Published in final edited form as:

J Pediatr Oncol Nurs. 2009 ; 26(4): 230–241. doi:10.1177/1043454209334417.

Coping with Cancer: A Web-based Educational Program for Early and Middle Adolescents

Susan O’Conner-Von, PhD, RN[Assistant Professor]

Center for Children with Special Health Care Needs, School of Nursing, University of Minnesota,
5-140 Weaver-Densford Hall, 308 Harvard St. S.E., Minneapolis, MN. 55455, 612-624-6647
phone, 612-626-6606 fax, ocon0025@umn.edu

Abstract

Educating patients is a primary responsibility of all nurses, however due to time constraints and staff shortages, pediatric oncology nurses are often unable to adequately prepare patients for cancer treatment. Instead, patients frequently rely on the Internet as a source of information about cancer, some of which can be outdated and inaccurate. Adolescents regard the Internet to be a valuable source of health information as it is easily accessible, less threatening and confidential. Considering the need for accurate, readily available information for adolescents with cancer, the purpose of this study was to develop and validate an innovative, interactive web-based educational program to prepare early and middle adolescents for cancer treatment. Entitled *Coping with Cancer*, this program was developed by the investigator after conducting in-depth interviews of adolescent cancer survivors and their parents. Based on the Transactional Model of Coping, the program focuses on enhancing the adolescent’s knowledge of cancer, cancer treatment, and healthy coping strategies. *Coping with Cancer* can be an effective resource for pediatric oncology nurses in providing ongoing education for adolescents with cancer.

Keywords

adolescents; cancer; Internet technology; web-based education

Background

Childhood Cancer

Every year in the United States approximately 12,400 children and adolescents under the age 20 are diagnosed with cancer (CureSearch, 2008; Keene, Hobbie & Ruccione, 2007). Although there have been improvements in the care of these children with overall cure rates approaching 80 %, cancer continues to be the leading cause of disease-related death in childhood (American Cancer Society, 2005; CureSearch, 2008; Smith & Hare, 2004). In fact, more children die from cancer than asthma, cystic fibrosis, congenital anomalies, diabetes, and AIDS combined (Hooke, Hellsten, Stutzer, & Forte, 2002).

Many advances in cancer treatment have been made; however, all children with cancer experience pain and 70% experience severe pain (Collins & Weisman, 2003; Institute of Medicine, 2005). Among hospitalized adolescents with cancer, pain was the most common symptom experienced with 87 % reporting their pain as moderate to severe (Ljungman et al, 1999). Pain activates the sympathetic nervous system and over time can cause adverse changes in the immunologic, metabolic, and endocrine systems of the body. “The longer pain goes untreated or poorly treated, the more difficult it is to manage and the longer lasting the effects” (Sentivany-Collins, 2002, p. 323). Unlike adults, children suffer more treatment-related pain than tumor-related pain. Treatment related pain can be a direct result of

interventions or an indirect negative effect of treatment such as chemotherapy or radiation (Sentivany-Collins, 2002). Procedures such as lumbar puncture, bone marrow aspiration, and intravenous insertion are common causes of pain. A meta-analysis of child distress during medical procedures by Kleiber and Harper (1999) found that children reported the pain related to procedures and treatments was the most difficult aspect of their cancer experience; moreover, it intensified with each painful procedure. A child with a previous negative painful experience is likely to expect the same negative experience with each procedure, which will heighten anxiety along with pain intensity (McGrath & Hillier, 2003). The anxiety produced in anticipation of painful procedures is sometimes so severe that children "exhibit symptoms such as nausea, vomiting, insomnia, nightmares, and skin rashes prior to the procedure" (Liossi, 2002, p. 5). Children diagnosed with cancer report that they fear pain more than the cancer (Conte, Walco, Sterling, et al. 1999). Childhood cancer survivors often recall the trauma related to enduring repeated painful procedures (Hockenberry & Hooke, 2007). Unfortunately, adolescents often believe that pain is an inevitable part of being a cancer patient (Woodgate & Degner, 2003).

Children with cancer rarely experience isolated symptoms (Hockenberry & Hooke, 2007). In addition to pain, fatigue and sleep disturbance often occur within a symptom cluster, resulting in changes in behavior and physical performance. These changes may have a negative impact on the child's ability to interact with family and friends and to meet developmental milestones (Hockenberry & Hooke, 2007). For adolescents, current research suggests that they possess an increased vulnerability to the distress caused by symptoms (Linder, 2008). Unfortunately, this distress may make the adolescent "fight the treatment" rather than the cancer (Docherty, Sandelowski, & Preisser, 2006; Walker, Wells, Heiney, & Hymovich, 2002).

Besides physical symptoms, child and adolescent patients report fear, helplessness, and uncertainty, which can lead to posttraumatic stress symptoms (Santacroce & Lee, 2006). Adolescents may report feelings of loneliness, isolation, despair and concern with being different from peers (Cassano, Nagel, & O'Mara, 2008; Earle & Eiser, 2007). In addition, they may experience situational anxiety, depression, or psychogenic reactions (Walker, Wells, Heiney, & Hymovich, 2002; Zebrack, Zeltzer, Whitton, Mertens, Odom, et al, 2002).

Given the potential negative consequences of cancer and cancer treatment, pediatric oncology nurses must provide education "to promote, to maintain, to restore, and to improve the health and comfort of the child with cancer" (Association of Pediatric Hematology/Oncology Nurses, 2007, p. 17). Unfortunately, health care professionals have little time for patient education (Beranova & Sykes, 2007), and pediatric oncology nurses in specific are often unable to adequately educate patients about cancer and cancer treatment due to busy schedules, time constraints and the nursing shortage (Tracy-Mitchell, 2002). Even in tertiary care cancer centers, it is difficult to provide the level of education needed by patients and families, instead they frequently rely on the Internet to find information about cancer and cancer treatment, some of which can be inaccurate or outdated (Lewis, Gundwardena, & Saadawi, 2005; Tracy-Mitchell, 2002). Adolescents especially regard the Internet to be a valuable source of health care information as it is easily accessible, less threatening, and confidential (Borzekowski & Rickert, 2001). Considering the need for accurate, current and readily available information about cancer and cancer treatment, the purpose of this study was to develop and validate a web-based educational program for early and middle adolescents entitled *Coping with Cancer*.

Review of Literature

Adolescence

Adolescence is considered the developmental period between childhood and adulthood that is a time of transition from dependence to independence. Early adolescence begins at approximately 10 years of age when the physiological changes of puberty start. Middle adolescence begins at approximately 14 years of age and extends through age 16 (Santrock, 2007). The period of adolescence is characterized by the shift from concrete operational thinking to the beginning of formal operational thought, that is, the internal manipulation of concepts, relations, and propositions. As a result, adolescents can consider possibilities and the abstract rather than just the realities and the concrete. The adolescent is able to use metaphor and expand the concepts of space and time. However, this cognitive change also contributes to the confusion, chaos, and sensitivity that adolescents experience. Specifically, adolescents may have difficulty during situations in which they feel out of control (Shave & Shave, 1989). Of paramount importance is body image, the need for privacy, striving for independence and cancer treatment can threaten these. Considering the developmental needs of adolescents, education about cancer and cancer treatment should include using correct terminology, answering questions honestly, promoting independence in decision-making, suggesting strategies for healthy coping and self-care, along with the protection of privacy.

Coping

The majority of research on coping in children and adolescents has evolved from the pioneering work of Lazarus and Folkman (1984) who defined coping as behavioral and cognitive efforts to manage external and/or internal demands that are appraised as exceeding the person's resources. According to Lazarus and Folkman, a person views a situation as stressful based on their appraisal of the situation to produce harm (primary appraisal) and their resources available for dealing with the situation (secondary appraisal). The focus of a person's coping effort is aimed at trying to meet the demands of the situation or controlling his/her emotions. Effective coping has been linked to having a sense of control, positive emotions, and available resources (Folkman & Moskowitz, 2004).

Coping strategies are learned behavioral and emotional responses to stressors and are used to adapt to the environment or to change it (Lazarus & Folkman, 1984). Choice and control are very important to adolescents, thus encouraging healthy coping strategies of the adolescent's choice meets these needs (McGrath & Hillier, 2003). The desire to be independent as possible and to seek information about cancer from the Internet, books, and magazines were considered important coping strategies in a study of adolescents and young adults coping with the onset of cancer (Kyngas, et al., 2001). Adolescents are more likely to use active coping strategies than younger children (Landolt, Vollrath, & Ribi, 2002), thus recommending cognitive / behavioral coping strategies such as imagery, music, relaxation, and distraction for the adolescent can provide pain relief, and decrease anxiety and emotional distress (American Academy of Pediatrics, 2001; American Pain Society, 2005; Santacroce & Lee, 2006).

Web-based Technology

Web-based health education can be an effective tool for nurses to use with patients as it offers a variety of advantages over printed materials. It is convenient to update and individualize, and offers interactive capabilities. Web-based education can provide guidance, information and encouragement for patients and families with geographic or time restrictions (Brillhart, 2007). For patients and families, it offers the ability to review information at any time, at their own pace and in the privacy of home (McGrath, Watters, & Moon, 2006). In a review of 420 computer based educational programs, Lewis (1999) found

the use of this type of technology associated with improved health outcomes, increased patient satisfaction, and fewer medical malpractice claims. She concluded that computer based educational programs were an effective strategy for increasing patient health care knowledge and skill development.

Although there is increasing literature on the use of web-based health education for adults (Wantland, Portillo, Holzemer, Slaughter, & McGhee, 2004), there is a paucity of research on web-based health education specifically designed for children and adolescents (Stinson, Petroz, Tait, Feldman, Streiner, McGrath, & Stevens, 2006). In a cross-sectional descriptive study of the web sites of the leading children's hospitals in the United States, only a few sites included content for children and adolescents (Kind, Wheeler, Robinson, & Cabana, 2004). Several studies have examined the use of electronic diaries for children with gastrointestinal problems (Walker & Sorrells, 2002) and chronic pain (Palermo & Valenzuela, 2003); however, most studies do not formally evaluate the technology. Web-based educational programs "must be based on sound design and educational principles, and contain current, accurate information" (Brillhart, 2007, p. 215). Most importantly, information must be available when the patient expresses readiness to learn (Hymovich, 1995). With the increasing use of the Internet as a source of health related information especially by adolescents (Gray, Klein, Noyce, Sesselberg, & Cantrill, 2005), pediatric oncology nurses must address the issue of providing accurate and current information for adolescent patients and their parents from diagnosis and treatment, through long term follow-up care.

Informational Needs

Few studies have addressed the informational needs of early and middle adolescents diagnosed with cancer. In a qualitative study of adolescents and young adults with cancer, social support, described as emotional and informational support, was their major coping strategy. These patients felt that searching for information about cancer was a "very good coping strategy" (Kyngas, et al., 2001, p. 9). Finding the facts about their cancer and its treatment helped them understand and therefore, cope with the disease (Kyngas, et al.). Furthermore, in a study of 40 adolescents (ages 13 – 17 years) with chronic disease, learning coping skills to take care of themselves and to learn from the experience of other adolescents were highly valued (Kyngas, 2003).

Decker, Phillips, and Haase (2004) used the *Information Preferences of Adolescents* (IPA) scale to measure the information needs of 74 newly diagnosed adolescents and 39 adolescents one to three years from diagnosis of cancer. Both groups of adolescents highly rated their need for information. Items rated the highest for both groups were (a) dealing with procedures, (b) relationships with friends, (c) getting back to school, (d) relationships with family, (e) finishing treatment, and (f) adjusting to the diagnosis. A key strength of this study was that the IPA was based on interviews of adolescents with chronic illness.

To summarize, great advances have been made in the care and treatment of children with cancer with overall cure rates approaching 80% (American Cancer Society, 2005; CureSearch, 2008; Smith & Hare, 2004). Yet, for adolescents the incidence of cancer has greatly increased during the last 30 years (Ries, 1999). A major factor contributing to the lack of knowledge regarding adolescents and their experience of cancer is that adolescents are often a part of larger study samples where they are not clearly delineated from a child or an adult population (Haase & Phillips, 2004). Compounding our lack of knowledge regarding adolescents and their experience of cancer is the fact that theories of adolescent development are based on research with healthy adolescents (Hinds, 2004). Unfortunately, this leads to a paucity of evidence addressing the unique needs of adolescents with cancer and interventions specifically aimed at improving their quality of life.

Methods

Phase 1: Review of Literature

The development of the *Coping with Cancer* web-based educational program was based on an extensive review of the pediatric cancer literature. Key components from the literature review that were included in this program were informational needs of adolescents, a variety of healthy coping strategies, interventions to facilitate understanding and normalizing feelings, advice from adolescent cancer survivors, and professional pediatric cancer resources for adolescents and parents.

Phase 2: Guiding Framework

Findings from the review of the pediatric cancer literature subsequently led to the selection of a guiding framework for the web-based program. The Transactional Model of Coping developed by Lazarus and colleagues (Lazarus & Folkman, 1984) served as a basis for designing the *Coping with Cancer* web-based educational program as it was created to enhance adolescents' coping with the stress of cancer and cancer treatment. It was hypothesized that increasing the adolescent's knowledge of cancer, cancer treatment, and healthy coping skills would result in decreased situational anxiety and stress, and ultimately improved quality of life for the adolescent undergoing cancer treatment.

Phase 3: Interviews of Adolescent Experts

Sample—Children diagnosed with cancer often seek information about their cancer from other children and not from health care professionals or their parents (Hymovich, 1995). Receiving advice and support from peers with cancer can be helpful and encouraging (Suzuki & Kato, 2003). Thus, a convenience sample of early and middle adolescents who had completed cancer treatment were invited to be key informant experts for the development of the web-based program. Potential adolescent participants for the study were recruited from an outpatient pediatric oncology clinic at a university medical center in the Midwest. A pediatric nurse practitioner at the clinic screened adolescents for their eligibility for the study. Inclusion criteria were: (1) early and middle adolescents ages 10 to 16 years, (2) who had completed cancer treatment within the past 12 months, and (3) were able to read and speak English. Exclusion criteria were: (1) early and middle adolescents who were unable to give assent due to physical or cognitive impairment and / or (2) adolescents whose parents would not give consent for participation.

Procedure—Participants and parents who voiced an interest in the study were referred to the investigator who explained the study. Parents provided written consent, and adolescents provided written assent for participation in the study. The Institutional Review Board at the study site approved this study.

Four adolescents and their parent(s) participated in the interviews (Table 1). A semi-structured interview guide was used to focus on (a) the adolescent's experience of cancer, (b) cancer treatment, and (c) their recommendations for essential content for the web-based program and (d) effective coping strategies. Interviews were conducted at a location and time convenient for the adolescent and parent(s). The investigator conducted all of the interviews except for one. In that case, a master's prepared research assistant with expert interview skills interviewed a mother of one of the female adolescents who requested to be interviewed at the same time as her mother, but in separate rooms. Interviews with adolescents ranged from 25 to 60 minutes; interviews with parents ranged from 40 to 70 minutes. All interviews were audio taped and later transcribed verbatim by a professional health care transcriptionist.

At the conclusion of the interview, each adolescent was asked to select from four website homepage prototypes, each with a different layout of colors and design. Each of the 4 adolescents independently selected the same prototype because of its graphic appeal.

Data analysis—Content analysis (Krippendorff, 2004) was used to analyze the interview data. Data were summarized and organized to reflect the issues and recommendations for essential content and coping strategies presented by the adolescents and their parents. The investigator and research assistant first examined the interview data separately and then worked together to systematically categorize the adolescents' experiences of cancer and cancer treatment, and recommendations for content and coping strategies

Results—The results of the content analysis revealed 4 dimensions of experiences with cancer and cancer treatment: (1) physical, (2) psychological, (3) social, and (4) spiritual. Sample comments from the adolescents are presented in Table 2.

Recommendations for web-based content included: (a) definitions of medical terms, (b) an explanation of the role of each member of the health care team, and (c) adding humor and games. Adolescents wanted the content to be explained "so I can understand it".

Recommended coping strategies included: (a) listening to music, (b) taking deep breaths during procedures, (c) spending time with family and friends, (d) watching funny movies, (e) playing cards, board games and video games, (f) staying connected with friends online, (g) asking for EMLA (eutectic mixture of local anesthetics) before procedures, and (h) sharing your feelings.

Parents spoke freely about their experiences of going through cancer treatment with their son or daughter. Every parent spoke of the need for accurate pediatric cancer resources.

Nate's mother commented,

"When he was first diagnosed I headed right to the computer. Bad thing to do – terrifying. There are a lot of sites out there that are scary. They tell the worst-case scenarios. Everyone with his type of cancer died. Most were about adult cancers and we did not know the difference."

Zoe's father noted, "The Internet is always there when the doctors are busy, but there's a lot of information and you have to be careful what you read." All of the parents spoke of being their child's advocate through the process of cancer treatment. Nora's parents stated, "You need to be proactive. Not only about your kid's physical health, but mental health too." Zoe's father recommended, "Pulling in everyone and anything that is available. We used the child life specialists, social worker and psychologist." Lastly, all of the parents shared the importance of hope. Annie's mother told the oncologists "I just want to hear you say she can be cured. We need that hope."

Phase 4: Construction of the Coping with Cancer Website

The investigator developed the scope and plan for the web-based program. Content for the program was derived from the pediatric oncology research literature and data from the adolescent and parent interviews (see Table 3). Core components of the program include information about (a) cancer, (b) cancer treatment, (c) feelings about having cancer, (d) dealing with friends and school, (e) healthy coping strategies, and (f) advice from the adolescent cancer experts. The program also includes a glossary of cancer related medical terms, a description of the role of each member of the health care team and a list of professional pediatric cancer Internet resources. The investigator ensured that the program

content was consistent with the standard educational materials received by adolescent patients and families at the pediatric oncology clinic.

The web-based program was constructed on an Apple Macintosh computer using Adobe Illustrator 10, Photoshop 7 and Adobe GoLive 8, all three applications by Adobe Systems (San Jose, CA).

The program homepage (Figure 1) displays a navigation menu located in a column on the left side of the page, with corresponding icons in the center of the homepage. Directions for navigating the web-based program are located on the homepage.

To keep the adolescent engaged throughout the program, information is presented through interactive activities. For example, in the Journal (Figure 2) a fictional character named "Brian" who is an adolescent cancer survivor, uses text messaging to answer questions from a newly diagnosed adolescent female about cancer and cancer treatment. Rollovers and interactive games were added to the web program to prevent boredom.

Phase 5: Content Validity

After construction of a preliminary version of the web-based program, two expert panels reviewed the program for content validity. One panel consisted of the same 4 adolescent experts who participated in the interviews. The other panel was a multidisciplinary group of 4 (2 women and 2 men) pediatric oncology experts. Two of these experts were from the same outpatient pediatric oncology clinic as the adolescent experts. The 4 experts consisted of a pediatric nurse practitioner in pediatric oncology, a pediatric oncologist, a pediatric cancer epidemiologist, and an internationally known pediatric nurse expert in pain, pediatric cancer, and web-based technology. Both panels of experts were given access to the web-based program for one month. Each expert was asked to independently complete a rating form of the program and to mail the form to the investigator's private mailbox in a provided stamped envelope.

Adolescent experts were asked four questions: (a) What did you think of the *Coping with Cancer* website? (b) Do you think that the website would have been helpful when you were going through cancer treatment? (c) If you answered "yes", what about the website would have been helpful to you? and (d) Can you think of anything that should be added to or removed from the program? (Table 4).

Pediatric oncology experts were asked to rate the *Coping with Cancer* program on (a) ease of access and navigating the program, (b) accuracy of information, and (c) appropriateness for age (early and middle adolescents). The scale developed was a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). All of the experts responded positively with ratings of a 4 (agree) or 5 (strongly agree). The rating form included an open-end question for additional comments and suggestions for improvement of the web-based program. The following are sample comments: "This direct, fresh approach with a terrific graphic interface will encourage them to explore and interact", "I like the general upbeat nature of the website as a whole", "The look of the site will entice the kids and make it easy to come back to".

All recommendations for revision were taken into consideration and changes to the web program were made accordingly. None of the adolescent or pediatric oncology experts reported problems with gaining access to or navigating the web program.

Phase 6: Field Test of the Coping with Cancer Website: Clinical Validity

The next step in the development and evaluation of the *Coping with Cancer* program is a field test of the program which is currently underway with a sample of 20 early and middle adolescents who are actively undergoing cancer treatment.

Discussion

This article describes the development of a web-based educational program for early and middle adolescents undergoing cancer treatment. The program was developed in accordance with the recommendations from the Research Working Group meeting titled "Moving the Research Agenda Forward for Children with Cancer" (National Institutes of Health) and the State of the Science Summit II for Pediatric Oncology Nursing, as the adolescent's voice was included and careful attention was paid to growth and development (Hare, 2005). Vital to the development of the program were the adolescent experts' insights and recommendations for essential content. Although only a small sample of adolescent experts and their parents were included, the in-depth interviews provided invaluable information. Moreover, all of the adolescents and their parents shared the desire to help others who were embarking upon the "cancer journey". Similar to the findings of Cassano, Nagel, and O'Mara (2008), the adolescent experts hoped to inspire others going through cancer treatment and were eager to share their words of encouragement and ideas about ways to cope with cancer and cancer treatment while trying to maintain a "normal" life.

In terms of coping strategies, all of the adolescent experts spoke of the importance of learning about their cancer and cancer treatment as a way of coping (Decker, Phillips, & Haase, 2004; Kyngas, 2003) and the use of some type of expressive therapy (music, art, journaling) in order to find meaning in their cancer experience (Hinds & Haase, 2003).

Lastly, acknowledging the wide spread use of the Internet as a means of finding health care information, web-based education gives pediatric oncology nurses the opportunity to meet the challenge of providing ongoing education for patients and families that is accurate and current as content can be added or changed as needed. Considering the improved rates of survival for adolescents with cancer, education about the importance of self-care, screening, transition to adult care, and healthy coping skills could potentially last a life time.

Conclusion

The web-based educational program *Coping with Cancer* is an innovative approach to assisting early and middle adolescents as they undergo cancer treatment. This program provides a safe place for adolescents to find accurate information about cancer, cancer treatment, and coping strategies, along with receiving advice and encouragement from peers who have completed cancer treatment. The ongoing development and refinement of this program will ensure a trusted web-based resource designed to improve the quality of life for adolescents with cancer.

Biography

Susan O'Conner-Von is an assistant professor in the Center for Children with Special Health Care Needs, University of Minnesota, School of Nursing, and a staff nurse at Children's Hospitals and Clinics of Minnesota in St. Paul, Minnesota.

Acknowledgments

The author gratefully acknowledges the adolescent experts and their parents, and the pediatric oncology experts who so willingly gave of their time to participate in this study, and Ann Garwick PhD, RN, LP, LMFT, FAAN for her thoughtful review of the manuscript.

This study was supported by a grant from the University of Minnesota Graduate School Grant-in-Aid program and the National Institute of Nursing Research (Grant # P 20 NR 008992; Center for Health Trajectory Research). The content is solely the responsibility of the author and does not necessarily represent the official views of the National Institute of Nursing Research or the National Institutes of Health.

References

- American Academy of Pediatrics. A Position Statement from the Committee on Psychosocial Aspects of Child and Family Health, 2000 – 2001. Author; 2001. The assessment and management of acute pain in infants, children, and adolescents.
- American Cancer Society. Cancer facts and figures. Atlanta, GA: Author; 2005.
- American Pain Society. APS Clinical Practice Guidelines Series, No. 3. Glenview, IL: Author; 2005. Guideline for the management of cancer pain in adults and children.
- Association of Pediatric Hematology/Oncology Nurses. Pediatric oncology nursing: Scope and standards of practice. Glenview, IL: Author; 2007.
- Beranova E, Sykes C. A systematic review of computer-based softwares for educating patients with coronary heart disease. *Patient Education and Counseling*. 2007; 66:21–28. [PubMed: 17084058]
- Borzekowski D, Rickert V. Adolescent cybersurfing for health information. *Archives of Pediatric Adolescent Medicine*. 2001; 155:813–817.
- Brillhart B. Internet education for spinal cord injury patients: Focus on urinary management. *Rehabilitation Nursing*. 2007; 32(5):214–219. [PubMed: 17899993]
- Cassano J, Nagel K, O'Mara L. Talking with others who “just know”: Perceptions of adolescents with cancer who participate in a teen group. *Journal of Pediatric Oncology Nursing*. 2008; 25(4):193–199. [PubMed: 18539910]
- Collins, J.; Weisman, S. Management of pain in childhood cancer. In: Schechter, N.; Berde, C.; Yaster, M., editors. *Pain in infants, children, and adolescents*. Philadelphia: Lippincott Williams & Wilkins; 2003. p. 517-538.
- Conte P, Walco G, Sterling C. Procedural pain management in pediatric oncology: A review of the literature. *Cancer Investigation*. 1999; 17:448–459. [PubMed: 10434956]
- CureSearch. Our research: Highest incidence age groups. 2008. Retrieved August 15, 2008, from <http://www.curesearch.org>
- Decker C, Phillips C, Haase J. Information needs of adolescents with cancer. *Journal of Pediatric Oncology Nursing*. 2004; 21(6):327–334. [PubMed: 15475469]
- Docherty S, Sandelowski M, Preisser J. Three months in the symptom life of a teenage girl undergoing treatment for cancer. *Research in Nursing and Health*. 2006; 29:294–310. [PubMed: 16847909]
- Earle E, Eiser C. Children's behaviour following diagnosis of acute lymphoblastic leukaemia: A qualitative longitudinal study. *Clinical Child Psychology and Psychiatry*. 2007; 12(2):281–293. [PubMed: 17533941]
- Folkman, S.; Moskowitz, J. *Annual Review of Psychology*. Vol. Volume 55. Palo Alto, CA: Annual Reviews; 2004. Coping: Pitfalls and promises.
- Gray N, Klein J, Noyce P, Sesselberg T, Cantrill J. Health information-seeking behaviour in adolescence: The place of the Internet. *Social Science and Medicine*. 2005; 60:1467–1478. [PubMed: 15652680]
- Haase J, Phillips C. The adolescent/young adult experience. *Journal of Pediatric Oncology Nursing*. 2004; 21(3):145–149. [PubMed: 15296043]
- Hare M. Comparing research priorities for pediatric oncology from two panels of experts. *Seminars in Oncology Nursing*. 2005; 21(2):145–150. [PubMed: 15991663]
- Hinds P. Adolescent-focused oncology nursing research. *Oncology Nursing Forum*. 2004; 31(2):281–287. [PubMed: 15017443]

- Hinds, P.; Haase, J. Quality of life in children and adolescents with cancer. In: King, C.; Hinds, P., editors. *Quality of life from nursing and patient perspectives*. Boston: Jones and Bartlett; 2003. p. 143-168.
- Hockenberry M, Hooke MC. Symptom clusters in children with cancer. *Seminars in Oncology Nursing*. 2007; 23(2):152–157. [PubMed: 17512443]
- Hooke C, Hellsten M, Stutzer C, Forte K. Pain management for the child with cancer in end-of-life-care: APON position paper. *Journal of Pediatric Oncology Nursing*. 2002; 19(2):43–47. [PubMed: 11973705]
- Hymovich D. The meaning of cancer to children. *Seminars in Oncology Nursing*. 1995; 11(1):51–58. [PubMed: 7740224]
- Institute of Medicine. *When children die: Improving palliative and end-of-life care for children and their families*. Washington, D.C.: The National Academies Press; 2005.
- Keene, N.; Hobbie, W.; Ruccione, K. *Childhood cancer survivors: A practical guide to your future*. Sebastopol, CA: O'Reilly Media; 2007.
- Kind T, Wheeler K, Robinson B, Cabana M. Do the leading children's hospitals have quality web sites? A description of children's hospital web sites. *Journal of Medical Internet Research*. 2004; 6(2):e20. [PubMed: 15249269]
- Kleiber C, Harper D. Effects of distraction on children's pain and distress during medical procedures. *Nursing Research*. 1999; 48(1):44–49. [PubMed: 10029401]
- Krippendorff, K. *Content analysis: An introduction to its methodology*. Thousand Oaks, CA: Sage; 2004.
- Kyngas H. Patient education: Perspective of adolescents with a chronic disease. *Journal of Clinical Nursing*. 2003; 12:744–751. [PubMed: 12919221]
- Kyngas H, Mikkonen R, Nousiainen E, Ryttilähti M, Seppanen P, Vaattovaara R, Jamsa T. Coping with the onset of cancer: Coping strategies and resources of young people with cancer. *European Journal of Cancer Care*. 2001; 10:6–11. [PubMed: 11827269]
- Landolt M, Vollrath M, Ribi K. Predictors of coping strategy selection in paediatric patients. *Acta Paediatrica*. 2002; 91:954–960. [PubMed: 12412872]
- Lazarus, R.; Folkman, S. *Stress, appraisal, and coping*. New York: Springer; 1984.
- Lewis D. Computer-based approaches to patient education: A review of the literature. *Journal of the American Medical Information Association*. 1999; 6:272–282.
- Lewis D, Gundwardena S, Saadawi G. Caring connection: Developing an Internet resource for family caregivers of children with cancer. *CIN: Computers, Informatics, Nursing*. 2005; 23(5):265–274.
- Linder L. Developmental diversity in symptom research involving children and adolescents with cancer. *Journal of Pediatric Nursing*. 2008; 23(4):296–309. [PubMed: 18638673]
- Liossi, C. *Procedure-related cancer pain in children*. Oxon, United Kingdom: Radcliffe Press; 2002.
- Ljungman G, Gordh T, Sorensen S, Kreuger A. Pain in paediatric oncology: Interviews with children, adolescents and their parents. *Acta Paediatrica*. 1999; 88:623–630. [PubMed: 10419246]
- McGrath, PA.; Hillier, L. Modifying the psychologic factors that intensify children's pain and prolong disability. In: Schechter, N.; Berde, C.; Yaster, M., editors. *Pain in infants, children, and adolescents*. Philadelphia: Lippincott Williams & Wilkins; 2003. p. 85-104.
- McGrath, P.; Watters, C.; Moon, E. Technology in pediatric pain management. In: Finley, G.; McGrath, P.; Chambers, C., editors. *Bringing pain relief to children: Treatment approaches*. Totowa, N.J.: Humana Press; 2006. p. 159-176.
- Palermo T, Valenzuela D. Use of pain diaries to assess recurrent and chronic pain in children. *The Suffering Child*. 2003; 3:1–14.
- Ries, L. Childhood cancer mortality. In: Ries, L.; Smith, M.; Gurney, J.; Linet, M.; Tamra, T.; Young, J.; Bunin, G., editors. *Cancer incidence and survival among children and adolescents: United States SEER Program 1975 – 1995*, National Cancer Institute, SEER Program. NIH Publication No. 99 – 4649. Bethesda, MD: National Institutes of Health; 1999. p. 165-169.
- Santacroce S, Lee Y. Uncertainty, posttraumatic stress, and health behavior in young adult childhood cancer survivors. *Nursing Research*. 2006; 55(4):259–266. [PubMed: 16849978]
- Santrock, J. *Adolescence*. New York: McGraw-Hill; 2007.

- Schave, D.; Schave, B. Early adolescence and the search for self. New York: Praeger; 1989.
- Sentivany-Collins, S. Treatment of pain. In: Baggott, C.; Kelly, K.; Fochtman, D.; Foley, G., editors. Nursing care of children and adolescents with cancer. Philadelphia: W. B. Saunders; 2002. p. 319-333.
- Smith M, Hare M. An overview of progress in childhood cancer survival. *Journal of Pediatric Oncology Nursing*. 2004; 21(3):160–164. [PubMed: 15296046]
- Stinson J, Petroz G, Tait G, Feldman B, Streiner D, McGrath P, Stevens B. E- Ouch: Usability testing of an electronic chronic pain diary for adolescents with arthritis. *Clinical Journal of Pain*. 2006; 22(3):295–305. [PubMed: 16514331]
- Suzuki L, Kato P. Psychosocial support for patients in pediatric oncology: The influences of parents, schools, peers, and technology. *Journal of Pediatric Oncology Nursing*. 2003; 20(4):159–174. [PubMed: 14567564]
- Tracy-Mitchell D. Educating our oncology patients during a nursing shortage. *Journal of Pediatric Oncology*. 2002; 19(6):234–235.
- Walker L, Sorrells S. Assessment of children's gastrointestinal symptoms for clinical trials. *Journal of Pediatric Psychology*. 2002; 27:303–307. [PubMed: 11909937]
- Walker, C.; Wells, L.; Heiney, S.; Hymovich, D. Family-centered psychosocial care. In: Baggott, C.; Kelly, K.; Fochtman, D.; Foley, G., editors. Nursing care of children and adolescents with cancer. Philadelphia: W. B. Saunders; 2002. p. 365-390.
- Wantland D, Portillo C, Holzemer W, McGhee E. The effectiveness of web-based vs. non-web-based interventions: A meta-analysis of behavioral change outcomes. *Journal of Medical Internet Research*. 2004; 6(4):e40. [PubMed: 15631964]
- Woodgate R, Degner L. Expectations and beliefs about children's cancer symptoms: Perspectives of children with cancer and their families. *Oncology Nursing Forum*. 2003; 30:479–491. [PubMed: 12719747]
- Zebrack B, Zeltzer L, Whitton J, Mertens A, Odom L, Berkow R, et al. Psychological outcomes in long-term survivors of childhood leukemia, Hodgkin's disease, and non-Hodgkin's lymphoma: A report from the Childhood Cancer Survivor Study. *Pediatrics*. 2002; 110:42–52. [PubMed: 12093945]

Figure 1.

Coping with Cancer Homepage

Note. A navigation menu appears in a column on the left side of the home page. Adolescents can also access information by clicking on the 6 corresponding icons in the center of the homepage.

Figure 2.

Coping with Cancer Journal Page 1

Note. Multiple rollovers appear throughout the program. For example, using your computer's mouse to rollover the word "oncologist" on the left side of journal page 1, displays the pronunciation and definition of oncologist in the right margin of screen.

Table 1

Sample Characteristics

Adolescent experts (pseudonym)	Age (years)	Gender	Type of cancer	Parent participant
1. Nora	11	Female	melanoma	mother & father
2. Annie	12	Female	synovial cell sarcoma	mother
3. Zoe	14	Female	osteosarcoma	father
4. Nate	16	Male	lymphoma	mother

Table 2

Experiences of Cancer and Cancer Treatment Identified by Adolescent Experts

Dimensions	Sample Comments
1. Physical	Could not sleep. Pain from getting poked. Getting stuck with needles was the worst thing. I got sick of getting poked. After chemo I didn't have any energy.
2. Psychological	I needed to have my family with me during procedures so I wasn't so scared. When I finally realized what was going on it was kind of shocking, it hits you and its weird. You worry about getting cancer again, it's like every little ache and I was thinking, it's back. I didn't fully understand cancer, so it was a scary feeling. Everyone needs to tell the truth and in words I can understand.
3. Social	Looked forward to going home to be with family and friends. I stayed connected with my friends at school. My teachers helped me stay in school. I talked with my sisters on the phone when they could not visit me in the hospital.
4. Spiritual	Stay strong, don't give up hope. You need to stay positive. I would pray with my mom. At first I asked why me? Then my faith pulled me though. We usually listened to Christian music, it made me feel good. Every day I said, I can get through this.

Table 3**Coping with Cancer Web-based Program Content**

Program component	Content
the journal	Using a fictional peer mentor "Brian" the journal guides a newly diagnosed adolescent through the initial shock of diagnosis of cancer, treatment options, possible side effects of cancer treatment, coping strategies, interacting with friends, dealing with school, normalizing feelings and using professional resources.
kid advice	Inspirational quotes and words of advice from the adolescent experts who have completed cancer treatment.
who's who	Health care team members and their roles.
glossary	Medical terminology with definitions and correct pronunciation.
parent stuff	Professional pediatric cancer resources.
coping tools	Using developmentally appropriate information in static and interactive forms, a variety of healthy coping strategies are introduced and described that can be used during cancer treatment (for example, listening to music, talking with friends, forms of distraction, deep breathing exercises). Adolescents are encouraged to practice these strategies at home and to ask a parent or friend to accompany them during procedures to be their "coach" while using these coping strategies.

Table 4

Evaluation of Coping with Cancer Website by Adolescent Experts

Question	Response
1. What did you think of the Coping with Cancer website?	<p>a) I liked it. I liked the colors and how you made the journal was so cool. I also liked how it was more like a teen site instead of a little kid site.</p> <p>b) It was really fun to look at it.</p> <p>c) I loved the colors and graphics. It provided great resources and knowledge. Very creative!</p> <p>d) This website is amazing! I wish I had a tool as effective as this when I was diagnosed and going through treatment.</p>
2. Do you think that the website would have been helpful when you were going through cancer treatment?	<p>a) yes</p> <p>b) yes</p> <p>c) yes</p> <p>d) yes</p>
3. If you answered "yes", what about the website would have been helpful to you?	<p>a) I would have known all the terms beforehand. Also the advice would have been really nice too.</p> <p>b) Coping with cancer; I felt like a freak.</p> <p>c) The information about cancer and the helpful advice.</p> <p>d) Everything is helpful, most important the resources for my parents to get information that is accurate and up to date.</p>
4. Can you think of anything that should be added to or removed from the website?	<p>a) No, not really.</p> <p>b) Maybe add some more games.</p> <p>c) No, it is great the way it is!! I loved it!!</p> <p>d) It's perfect!</p>