Altruism—A Coping Mechanism for Patients on Clinical Trials: A Nursing Perspective

Judith Brown Sanders, RN, MSN, PMHCNS-BC, Julie S. Seda, RN, FNP-BC, and Carl G. Kardinal, MD

Altruism often is expressed by patients with advanced cancer as a coping mechanism and a motivational factor for participation in clinical trials. Those who participate develop a sense of hope that their life is a contribution, which may continue to live beyond their deaths.

A 44-year-old Caucasian woman, H.C., was diagnosed with stage IV ovarian cancer. She underwent surgery and was given the option to participate in a clinical trial or receive standard treatment. H.C. decided to participate in the study and verbalized many reasons for her participation. When asked how she made the decision to participate, she stated that she wanted to advocate for better cancer treatment and felt her participation in a clinical trial was turning adversity into advocacy to support this endeavor. She stated that she wanted to “help future cancer patients” and also “get the best treatment I can for myself in fighting this disease.”

When asked if she felt trapped by a lack of therapeutic alternatives, she replied, “No, but I would be trapped by death if I did not take this opportunity, and it might help others.” She continued saying, “I am contributing to the future of cancer treatment. Maybe they can put my results together with lots of others and they will come up with a cure; if not in my time, it will help others.”

H.C. is an example of being motivated by a therapeutic benefit because of the outcome she hopes to achieve. In addition, she is an example of a patient who expresses altruistic motivation in the face of his or her advanced disease.

Altruism can be a positive means of coping and can be a motivating force for participation in clinical trials. Several studies have documented the prominence of altruism as a reason for participation (Bevan, Chee, McGhee, & McInnes, 1993; Rosenbaum et al., 2005). However, altruism usually is not the primary motivating factor. Self-interest in obtaining a therapeutic benefit appeared to be the dominant motivating factor (Edwards, Lilford, & Hewison, 1998; Nurrgat et al., 2005). Most patients with advanced cancer participate in clinical research for a potential therapeutic benefit. This can be the result of a “therapeutic misconception,” which means that the primary reason for the clinical trial is to benefit the individual patient rather than the advancement of scientific knowledge (Miller & Rosenstein, 2003).

Patients With Advanced-Stage Cancer

Fifty patients with advanced cancer being treated in early phase II clinical trials were randomly selected to be interviewed on their perception of hope and their expressions of altruistic motivation as a coping mechanism. Prior to the interviews, patients signed an informed consent to participate in the clinical trial. In addition, they were informed in writing explaining the interview process, purpose, and how findings would be used. Participants also were asked to give their consent to participate in the interview and were assigned a number to maintain confidentiality. The semistructured interviews averaged 45 minutes in length. Institutional review board approval was obtained prior to the beginning of the interviews.

Participants gave a variety of responses that expressed examples of altruistic motivation. A 32-year-old man with acute leukemia was asked how he felt about being a subject in the evaluation of a new drug. He replied, “I’m glad to be on it,” and, pointing behind his back, he added, “I have to be—for the men coming after me.” He was very articulate in describing his strong altruistic feelings, as well as his belief that the new treatment offered him hope of another remission.

Patients expressed many emotions during the interviews. Some had feelings of entrapment because of a lack of therapeutic alternatives. Others expressed feelings of being merely an experimental subject evaluating new drugs. However, one patient denied feeling trapped by a lack of therapeutic alternatives and responded, “I signed the papers to help the next guy.”