Who Am I? Reflections on Self-Image Among Patients With Cancer in Clinical Trials

Connie M. Ulrich, PhD, RN, FAAN

Patients with cancer who participate in research face difficult challenges. Their lives change in many ways, and they often question their self-image. Self-image includes how patients see themselves and who they want to become. The current commentary addresses the issue of self-image in patients with cancer who participate in clinical trials and how their sense of who they were changes as they shift from patients with cancer to research participants. Patients with cancer who participate in research may suffer from multiple identity transitions, ranging from physical alterations in appearance and bodily capabilities to psychological burdens of job loss and the inability to contribute financially to their families. The author aims to provide insight as to how researchers can help patients find meaning in their lives during the process of participation in clinical trials as they undergo identity transitions.

To some degree, all people are defined by the roles they assume in meeting their life’s goals. In daily conversations with others, self-identification is perfunctory. People often identify by profession by saying, for example, “I am a doctor,” “I am a nurse,” “I am a lawyer,” “I am a carpenter,” or “I am a stay-at-home mom.” The immediate introductory exchange of civilities brings certain images to mind, and those images shape subsequent perceptions, responses, and behaviors toward others. When a person is diagnosed with cancer and becomes a participant in a clinical trial, that self-image changes. Mathieson and Stam (1995) described the change in self-image as a process that involves evaluating the meaning of the illness within the context of social relationships and the medical system. As part of a larger study on the benefits and burdens of research participation in clinical trials for cancer research by Ulrich et al. (2012), the current commentary discusses participants’ perceptions of self-identity transitions as they try to make sense of who they were and who they are while enrolled in research. Thirty-two patients with cancer who participated in clinical trials at a cancer center in the northeastern United States were interviewed about their research experiences. All data were recorded, transcribed verbatim, and analyzed following standard qualitative procedures (Denzin & Lincoln, 2000; Krueger, 1998; Ulrich et al., 2012). Study methods are described in detail in a previously published article (Ulrich et al., 2012).

Decisions After Diagnosis

A diagnosis of cancer causes a range of emotional responses, including fear, uncertainty, anxiety, and distress, as well as other physical, psychological, and spiritual burdens (Holland, 2003; Ulrich et al., 2012). A diagnosis of cancer can create a greater sense of dread than illnesses that have worse prognoses (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). Immediate concerns come to mind as to what to do, where to seek appropriate help, which options exist, what is going to happen to the body, and what the chances of survival, curing the cancer, or beating the odds of recurrence are. An abrupt role reversal also occurs; patients suddenly become reliant on others instead of relied on. Patients must find their way through a maze of appointments and procedures related to their specific protocol, as well as understand the medical linguistics of the diagnosis, prognosis, and research participation.
requirements. Dresser (2012) noted, “When we are seriously ill, we are expected to make choices that can be among the most significant in our lives” (p. 65). One of those significant choices includes whether to enroll in a clinical trial. Clinical trials entail various procedural aspects that require different degrees of commitment from participants. Participation may include blood work, daily or weekly infusions of an experimental drug for a specified time period, radiographic imaging, or immunotherapy.

Loss of Self-Image

As participants were interviewed to better understand their reasons for participating in clinical trials and some of the challenges they faced, an overwhelming number said the phrase, “I used to be” (Ulrich et al., 2012). That phrase not only reflected the desire to remain attached to a professional occupation or work-related identity, but also the more intimate and simple enjoyments in life that often are taken for granted. For example, participants said, “I used to be able to ride my bike,” “I used to be able to cook for my friends,” and, “I used to be able to care for others.”

Those regrets were real, painful, and emotionally laden. The “used to be” comments were a reminder that something was lost and may not return. Many patients with cancer suffer physical and psychological loss after a diagnosis of cancer, regardless of whether they participate in research (Die Trill, 2012). The sense of loss worsens with a diagnosis of cancer at an advanced stage and could be compounded by ensuing treatment options (e.g., chemotherapy, radiation, surgery, immunologic therapy, participation in research).

Holland (2003) argued that suffering of the mind is an authentic and weighty concern among patients with cancer. The burden that patients often bear includes all dimensions of well-being (e.g., psychological, social, spiritual, existential) and poses a significant threat to achieving short- and long-term goals as well as the meaning and purpose of life (Holland, 2003).

Reasons for Participation in Clinical Trials

For some patients, participating in research may be a final option for a potential cure when limited treatment options exist (Ulrich et al., 2012). It also may give research participants a sense of hope or a feeling of control over uncontrollable events (Ulrich et al., 2012). However, enrolling in a clinical trial also comes with risks. Suffering of the mind may be worsened for research participants with a poor prognosis because of the potential adverse effects and the uncertainty of experimental treatments, the benefits and burdens of being in the placebo arm of a clinical trial, the missed opportunity of standard treatment if the trial does not provide positive results, the pressure to continue treatment as the sole provider for a family, the contemplation of death, and the loss of identity. One participant commented on his concerns about the placebo arm of the clinical trial by stating, “I hoped, myself, that I got an absolute drug, not a placebo.”

Determining when identity loss begins, what triggers its occurrence, and at what point it begins to interfere with everyday life is difficult. One participant expressed concern about the benefits of research participation if it causes a change in self-image or a loss of identity by responding with this question: “Is it reasonable for me to turn myself into somebody that I don’t recognize and nobody else recognizes, and, you know, prop me up in a corner? No, it may not be. So, there’s a lot to weigh.” After a patient perceives a loss of identity through physical changes (e.g., baldness, weight loss), research participation can provide meaning in a way that differs from the traditional person-centric identity label based on day-to-day roles because it may allow participants to give back to society by contributing to knowledge of the disease or potentially lowering the risk of cancer for family members in the future.

Self-Sacrifice

Research participants are self-sacrificing in that they volunteer to give their time, their bodies, and potentially their lives to advance scientific goals and provide better treatment options for patients with cancer in the future. Some patients participate in clinical trials for altruistic means or to give back to the cancer community. A participant interviewed exemplified that purpose by stating, “If I don’t get the benefits, it’s fine. I know that one person after me is going to be saved.”

Individual identity changes in patients with cancer who participate in clinical trials. They might lose their hair, experience unpleasant side effects from experimental drugs, feel more tired, or suffer other adverse effects from procedural aspects of the trial. Researchers are careful about not creating inflated expectations for benefit in clinical trials because of concern for therapeutic misconception (i.e., when participants conflate research with traditional clinical care and perceive that personal benefit is the goal of participation) (Appelbaum, Roth, Lidz, Benson, & Winslade, 1987).

Researchers should find a way to convey purpose for research participants that values their sacrifice for the benefit of future patients with cancer. Voicing value for the dignity of research participants in the face of an unrelenting disease and the risks they undertake to advance the goals of clinical research is an intrinsic benefit and warrants additional discussion. As noted by Chochinov, Hack, McClement, Kristjanson, and Harlos (2002), “Dignity is distinctive in that it also has an external component based on the perception of one’s worthiness of honour and esteem from others” (p. 441). Many patients express gratitude when researchers take care of them, and they feel as if they are not just another number in a clinical trial. Patients feel comfortable and respected when the research team focuses on them.

Implications for Practice

- Request a research team meeting with the principal investigator to discuss participants’ mood disturbances and other concerns.
- Initiate a consultation or referral to the cancer care supportive groups available to the research team (e.g., social work, psychology, psychiatry).
- Ask patients and caregivers about their preferences, values, and goals for research participation, as well as any self-identified changes that they perceive.
as individuals. Knowing what gives patients a sense of dignity during trials or how researchers can better support them could improve participants’ outlook during clinical trials. In a study on dignity therapy for the seriously ill, Chochinov et al. (2005) asked patients about their hopes, dreams, and accomplishments in life. Those questions can be part of ongoing conversations with research participants to address identity concerns and provide supportive interventions.

Loss of Productivity

Many patients said that they lose their sense of productivity during participation in a clinical trial, which often was related to feeling tired and not feeling like getting out of bed. Productivity can be measured in a variety of ways, but usually is linked to employment, according to the interviews. Although some participants maintain employment during trials, many are not able to, despite their desire to remain productive. For one participant, remaining in the study was a way to accomplish something. Other participants mentioned the burden of having to take time away from work or that they worked hard all of their lives before the diagnosis of cancer. As Grant (2011) said, “There’s a wealth of evidence that people want to do meaningful work” (p. 98). Doing work in the form of clinical trials that benefit others and contribute to future research is meaningful and productive. Although productivity in research participants may differ from traditional employment, engaging in a dialogue about how they find clinical trials to be productive gives value to their participation.

Implications for Nursing

Fallowfield (1995) argued for the inclusion of psychosocial interventions to support the emotional needs of patients with cancer. Although significant progress has been made in interventions for patients with cancer (e.g., mind-body relaxation techniques, music and art therapy, counseling, education), little empirical data exist that use those techniques for participants in clinical trials (Barsevick, Sweeney, Haney, & Chung, 2002; Fallowfield, 1995; Turner et al., 2011). Future research should test methods to help participants in cancer clinical trials to improve overall mood and levels of stress. Clinical research nurses also are in a key position to identify feelings of distress and loss of identity in research participants, and they can connect patients with psychosocial resources. Nurses can ask research participants whether they want individual or family psychological counseling or a different type of support.

Conclusions

What brings meaning to life is different for each person. A person is a reflection of many aspects, including family, culture, and environment, but that reflection can change instantly with a diagnosis of cancer. Cancer can change patients’ perceptions of who they are and who they want to be. Researchers should work to learn what patients value, what they fear, and what brings them joy, as well as their purpose for participating in the trial. Researchers are in a unique position to unravel the self-image concerns that participants express through shared-decision making and open communication, so patients can confidently say, “I am a research participant.”

The author gratefully acknowledges Christine Grady, PhD, RN, Kathleen Knafl, PhD, and Gwenyth Wallen, PhD, RN, for their thoughtful reviews.

References