

Follow-Up Care in Cancer Survivors: Newsletters Can't Do It Alone – A Report from the Childhood Cancer Survivor Study (CCSS)

AC Mertens, JR Steele, P Goodman, KC Oeffinger, LL Robison, MM Hudson.

**PURPOSE:** Tremendous strides have been made in treating children diagnosed with cancer, but the intensive treatments that save lives also increase the risk for health problems later in life. Survivors can serve as the front-line defense against future problems only if they are knowledgeable about their cancer history and confident in their ability to promote their own health care, and improve their quality of life.

**METHODS:** The CCSS is a resource designed to investigate long-term effects among 5-year survivors of childhood and adolescent cancer diagnosed between 1970-1986. Eligible diagnoses for study participants included leukemia, lymphoma, neuroblastoma, CNS malignancy, bone or soft tissue sarcoma and Wilms tumor. Biannual newsletters have served as the primary educational tool, with articles addressing risk factors for specific late effects and recommendations for follow-up care (newsletters available at [www.cancer.umn.edu/ltfu](http://www.cancer.umn.edu/ltfu)). Data is from a survey distributed between 2002-2003.

**RESULTS:** Of the 9,126 adult survivors of childhood cancer survivors who responded to this survey, 5,625 (62%) stated they read a CCSS newsletter in the previous 2 years. Readers were more likely to be female (OR=1.7, 95%CI=1.5-1.8), white non-Hispanic (OR=1.6, 95%CI=1.4-1.8), older--age over 40 versus age 18-20 (OR=4.0, 95%CI=3.2-4.9), and to have seen a health care professional in the past 2 years (OR=1.9, 95%CI=1.7-2.2). Compared to surgery alone, a slight increase was seen for survivors treated with combination chemotherapy/radiation regimens (OR=1.3, 95%CI=1.1-1.6). Significant differences in readership were noted between diagnoses, with Hodgkins disease survivors the highest (73%), and CNS malignancy survivors the lowest (50%) ( $p<0.01$ ). Among readers, 66% reported no anxiety after reading about their chances of developing health problems related to their cancer treatment, and 24% reported seeking more information about possible health problems. Only 5% of those who saw a health care provider shared a newsletter at the visit.

**CONCLUSION:** Newsletters are one way to inform survivors about their increased health care risks, but more communication channels are needed to reach younger, diverse populations. Acting on information about risk is low; further research into effective communication methods is needed to improve survivors' ability to be strong advocates for their own health and psychosocial well-being.

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