Feasibility, Acceptability, and Usability of Web-Based Data Collection in Parents of Children With Cancer

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Childhood cancer is rare, affecting about 10,400 children 15 years and younger each year in the United States (National Cancer Institute, 2008). As a result, collaborative multisite studies are necessary to ensure adequate sample sizes of pediatric patients for disease-directed and cancer-control studies. Within the Children’s Oncology Group, the nursing discipline has made great strides in bringing nursing research expertise into the cooperative group mechanism to systematically study the responses of children and families to cancer and its treatment (Ruccione, Hinds, Wallace, & Kelly, 2005). These types of studies typically include complex self-report instruments that require time for participants to complete, as well as expensive and extensive data entry. Novel methods for data collection and management are needed to facilitate future nursing research within the cooperative group structure.

Internet technologies increasingly are being applied to health outcomes and psychological research. Establishing Web-based electronic portals where study participants can complete self-report questionnaires has become common (Cronk & West, 2002). The application of innovative Internet technologies for data collection and intervention delivery, such as treatment decision-making research, holds considerable promise for facilitating an even broader range of behavior studies to improve outcomes for children with cancer and their families (Burns, Robb, & Haase, 2009).

Literature Review

To the extent that researchers have directly compared Web-based to paper-and-pencil data collection, measurement properties have been reported to be comparable or even improved with Web-based instruments (Bliven et al., 2001; Cronk & West, 2002; Gwaltney, Shields, & Shiffman, 2008; Pettit, 2002; Truell, Bartlett, & Alexander, 2002). No significant differences have been observed in item variance or mean scores (Bliven et al., 2001; Cronk & West, 2002), scale completion rates (Bliven et al., 2001; Truell et al., 2002), response set biases (Pettit, 2002), or psychometric properties (Bliven et al., 2001; Pasveer & Ellard, 1998; Vispoel, Boo, & Bleiler, 2001). Krantz and Dalal (2000) reviewed

Purpose/Objectives: To determine the feasibility of Web-based, multisite data collection using electronic instruments and the feasibility, acceptability, and usability of that data collection method to parents of children with cancer.

Design: Prototype development and feasibility study.

Setting: Three Children’s Oncology Group centers in the United States.

Sample: 20 parents of children with cancer who made a treatment decision within the previous six months.

Methods: Eight instruments were translated from print to electronic format and deployed using a secure Web-based server. Parents completed printed versions of two of the instruments to assess comparability of the two formats. A post-survey interview focused on parents’ computer experiences and the acceptability and ease of use of the instruments.

Main Research Variables: Time to orient parent to Web site, time to complete instruments, investigators’ field notes, and post-survey questionnaire.

Findings: Eighty percent of parents preferred the Web-based data collection and found it at least as easy as completing paper-and-pencil instruments. All parents, regardless of their computer expertise, were comfortable with the electronic data collection system. Statistical analysis demonstrated no evidence of systematic or clinically significant bias.

Conclusions: The Web-based data collection was feasible, reliable, and preferred by most study participants. The authors will use this strategy in future intervention trials of parents making treatment decisions.

Implications for Nursing: Web-based data entry is feasible and acceptable to parents of children with cancer. Future multicenter collaborative studies should develop and test nursing interventions to support parents making treatment decisions.