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Working Toward Normalcy Post-Treatment: A Qualitative Study of Older Adult Breast and Prostate Cancer Survivors

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Abstract

Purpose/Objectives—To develop a better understanding of how older adult survivors of early-stage breast and prostate cancer managed the work of recovery.

Research Approach—Multiple case study design embedded in a larger randomized, controlled trial of a nurse-led patient navigation intervention.

Setting—Community-based research conducted via in-home visits and by phone with participants residing in non-metropolitan areas of a mid-Atlantic state.

Participants—Rural-dwelling adults aged 60 years or older with early-stage breast or prostate cancer and the people who support them (11 dyads).

Methodologic Approach—An approach to grounded theory analysis was used to evaluate the fit between existing theoretical knowledge and case findings and to generate new knowledge about the cancer recovery process.

Findings—Working toward normalcy was a core process of cancer recovery prompted by participants' internal experiences and external interactions with their environments. This ongoing, iterative, and active process involved multiple concurrent strategies that were not necessarily medically oriented or cancer specific. Working toward normalcy resulted in movement along a continuum of self-appraisal anchored between participants experiencing life as completely disrupted by cancer to a life back to normal. A greater sense of normalcy was associated with higher engagement in valued activities and increased physical and psychological well-being.

Conclusions—In addition to the core process of working toward normalcy, multiple theories from nursing, sociology, psychology, and gerontology helped to explain case findings. This

knowledge could serve as a foundation on which to design survivorship care that supports the goals of cancer survivors working toward normalcy post-treatment.

Interpretation—Post-treatment wellness goals can include a desire to reestablish or maintain a sense of normalcy. Nursing actions that promote survivors' efforts to be perceived as capable, stay engaged in valued activities and roles, maintain a sense of control over their lives and bodies, and make plans for the future may help meet this goal. Existing theories about identity, dignity, inner strength, and the work of illness can inform nursing interventions.

Keywords

neoplasms; survivors; normalcy; grounded theory; oncology nursing; rural population

Cancer survivors may take months or years to fully adjust to life following cancer treatment, and they may never do so (Buzaglo et al., 2013). The Institute of Medicine published a landmark report that highlighted the depth and breadth of survivors' unmet needs post-treatment (Hewitt, Greenfield, & Stovall, 2006). Because of the influence of this report and the research it inspired, cancer is increasingly viewed as a chronic condition that requires medical, rehabilitative, and psychosocial support well after treatment has ended (Viswanathan et al., 2014). As the population grows, so does the demand for high-quality survivorship care that addresses the needs of increasing numbers of aging cancer survivors who are living longer following cancer treatment (Siegel et al., 2012).

Transitional survivorship, sometimes referred to as a period of re-entry, has been defined as a phase of adjustment that immediately follows completion of primary cancer treatment (Ganz, 2009; Mullan, 1985). During this phase, cancer survivors may continue to perform numerous illness-related tasks associated with adjuvant treatments, rehabilitative therapies, and ongoing cancer surveillance while managing their everyday lives (Klimmek & Wenzel, 2012). In addition to these activities, transitional survivorship involves recovering a sense of wholeness, reconstructing identity, and adjusting life plans in the wake of cancer and its consequences (McCann, Illingworth, Wengström, Hubbard, & Kearney, 2010; Reeve, Lloyd-Williams, Payne, & Dowrick, 2010). Managing life in this new normal during cancer recovery can be considered a form of work involving effort, resources, and tasks on the part of survivors and those who support them. Therefore, the purpose of this study was to develop a better understanding of how older adult survivors of early-stage breast and prostate cancer manage the work of recovery from primary breast and prostate cancer treatment.

Methodologic Approach

The analysis reported in the current article was embedded within a larger randomized, controlled trial of a nurse-led supportive intervention for rural-dwelling cancer survivors and the people who support them (Wenzel, Jones, Klimmek, Krumm, et al., 2012; Wenzel, Jones, Klimmek, Szanton, & Krumm, 2012). The research reported in the current article used an intensive, multiple case study design (Stake, 1995) and grounded theory analysis techniques (Charmaz, 2006) to evaluate the fit between existing theoretical knowledge related to the process of managing recovery and to generate new theoretical knowledge

about that process. Case study methods are particularly useful for generating theory and evaluating how well existing theories may help to explain phenomena of interest (Stake, 1995). The authors retained concepts and relationships from existing theoretical knowledge that helped to explain participants' behaviors following primary cancer treatment and provided a good fit with overall case findings. The end result was a set of working hypotheses about the process of recovery post-treatment.

Participants

Cognitively intact, community-dwelling adults aged 60 years or older who had been recently diagnosed with early-stage breast or prostate cancer were selected from an ongoing randomized, controlled trial of a nurse-led patient navigation intervention being delivered to patient–support person dyads in a rural setting in central Virginia (Jones, Steeves, & Williams, 2009; Wenzel, Jones, Klimmek, Szanton, et al., 2012). For the current substudy, the authors collected data through daily written journals, multiple in-depth interviews lasting one to two hours each, and notes on telephone calls between research team members and participants (patient participants and their support people) conducted at least once every two weeks from the time of enrollment through at least one month post-treatment completion. Interview guides were initially framed using existing theory borrowed from the sociology of illness work, particularly Corbin and Strauss' illness trajectory framework (Corbin & Strauss, 1988; Klimmek & Wenzel, 2012). Self-report written questionnaires, including scales designed to measure anxiety and depression (Zigmond & Snaith, 1983) and cancer-related quality of life (Cella & Tulsky, 1993; Cella et al., 1993), were administered to survivor participants at baseline, around the time of cancer treatment completion, and three months following treatment completion. Ethics approval was obtained from the institutional review boards of all study sites, and written informed consent was obtained from all participants prior to data collection. Interviews were audio recorded and transcribed verbatim with participants' permission.

Analysis

Analysis of the qualitative data involved open and focused coding of transcripts from in-depth interviews, typed researchers' notes from biweekly call logs, and daily journals (Saldana, 2013). All data were uploaded to data management software ATLAS.ti, version 6.2.27. Researchers' field notes and individual item responses and overall scores on questionnaire instruments measuring anxiety and depression and quality of life were used as contextual data to provide a more complete picture of participants' experiences throughout the study period. This involved looking at patterns and trajectories of experiences within and across cases and comparing those trajectories to results of the qualitative analyses (Stake, 1995).

Identifying and Generating Theory

Although the larger study involved dyads consisting of cancer survivors and the people who supported them, this substudy focused primarily on the experiences of the dyad members who were treated for cancer. Data collected from support people were used to deepen investigators' understanding of the experiences of survivor participants. The investigator primarily responsible for conducting the analysis met weekly with another PhD-prepared

oncology nurse researcher to discuss the data, coding, and the interpretive process. These results were then discussed with a third PhD-prepared researcher. After analyzing the first few cases, both researchers agreed that getting back to normal life appeared to be a core behavioral and social process of the work of transitional cancer survivorship (Holton, 2013). This interpretation appeared to be consistent with a large body of prior behavioral research involving similar populations of cancer survivors. Data from the next few cases examined also supported getting back to normalcy as a core social and behavioral process following completion of primary cancer treatment. Therefore, as analysis proceeded, emerging categories related to this process (e.g., strategies used to establish or maintain a sense of normalcy) were compared to findings from prior research on early cancer survivorship. The primary investigator initially coded transcripts of interviews, daily journal entries, logs from telephone calls with participants, and other materials using in vivo codes containing language that reflected participants' unique or shared meanings related to their experiences of establishing or maintaining a sense of normalcy following primary cancer treatment (Charmaz, 2006). Focused codes that integrated existing in vivo codes into larger categories salient to the process of working toward normalcy following cancer treatment were then applied. Finally, the primary investigator generated theoretical codes that further synthesized focused codes into conditions, strategies, or consequences of the process of getting back to normal post-treatment. During the constant comparative process of generating theoretical codes, the authors also reviewed middle-range theories of nursing science, as well as theoretical literature from related health disciplines, such as sociology, psychology, and gerontology. The goal of this effort was to identify theoretical knowledge that helped to explain or interpret participants' attempts to establish a sense of normalcy post-treatment. Per recommended best practices in case study research, the theories and concepts the authors found most salient to the understanding of normalcy were then applied to each case to assess fit and the possible need for theoretical rejection, revision, or expansion to fully encompass and explain case findings. The current article presents a theoretical perspective on getting back to normalcy following cancer treatment that is grounded in data from the authors' case analyses, as well as examples of existing theories that, when applied to case findings, were useful in helping to explain and interpret behaviors identified as part of getting back to normal.

Findings

The authors analyzed eight cases of breast cancer survivorship and three cases of prostate cancer survivorship. All cases involved at least one rural-dwelling adult who had received a new cancer diagnosis and one designated support person. On average, the participants with a cancer diagnosis were aged 70 years or older, with some exceptions. Characteristics of these cases are summarized in Table 1. Every participant resided in a rural area, as defined by the U.S. Census Bureau's (2015) definition of non-metropolitan area, with most living an hour or more from the cancer center. Working toward normalcy was a core process of recovery from cancer treatment, which was prompted by participants' internal experiences and external interactions with social, medical, and other personal environments; involved multiple strategies; and resulted in movement along a continuum of perceived normalcy from feeling less normal to back to normal or a new normal. When trajectories of

longitudinal self-report data from questionnaires were mapped onto participants' written and verbal reports of their experiences of normalcy post-treatment, higher levels of perceived normalcy were associated with a greater sense of overall well-being and quality of life, and lower levels of anxiety and depression. The process of working toward normalcy was iterative and involved many steps, with participants sometimes experiencing minor or major setbacks along the way. Although some participants eventually expressed having fully achieved normalcy post-treatment, a sense existed that it was always possible to slip backward along the continuum. As such, striving for or maintaining a sense of normalcy post-treatment was a full-time and ongoing pursuit. Figure 1 presents a visual depiction of this process.

Conditions Prompting Working for Normalcy

Although survivor participants and their support people sometimes had difficulty articulating clear goals in the months following cancer treatment, they were motivated by a strong desire for their lives to get back to normal. Getting back to normal was an emotional and psychological need, as well as a practical one. The pivot toward behaviors to reestablish or maintain a sense of normalcy was often prompted by internal or external conditions that included experiences of symptoms or late effects of treatment, as well as interactions with social, medical, and other personal environments. Internal experiences, such as symptoms or late effects, served as a barometer by which participants treated for cancer would judge progress toward recovery or a sense of the body's return to normalcy. In some cases, participants appeared to normalize ongoing symptoms, such as pain, as an expected consequence of aging or other health conditions rather than as a consequence of cancer illness or treatment (see Figures 2 and 3). By interpreting these experiences as expected or non-cancer-related, participants avoided dwelling on the possibility of a new cancer-related disruption that might interfere with the process of getting back to normal. In contrast, situations in which symptoms or late effects were interpreted as signaling ongoing or new cancer-related health problems were experienced as stressful and indicative of a failure to meet the expectations of cancer recovery. Social interactions provided other opportunities for participants to appraise progress toward a sense of normalcy. For example, some participants resisted family members' and neighbors' attempts to provide care and assistance in the wake of cancer treatment, interpreting these overtures as a sign that they were seen as sick or less capable than others. These interpretations stood in contrast to most participants' self-identities, who were autonomous individuals and generally took care of others. Similarly, medical contexts, such as return visits to the cancer center for follow-up appointments, were fraught with possibilities for participants who had completed cancer therapies to be made to assume the sick role once more and, therefore, feel less than normal. However, positive feedback from cancer care providers, such as receipt of a cancer-free diagnostic examination, was another metric by which participants could judge progress toward a return to normalcy. Other medical milemarkers along the road toward normalcy included the end of surgery or radiation, postoperative removal of drains or other medical devices, completion of follow-up diagnostics, or the first appointment with the cancer care provider following primary therapy. Taking adjuvant therapies, such as aromatase inhibitors to reduce the risk of cancer recurrence, did not appear to prevent participants from working toward normalcy. However, in at least one case, a woman who had temporary breast forms

but who had not yet received a permanent, fitted breast prosthesis found it difficult to launch into the work of getting back to normal until the prosthesis arrived.

Interactions with other aspects of participants' personal environments provided additional opportunities for appraisal of position on the normalcy continuum. Experiences of functional limitations in home or work settings, such as restricted mobility of the upper arm, weightlifting restrictions following breast cancer surgery, or the inability to perform work outdoors without frequent breaks to urinate in the case of one prostate cancer survivor, served as reminders of changes or losses that signified a departure from normal life. Some participants chose to cease engaging in these valued activities altogether rather than continue to experience the negative emotions associated with these functional difficulties. In contrast, re-engagement with former or new valued activities, such as volunteer or occupational work, following treatment were often reported immediately preceding participants' reports that life had more or less returned to normal or had at least stabilized to some kind of new normal post-treatment.

Strategies for Working Toward Normalcy

Participants used a variety of strategies to move along the continuum, including (a) retaking control of the body and everyday routines, (b) interpreting symptoms and late effects as expected with normal aging, (c) focusing on the needs of others, (d) expanding life space, and (e) making plans for the future. These strategies sometimes overlapped and were often performed concurrently and iteratively as participants moved back and forth along a continuum anchored between life as completely disrupted by cancer and feeling less than normal and life as stable and feeling back to normal (even if it was a new normal). As participants used these strategies, they were constantly appraising their own and others' perceptions of how they were doing and how close to normal their lives were.

Consequences of Working Toward Normalcy Post-Treatment

Survivor participants' self-appraisals of having a greater or lesser sense of normalcy that fell somewhere along a continuum of normalcy (from more normal to less normal) was a consequence of strategy use and reflected participants' identities and beliefs about their health, capabilities, and future post-treatment. When asked about who they were as a person, even immediately following cancer treatment, most survivor participants reported that they usually considered themselves to be well, capable, and autonomous individuals. When they experienced a negative appraisal event, such as a perceived loss of function, or when they sensed that another person saw them or treated them as sick or less capable, survivor participants moved backward on the continuum of normalcy toward feeling less normal. Backward movement was associated with reported feelings of illness, lack of control, and disability, and movement toward a greater sense of normalcy was associated with feelings of wellness, control, and quality of life. This finding was supported by questionnaire data, including visual depictions of trajectories of participants' scores for anxiety, depression, and cancer-related quality of life at the time of diagnosis, around the time of cancer treatment completion, and three or more months following primary treatment. Times at which survivors and their support people reported feeling less normal corresponded to changes in trajectories of anxiety (higher) and functional quality of life (lower). In this sense, self-

assessments of whether life was more or less back to normal became a sort of proxy for overall wellness and quality of life.

Existing theoretical knowledge related to the work of illness and normalization of illness experiences from the fields of nursing, sociology, psychology, and gerontology provided additional guidance when interpreting the data. These are summarized in Figure 4, which provides the current authors' and cited sources' interpretations of the assumptions underlying existing theories. For example, across-case findings of participants' attempts to embrace an identity as well, capable, and autonomous individuals during and following cancer treatment were consistent with rejection of the sick role, a sociologic concept that explains why people adopt identities of wholeness or wellness, even in the face of life-threatening illness or chronic conditions. Grounded theory on preserving human dignity provided an excellent fit with findings related to participants' desires to remain and be seen by others as autonomous and capable. Activity and continuity theories of aging captured participants' efforts to remain engaged in valued roles and activities they had enjoyed prior to the cancer diagnosis. Inner strength theory, although originally formulated as specific to females, framed the authors' understanding how female and male cancer survivors drew on internal resources and sought to establish new goals and find meaning in their experiences as part of the process of working toward normalcy. The authors' framework for understanding the work of transitional cancer survivorship provided an inventory of medical, biographical, and everyday activities observed as part of participants' working toward normalcy post-treatment. By fitting case findings to these existing bodies of theoretical knowledge, the authors were able to provide a basis through which the findings could be transferred to broader cancer survivor populations and contexts.

Discussion

The core process of older adult breast and prostate cancer survivors and their support people working toward normalcy post-treatment is consistent with findings from numerous previous studies involving cancer survivors with a variety of cancer types in a variety of settings. Cancer survivors report that getting back to normal or coming to terms with a new normal is often an important goal (DeMarco, Picard, & Agretelis, 2004; Keim-Malpass & Steeves, 2012; Molassiotis & Rogers, 2012; Sherman, Rosedale, & Haber, 2012). Striving for normalcy has been identified as a common coping strategy of cancer survivors who are male or female (McCaughan, Prue, Parahoo, McIlpatrick, & McKenna, 2012), diagnosed with a variety of cancer types at early and advanced stages (Fitch, 2012; Hammer, Mogensen, & Hall, 2009; Ottosson, Laurell, & Olsson, 2013), younger (Kyngäs et al., 2001) and older (Rubin, Chavez, Alderman, & Pusic, 2013), and socioeconomically and ethnically diverse (Blinder, 2012; Schapmire, Head, & Faul, 2012). Details regarding what constitutes a normal life can vary considerably from person to person, but survivors' self-reports commonly include getting back to work and other activities of everyday life (Blinder et al., 2012; Böttcher et al., 2013; Corbeil, Laizner, Hunter, & Hutchison, 2009; Denford, Harcourt, Rubin, & Pusic, 2011; Ottosson et al., 2013; Vrkljan & Miller-Polgar, 2001); having control over one's body, choices, and routines (Sherman et al., 2012); socializing and leisure (Miedema, Hamilton, & Easley, 2007); body image recovery and being seen as normal by others (Denford et al., 2011; Fitch, 2012; Rubin et al., 2013); and not feeling ill

(Palmer, Bartholomew, McCurdy, Basen-Engquist, & Naik, 2013). Achieving and maintaining some sense of normalcy following cancer treatment has also been associated with important outcomes, such as improved functioning (Larsson, Jönsson, Olsson, Gard, & Johansson, 2008), social engagement (Blinder et al., 2012), psychological and emotional well-being (Corbeil et al., 2009), hope (Hammer et al., 2009; Schapmire et al., 2012), and cancer-related quality of life (Specia, Robinson, Goodey, & Frizzell, 1994). Therefore, creating a sense of normalcy following cancer treatment can be crucial to maintaining health and wellness during cancer survivorship.

Cancer does not occur in a vacuum; rather, it occurs in the wider context of complex life trajectories that involve multiple developmental, socioeconomic, psychological and biologic changes over time (Klimmek & Wenzel, 2012). Aging cancer survivors must deal with consequences of cancer and related therapies that may overlap with simultaneous effects of other chronic conditions or life changes that can serve as barriers to a return to normalcy. Oncology nurses should be attentive to the specific needs of older adult cancer survivors, particularly as they relate to setting goals, planning for the future, physical and social functioning, cancer- and non-cancer-related symptoms, engagement in valued activities, and ability to maintain independence (Bellury et al., 2013; Deimling, Sterns, Bowman, & Kahana, 2007; Lyons, Erickson, & Hegel, 2012; Wenzel, Jones, Klimmek, Krumm, et al., 2012). Older adult survivors seeking to reestablish a sense of normalcy may benefit from education and assistance distinguishing normal, aging-related changes from pathologic changes from cancer, other illnesses, or possible late effects of cancer therapies. When appropriate, nurses should make referrals to other members of the interdisciplinary care team, such as oncology social workers, financial counselors, and rehabilitative specialists.

Strengths and Limitations

This study was limited by a case study approach that supports generalization to theory as opposed to populations. This means that, although patterns detected within and across the 11 cases of early-stage breast and prostate cancer survivorship may be found in other, broader populations, this must be studied further in a larger, more generalizable sample before such conclusions can be drawn. However, a strength of the study is the generalization of the theoretical findings to a body of existing knowledge developed from numerous other survivorship research studies on diverse cancer survivor populations. Theoretical generalizations are one way that case study methods overcome the limitations of a small number of participants. Although the current study involved dyads including an older adult rural-dwelling cancer survivor and at least one support person as the unit of analysis, the focus of the results reported in the current article was primarily on the experiences and actions of the individual breast and prostate cancer survivors. Although the larger study captured social and behavioral dynamics within each dyad that have potential relevance for improving the understanding of the process of working toward normalcy post-treatment, those findings will be reported in a future article.

Implications for Nursing and Conclusion

A holistic model of survivorship care demands that nurses adapt health education, services, and care to assist survivors in achieving wellness (Haylock, 2011). This may require

oncology nurses to assist cancer survivors and their families to construct and maintain a sense of normalcy post-treatment. High-quality, patient-centered care should be theory-driven and based on the best available evidence to meet the needs of unique care recipients (Knobf, 2013; Morgan & Yoder, 2012). Oncology Nursing Society, Institute of Medicine, and the American Cancer Society have called for the generation of new knowledge and theory to guide survivorship care (Bellury et al., 2013; Lester, Wessels, & Jung, 2014; Siegel et al., 2012; Stricker & O'Brien, 2014). This focus has led to a variety of innovative practice interventions and policies, including the creation of nurse-led survivorship clinics and other novel mechanisms for providing ongoing care and support (O'Brien et al., 2014). Although numerous studies have evaluated a wide variety of nursing efforts to assist survivors in achieving their goals post-treatment, relatively little attention has been paid to development of theory and best practices to assist survivors in achieving and maintaining this vital sense of normalcy. This constitutes an important gap in oncology nursing knowledge that should be filled through additional research on supportive care models consistent with the need for normalcy post-treatment. In addition, this study highlighted important overlaps between cancer-related symptoms or late effects of treatment and older adult participants' expectations regarding normal aging. Interpretation of these experiences was complicated for some by the presence of other underlying chronic conditions, a common phenomenon among aging cancer survivors (Deimling, Sterns, Bowman, & Kahana, 2005). Chronic conditions can serve as barriers to a return to normalcy by amplifying negative effects of cancer illness and treatment. Similarly, cancer therapies can exacerbate preexisting comorbidities, leading to additional symptoms and functional limitations (Deimling et al., 2007). Therefore, future research should address the role that chronic conditions may play in disrupting a return to normalcy post-treatment, as well as strategies that nurses can use to support normalcy among growing numbers of survivors who are experiencing simultaneous effects of cancer, other chronic conditions, and aging-related changes. The current study focused primarily on efforts to reestablish normalcy during the first several months following cancer treatment. However, given the invasive and frequently more intensive nature of ongoing cancer surveillance, best practices for supporting normalcy in the years extending beyond the first year post-treatment should also be explored.

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Knowledge Translation

Survivors and the people who support them may strive to create a sense of normalcy post-treatment, which has implications for survivorship care and what it should look like.

Nursing actions that promote survivors' ability to be perceived as capable individuals, engage in valued activities and roles, maintain control over their bodies and daily routines, and make plans for the future may help meet the need for normalcy.

Nurses should respect differences in definitions of wellness and normalcy post-treatment by encouraging survivors to define for themselves what wellness looks like in their own lives, their strengths and capabilities, and areas where they might need to strategize or seek additional support to meet their goals.

Figure 1.
Process of Working Toward Normalcy Post-Treatment

Retaking Control Over My Body and Activities

- Engagement in prior social roles and everyday activities, sometimes with adaptations
- Able to perform activities of daily living and instrumental activities of daily living independently
- Daily routines do not revolve around medical visits or cancer-related tasks.
- Symptoms and late effects are well managed.

On working toward normalcy: "I've tried to do as much as I could. So I wouldn't be handicapped. . . . So far, I've been doing good. I've been taking my own baths, driving, getting in and out of the tub."

On not attaining normalcy: "As my illness has progressed, I have become more and more disabled and very, very upset because I could do so little."

Interpreting Symptoms and Late Effects of Treatment as Expected With Normal Aging

- New and ongoing symptoms not interpreted as signs of declining health or illness

"I'm back almost to my normal self. I get a little tired. . . . I don't know if that's because of—whatever, you know—or just that I'm getting old. But I'm doing really, really good."

Focusing on the Needs of Others

- Volunteering and informal helping
- Prayer for others
- Supporting other cancer survivors

"As long as you're helping somebody else, you don't have much time to think about yourself."

Expanding Life Space

- Not tethered to certain radius around cancer center
- Return to work, volunteer, or social or faith communities and settings
- Trips out of town

"I had to get motivated to get up and just keep moving because, if I sit here [in the house], I know that I could feel that it wasn't going to get any better, just sitting here and taking pills."

Making Plans for the Future

- Planting gardens
- Planning vacations

"At first, when [my diagnosis] first happened, I said, 'Well, we are canceling vacation for this year. We're not going to go anywhere. We're not going to do anything.' But as I got better and I felt better, and things happened the way [they] did, I decided we have to do this [go on vacation]."

Movement Along the Normalcy Continuum: Being Perceived by Others as Healthy, Capable, and Autonomous

- Acknowledgment of an identity beyond that of cancer survivor
- Social interactions that do not require cancer-related updates or retelling of the cancer narrative

"After a while, it gets old. I had to just answer every day and talk about my health problems. . . . I really don't have a lot of people question me anymore. It's just our normal, routine life now."

Figure 2.
Strategies and Consequences of Working Toward Normalcy

Case Study

Mrs. Smith was an African American woman in her 70s who lived with her husband in a rural county. Prior to her cancer diagnosis, she was very active in her church and local community. She loved tending to her garden and helping neighbors, as well as taking care of the house. She had no history of major health problems, and her diagnosis of stage I breast cancer came as a shock. Although her oncologist presented breast-conserving surgery and mastectomy with surgical reconstruction as treatment options, she chose to undergo a mastectomy without reconstruction. The surgery went as planned, and Mrs. Smith experienced a faster-than-expected physical recovery with no signs of lymphedema or other late effects, but she noted that she sometimes felt more tired than usual. Her children and other family members stayed with her for about a week following the surgery, and they continued to check in regularly by phone. Neighbors and church members also stopped by every other day for several weeks postoperatively, often dropping off food and offering to help out around the house. Her husband took over some of the household duties, including cooking and cleaning. By six months postsurgery, Mrs. Smith had resumed most of these responsibilities around the house. By one year following treatment, Mrs. Smith was able to say life was back to normal.

Strategies Used to Work Toward Normalcy

- **Taking control over body and routines:** Mrs. Smith appreciated her family and friends' efforts to help out around the house. However, it was difficult to accept others doing the household work she was so used to doing herself, particularly because she no longer had control over how it was done. During the immediate postoperative phase, a family member assisted her with bathing and changing her surgical wound dressing. Getting back to normal meant resuming household activities she had normally performed herself, as well as assuming individual responsibility for self-care activities.
- **Interpreting symptoms and late effects as normal:** Although Mrs. Smith continued to experience symptoms, such as pain and fatigue, in the weeks following her surgery, she was hesitant to associate these symptoms with her cancer experience.
- **Focusing on the needs of others:** During and following cancer treatment, Mrs. Smith found it challenging to be on the receiving end of care. It was not until she began helping out again in her community and at her church that she began to feel life was getting back to normal. She also began organizing community activities for a cancer nonprofit, which she felt gave her a chance to give back to others touched by cancer.
- **Expanding life space:** As Mrs. Smith recovered from surgery and regained her confidence going out in public, she also began to travel farther away from home. Returning to normalcy meant spending more time in places she had frequented prior to her diagnosis and less time at the cancer center. She began by walking around her neighborhood, then drove herself into town, and returned to her church community. She said that she felt more confident going out in public when she received her permanent breast prosthesis several months following surgery.
- **Making plans for the future:** After receiving her diagnosis, Mrs. Smith put plans for a long-distance vacation on hold. It was not until several months following her surgery, once she had recovered physically and received her permanent breast prosthesis, that she and her husband began to make plans for a vacation the following summer. This vacation was made possible, in part, by the knowledge that she no longer had to remain within a certain proximity of the cancer center, which was necessary for several months postsurgery.

Figure 3.
Mrs. Smith's Case Study

Rejection of the Sick Role

Falling ill may be associated with assumption of a sick role, in which the individual is no longer considered normal and exempted from certain expectations of society. The sick role implies an obligation to get better and to seek help from and cooperate with medical professionals. Individuals diagnosed with cancer may reject the sick role because being perceived as sick may lead to negative feelings of inadequacy, vulnerability, or failure.

Potential applications to nursing care

- Assess for how people wish to be identified.
- Do not assume labels, such as “patient with cancer” or “cancer survivor,” are acceptable.
- Acknowledge strengths and progress toward goals and milestones.
- Provide and reinforce self-management interventions.

Middle Range Theory of Attributed Dignity and Dignitas Concept

Attributed dignity: This term describes a state characteristic of self that can be affected by interactions with others. Cancer survivors may appraise their dignity based on their sense of self-value, self in relation to others, perceived value from others, and respectful behaviors.

Dignitas: This term explains how nurses’ interactions with patients reflect aesthetic values that may uphold or degrade dignity, which suggests that nurses should maintain constant awareness that all caring actions carry meanings that may differ from patient to patient.

Potential applications to nursing care

- Create a patient-centered clinical environment that promotes feelings of wellness, control, and capability or achievement as opposed to illness, lack of autonomy, and disability.

Continuity Theory of Normal Aging and Activity Theory

Continuity: Social and psychological well-being is preserved by maintaining external continuity (maintaining same or similar behaviors, social relationships, and environments) and internal continuity (recognizing connections between past experiences and inner changes to ideas, temperament, affect, or preferences).

Activity: Satisfaction in later life is associated with activity and social engagement.

Potential applications to nursing care

- Identify barriers to engagement in prior valued activities or social roles (e.g., financial difficulties, cancer stigma, spiritual distress).
- Address barriers in partnership with an interdisciplinary care team.

Inner Strength Theory

Inner strength is developed by rearranging life priorities and cultivating new skills to live a normal life post-treatment. Dimensions of inner strength include (a) knowing and searching for meaning, (b) nurturing relationships and spirituality, (c) facilitating desired change, and (d) having a positive attitude.

Potential applications to nursing care

- Setting goals should be patient-driven.
- Nurses can work with people treated for cancer to identify rehabilitative support needs to recover skills or to adopt problem-solving strategies needed to engage in valued activities and roles.

Work of Transitional Cancer Survivorship

Survivorship following cancer treatment involves three types of overlapping and reciprocally interactive work: (a) the illness-related work of medical surveillance, ongoing therapies, and rehabilitation; (b) the biographical work of coming to terms with changes caused by cancer, reconstructing one’s identity and life plans, and moving forward; and (c) everyday life work into which the other two must be integrated. A sense of normalcy may be achieved once illness-related and biographical work are integrated and managed in such a way as to permit performance of everyday work and routines.

Potential applications to nursing care

- Assess for and address difficulties integrating survivorship care (e.g., medical appointments, ongoing therapy and rehabilitation, surveillance) into everyday life routines.
- Do not assume people will prioritize medical tasks over other types of work.
- Assess for and address the biographical work of reconstructing identity, including grief, image recovery, and making plans for the future.

Figure 4. Applications of Theory to Delivering Nursing Care That Supports Working Toward Normalcy

Note. Based on information from Atchley, 1989; Havighurst & Albrecht, 1953; Jacelon & Choi, 2014; Klimmek & Wenzel, 2012; Lubkin & Larsen, 2006; Lyons et al., 2011, 2012; Parsons, 1951; Pols, 2013a, 2013b; Roux et al., 2004.

Characteristics of Participants

Table 1

Case	Support Person	Treatment	Age (Years)	Race	Education	AHI (\$)	Marital Status	CC
Early-Stage Breast Cancer								
1	Daughter	Mastectomy	70–74	African American	High school degree or GED	Less than 8,000	Widow	3
2	Daughter	Mastectomy and chemotherapy	65–69	African American	High school degree or GED	8,000–14,999	Divorced	2
3	Male spouse	Mastectomy	75–79	Caucasian	High school degree or GED	35,000–49,999	Married	1
4	Female friend	Mastectomy	70–74	Caucasian	Associate degree	NR	Widow	1
5	Female cousin	Lumpectomy and external radiation	70–74	African American	Associate degree	25,000–34,999	Divorced	0
6	Male spouse	Mastectomy	70–74	African American	High school degree or GED	25,000–34,999	Married	1
7	Son	Mastectomy	70–74	Caucasian	Higher than bachelor's degree	Greater than 50,000	Married	Greater than 5
8	Female friend	Mastectomy	60–64	Caucasian	Bachelor's degree	Less than 8,000	Single	1
Early-Stage Prostate Cancer								
9	Brother	Prostatectomy	60–64	Caucasian	Associate	NR	Widower	1
10	Female spouse	Prostatectomy	60–64	Caucasian	High school	NR	Married	1
11	Female spouse	Hormone therapy and radiation	70–74	Caucasian	Higher than bachelor's degree	Greater than 50,000	Married	1

AHI—annual household income; CC—number of chronic conditions; NR—not reported