equipment, procedures, and transferring to examination tables (Iezzoni, Kilbridge, & Park, 2010). In a study of predictors of quality of life for long-term cancer survivors with preexisting disabling conditions, Becker, Kang, and Stuifbergen (2012) found that participants had poorer physical well-being than survivors without such preexisting conditions.

Despite the challenges associated with cancer survivorship, health-promotion activities can positively impact survivors by improving quality of life, psychological function, and fatigue (Alfano et al., 2009; Brown et al., 2011; Conn, Hafdahl, Porock, McDaniel, & Nielsen, 2006; Groff et al., 2010; Harding, 2012). Similarly, wellness interventions tailored to those with chronic and disabling conditions can positively impact health (Stuifbergen, Morris, Jung, Pierini, & Morgan, 2010). However, not much is known about the experience of cancer survivorship in people with preexisting functional disabilities or how to best tailor health-promotion interventions to meet their needs. Therefore, the purpose of the current qualitative descriptive study was to explore the experience of living with a cancer diagnosis in the context of a preexisting functional disability and identify the strategies used to promote health and the topics that should be included in a wellness intervention program tailored to those survivors.

Using the operational definition from federal surveillance studies, the current study defined functional disability broadly as "limited in any way in any activities because of physical, mental, or emotional problems" (Centers for Disease Control and Prevention, 2005, p. 17). The conceptual orientation was based on an explanatory model of health promotion and quality of life in chronic disabling conditions (Stuifbergen, Becker,

Rogers, Timmerman, & Kullberg, 1999; Stuifbergen, Seraphine, Harrison, & Adachi, 2005). The model suggested that the quality of life for all people with disabilities resulted from complex interactions among illness severity; antecedent factors such as resources, barriers, social support, and self-efficacy; and health-promoting behaviors.

Methods

Data were collected as part of a study of health promotion for cancer survivors with preexisting disabling conditions. The first phase began with a nationwide survey of factors that predicted health-promoting behaviors and quality of life among cancer survivors who had completed active treatment. As reported in Becker et al. (2012), 145 adult cancer survivors who had chronic and disabling conditions prior to their cancer diagnosis and treatment were contacted and asked to complete a mailed survey. In the current study's second phase, focus group participants discussed their experiences of living with a cancer diagnosis in the context of a preexisting functional disability, and provided information that could be used to adapt a wellness intervention for cancer survivors with other prior disabling conditions.

Focus group methodology was chosen to capitalize on the richness that can come from a group's discussion of complex health issues. The focus groups were held in Chicago, IL; Villanova, PA; Ann Arbor, MI; and Austin, TX. Three disability research programs assisted in the organization of focus groups in their respective communities. The fourth focus group was organized by the researchers in their own community. Following institutional review board approval, participants were recruited by the local staff of disability research programs and via the researchers' contacts with individuals who participated in the study's earlier survey phase. A flier describing the focus group study and the inclusion criteria was given to participating research programs. Participant inclusion criteria included a self-reported cancer diagnosis and a functional disability prior to the cancer diagnosis, the completion of active treatment, the ability to speak English, and being aged 21 years or older. Given the current study's qualitative approach and focus group format, a convenience sample of 19 participants was recruited and split among the four groups. The sample size was based on the number of participants who could be recruited at each study site; no participants dropped out of the study. Participants received a \$75 money order for participating.

Procedure

All focus groups were held in locations convenient to people with disabilities in their respective communities. Three were held in universities or medical centers and

one in a local independent-living center. Because transportation can be a barrier for people with functional limitations, transportation reimbursement also was offered.

The second author, an experienced focus group moderator, developed the focus group guide and conducted three of the focus groups. The fourth author, also an experienced focus group moderator, was trained by the second author and conducted the fourth group. Homogeneity of moderation was ensured by using identical interview questions and reviewing the transcribed group discussions for consistency in the interview process and questions. All focus groups met once, were audio recorded, and sessions lasted from 60–90 minutes. Assistant moderators were recruited at the sites to take field notes and assist the moderator with meeting logistics. Two participants with sensory impairments participated with the assistance of accommodations that included large print for written materials and auditory implants that magnified sound. Focus group participants completed a brief background survey that provided demographic information, type of cancer diagnosis, stage of cancer, type of treatment (e.g., chemotherapy, radiation, surgery), degree of assistance needed, time since diagnosis, and completion of active treatment. The focus group interview questions were developed by Stuifbergen, Harrison, Becker, and Carter (2004) for a study that refined a similar wellness intervention for people with chronic and disabling conditions. The sessions were modified slightly to make them specific to cancer survivorship. At each focus group session, the moderator welcomed the participants, obtained informed consents, and then reviewed the focus group procedures with them. The sessions began with an ice-breaking question: “How long have you been a cancer survivor?” The moderator then asked, “What is it like to live with cancer and a preexisting functional limitation?” and, “What do you do to take care of your health?” The moderator asked the participants to consider a list of topics covered in the wellness intervention originally designed by Stuifbergen et al. (1999) (see Figure 1). Participants were asked whether the topics

- Understand the potential for health in the context of cancer survivorship and a preexisting disabling condition.
- Identify specific information that may impact the ability to enact health-promotion behaviors and to achieve potential outcomes.
- Recognize lifestyle adjustments that assist in maximizing health.
- Identify sources of stress and strategies for stress management.
- Understand strategies to enhance physical activity.
- Identify strategies to promote nutritional health.
- Develop strategies to improve interpersonal relationships.
- Develop strategies to support and maximize a proactive approach to managing health.

Figure 1. Wellness Program Topics

addressed important issues for cancer survivors with preexisting disabilities. They also were asked whether other topics should be included, and what the most important topics for cancer survivors with disabilities might be. At the sessions’ end, participants received survivorship information about local resources and a link to the National Coalition for Cancer Survivorship’s survivor toolkit.

Data Analysis

A research assistant transcribed audio recordings from three of the four focus groups. The fourth tape could not be transcribed because of equipment failure. However, the moderators’ notes plus the notes from two note takers remained available for analysis. The moderators compared the transcriptions with their notes to check for accuracy. Data were analyzed inductively using Patton’s (2002) qualitative content analysis procedures. The interview transcripts were reviewed line by line for significant phrases and statements. Those data chunks were coded with tentative labels and combined into similar groupings to form core categories of information that addressed the study’s aims. To promote the findings’ trustworthiness, the first author independently analyzed the data and met with the second author to discuss coding results, preliminary analytic categories and tentative findings, and to finalize the results. Any differences between the two authors’ interpretations of the data were resolved by reviewing the focus group transcriptions again and creating a shared understanding of the issue in question. The results also were compared with written responses to open-ended questions and other comments on the 145 mailed surveys; the survey responses were consistent with the focus group data. Because 11 focus group participants also took part in the mailed survey, their survey comments were not included in this comparison.

Results

Study participants were predominantly non-Hispanic Caucasian, well-educated, older adult women (see Table 1). Although the study was not limited to women, no men volunteered to participate. The participants’ preexisting functional disabilities were mainly neuromuscular or orthopedic, including multiple sclerosis, spinal cord impairment, arthritis, and post-polio syndrome. The majority of the 19 participants were breast cancer survivors who were diagnosed an average of 10 years earlier. The content analysis results are presented in three sections, according to each study aim.

Living With a Cancer Diagnosis

Four analytic categories were derived from the data: (a) the “double whammy,” the experience of managing

a cancer diagnosis in addition to living with a chronic disabling functional limitation; (b) cancer care challenges associated with a preexisting disability; (c) the impact of cancer treatment; and (d) the importance of advocacy and social support. This constituted a strong undercurrent throughout the group dialogues in all four focus groups. One participant said:

We all think we are dealing with more than one thing, but sometimes if we have a physical handicap,

Table 1. Demographic Characteristics (N = 19)

Characteristic	$\bar{X}$	SD
Age (years)	59.5	9.6
Age when diagnosed with primary disabling condition (years)	37.5	14.5
Time since cancer diagnosis (years)	9	9.5
Characteristic	n	
Focus group location		
Austin, TX		4
Villanova, PA		4
Chicago, IL		6
Ann Arbor, MI		5
Ethnicity		
Caucasian		13
African American		4
Asian American		1
No response		1
Education		
High school		2
College or some college		11
Master's or doctorate		6
Marital status		
Married		8
Divorced		5
Widowed		3
Never married		2
Lives with significant other		1
Source of functional impairment		
Multiple sclerosis		4
Arthritis		3
Post-polio syndrome		3
Spinal cord impairment		2
Other ^a		7
Type of cancer		
Breast		11
Colorectal		2
Bladder		2
Gynecologic		1
Melanoma		1
Thyroid		1
Kidney		1
Type of cancer treatment ^b		
Surgery		18
Chemotherapy		7
Radiation		8

^a Other sources were bacterial meningitis, blindness, bone disease, cardiovascular disease, chronic back pain, diabetes, and hearing impairment.

^b Most participants received more than one type of treatment.

Note. All participants were female.

physically, you are dealing with a double whammy in a way that other people can't understand. You're already stressed out trying to deal with polio problems or, you know, "Oh my gosh I've gotta get a CAT [computed axial tomography] scan but there is no parking nearby. How can I get there?" My strength is already gone from having the polio and now you have to deal with your cancer, so it's heavier to deal with.

Other participants made similar observations and discussed the devastating impact of receiving a cancer diagnosis and struggling to manage the clinical care issues and emotional effects of a dual diagnosis. Comments included, "It seems like it is always something [else]," "Oh my God, here we go," and, "I don't want to do one more thing, but I guess that's not a choice."

The cancer diagnosis and treatment experience precipitated challenges for the participants. They recounted difficulties in obtaining care from cancer-care providers who seemed unable to understand or accommodate the needs of people with preexisting functional limitations and disabling diseases.

I was already experiencing post-polio syndrome and probably about 18 surgeries [before breast cancer surgery], but I am angry because I feel no matter what I say to any person in the medical profession, it goes in one ear and out the other, perhaps because they haven't had the personal experience to believe what I'm saying is still important.

That participant then described a harrowing experience with postanesthesia care following breast surgery that illustrated a staff misunderstanding regarding her respiratory compromise associated with post-polio syndrome. Others described difficult hospitalization experiences in which providers appeared indifferent to participants' needs for assistance with self-care activities; others described problems with accessing facilities that had substantial barriers for people with mobility and visual impairments. Many worried about their oncologists' ability to recommend cancer treatment that took their underlying diseases into account. One woman with multiple sclerosis (MS) worried about managing her MS treatment regimen along with her breast cancer care.

It was difficult to sort through what medicines I was taking for MS versus what medicines I was going to be taking for cancer and [I] ended up sorting through those and figuring out which ones I could leave off for the MS and that was in the cancer cartel.

Participants described their experiences with cancer treatments in the context of their preexisting conditions. Many recounted challenges associated with postsurgical care.

So, getting through the treatment, I stayed with a friend of mine who is a nurse, as I was on crutches and it was hard with my MS because I don't have a whole lot of upper body strength. So, the crutches weren't the most ideal things for me to have, so that made it difficult, too.

The difficulty of decisions about chemotherapy and radiation therapy also surfaced. Some participants explained how these treatments adversely impacted their already compromised functional mobility and energy levels.

It's cumulative. You have fatigue anyway, but just with chemo[therapy] and radiation, it just takes its toll. And that's scary to lose. You may gain it back when you quit, but sometimes not.

Finally, the importance of advocacy and social support was clear in the "double whammy" context. Participants described their efforts to be their own advocates and educate their cancer-care providers about their preexisting conditions. One woman struggled with obtaining appropriate pain medication when she had a mastectomy and reconstructive surgery. Although the pain medication regimen for her chronic arthritic pain worked well, hospitalization for cancer surgery created new problems.

The fact that I'm on this pain control regimen, doctors wanted to ignore it, I'm sure they wanted to ignore it, he didn't want to deal with somebody with fentanyl patch and oxycodone, just didn't want to deal with that. So if you don't advocate for yourself, forget it.

She later observed, "Sometimes you get tired of fighting for yourself and trying to educate everybody." Others echoed this sentiment; however, they emphasized the need to "become your own case manager and advocate." Important social support for surviving the added challenges of a cancer experience included family, friends, and spiritual connections. "It's important to have somebody you trust to go through the process with you for the cancer treatment and when you're doing intense procedures and making treatment decisions."

Health-Promotion Strategies

Strategies that participants used to promote health while surviving cancer included physical activity, nutritional support, management of their healthcare providers and medical regimens, and lifestyle adjustment. Examples of preferred physical activities included walking, water exercise, biking, and swimming. However, some of those activities posed a challenge because of functional limitations and problems with the accessibility of health clubs and other exercise settings. Participants with neuromuscular disorders shared their

difficulties in finding warm water swimming pools. However, the participants from Chicago mentioned a local fitness center that emphasized accessibility and focused on the needs of people with disabilities. Their experiences underscore the major role the environment plays in health promotion for people with disabilities. Dietary strategies varied somewhat, but typically included the importance of eating fruits and vegetables, foods without additives, and dietary supplements.

The importance of managing multiple healthcare providers and medical regimens dominated much of the discussion. Participants encountered cancer-care providers insensitive to their other medical needs and limitations. As participants moved through cancer treatment and beyond, they emphasized the importance of communication in coordinating care among specialists and primary-care providers. Determining the cause of new symptoms was particularly challenging in the context of multiple diagnoses managed by different specialists.

One of the things I really don't like about MS, it just makes you almost sound like a martyr if you really sit down and talk to a doctor and say "Here's what I'm feeling." And sometimes they say, "Well that's just life." Well, no, I don't think so, you know, it isn't. Adding on the cancer problems makes you think you could either hide and just keep quiet or really kind of assert, "No, I really think you need to look at this; you need to allow the possibility that there may be some additional problems here."

Health-promotion strategies also included lifestyle adjustments such as stress reduction, energy conservation, and requesting help. Participants explained that stress and fatigue diminished their sense of wellness and that they engaged in activities such as relaxation exercises, pacing activities throughout the day to allow for periodic rest, yoga, and acupuncture. Some described having been reluctant to reach out to others for emotional support or assistance with cancer-care needs. They observed that they had learned to overcome such reluctance and change their hesitancy to accept help. One described responding to an offer of meals from her son's school.

I said, "Oh no! I don't need that. No, I'm not getting sick from chemo[therapy] and I'm fine." And one woman was so persistent. Finally, I agreed to one meal per week and you know what? And that was the most wonderful thing. And it took a load off my mind.

Wellness Program Development

Participants reviewed the proposed topics for a wellness program tailored to their needs and offered feedback and additional suggestions for future program

development. Although they concurred with the proposed topics, they emphasized the importance of teaching individuals how to manage their care via self-advocacy and education, and to find accessible healthcare settings with providers sensitive to their needs.

Getting to the doctors is a huge issue. I had stopped seeing my surgeon because his office is not accessible. I now question if I had to go through radiation and chemotherapy again, how would I do it, not being as mobile as I was when I [had] cancer for the first time.

Participants offered caveats about the physical activity and nutrition topics, including the importance of tailoring activities and nutritional intake to meet unique needs and limitations and how to find resources for assistance with this. Participants also suggested topics specific to cancer, including the importance of ongoing cancer surveillance, use of survivor support groups, management of economic and insurance issues unique to individuals with multiple chronic conditions, and dealing with the fear of possible cancer reoccurrence.

To me, it's a concern in the economics of the health-care industry when you have a chronic disabling condition and you also have cancer. Is there going to be limitations on what gets covered? If you already look on the bottom line on your insurance and you're one of the people that the numbers are a little bigger . . . are there going to be things that are going to be curtailed?

Discussion

The diagnosis of cancer along with a preexisting functional limitation represented a double whammy for these participants. Difficulties in finding healthcare providers equipped to manage the cancer and other underlying conditions surfaced in the four focus groups. That finding is similar to Iezzoni et al. (2010) and Iezzoni, Park, and Kilbridge (2011) who showed that mobility impairment and physical access barriers can adversely impact the process of diagnosis, treatment, and recovery from breast cancer. Unfortunately, many healthcare providers are poorly prepared to care for people with prior disabling conditions. Barriers to good care include negative attitudes about working with people with disabilities, communication barriers, and lack of disability-related training and teaching materials in academic nursing and medical programs (Iezzoni, 2006; Larson, Carrothers, & Premo, 2002; Martin, Rowell, Reid, Marks, & Reddihough, 2005; Shakespeare, Iezzoni, & Groce, 2009; Smeltzer, Robinson-Smith, Dolen, Duffin, & Al-Maqbali, 2010).

In a survey by Virgo, Lerro, Klabunde, Earle, and Ganz (2011), primary-care physicians and oncologists

reported concerns about being adequately prepared to provide appropriate care to cancer survivors. However, provision of health-promotion services to cancer survivors is an integral component of survivorship care (Ganz, Casillas, & Hahn, 2008; McCabe & Jacobs, 2008).

The concept of self-advocacy appeared in the discussion of all of the focus group questions. Survivors spoke at length of trying to educate cancer care providers about their unique needs and included self-advocacy as a health-promotion strategy and an important component of wellness programs for cancer survivors with preexisting functional limitations. The importance of self-advocacy has been found in other studies of healthcare experiences in people with functional impairments (Sharts-Hopko, Smeltzer, Ott, Zimmerman, & Duffin, 2010) and was characterized as "fighting for everything" in a study of women severely affected by MS (Edmonds, Vivat, Burman, Silber, & Higginson, 2007). Self-advocacy has long been identified as important for cancer survivors (Hoffman & Stovall, 2006).

The participants suggested that wellness programs include an emphasis on managing the economic impact of having a cancer diagnosis and a preexisting comorbid condition that also may necessitate ongoing care interventions. Worries about dual diagnoses prompted concerns about insurability and growing out-of-pocket expenses not covered by third-party payers. That concern is supported by Weaver, Rowland, Bellizzi, and Aziz (2010) in a study of health disparities in access to care for cancer survivors in the United States; investigators found that more than two million cancer survivors did not access one or more needed medical services because of financial troubles. Although wellness programs for cancer survivors should include existing strategies for obtaining necessary care, health-policy changes must support appropriate care for the growing number of cancer survivors and people with disabilities. The Patient Protection and Affordable Care Act of 2010 is designed to improve accessibility, quality, and affordability of health care for people with disabilities (American Association of People With Disabilities, 2011); however, political and judicial challenges leave its fate uncertain.

The concept of health promotion resonated with study participants. They provided multiple examples of how they work to take care of their health. Their challenges to staying healthy offer areas where nurses and other healthcare providers can partner with them to enhance their health. Given the possibility that various forms of cancer-related disability and altered function may have an added effect on preexisting disabilities, future studies should investigate this phenomenon and address how to best promote health.

Limitations

The present findings are limited to the study participants' voices. Because participants were mostly non-Hispanic Caucasian, well-educated women who lived in urban or suburban areas and had access to high-quality healthcare facilities, larger studies including more diverse groups are warranted. Although the focus group format capitalized on a social context that encouraged participants to reflect on one another's ideas, it also may have limited the information any one participant can share or inhibited the expression of minority opinions (Patton, 2002).

Conclusion

This study reveals nuances associated with the experience of a cancer diagnosis in the context of a preexisting functional limitation. As survivors described the "double whammy," they revealed important lessons for their healthcare providers. Health-promotion strategies encompassed many of the tactics that other cancer survivors employ; however, the need for adapting such measures to the unique issues associated with functional limitations and preexisting, often debilitating chronic diseases is evident. Suggestions for modifying wellness programs for these cancer survivors include attention to the preexisting conditions as well as the challenges of the physical, emotional, social, and economic sequelae of a cancer diagnosis.

Implications for Nursing

The current study's findings suggest that new educational efforts must be made to provide nurses and

other healthcare providers with skills and tools to care for survivors who may have multiple comorbidities and functional limitations. In addition, implementation of oncology nurse navigation services for those survivors with complex medical conditions has potential to remove barriers to care, improve interdisciplinary communication, and enhance care outcomes (Lee et al., 2011; Pedersen & Hack, 2010). As such, future studies should evaluate the impact of navigation services in that population.

Nurses who design wellness programs for cancer survivors with other preexisting conditions must address self-advocacy strategies for both sets of needs. Such strategies can be as simple as providing participants with names of care settings that successfully accommodate people with functional limitations (e.g. having adjustable examination tables that allow easier transfer from a wheelchair) or as complex as teaching advocacy strategies to influence public policy.

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