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Research Information Knowledge, Perceived Adequacy, and Understanding in Cancer Clinical Trial Participants

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Most people with cancer want to know as much as possible about their type of disease and treatment options (Cox, Jenkins, Catt, Langridge, & Fallowfield, 2005; Jenkins, Fallowfield, & Saul, 2001). A 2007 report from the National Cancer Institute entitled *Patient-Centered Communication in Cancer Care: Promoting Health and Reducing Suffering* (Epstein & Street, 2007) emphasized the critical need for research on outcomes of communication between health professionals and people with cancer. The need to evaluate patient outcomes of receiving education about the opportunity to join a cancer clinical trial is particularly important because of the association of clinical trial participation to better health outcomes (Horstmann et al., 2005). Health professionals often misunderstand patients' perspectives and comprehension about standard treatment options (Janz et al., 2004). Far less is known regarding patients' actual and perceived adequacy of knowledge about a cancer clinical trial prior to deciding whether to join a trial (Biedrzycki, 2010).

The current study describes the relationship between the adequacy of research information (actual knowledge, perceived adequacy of information, and perceived understanding) and the decision to join a cancer clinical trial, as well as satisfaction with this decision. Specifically, the study aimed to describe the relationships between (a) actual knowledge and participation in a cancer clinical trial and satisfaction with this decision, (b) perceived adequacy of information and participation in a cancer clinical trial and satisfaction with this decision, and (c) perceived understanding and participation in a cancer clinical trial and satisfaction with this decision.

Background and Significance

The distinction among the concepts of clinical trial awareness, information, and knowledge is not clearly

Purpose/Objectives: To describe the adequacy of research information among people with cancer at the time they accept or decline participation in a cancer clinical trial.

Design: Cross-sectional, descriptive.

Setting: An urban, academic, National Cancer Institute–designated comprehensive cancer center.

Sample: 197 patients with advanced gastrointestinal cancer.

Methods: Mailed survey; self-reported data.

Main Research Variables: Adequacy of research information (actual knowledge, perceived adequacy of information, and perceived understanding), cancer clinical trial participation, and satisfaction with the decision to participate.

Findings: Most respondents (88%) perceived themselves as having adequate information to make an informed decision regarding cancer clinical trial participation. In addition, 35% demonstrated adequate knowledge of basic clinical research.

Conclusions: Patients decide to accept or decline cancer clinical trials without having adequate knowledge.

Implications for Nursing: Nurses have an important role in educating patients regarding cancer clinical trials. The ideal teachable moment may not occur at the time of diagnosis; other less stressful opportunities may present when the patient is more receptive.

defined in the literature. Collectively, the terms have been associated with cancer clinical trial participation and satisfaction with this decision (Lara et al., 2005; Mathews, Restivo, Raker, Weitzen, & DiSilvestro, 2009; Meropol et al., 2007; Quinn et al., 2007; Umutyan et al., 2008). After a mass multimedia campaign and passage of legislation that mandated third-party reimbursement of cancer clinical trial–related care in California, patients visiting a major cancer center, their families, and friends (N = 1,081) were surveyed (Umutyan et al., 2008). Although knowledge was not tested, cancer clinical trial awareness significantly increased as measured