In My House Are Many Rooms: A Proposed Model to Examine Self-Concept

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We are sharing a model that we have used to increase our understanding of the impact of cancer on individuals and families and to assist us as we work with these individuals to live with the challenges they encounter. This article is not a synthesis of the research conducted in the area of self-concept or the literature currently published. It does integrate research, theory, and practice experience to enhance understanding of cancer-related changes in self-concept. The origin of our use of the proposed model dates back to the mid-1970s, when we were involved in “Make Today Count,” a support group for individuals encountering life-threatening illness. Most of the individuals we had the privilege of working with were dealing with cancer; the impact of their cancer molded our thinking, but our real-life encounter with stroke taught us firsthand that the model has wider applications. In fact, it was our personal experience with the changes associated with stroke during those earlier days that motivated us to pursue the use of such a model. At this time, the model will be presented within the context of cancer and its treatment. However, the model’s application or use with individuals experiencing other health-related problems should be apparent. In fact, nurses working in medical-surgical practice arenas who see not only patients with cancer, but also patients with a wide variety of diagnoses, will be able to generalize much of the model to other situations.

Introduction

The impact of cancer frequently is a topic of discussion by and for healthcare professionals. We acknowledge that the diagnosis and treatment of cancer, as well as living with the disease, have the potential to cause a tremendous effect on quality of life. Yet, do we adequately grasp the magnitude of the impact for the individuals actually experiencing it? Cancer frequently is identified as the most dreaded diagnosis an individual can receive. In addition, even though we boast tremendous advances in treatment, improved cure rates, and longer survival with the disease, cancer continues to be associated with death. Life after a cancer diagnosis is perceived as involving pain, suffering, disfigurement, and similarly negative consequences. Unfortunately, because of the nature of the majority of the current treatments, many survivors of the initial experience with cancer find themselves having to deal with long-term side effects or consequences. Although the survivorship movement is making great strides, the magnitude of these problems has yet to be fully appreciated by healthcare professionals. Because cancer treatments always are changing in our fight to overcome the disease, the long-term effects scenario also is ever-changing. Often, by the time we have a large enough cadre of individuals far enough out from a given treatment protocol to allow us to adequately document the long-term negative sequelae, the treatments have changed to improve short-term results. In addition, individual disease and treatment trajectories vary with a wide range of combinations over time. Consequently, it is extremely difficult to obtain a clear picture of who can be expected to experience which long-term consequences. One fact, however, is certain—life will never be quite the same as it was before a cancer diagnosis.

Self-Concept

A number of terms are used when we engage in discussions about the impact of cancer on the lives of individuals for whom we have the opportunity to provide care. Some of the terms used frequently include self-concept, body image, self-image, and self-esteem. In our model, we use the term self-concept as the mental picture we have of ourselves and how we feel about that picture. It is as though in our mind’s eye we actually are able to “look” at ourselves and make an evaluation. At any one point in our lives, we actually have multiple identities—not in a psychiatric or pathologic sense, but in terms of roles. For example, although our roles as nurses often may seem to be encroaching on all of our existence, simultaneously we are spouses, parents, friends, nurturers of others, gardeners, house cleaners, etc. The roles involve relationships with different individuals and a variety of expectations. Our feelings concerning these various roles fluctuate constantly.

Effect of Cancer on Self-Concept

When an unexpected and undesirable event such as a diagnosis of cancer occurs, it has the potential to trigger an almost “domino-like” effect in multiple areas of the lives of the people involved. Cancer has an effect not only on the individual with the diagnosis, but also on family members and friends. Changes that affect self-concept alter how we view ourselves, our situation, and the people around us.

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The consequences imposed by cancer often trigger multiple losses and a response not unlike the grief process. There is considerable fear of the unknown, especially in light of all of the hearsay information received. In addition, there is the stress of the uncertainty of not knowing if the proposed treatments will be effective. When side effects and treatments interfere with individuals’ abilities to accomplish usual routines, chaos can result.

### Potential Role for Healthcare Professionals

As nurses, we have an opportunity to make a difference in the lives of the individuals we work with who are dealing with the impact of cancer on their lives. Our professional knowledge and experience with other patients and family members serve to partially equip us to provide support along the way. Admittedly, no two individuals and no two cancers are exactly alike. Therefore, we have to exercise caution and not see ourselves as truly knowing what an individual is experiencing or having all the answers. Instead, we can pull from professional knowledge and our repertoire of experience and listen to their stories. As professionals, we possess “book” knowledge and generalizable knowledge regarding the disease or illness and treatment (Good, 1992; Harvath et al., 1994). Families and individuals with cancer bring local knowledge (Geertz, 1983) or awareness of information that is unique to their situation. As we partner with them in our approach to provide care, we must blend our scientific knowledge and understanding of the information unique to their situation. In so doing, the level of our care is enhanced (Harvath et al.; Tanner, Benner, Chesla, & Gordon, 1993). The proposed model aids us in learning the local knowledge that is essential to providing optimum individualized care.

The model we offer has served us well in this endeavor, and we share it hoping it will help you to better serve the individuals you encounter in your roles as healthcare providers. Cancer has a way of changing relationship-building rules. Individuals with cancer and family members frequently allow us into their world at a level not often experienced with others. Such is the experience of oncology nurses who have worked closely with patients and families facing cancer as a life-threatening illness. As we do our best to attend to the people with whom we work, we can and do have an opportunity to make a difference. We cannot rewind the tape and erase the occurrence of the diagnosis of cancer, but we can listen to patients’ stories, help them to script a less devastating scenario, and address ways to improve their quality of life.

### Model

Using the visual analogy of a house and the reality that there are many rooms in each house provides the framework for the development of the proposed model for self-concept and the impact of cancer. We take on diverse identities in the various rooms of our houses and often feel differently about ourselves in the many rooms. Each of the rooms in our houses has the potential for unique individualization in terms of meaning and role identification.

We will progress through the aspects of the model and then proceed with a discussion of changes seen with cancer. It seems fitting to start with the exterior of the house, as this is what we see first (see Figure 1). Houses come in many different sizes, shapes, and designs. Some are very stately in appearance: others simple, yet inviting. The exterior of a house includes its roof and outer finish. Houses may have multiple large windows or little opportunity to view the interior. Front doors may invite many to enter or may be small and somewhat difficult to access.

Houses may or may not include a garage. For many, the garage is their access to the world, an opportunity to interact with others outside the house. The garage symbolizes mobility and the ability to get out and do things. The garage may be an attached and even integrated part of the overall structure, or it may be detached and rather inconvenient. In other instances, the garage actually may become a place to store items that do not otherwise fit into the house. In such cases, the garage may not contain a vehicle for transportation to other places.

Now let us look into the house. First, we will focus on the kitchen (see Figure 2). In many houses, the kitchen becomes a major focal point: a place of warmth, delicious aromas, and nurturing. For some, it is a place for self-expression through creating elegant dishes and elaborate meals. Although not always designed to be a place of gathering, close family and friends often come here knowing the security the kitchen offers. Many of the tasks undertaken here offer opportunity for a close interaction and time of sharing.

A dining room may be an integrated part of the kitchen or a totally separate room. It is here that people “sit for a while” to receive the nurturing provided by the chef of the day in the kitchen. A large dining room provides the setting for special family holiday meals and celebrations, complete with memories of “how we have always done it.” Memories with family and friends are made here as time is spent conversing and consuming the meals prepared.

The family room often is envisioned as a large room designed to allow for interaction. Visiting with family and friends occurs within its multiple settings that can include a warm and inviting fireplace. It is the warmth of the fire in the family room that invites one to come and relax for a while.

Recreation rooms take on many designs depending on the dwellers in the house (see Figure 3). This room is more than a place for fun and games—ranging from pool to darts or video games. It supports the critical role of re-creation. The recreation room facilitates the nurturing of the artistic self. This may be through the creation of music on a piano or expressing self through art in the medium of paints or photography.

The nursery is a place full of anticipatory dreams and hopes for the future with a wide variety of anticipated numbers and plans (see Figure 4). Here, the role of parent becomes a reality. Later, this room has the potential to
become identified as the children’s room. It changes over time as the children age and mature, moving on to houses of their own.

The bedroom lends itself to discussion of sexual identity and sexuality. Although this is not restricted to sexual activity with another individual, we are remiss if we do not address it. In the bedroom, we experience intimate interaction with our partners. Our beds become warm, inviting havens for rejuvenation through sleep. This room contains the closets that store our clothing items—an essential part of our identity. Frequently, there are mirrors in our bedrooms that allow us to see how we look before venturing out into the world. Much of our sense of attractiveness is centered in this room.

The size of the meditation room varies greatly (see Figure 5). This is where we nurture our spiritual selves. It may be through the identity of a relationship with a holy higher being, prayer, and worship, or it may be through quiet, reflective time involving imagery and journaling. The room often contains symbols that provide an inner comfort and structure to our meditation. The invitation is to escape from the hectic pace of daily life into a quiet respite designed to help gain inner strength and courage.

The den or office in our house symbolizes our working or professional selves (see Figure 6). For some, this is closely tied to “earning a living” through receiving a paycheck that makes it possible to provide for loved ones. As with many of the other rooms, the size and significance of the den can vary greatly, there is no one size fits all. Similarly, the decorations and furnishings in the den are very individualized. Because of the amount of time spent in our working world, often our work or professional identity may tend to overpower others. In addition, sometimes it is easier to remain busy and retreat to our den rather than deal with challenges in the other rooms of our houses.

The basement provides the much needed space for storage. This is where we often stuff things that we do not know what to do with at the moment. At times, it contains the things we do not want to deal with and, frequently, things we do not want others to see. Although for some highly organized individuals the room may be neat and orderly, it has the tendency to become cluttered and overloaded. It actually may accumulate items that later become trash.

Now we come to the attic of our house. Although frequently not regarded as a room in our traditional houses, the attic in the model is very significant. Memories are stored in the attic. These may provide for warm recollection of special events or may be reminders of some hard times. This is the room where we often must go to find direction from our past to help us cope with the present and the future.

With the rooms in our house and the identities accompanying them articulated, we can proceed to discussion of the impact of cancer on self-concept using the proposed model. We will proceed once again through each of the rooms identified. Examples of changes imposed by cancer and cancer treatment will be shared as seen through the eyes of the individuals who experienced the altered quality of life. Their specific knowledge has contributed to the development of the model.

Diagnosis of Cancer
and the House Model

The words “you have cancer” or “it is cancer” are some of the most poignant in the human language. They have the ability to stir up a complete host of reactions that reverberate throughout all aspects of individu-
Surgery, radiation therapy, chemotherapy and biotherapy, or a combination of these treatments, make up our arsenal against cancer. Albeit essential to stop the rampant growth of the malignant cells, treatment has numerous undesired effects. Although more targeted treatments are in development, the majority of our therapies do cause significant damage to normal cells. Unlike with treatments for other conditions, in cancer care, individuals must submit themselves to damaging treatments to get better.

The impact of changes with surgical intervention frequently involves gender-specific procedures. They have the potential to impact self-concept as related to surgical removal of a body part associated with our identity as male or female. Examples commonly found in the literature include mastectomy, hysterectomy, prostatectomy, and orchietomy. However, these are not the only cancer-related surgical interventions that are known to alter life experiences and certainly do not encompass the cancers that affect the lives of the individuals involved. Others that readily come to mind are head and neck surgeries, pneumonectomy, limb amputation, and procedures such as rotationalplasty. Detailed discussion of these procedures and their impact on the patients and family members is beyond the scope and intent of this article. We would, however, be remiss if we did not articulate at least some of these life-altering physical changes. Some are more outwardly visible; others may not be apparent to other people but are excruciatingly visible to individuals’ inner selves.

Radiation therapy is most often a regional or localized therapy with a varied side-effect profile depending on the area of the body being treated and the type and duration of the treatment. Chemotherapy also has a varied side-effect profile, depending on the specific agents administered, dose, and duration of therapy. Once again, detailed discussion of these side effects is beyond the scope of this article; however, certain points are important as they relate to the model. As mentioned previously, these treatments mean that the individuals must submit to toxic effects that serve as constant reminders of their cancer. Focused study of the side effects that accompany cancer therapy has led to the awareness that the symptoms frequently occur in clusters. Thus, successful management of these effects requires a carefully orchestrated, planned approach. Often, our view of adequately controlled side effects is not congruent with what the individuals experiencing them tell us in their stories. As with surgical changes, some of the side effects cause visible changes and others are less outwardly apparent. Both the visible and less outwardly apparent effects contribute to the impact on quality of life for the individuals with cancer and their family members.

Rather than delving into the side effects in detail, our discussion will shift to use of the house model to explore the impact of cancer, treatments, and side effects. Obvious physical effects such as alopecia, weight loss or gain, cachexia, skin changes, and surgical amputation are seen as changes in the exterior appearance of our house (e.g., hair loss is visualized as the shingles falling off, skin changes are visualized as the paint peeling or changing color, amputation is visualized as the loss of long-standing shutters). Although we, as professionals, often see individuals with these physical changes and actually can look beyond the alterations to their inner selves.

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The rippling effect of cancer carries on to leisure time in the recreation room. Neuropathies, often ignored until they interfere with the ability to sew, play the piano, or experience other activities have a devastating effect. When fatigue limits the energy an individual has, difficult choices must be made as to whether the day includes only work or allows for play. Time off for treatments may have used up all available sick leave and paid time off. Financial burdens associated with cancer have a far-reaching impact that carries over to dealing with the reality of not having adequate funds for vacations and fun.

When cancer affects fertility, or pregnancy is not indicated because of associated hormonal changes, the impact on the nursery can be painful. Adoption cannot even be seen as a viable option for many. Thus, dreams are shattered as plans for family size fade. When individuals with cancer are older, families actually may experience parent-child role reversal. Children find themselves providing personal care for ill parents.

The impact of changes in the bedroom has a wide-reaching effect. Feeling unattractive sexually interferes with the willingness to experience closeness with a loved one. This can be further complicated when changes include impotence, loss of libido, or mucous membrane alterations. When the ability to sleep is altered, nighttime rejuvenation slips further from reality and nights become fraught with nightmares and fears.
Many possessions can accumulate in the basement. Some of this is a result of not having the time or energy to deal with them as cancer becomes the central focus. There may be uncertainty if items will ever be needed again, so they are placed out of sight in the basement.

Unfortunately, we sometimes overlook the need for quiet time in the meditation room. Emphasis may be placed on striving to “do things” rather than giving ourselves permission to journal and meditate. When illness is seen as life-threatening, individuals may question their long-held beliefs and not know if it is okay to ask questions.

As fatigue interferes with the ability to maintain a regular schedule of usual activities, difficult decisions need to be made. How should the limited energy be spent? Sally used to say, “My family has to know that if I spent my quarter’s worth of energy going to the mall with a friend, there will be no laundry or evening meal. Sometimes they don’t see the same priorities I do.” Cognitive changes can alter people’s ability to continue professional roles that involve critical thinking.

At times, the challenges of the present seem overwhelming during the cancer experience. It may be tempting to turn to the attic as sometimes it is easier to live with memories than the present or even the future. This is further complicated when the present is filled with negative experiences and the future is uncertain.

**Implications for Nursing**

As nurses, we can provide support to assist individuals in transcending the experience of cancer. This involves coming through and learning from the experience. Numerous individuals with cancer have told us “although I would never wish this [cancer] on anyone, I am a better person because of it, and I would not want to give that up for anything.” Such individuals have been able to successfully remodel their houses to accommodate the changes imposed by cancer and cancer treatment. It involves finding new meaning in life and, for many, redefining quality of life.

Often during treatment, individuals will ask, “Will things ever return to normal?” What they must learn is that seldom do things stay the same even outside of life with cancer. In fact, they grow through the experience and learn a new normal. This is not necessarily a lesser normal, but most often it is different. Individuals with cancer and family members can learn to “make today count” because they have the opportunity, not because they may not have another chance to do a given activity. It involves living in the moment versus for the moment. Yesterday is gone and with it the old normals. Tomorrow never comes, the clock continues to tick, and time often is more limited than we realize. Today is the present—a gift of time to enjoy and cherish. Cancer can give individuals permission to do just that.

As nurses, we can pull from our knowledge and from the experiences of others to support individuals facing what may seem like overwhelming challenges. There may be a need for remodeling in the house or altering the exterior to facilitate coping. The model can help us as we work with individuals and listen to their stories. Remodeling or making alterations involves changes in the amount of time spent in rooms as well as the activities performed. There may be a need to reset priorities and find ways to conserve energy for the desired activities. Look Good . . . Feel Better® (www.lookgoodfeelbetter.org) is an example of an American Cancer Society program that can help individuals with the exterior of their houses—the aspects that are most visible to outsiders. There may be a need to work with other family members to help them adjust to the physical changes also.

Our ability to assist is dependent on the specific knowledge individuals share with us. If individuals cannot cook, perhaps they can plan the meals that church members provide. The kitchen may no longer be a central gathering place with friends. Perhaps there is a need to start using the warmth of fireplace to nurture relationships. In the recreation room, it may be necessary to identify new, less physically active, fun entertainment, such as cards and board games. This also may involve changes in the expectations of friends. The meditation room can become a sanctuary for quiet time and spiritual strengthening.

The basic structural frame of the house remains the same, but part of remodeling may involve moving walls. The nursery may need to decrease in size; the den or recreation room also may change in shape or composition as patients learn new creative outlets. Family rooms may require alterations to be more inviting to friends afraid to say the wrong thing. It may be necessary to make adjustments and be open to welcome new friends. Recreation may involve taking the opportunity to use creative skills in new ways.

Providing psychosocial support to individuals facing cancer and their families and friends is an essential role for healthcare providers. Rather than waiting for a crisis event, preventive maintenance in the form of front-end loading with services is important. Thus, it is important that we hear the stories, are aware of the resources available, and provide the necessary referrals for support.

**Conclusion**

As the changes that accompany cancer occur, individuals find themselves asking critical questions: Who am I? Who did I think I was? Who do I want to be? What is important? Whose me am I? The last but certainly not the least important question is Who understands?

It is our desire that the model “In my house are many rooms” will provide guidance for healthcare professionals who provide the essential listening ear. We cannot eliminate many of the changes experienced, but we can work together to address issues of quality of life in the face of cancer and cancer treatment.

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