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 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.