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Development and Evaluation of an Educational Interactive CD-ROM For Teens with Cancer

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INTRODUCTION

It is estimated that by the year 2010, one in every 250 persons age 15-45 years will be a childhood cancer survivor.¹ With this increase, efforts should be directed toward educating these patients about their illness, helping them to manage their life experiences, and promoting their normal psychosocial development during their treatment period and thereafter. Research has identified the complexities and challenges that a diagnosis of cancer brings to the adolescent as well as the crucial need for support and intervention. However, an extensive review of the literature found a paucity of information on available cancer education resources directed specifically to adolescents.

Traditionally, young people have been viewed as passive recipients of health care, with little involvement in the treatment process and as relatively uninformed about their health condition. Yet, the importance of information for children and adolescents with cancer has been identified in several studies.^{2,3,4} Physical appearance, current treatment, nonspecific cancer information, future outlook, familial implications, communication, health behavior, teenage identification, and use of medications are main concerns.^{5,6} It has also been found that adolescents worry that information is withheld from them; inadequate information is regarded as the second most important problem after physical symptoms caused by illness.⁷ In a questionnaire study, Griffith and Hart⁸ identified the factors that helped adolescent survivors cope, and one important factor was to take part in decision-making concerning their care.

Specifically, U.S. and European studies show that children and adolescents want more information about their bodies, their illnesses, and their treatment.^{9-10,11} They need to know their diagnosis and treatment to establish trust with health care professionals (HCPs), encourage direct communication among family members, and enhance their adjustment.^{12,13}

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CONFLICT OF INTEREST

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If not told of their diagnoses, they may experience feelings of isolation, confusion, and fear.¹² Ideally, the decision about what types of information to disclose, when and by whom, should be made by the adolescent patient. Interventions that emphasize adolescent abilities, educate them about their disease and treatment side effects, encourage self-care and coping strategies on managing their disease are strategies to promote self-esteem.¹⁴

The health care delivery system has seen an increase in computer-based patient education.¹⁵ Computers have also become a common tool in the educational system, allowing children to learn on their own or to supplement traditional teaching methods. Computer-based patient education can take advantage of these methods by incorporating them into an interactive multimedia program. Games, music, animation, and graphics can engage the user while relating important information.¹⁶ Since children are often computer savvy, a CD-ROM was conceived as an ideal tool to convey important concepts to adolescents about their cancer. Moreover, our previous experience, developing and evaluating a CD-ROM for children with leukemia¹⁷ strongly suggested that one for adolescents with solid tumors would also be successful. Specifically, the previous study was targeted to a different pediatric population - 4-11 years of age with leukemia¹⁷. The development of a CD-ROM provided a template for the current more complex effort, in that the target population with solid tumors represents a very different demographic group (e.g., 12-18 year-old adolescents with a higher reading and comprehension level, with different preferences for animation and games, a greater interest in survivorship and future issues), and a much broader variety of tumors and disabilities.

The purpose of the present study was to create and evaluate an interactive multimedia CD-ROM to educate adolescents about their cancer. It was hypothesized that an interactive CD-ROM format would enable survivors of solid tumor to learn and retain information about their cancer far better than a book with similar information, and that those in the (experimental) CD-ROM group would perceive they had a better quality of life than those in the (control) book group. It was also hypothesized that adolescents in the CD-ROM group would have better coping skills and feel more in control of their health when compared with those using the book.

METHODS

Phase I: Assessment of Need and Preferences

The initial goal of Phase I was to identify preferences of potential users on content and mode of presentation, and to create and evaluate a developmentally appropriate multimedia CD-ROM prototype for adolescents with solid tumors. This included telephone surveys with eleven HCPs caring for adolescents with cancer at various U.S. hospitals: pediatric nurse practitioners, pediatric oncologists, art therapists, a child life specialist, a social worker, and a developmental psychologist. These surveys, conducted by the Project Manager and Pediatric Hematology/Oncology Nurse Practitioner included questions on whether an interactive multimedia CD-ROM would be useful for those 12-18 years of age with solid tumors, what issues are of greatest concern, misconceptions held by these adolescents and what HCPs say to clarify misconceptions, what questions are of greatest concern to parents upon completion of therapy, and how the HCPs obtain informed assent from older children.

These surveys were followed by two focus groups (conducted by the Study Investigator and the study team), one with seven adolescents with solid tumors, and one with their parents. Questions for adolescents included their personal experiences during diagnosis and treatment, how they learned about side effects, resources they received for understanding their cancer and how to cope with it, their understanding of clinical trials and consent, issues in dealing with family, friends, and classmates, how cancer changed their lives/future,

whether an interactive multimedia CD-ROM should be developed for adolescents with cancer and what the content should be, and their thoughts about features they like and dislike, specifically related to games, look and feel of such a CD-ROM, and voiceover. Questions for parents were similar, except that answers provided insight into the parents' opinions regarding these issues.

The results of the HCP telephone surveys and focus groups with adolescents and parents were categorized into several topic areas, and the three most common or important topics were chosen to form the basis for development of a prototype CD-ROM for evaluation by potential users: *How Chemotherapy Works*, *Back-to-School Issues*, and *Coping Skills*. This was evaluated by sixteen patients, 12-18 years of age, either currently on treatment or no more than three years off treatment for solid tumors.

Results of the initial focus groups and prototype evaluation revealed several findings. First, adolescents emphasized their desire to learn about their disease, treatment, and how it would impact their lives. Specific concerns were dying, the strongest concern at initial diagnosis often not articulated, loss of control with their experience in long hospital stays, treatment schedules, procedure, and the effects of sedation. Further included were hair loss, pain, side effects of chemotherapy, missing time with friends and loneliness, especially when friends acted differently or moved ahead with their plans. As one adolescent stated, "Having cancer changes everything – the way you look at everyone and everything."

Second, parents also supported the idea of an educational CD-ROM and affirmed the topics above. Some described difficult school situations for their children relating to lack of knowledge and compassion. "They want information; they just don't know where to get it." Both adolescents and their parents expressed the opinion that doctors and pamphlets often use words and explanations that are too complicated to understand.

Finally, the HCPs opined that adolescents want to learn and understand the entire spectrum of information related to living with cancer, including information on critical issues: hair loss, body image, self-esteem, peer relationships, what causes their cancer, and their potential for dying. They agreed that cancer during adolescence is a life-altering event that poses many challenges for patients and their families.

The initial HCP surveys and focus groups therefore allowed identification of key categories of information for adolescents and their families, based on their experience with the diagnosis, treatment, and survival periods. Responses gleaned in the different components of the CD-ROM prototype evaluation further confirmed the need for such a product, and guided the identification of topic areas and the complete development of the CD-ROM in Phase II.

Phase II: Development and Evaluation of the CD-ROM

Content and Format of CD-ROM—The Phase I prototype evaluations were augmented by an additional evaluation session with thirteen patients with solid tumors who were 12-18 years of age at an university-affiliated pediatric oncology center. This further clarified the specific information needs of adolescents with solid tumors, as well as content and style of the CD-ROM. Both Phases I and II prototype evaluation sessions guided the design of the final product that included using a television network theme, optimizing visual appearance (such as larger font size and fun fonts like *comic sans*), and assuring user-friendly navigation. Recommended content suggestions included showing teens with cancer (i.e., photos, videos), featuring a detailed *Late Effects* section with survivor success stories and information about life after cancer, adding voiceover to accommodate different modes of learning as well as possible visual handicaps, including more interactive games, adding an

interactive glossary for complicated medical terms, and providing more detail on treatment (e.g., central lines), types of cancer, side effects, treatment team, back-to-school and hair loss issues, fertility, and sperm-banking options.

Development of outline, script, and adaptation to reading levels: The results of Phase I and feedback in early Phase II guided development of topics for the CD-ROM. The script was written by the research team's pediatric oncology nurse practitioner. Feedback and suggestions were provided by a 16-member multi-disciplinary panel including experts in pediatric oncology, developmental psychology, children's health promotion, as well as nine adolescents with solid tumors. Where feasible, the CD-ROM's reading level was maintained at eighth grade or below. The script included both text and voiceovers that in combination were intended to enhance understandability.

This information is presented so that when the CD-ROM opens, the user can select from seven TV screens like a network station. Each screen represents one of the topics in Table I. While the user has the option to select any screen, first-time users are encouraged to visit *Teens Talk* first. This section provides newly diagnosed teens with information and reassurance by the examples of other teens who have had this experience. The user can then navigate easily from one area to another throughout the CD-ROM, using TV screens or menus. A glossary is included to explain specific terms (highlighted in the text) and games are included throughout the CD-ROM to enhance learning.

Producing the CD-ROM: Integration of the content into the multimedia presentation:

The resulting interactive multimedia CD-ROM with text, graphics, multiple videos, music, voiceover and games was produced using Macromedia Director 7.0, Adobe Photoshop 10.0, and Adobe Illustrator 9.0. It is accompanied by a User's Manual that includes detailed content of the CD-ROM, instructions on how to use the CD-ROM, minimum requirements for running it, and explanation of various icons used throughout the CD-ROM.

Evaluation of the CD-ROM: The CD-ROM was tested for its effectiveness in six domains: health locus of control, quality of life, self-efficacy, coping abilities, knowledge of cancer and its treatment, and acceptability by adolescents, their families, and HCPs.

Eligibility, inclusions, and exclusions: Eligibility, inclusions, and exclusions are summarized in Table II. Although not all institutions required consent from older children, this study was explained to all adolescents approached; they were also told that they did not have to participate if they did not wish to, per IRB requirements. Informed consent was obtained from all parents prior to seeking consent from their children. Participating adolescents who completed both the pre- and post-testing interviews received \$40 in cash, as well as a complimentary copy of the final CD-ROM as compensation.

Study sites and IRBs: The study was conducted at four pediatric oncology programs - in Los Angeles (California), District of Columbia, Hershey (Pennsylvania), and New York City, where subjects were recruited by respective study teams and lead investigators at each site during clinical visits. Potentially eligible subjects who did not have current visits scheduled were contacted at home by study teams and informed about the possibility of study participation. Subjects were recruited only if they were interested in participating after hearing study details and having all questions answered to their satisfaction. The study was conducted at all sites after obtaining approval from relevant IRBs and obtaining consent as required. Since it proved difficult to recruit the targeted number of subjects at these study sites, flyers were developed and distributed through pediatric oncology centers nationwide, and a pediatric oncology camp in Virginia. Interested subjects were asked to call Degge

(main study site) and talk with the investigator or senior study team member to get details of study participation, including the consent process.

Research Design: Subjects were assigned via simple randomization in a pre-post design to one of two treatment levels: the CD-ROM and a Handbook containing essentially the same information for childhood cancer patients, i.e., a consolidation of patient handbooks given to patients and their families at the hospital study sites. Altogether, 185 adolescents were approached: 71 were randomized to one of the two treatment levels: CD-ROM or Handbook. Randomization was done at Degge with interviewers at each study site calling a toll-free number. Each subject was assigned an ID number, and the subject received the CD-ROM or Handbook after the first interview (pre-testing session). At this session, teens were administered questionnaires in person or via phone (if they were not able to travel to the treatment centers, i.e., study sites) by trained healthcare professionals. Teens and interviewers had copies of the questionnaire. Teens read the questions aloud and provided answers that were marked on both questionnaire sets; if necessary, interviewers provided assistance with reading. Teens were then asked to review either the Handbook or CD-ROM in the next three months. Approximately three months after receiving the Handbook or CD-ROM, the same questionnaires were administered. An additional use and acceptability survey was conducted with parents/guardians of the teens.

Sample size calculation was based on information available on KIDCOPE and MHLC (Multidimensional Health Locus of Control). KIDCOPE effect size was derived from the prior leukemia study, and MHLC effect size was based on the published literature¹⁸. Fifty participants in each group were needed, assuming 80% power and at 0.05 significance level. No information was available for the other instruments used in this study on which to base sample size.

Data collection instruments included: (1) *Demographic data form*. At the beginning of the study, data were collected on adolescent's age, gender, ethnicity, tumor type, and race; data on parent (or primary caregiver) included gender, ethnicity, race, and years of schooling; (2) *Health Locus of Control*. Nine items of the 18-item Wallston Multidimensional Health Locus of Control Scale B (MHLC-B)¹⁸ were measured on a 6-point Likert scale from "strongly disagree" to "strongly agree." Traditionally, locus of control scales have three subscales: internality, powerful others, and chance; (3) *Quality of Life*. Sixteen items, loading on two factors of the 21-item Pediatric Oncology Quality of Life Scale (POQOLS)^{19,19} were selected. The POQOLS, measured on a 6-point Likert scale from "Never" to "Very frequently" provides a total score which may be used as well as three factor scores: (a) emotional distress, (b) physical function and role restriction, and (c) reaction to current medical treatment. Items loading on reaction to current medical treatment were deleted because eligible adolescents in our study could be up to three years out from treatment. POQOLS was originally developed as a parent report measure with each statement beginning with "My child". Good internal reliability and validity were observed for the parent report version. For this study, however, "I've" was substituted for "My child" to facilitate self-reporting. The 16-item modified POQOLS refers to behaviors in the two weeks prior to the interview; (4) *Coping Style*. KIDCOPE (Older Version)²⁰⁻²³ measures coping in adolescents 13-18 years of age and the variety of coping styles different adolescents use in particular situations. In KIDCOPE (Older Version), the respondents are first asked to think of a problem they had in the past three months related to their cancer. Adolescents who insisted they had had no cancer-related problem were asked to think of another problem with these exceptions coded. The respondents were then asked to read 10 coping strategy statements to rate each to measure frequency of use and how much it helped. Frequency of use of each strategy was measured on a 4-point Likert scale from "Not at all" to "Almost all the time." A 5-point scale, "Not at all" to "Very much," measured how much

the strategy helped. The resulting four subscales (two related to Positive Approach with four items, and two related to Negative Approach with seven items) were Positive Approach Coping (PACope), Positive Approach Help (PAHelp), Negative Approach Coping (NACope), and Negative Approach Help (NAHelp); (5) *Self-efficacy*. Self-efficacy (SE) is a central construct in Bandura's Social Cognitive theory and central to behavior change.²⁴ In 1986, he defined it as "people's judgment of their capabilities to organize and execute courses of action required to attain designated types of performances. It is concerned not with the skills one has, but with the judgments of what one can do with whatever skills one possesses." To measure self-efficacy, subjects are most commonly asked their degree of confidence to perform a specific task with SE Strength formed by summing the confidence ratings. The decision was to use a question that had been used for another SE scale administered to students, which had shown good internal reliability and factor scores. "How sure are you that you can do each of the following almost all of the time?" That question was followed by 10 statements about behaviors that were explicitly addressed in the CD-ROM. Measurement was on a 5-point Likert scale from "Not at all" to "Very sure"; (6) *Cancer Knowledge*. The *Cancer Knowledge* questionnaire was developed by Degge to measure the impact of the CD-ROM or the Handbook on the adolescent's knowledge of cancer and its treatment. Fifteen multiple-choice questions were selected by consensus among senior members of the research team. The answers were required to be in both the CD-ROM and the Handbook and to have been addressed in different areas of the CD-ROM. Four choices were offered. A perfect score consisted of 26 correct answers (as some questions had multiple correct answers) and no incorrect answers. Each correct answer earned one point for a maximum of 26; one point was subtracted for each incorrect answer; (7) *Acceptability, Use, and Satisfaction* (measured at post-test only). Both adolescents and parents (or primary caretakers) using the CD-ROM or Handbook completed brief self-administered questionnaires to ascertain who used the CD-ROM/Handbook, for what length of time, how frequently, and acceptability (e.g., ease of use, likes/dislikes) and availability preferences (where and when the CD-ROM or Handbook should be available). Responses were scored on a 4-point Likert scale from "Strongly Disagree" to "Strongly Agree". HCPs also completed self-administered questionnaires to assess acceptability and availability preferences. The questions for all of the *Acceptability and Use* instruments were both closed and open-ended to encourage individual comments.

Interviewer training: In order to conduct pre- and post-tests in a consistent manner across all sites, five interviewers (health care providers at each of the study sites, such as nurse practitioners, social workers, or research assistants) were trained using a video-taped demonstration interview (recorded at Degge, featuring the investigator and the pediatric hematology/oncology nurse practitioner), and then received a detailed interview manual. The same interviewers were used for both pre- and post-testing sessions, and a toll-free number was available for assistance during testing. To assure coherence, the interview training process included a pilot test of the administration of the questionnaire with some of our ongoing adolescent script reviewers.

Interview Process: Questionnaires were administered in person at the respective study sites, or in some cases at the subject's home, if unable to travel to the study site, or via phone, when it was not possible to have a face-to-face interview with the subject due to illness and not being able to commit to a specific interview time, or due to travel distance. The questions were read aloud by the subjects; the interviewer helped read along when necessary. In case of phone interviews, the questionnaires were mailed to the parents ahead of time, who were asked to keep these sealed until the time of the phone interview, so the teens couldn't see them beforehand and try to get help with answers. Initial test questions were read aloud with the subjects to indicate whether the participant understood how to

respond. The interviewers knew of the experimental condition because they distributed the intervention immediately following the pre-test and asked questions relative to the specific intervention at post-test. Also, it was not possible to prevent the adolescents and parents from divulging their specific intervention.

Data Analysis: All data from the interviewer forms were cleaned and entered into a Microsoft Access database. SPSS Version 12 was used to generate descriptive statistics and to run t-tests on the pre- to post-intervention change scores of the CD-ROM and Handbook groups to evaluate the various measures described above.

RESULTS

Sample description

Even though a total of 165 subjects was considered eligible at the time of grant application, many refused to participate mainly due to following reasons: no longer eligible (partly due to delay in study funding as they were either >3 years off treatment, or >18 years old, or had moved away); too sick to participate or continue, or had recently relapsed; too busy with school and other activities; lack of interest, since this chapter in their life was over; or due to death during the evaluation phase. The final sample consisted of 35 families in the CD-ROM group, and 30 families in the Handbook group.

Seventy-one teens (38.4%) with solid tumors and no more than three years out of treatment were recruited out of 185 approached at six sites. Six of those completing pre-intervention questionnaires did not complete follow-up questionnaires and were dropped, leaving 65 for analysis.

The demographics of the participants are presented in Table III. The average age was 14.8 (S.D. 1.96) years, ranging from 12-18 years; 50.8% were in treatment, whereas 49.2% had been out of treatment an average of 14.8 months (S.D. 11.65), ranging from 6 days to 33 months. Demographic variables were not significantly different between teens assigned to the CD-ROM and those assigned to the Handbook.

Reliability of Measures

Chronbach's Alpha was used to evaluate internal reliability for the following measures: Health Locus of Control, Quality of Life, Self-Efficacy, KIDCOPE, and Cancer Knowledge. Satisfactory Chronbach's alpha scores for internal reliability, ranging from 0.61-0.93, were achieved for MHLC, POQOLS, SE, and the four subscales of KIDCOPE.

Outcomes of Intervention

Frequency and Duration of Use and Satisfaction in Teens—A total of 65.7% of 35 teens in the CD-ROM group, and 60.0% of 30 teens in the Handbook group used their assigned intervention to learn about cancer. Of those teens who reviewed the CD-ROM, 91.4% indicated "YES, the CD-ROM was easy to use" compared to 56.7% of the Handbook group. As shown in Table IV, of the total teens in both intervention groups, a higher proportion reported using the intervention a few times versus many times (45.5% vs. 21.2% of 35 patients for the CD-ROM; 40.0% vs. 10.0% of 30 patients for the Handbook). The proportion reporting that they used the CD-ROM many times was approximately twice that of those reporting use of the Handbook many times. The number of teens reporting that they used the CD-ROM or the Handbook many times was small in both groups (7 vs. 3) and the difference insignificant ($p=0.313$).

Based upon responses relating to enjoyment and ease of use, a larger proportion of teens using the CD-ROM reported they would recommend it to other teens (N=30; 85.7%) than those using the Handbook (N=19; 63.3%). Both groups of adults indicated the best time to receive the intervention would be at start of treatment (CD-ROM group (N=21; 65.6%); Handbook group (N=20; 69.0%)), versus during, before, or after treatment.

Intervention Impact—Table V summarizes the overall results of the different tests evaluating the dimensions of possible changes that were hypothesized. In summary, there was a significantly greater change ($p = 0.016$) in the CD-ROM group who showed an increase in MHLC scores reflecting increased feelings of control over health when compared to the Handbook group. However, there were no significant group differences between pre-post scores for the two interventions in the Quality of Life, Self-efficacy, KIDCOPE, or Cancer Knowledge measures. Of the four KIDCOPE measures, PACope, PAHelp, NACope, and NAHelp, there were also no significant change score differences from pre- to post-test between the CD-ROM and the Handbook groups.

Learning style—A series of three questions was asked to rank the teens' favorite way to learn about cancer. As shown in Table VI, the CD-ROM teen group chose "A real person talking to you" as the first choice followed by a CD-ROM, while the Handbook group chose the CD-ROM and the internet equally as their first choice. "A Book" was least liked by CD-ROM group teens compared with other choices. Teens in the Handbook group ranked "A Book" fourth.

Open-ended Responses—The last questions were open-ended and inquired as to what teens and adults liked/did not like about the intervention they received. About a third of adults in both groups made comments. Some of the responses were used to change the final version of the CD-ROM, as mentioned in the *Content and Format of CD-ROM* section above, e.g., improved visual appearance, chemotherapy animation, more information in the *Late Effects* section, more voiceover, improved interactive glossary, and an overall MENU for the entire CD-ROM.

Health care providers—Copies of the CD-ROM prototype and evaluation forms were sent to 143 HCPs, who had cared for children with solid tumors for an average of 12.1 years (S.D. 9.58). Ninety (62.9%) returned the evaluations, of which 19 (21.1%) were physicians (including 17 pediatric oncologists/hematologists) and 37 were nurses (41%). Twenty HCPs (22.2%) had no prior experience using CD-ROM technology. More than 90% of them thought the CD-ROM is complete, and 97% agreed that the CD-ROM provides needed information for teens with solid tumor; almost as many (96%) thought it provided useful information for parents as well. About 92% of HCPs said they would recommend this CD-ROM to parents of teens with cancer, and just as many (92%) responded that they would like to make this program available to their patients.

DISCUSSION

Our study focus groups and prototype evaluations of adolescents with cancer revealed not only inadequate information and lack of involvement in their own care, but also a loss of control. Conquering Cancer Network: Empowering Teens with Tools, Info, and Inspiring Stories was created to empower adolescents to face their cancer challenge and facilitate their return to a productive life in their survivor period. This CD was met with much enthusiasm by teens in both acceptability and use, as significantly more of those who reviewed would recommend it to other teens with cancer compared to the Handbook group. Teens ranked the

CD-ROM as their first choice for a learning tool, consistent with the literature review advocating the benefits of interactive, multimedia patient education.^{15, 16}

Results from this study showed that CD-ROM users scored higher in the Wallston Multidimensional Health Locus of Control Scale than those using the Handbook, thereby supporting the theories that knowledge and support give adolescents a sense of control in their lives. When evaluating our previous CD-ROM, *Kidz with Leukemia: A Space Adventure*,¹⁷ the health locus of control also increased among children who used the CD-ROM compared with the control group, indicating that the CD-ROM helped children have greater feelings of control over their health.²⁵

The CD-ROM was favorably received, even though its impact was not demonstrated in tested domains other than health locus of control. The small sample size limited the power of the study and may have affected the ability to detect group differences. Budget and time constraints limited the ability to extend subject recruitment. However, given the means between the groups were relatively similar on most measures, it is unclear if a larger sample size would result in significant group differences.

The timing of testing and duration of use may have contributed to the results. Adolescents said that the CD-ROM/Handbook should have been given at diagnosis when they wanted it and were motivated. Due to constraints of recruitment, by the time they received the CD-ROM/Handbook, the adolescents were acclimated to their situations and were more knowledgeable about their condition, and some were off treatment.

In summary, Conquering Cancer Network: Empowering Teens with Tools, Info, and Inspiring Stories was created to empower adolescents to face their cancer challenge and facilitate their return to a productive life in their survivor period. It was also designed to provide parents a medium to better understand their child's illness and therapy and to serve as a resource for HCPs and educators. The information enhances and does not replace expert medical advice. This CD-ROM represents a prototype for new tools for caring for chronically ill patients, particularly adolescents. The unanimous opinion from all teens who reviewed the CD-ROM was that they wished they had received this learning tool at diagnosis. The CD-ROM was effective in improving health locus of control and got high marks from adolescents with cancer, their families, and healthcare providers even though several other measures demonstrated no significant differences in the two types of interventions. Recommendations for further research would be to pursue: (1) the most effective time for intervention, e.g., investigate the effect of providing the CD-ROM at various times at, or following diagnosis; (2) assess both the short and long-term impact of this tool; and (3) assess the value of providing access to this CD-ROM online instead of via a CD-ROM, so that the time and frequency of use could be investigated for effects on the measures used in this study.

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Table I
CD-ROM Contents

Teens Talk	Shows teens with cancer talking about their experiences of living with cancer. Feelings and thoughts are discussed related to treatment, changes in appearance, school issues, relationships with family and friends, isolation, fears related to dying, and the overall impact of how cancer changes your life and your perspective
What is Cancer?	Provides a basic introduction of normal cell growth, cancer cell growth, and specifically “what is a solid tumor?” The user can then select the type of tumor s/he wants to learn about. Each type of solid tumor is described in terms of definition, who gets it, symptoms, diagnostic tests, and treatment.
Research	Explains the “who, what, and where” of clinical trials and the consent/assent process via a <i>Whodunit?</i> – <i>Research Mystery</i> theme.
Treatment Plan	Introduces the treatment team, explains various blood and diagnostic tests, types of central venous catheters, pain management, and types of treatment. The user can also play the <i>Tumor-nator</i> game and learn about various tumors by blasting cancer cells and scoring points.
Side Effects	Explains side effects of different treatments including chemotherapy and radiation therapy. For example, this includes effects of cancer treatments on different blood cells, and on other body organs. The user can visit “The Advisor” and get tips and suggestions on how to cope with these side effects. The user can also test his/her knowledge by taking an Interactive Quiz.
Late Effects	Presents inspiring true stories of cancer survivors who are now young adults living full, meaningful lives. The concept of ‘late effects’ is explained, and the importance of long-term follow-up is emphasized. Future concerns such as career, insurance, marriage, fertility, and self-advocacy are addressed. This section is an especially serious one and may sound scary or frighten the adolescent; it is suggested that they read a little bit at a time, optimally with a parent or HCP.
Resources	Lists valuable resources for adolescents with cancer and their families, including active sites accessible via the Internet, such as NCI information resources, cancer research groups, medical organizations & societies, community resources & support groups, financial assistance, wish fulfillment organizations, and sibling resources. Included is also a list of printed educational resources. Chemotherapy drug fact sheets were developed for the CD-ROM and are available for downloading.

Table II
Inclusion Criteria

Age	12 - 18 years
Diagnosis	Any kind of solid tumor
Treatment status	Currently on treatment, or 3 years off treatment
Education level	Not more than one grade behind in school; literate in English
Prior participation	No participation in previous focus or evaluation groups involving the development of this CD-ROM; not photographed or videotaped for the CD-ROM prior to the interview
Computer access	Access to a computer with a CD-ROM drive and sound card
Consent / Assent	Signed consent / assent form by teens (and if required by IRB, by parents as well)
Parents / Guardians	Understanding spoken English and minimum 8 th grade education

Table III

Subject Characteristics

Population	CD-ROM		Handbook		Total	P value	
	N	% of Total	N	% of Total	N	% of Total	
Cancer Patients	35	53.8%	30	46.2%	65	100.0%	
Age							
12-14	13	20.0%	18	27.7%	31	47.7%	0.066
15-18	22	33.8%	12	18.5%	34	52.3%	
Ethnicity							
Hispanic	9	13.9%	6	9.2%	15	23.1%	0.586
Non-Hispanic	26	40.0%	24	36.9%	50	76.9%	
Race							
White	27	41.5%	22	33.8%	49	75.3%	0.674
African-American	4	6.2%	6	9.2%	10	15.4%	
Asian	1	1.5%	1	1.5%	2	3.1%	
Other*	3	4.6%	1	1.5%	4	6.2%	
Gender							
Female	13	20.0%	11	16.9%	24	36.9%	0.968
Male	22	33.8%	19	29.2%	41	63.1%	
Treatment							
On	17	26.1%	16	24.7%	33	50.8%	0.702
Off	18	27.7%	14	21.5%	32	49.2%	

* Other = Other race or more than one race

Table IV
Teen Reports of Their Use of the CD-ROM and the Handbook

	CD-ROM	Handbook	P value
Use by teens	N = 35	N = 30	
<i>A few times</i>	15 (45.5%)	12 (40.0%)	0.739
<i>Many times</i>	7 (21.2%)	3 (10.0%)	0.313
No adult help ^I	26 (74.3%)	18 (60.0%)	0.156

^I Reflects teen perception

Table V
Pre- and Post-test Results of Measures in Five Domains (Health Locus of Control, Quality of Life, Self-efficacy, Cancer Knowledge, and KIDCOPE) in the CD-ROM and Handbook Groups

	CD-ROM (N=35)		Handbook (N=30)		Mean difference
	Pre-test	Post-test	Pre-test	Post-test	
MHLC					
Mean	33.40	37.26	34.40	35.37	0.97
S.D.	5.62	4.60	6.38	4.74	
t-value (change scores, post-test less pre-test) = 2.479, df = 63, p = .016					
POQOLS					
Mean	86.63	85.46	86.87	88.20	1.33
S.D.	17.84	20.98	14.27	14.92	
t-value (change scores, post-test less pre-test) = 0.787, df = 63, p = .434					
Self-efficacy					
Mean	37.60	38.91	37.70	38.30	0.60
S.D.	7.63	9.27	7.12	4.74	
t-value (change scores, post-test less pre-test) = 0.413, df = 63, p = .681					
Cancer Knowledge					
Mean	15.26	15.20	14.55	16.10	1.55
S.D.	3.22	3.60	3.46	3.40	
t-value (change scores, post-test less pre-test) = 1.151, df = 63, p = .254					
Coping Strategies					
Positive/Approach					
Mean	6.57	7.23	6.57	6.80	0.23
SD	2.64	2.81	2.39	2.57	
t-test p-values (change scores, post-test less pre-test) Positive/Approach = 0.557					
Negative/Avoidance					
Mean	7.34	6.77	7.67	6.87	-0.80
SD	3.30	3.47	3.10	3.14	
t-test p-values (change scores, post-test less pre-test) Negative/Avoidance = 0.811					
Positive/Approach Help					

CD-ROM (N=35)			Handbook (N=30)		
	<i>Pre-test</i>	<i>Post-test</i>	<i>Mean difference</i>	<i>Pre-test</i>	<i>Post-test</i>
Mean	10.00	9.80	-0.20	9.77	9.70
SD	3.91	4.10		3.07	3.45
t-test p-values (change scores, post-test less pre-test) Positive/Approach Help = 0.893					
Negative/Avoidance Help					
Mean	7.57	7.17	-0.40	7.93	7.30
SD	3.93	4.29		3.91	3.26
t-test p-values (change scores, post-test less pre-test) Negative Avoidance Help = 0.841					
<i>Mean difference</i>					
					-0.07

Table VI
Number of Teens in Each Study Group (Book/CD) stratified by favorite* ways of learning about cancer

Intervention Group	Ranked as favorite way of learning*				
	A Book	A CD-ROM computer program	The Internet	A video tape	A real person talking to you
Teen CD-ROM (n=35)	2	9	8	4	12
Teen Handbook (n=30)	3	9	9	1	8
TOTAL	5	18	17	5	20

* Favorite (1st choice) of the top three preferences indicated by teens