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

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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; Nurgat 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.”
Patients were asked if they felt as if they were merely experimental subjects. Responses ranged from denial to affirmation that this would help future patients with cancer. Examples of these responses included: “No, because I’m contributing to the future;” “I feel like a guinea pig, at times, but hopefully this will help others, too;” “Sure, I’m here as an experiment. I want to help humanity. I’m glad to do it;” and “I want to give whatever is good of my body to science.” These representative quotes demonstrate that these patients had an altruistic motivation for being a part of a clinical trial. They focused on the potential positive outcomes of the study and viewed themselves as valued participants rather than dispensable laboratory subjects.

Supporting Patients Who Express Altruism

Altruism is a positive coping mechanism for patients enrolled in a clinical trial. Nurses can incorporate this concept into comprehensive psychosocial assessments and support patients who express altruistic motivation.

How can nurses recognize and support the concept of altruism and help patients use this as a positive coping mechanism? Nurses must understand the mechanisms of positive coping behaviors, which can facilitate a decreased sense of anxiety, powerlessness, depression, denial, and anger, emotions expressed by patients with advanced cancer. Nurses can help patients experience coping and gain a sense of control over their emotions and, consequently, feelings about their advanced disease.

Nursing assessment and nursing intervention strategies need to focus on the framework of coping, which involves examination of the context as well as the stressor. As part of a comprehensive holistic approach to patients with advanced cancer, the nursing assessment is the basis for all nursing interventions. To assess altruism as a positive coping mechanism for patients with advanced cancer, three key psychosocial assessment questions may be used (see Figure 1).

Providing psychosocial support to the patient and family requires specific and planned interventions. These interactions should focus on modifying the context (situation) of the stressor (cancer). What interventions can be used to support patients who express altruistic motives as a reason for entering into a clinical trial? Active listening for a reference to an altruistic outcome or motive that the patient may be expressing is paramount to beginning the discussion with the patient. This involves helping patients explore their feelings about altruism and their advanced cancer status, which reinforces statements such as, “Tell me more about how you feel this could help others” or “Tell me more about your commitment to wanting to help others.”

Acting as a patient advocate is important for nurses who accompany the patient through the process of deciding to participate in a clinical trial, signing the consent form, receiving and completing treatment, and then discontinuing the study (Klimanzeski, 2006). Each step of the way, the patient needs an advocate to help continue the journey. Sensitivity to the patient’s cultural and religious beliefs and how this may influence participation and understanding of a clinical trial is paramount, as is respecting the patient and family’s perceptions of illness (Bush, 2006; Klimanzeski, 2006). Acting as a liaison between the cancer care team to keep the patient and family informed of the progress or lack thereof enables the nurse to provide needed support to the patient (Klimanzeski, 2006). Assessing the information needs of the patient and family, their readiness to learn, and providing patient education information about symptom management and disease status is another strategic intervention (Klimanzeski, 2006). The patient and family should not be overwhelmed with information. Nurses can moderate this flow through repetition in a variety of formats. This method of information sharing allows the patient and family to incorporate the information at their own pace. Nurses are contributors to facilitating balance between educational information and emotional support (Bush, 2006).

Conclusion

In the advanced stage of cancer, the concept of altruism can be an important motivational factor for participation in clinical trials, even if it is not the primary motivation to participate (Rosenbaum et al., 2005). Often, a subsidiary altruistic motive accompanies the primary motivation factor of hope for therapeutic benefit. Patients frequently expressed the feeling that even if the investigational trials do not benefit them, it might be of help to others who come after them. They develop a commitment to finding an effective treatment for cancer, which gives them a renewed sense of hope for the future and possibly a sense of immortality in that their contributions may live on. Nurses caring for patients with advanced cancer on clinical trials need to recognize that altruistic motivation can be an effective coping mechanism and can provide psychological benefits for their patients.

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References


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