Brief Report: Health Beliefs Among Survivors of Childhood Cancer

Kenneth P. Tercyak,1 PhD, Marsha Nicolas,2 MA, Tracy Councill,2 MA, Sowmya Prahlad,2 MS, Kathryn L. Taylor,2 PhD, and Aziza T. Shad,4 MD
1Departments of Oncology and Pediatrics and Lombardi Comprehensive Cancer Center, Georgetown University Medical Center; 2Lombardi Comprehensive Cancer Center, Georgetown University Medical Center; 3Department of Oncology and Lombardi Comprehensive Cancer Center, Georgetown University Medical Center; 4Department of Pediatrics and Lombardi Comprehensive Cancer Center, Georgetown University Medical Center

Objective To describe interest in cancer screening and tobacco-control procedures (nicotine-addiction susceptibility testing) among survivors of childhood cancer and to identify psychosocial modifying and readiness factors associated with survivors’ interest, based on the children’s health belief model. Methods Twenty-eight survivor–mother dyads were interviewed as part of a preliminary study (mean age of survivors = 15.4 years at time of interview, 10.1 years at time of diagnosis, and 12.0 years at end of treatment); interviews consisted of well-validated self-report items and measures of health beliefs. Results In sum, 57% and 61% of survivors were interested in screening and susceptibility testing, respectively. Survivors who rated themselves as more competent, more concerned about cancer, and more vulnerable to cancer were more interested in participating in screening. Regarding interest in nicotine-addiction susceptibility testing, survivors were more interested when they perceived greater vulnerability to the harm of smoking and when they had mothers who perceived themselves to be in better health. Conclusions Preliminary data suggest that psychosocial modifying and readiness factors are associated with survivors’ interest in cancer screening and tobacco-control procedures and that additional research in this area is warranted.

Key words pediatric cancer; cancer survivors; health beliefs; health behaviors; screening.

Children treated for cancer stand a greater chance of being cured of their disease than ever before. Among the areas of interest to pediatric psychologists working with this special population are survivors’ health beliefs, including their interest in participating in cancer screening and tobacco-control procedures, with the reason being twofold: first, cancer screening holds the potential to significantly reduce cancer mortality and morbidity; and, second, participation in routine surveillance is recommended for all survivors (Bottomley & Kassner, 2003; Keene, Hobbie, & Ruccione, 2000).

With respect to tobacco control, effective screening does not presently exist, as there is no known way to determine with certainty who is more likely to smoke and who is more likely to develop lung cancer as a result of smoking (Hall, Madden, & Lynskey, 2002). However, recent advances in molecular genetics have identified not only a number of possible candidate genes for nicotine addiction but also DNA-based nicotine-addiction susceptibility tests that may be able to predict which individuals become dependent smokers following experimentation (Hall et al., 2002).
Given that health beliefs affect adherence to cancer-control procedures (Strecher & Rosenstock, 1997) and that nearly one quarter of pediatric cancer survivors grow up to become smokers (Emmons et al., 2002), it will become increasingly important to understand how this special population’s health beliefs may bear on their interest in cancer screening and tobacco control. In adult cancer and tobacco-control research, the health belief model (HBM) has been widely used and found to explain a significant portion of the variance in outcome behaviors (Strecher & Rosenstock, 1997). Fortunately, a developmental adaptation of the HBM exists for children—the children’s health belief model (CHBM; Iannotti & Bush, 1993). The CHBM is based on research using concepts derived from the HBM and other theories. The model consists of several psychosocial modifying and readiness factors that are hypothesized to exert direct and conditional effects on children’s expected and actual health behaviors. Research with CHBM factors has shown them to be valid, stable across time, and associated with outcome behaviors (Bush & Iannotti, 1988, 1990). The HBM and CHBM are similar in that they each predict that the perceived benefits of a health behavior and the perceived severity of an illness must be sufficiently high to motivate individuals to engage in health protection. Prior work with pediatric cancer survivors suggests that survivors may view themselves as vulnerable to illness and that they are aware of the relationship between behavior and health (Mulhern et al., 1995; Tyc, Hadley, & Crockett, 2001). In addition, pediatric cancer survivors who are more resilient and competent (i.e., those with positive temperament, resistance to peer pressure, high self-esteem, strong social support) may be more apt to make better decisions about their health, such as engaging in less risk taking (Hollen, Hobbie, Finley, & Hiebert, 2001). Thus, CHBM constructs seem useful to study and evaluate survivors’ health beliefs and interest in health protection.

The specific aims of this preliminary study were to describe survivors’ interest in cancer screening and tobacco-control procedures (nicotine-addiction susceptibility testing) and to identify CHBM psychosocial modifying and readiness factors associated with interest. Based on the literature, our hypothesis was that interest in cancer screening and tobacco-control procedures would be associated with survivors’ health beliefs such that lower perceptions of good health, higher competence, lower risk taking, higher concern about illness, and higher threat perceptions would be positively associated with interest.

**Method**

The sponsoring university’s institutional review board gave approval for the following procedures. Names and contact information for childhood cancer survivors between the ages of 10 and 25 and their parents were identified from tumor registry data. To be eligible for this study, survivors needed to be diagnosed and treated for cancer before age 21, and they needed to be off treatment and disease-free for at least 1 year at the time of the study. Survivors and parents were contacted by mail and telephone. Those who provided informed consent or assent were enrolled into the study. Data collection occurred via a 20- to 30-min structured interview, without other family members present. Participants received a $5 gift certificate to a media store to acknowledge their time and effort.

Fifty-six children were identified by clinic staff as being eligible for this study, and 90% had valid contact information. Among those with valid contact information, 92% were determined eligible following screening. The study’s consent rate among survivors was 74%, Primary reasons for refusal were lack of time and interest. However, the study’s participation rate dropped to 61%, as 6 enrolled survivors did not go on to complete an interview. These individuals passively opted not to participate by not responding to repeated contacts. Overall, there were no differences between survivors who did and did not consent to study with respect to gender and age, $\chi^2(2) = 1.99, p = .37$, and $t(39) = -0.62, p = .54$, respectively. There were also no detectable gender or age differences between those survivors who did and did not complete a survey, $\chi^2(2) = 5.25, p = .07, t(31) = -0.46, p = .65$, respectively.

The final study sample consisted of 28 survivor–mother dyads. The sample of survivors was 50% female, had an average age of 15.4 years ($SD = 4.6$), and was 71% Caucasian; 93% of survivors were attending school on a full-time basis, and 92% reported earning mostly As and Bs in school. The survivors’ medical characteristics (obtained via parent interview and verified through medical record review) were as follows: 39% were treated for leukemia, 18% for sarcomas, 11% for Hodgkin’s disease, 7% for brain tumors, and the remaining survivors were treated for other cancer types. Regarding treatment methods, 32% of survivors had been treated with chemotherapy only, 25% with chemotherapy plus radiation, 21% with chemotherapy plus surgery, and the remaining survivors were treated via another method (e.g., surgery only) or a combination.
of methods. On average, survivors were 10.1 years old when first diagnosed ($SD = 5.6$, $Mdn = 9.9$) and 12.0 years old when treatment ended ($SD = 5.5$, $Mdn = 11.3$); at the time of study, they had been off treatment for 3.7 years ($SD = 2.2$, $Mdn = 3.1$). Within the sample of mothers, 71% were Caucasian, 57% were college graduates, 68% were married, and 57% were employed on a full-time basis.

**Measures**

**Cognitive/Affective**

*Perceived health status.* A 4-point Likert item, used and validated in previous cancer research with children, was included to assess perceptions of personal health: “How would you rate your overall health?” ($1 = poor$, $4 = excellent$; Tercyak, Peshkin, Streisand, & Lerman, 2001). Competence. Competence in academics and school was conceptualized in this study as a proxy indicator of overall competence and achievement, since it is a core domain of children’s self-perception (Harter, Waters, & Whitesell, 1998). Academic competence was assessed using an adapted version of a multi-item scale administered by Wills and colleagues (2001). This 7-item scale probed confidence and competence in three areas: one’s ability to succeed in school, one’s liking of school, and one’s academic difficulties. Each item was rated on a 5-point Likert scale ($1 = not at all true$, $5 = really true$); these ratings were summed to form a scale where higher scale scores indicated increased competence (Cronbach’s coefficient $\alpha = .65$).

*Health risk-taking (tobacco use).* An item from the Centers for Disease Control and Prevention (CDC) was used as a proxy indicator of health risk-taking via smoking experimentation, as health risk-taking has been shown to be strongly correlated with youth cigarette use (Clark, Sommerfeldt, Schwarz, Hedeker, & Watel, 1990). The item wording was as follows: “Have you ever tried or experimented with cigarette smoking, even a few puffs?” ($0 = no$, $1 = yes$; CDC, 2000).

**Environmental**

The study ascertained the perceived health status and tobacco use of each survivor’s mother. Health status was rated on a 5-point Likert scale ($1 = excellent$, $5 = poor$), and tobacco use was coded as nonsmoker or current/former smoker.

**Motivations**

*Illness concern.* Concern about illness was assessed with two items: “How often do you think about your health?” and “Do you ever think about getting sick?” Both of these items were rated on a 4-point Likert scale ($1 = not at all$, $4 = a lot$) and have been used in pediatric cancer control research (Tercyak et al., 2001). The items were summed to form a total illness concern scale ($r = .36$, $p = .03$).

**Perceived Illness Threats**

*Perceived vulnerability.* Perception of vulnerability to cancer was assessed by one item, rated on a 4-point Likert scale: “Do you ever worry about cancer happening to you again someday in the future?” ($1 = not at all$, $4 = a lot$; Tercyak et al., 2001). Perception of vulnerability to the harm of smoking was assessed by one item, adapted from the National Youth Tobacco Survey (CDC, 2000): “Can people get addicted to using tobacco just like they can get addicted to using cocaine or heroine?” ($1 = definitely yes$, $4 = definitely not$).

**Interest in Cancer Screening and Tobacco-Control Procedures**

Given the heterogeneity of the cancer types experienced by survivors in this sample, interest in cancer control via screening was assessed with a single item, adapted from previous research: “If there was a way that your doctor could tell if it was likely that cancer was going to happen to you again someday in the future, how strongly would you be interested in this information?” ($1 = not at all$, $4 = a lot$; Tercyak et al., 2001). This item was purposely worded to be general and without reference to a particular cancer screening test, to adequately capture each survivor’s overall interest. Interest in tobacco control via nicotine-addiction susceptibility testing was also assessed with a single item: “Someday, scientists may be able to predict who is at greater risk for growing up to become addicted to smoking, based on a person’s genes (their DNA). If this information were available, how strongly would you be interested in learning about your genetic risk for developing a smoking habit?” ($1 = not at all$, $4 = a lot$). Responses to the item were then followed up by a single open-ended item, to clarify the purpose of survivor’s interest.

**Results**

Descriptive statistics were used to summarize findings from ordinal and categorical variables. To ease interpretability, similar response options were collapsed. In the case of interest in cancer screening and tobacco-control
procedures, interest was defined as a response of 3 (a fair amount) or 4 (a lot).

In sum, 57% of survivors were interested in screening information, and 61% were interested in susceptibility testing. When examined together, significantly more survivors were interested in both procedures (46%) versus one procedure (25%) or neither procedure (29%). $\chi^2(1) = 6.60, p = .01$. Regarding self-health ratings, 79% of survivors rated their overall health as good or excellent, and 75% had not experimented with smoking. With respect to maternal influence, 93% of mothers reported themselves to be in good to excellent health, and 64% were current or former smokers. Regarding concern about illness, 57% of survivors thought about their health a fair amount or a lot; however, only 11% of survivors reported frequent thoughts about becoming sick, and only 14% reported frequent worries about cancer recurrence. Sixty-one percent thought smoking was definitely harmful.

To determine which, if any, CHBM factors were significantly associated ($p < .05$) with interest, bivariate tests were conducted between the psychosocial modifying and readiness factor variables and the interest in cancer and tobacco-control variables. Competence ($r = .52$), illness concern ($r = .40$), and perceived vulnerability to cancer ($r = .34$) were associated with cancer control; age ($r = .46$), maternal perceived health status ($r = -.50$), and perceived vulnerability to the harm of smoking ($r = -.37$) were associated with tobacco control.

**Discussion**

The results of this preliminary study suggest that slightly more than one-half of survivors are interested in cancer screening and tobacco-control procedures and that such interests are associated with one another and with survivors' health beliefs. And regarding survivors' health beliefs and behaviors, several interesting observations are noted when these data are compared to other norms. The National Longitudinal Study of Adolescent Health found that 93% of adolescent respondents reported their health as good or excellent and that 43% of adolescents had never experimented with smoking (http://www.cpc.unc.edu/projects/addhealth/). Thus, survivors of childhood cancer may view themselves as less healthy, but they engage in less risk taking. Survivors were also somewhat less apt to view smoking as definitely addictive (61%) relative to community controls (76%; American Legacy Foundation, 2000).

In terms of survivors' concerns about illness and perceived vulnerability to cancer, the data indicate that little time is spent thinking about health and that most survivors do not appear to ruminate over thoughts of becoming sick or of a cancer recurrence. Compared with children without cancer, these data suggest fewer health and cancer concerns (Tercyak et al., 2001). This finding is somewhat counterintuitive. Perhaps the cognitive adaptive style assumed by some pediatric cancer survivors is similar to that of children with cancer (Phipps & Steele, 2002), which might include the tendency to repress in favor of appearing less concerned.

Based on the CHBM, the cognitive-affective factor variable that was most strongly associated with interest in cancer screening was competence. One possible explanation for this finding is that holding one's self in high regard and feeling competent are part of a constellation of psychosocial attributes that coexist with other positive and healthy self-attributes, beliefs, and behaviors. The findings by Hollen and colleagues (2001) support this explanation. Illness concern and perceived vulnerability to cancer were also associated with interest in cancer screening, and this finding is similar to what has been found in the adult cancer control research literature (Strecher & Rosenstock, 1997). These and other studies (e.g., Kahn, Goodman, Slap, Huang, & Emams, 2001) provide partial support for factors hypothesized to account for screening outcomes based on the HBM and CHBM.

In terms of tobacco control, CHBM-derived factor variables associated with interest in nicotine-addiction susceptibility testing included maternal perceived health status and perceived vulnerability to the harm of smoking. Bush and Iannotti (1988) hypothesized that parents' own beliefs and behaviors are important determinants of their children's, particularly with regard to tobacco use. Research with adults suggests that positive perceptions of health are related to interest in tobacco-control procedures (Wagner et al., 1990). Thus, it is not surprising that interest in tobacco control was higher among survivors whose mothers perceived themselves to be in relatively better overall health. As for the association between perceived vulnerability and tobacco use, it is unclear what survivors' reasons are behind their interest in learning this information. There is some concern that persons who participate in testing and who are not identified as being at increased risk of becoming nicotine dependent might otherwise begin to experiment with smoking or maintain or escalate their smoking behavior (Hall et al., 2002). Given that the
level of tobacco-use experimentation in this study was quite low (25% yes), it is unlikely that nicotine-addiction susceptibility testing would promote tobacco use in this special population. Nevertheless, this raises an important and interesting area of exploration for further study.

There are a number of limitations to the current investigation, including its small sample size, demographic homogeneity, cross-sectional design, reliance on single-item assessment, and the exclusion of items and measures regarding the perceived impact of the illness (i.e., cancer-specific distress). These limitations adversely affect study power, reliability, validity, generalizability, the ability to draw conclusions about the causal nature of the associations observed, and the ability to consider and test multiple-variable models; they also do not address survivors’ overall psychological well-being. As such, the findings should be interpreted cautiously. Further, the assessment of competence in academics and school was a crude proxy indicator of overall competence and achievement, and the wording of the two perceived vulnerability items were not comparable. Future work should assess additional domains of self-perception and should maintain parity between vulnerability item referents. Finally, it is not yet known how survivors’ interest in cancer screening and tobacco-control procedures may translate into actual health behaviors. Nevertheless, as the intent of this preliminary study was to be hypothesis generating, these and other limitations could be overcome by larger, more well-controlled and detailed investigations.

Given the rising importance of interest in, and adherence to, cancer surveillance in promoting health after childhood cancer, and given the likely emergence of DNA-based testing (and other forms of biomarker testing) to guide and inform cancer-risk profiling and reduction (Joseph et al., 1997; McClure, 2002), pediatric psychologists are in a unique position to conduct further research in this area. As pediatric oncology team members, they are also well poised to offer counseling in health behavior and health education as part of late-effects programs. The results suggest that some, but not all, survivors will likely be receptive to such comprehensive programs. Reaching out to all survivors will be an important task both in preventing and controlling secondary and new primary cancers and in improving survivors’ quality of life.

Acknowledgments

This research was supported by the American Cancer Society (IRG9715204; to KPT). Manuscript preparation was supported by the National Cancer Institute at the National Institutes of Health (CA91831) and the Lance Armstrong Foundation (to KPT). We thank Jessica Donnelly and the staff of the Pediatric Hematology-Oncology, Blood and Marrow Transplantation Clinic at the Lombardi Comprehensive Cancer Center for their assistance with data collection. Special thanks are also extended to the families who participated in this research.

Ms. Nicolas is currently affiliated with Argosy University, Washington, DC.

A portion of these findings were presented at the 2002 International Conference on the Long-Term Complications of Treatment of Children and Adolescents for Cancer, Niagara-on-the-Lake, Ontario, Canada; and at the 2002 National Cancer Institute/American Cancer Society Cancer Survivorship Conference, Bethesda, MD.

References


**Note**

1. This is a legitimate concern, particularly in light of the developing cognitive capacities of children and adolescents. To explore this issue, we briefly examined open-ended responses to a single survey item that proceeded the tobacco-control interest item. The data suggest that the majority of survivors were interested in this information for preventive purposes (e.g., to make a greater effort to refrain from smoking) and that none were interested in this information to promote their own smoking.