

# Recruitment and Retention of Older Adolescent and Young Adult Female Survivors of Childhood Cancer in Longitudinal Research

Mary Ann Cantrell, PhD, RN, CNE, Teresa Conte, PhD, CRNP, Melissa Hudson, MD, Aziza Shad, MD, Kathy Ruble, RN, CPNP, AOCN®, PhD, Kaye Herth, PhD, RN, FAAN, Alyssa Canino, BSN, RN, and Sinead Kemmy, BSN, RN

Conducting studies to test the efficacy of targeted interventions among childhood cancer survivors is an identified need to advance their care and to improve their health-related quality of life (HRQOL) (Finnegan et al., 2009; Kazak et al., 2010; Speechley, Barrera, Shaw, Morrison, & Maunsell, 2006; Zeltzer et al., 2008). Researchers across disciplines have identified subgroups of childhood cancer survivors at risk for poorer HRQOL (Hudson et al., 2003; Kazak et al., 2010; Zeltzer et al., 2009). Female survivors of childhood cancer are one subgroup of survivors at risk for poorer physical and psychosocial functioning after treatment (Armstrong, Sklar, Hudson, & Robison, 2007; Shankar et al., 2005; Wu et al., 2007; Zelter et al., 2009). Although conducting investigations among childhood cancer survivors is essential for promoting their physical and emotional well-being, recruitment can be a challenge.

Survivors of pediatric cancer are a challenging clinical population to recruit and retain as research participants (Hinds, Burghen, Haase, & Phillips, 2006; Patenaude & Kupst, 2005; Smith & Hare, 2004; Tercyak, Donze, Prahlad, Mosher, & Shad, 2006). The recruitment and retention of older adolescent and young adult (AYA) childhood cancer survivors for research studies may be even more challenging because of their developmental stage, lifestyle characteristics, and less frequent contact with pediatric oncology centers (Tercyak et al., 2006). The purpose of the article is to describe the planning and design of a longitudinal study to maximize the recruitment and retention of a sample of AYA female survivors of childhood cancer. The article also reports the multiple strategies and efforts of, as well as the challenges encountered by, the study team in the recruitment and retention of the survivors at the 18-month mark of the recruitment phase in a three-year study.

**Purpose/Objectives:** To describe the challenges encountered in the recruitment and retention of a sample of older adolescent and young adult female survivors of childhood cancer for a longitudinal study testing a targeted psychosocial intervention aimed at enhancing hope.

**Data Sources:** Published literature on constructing longitudinal intervention studies and strategies in the recruitment and retention of childhood cancer survivors in research was used to develop the protocol of this study.

**Data Synthesis:** Using empirical literature to construct the study's design resulted in achieving certain goals for the design, but not in the recruitment and retention of study participants. Using online technology to deliver the intervention and collect data was efficient and effective. Traditional approaches to recruitment and retention of those survivors, however, were not effective. Use of more novel approaches to enroll study participants demonstrated only modest success.

**Conclusions:** Additional research is needed on strategies to successfully recruit and retain older adolescents and young adult female survivors of childhood cancer in longitudinal intervention studies.

**Implications for Nursing:** The improvement in the psychological well-being of female survivors of childhood cancer remains an important outcome in ongoing care. The need to continue to identify creative and effective ways to recruit and retain those survivors is warranted.

Van Mechelen and Mellenbergh (1997) posited that longitudinal studies provide the only method for directly studying the natural course of human growth and development. In addition, longitudinal studies are critical to measuring the short-term and long-term effects of intervention research. Regardless of the objective, longitudinal research involves the successive measurement of the same participants' attributes at different points in time. Decisions in the design and planning of a longitudinal study involve the number of study participants, the use