Published in final edited form as:
Patient Educ Couns. 2002 April ; 46(4): 297–307.

Development and Evaluation of an Interactive CD-ROM for Children with Leukemia and Their Families[1]

Mary Alice Dragone[a], **Patricia J. Bush**[b], **Judith K. Jones**[a,*], **David J. Bearison**[c], and **Sharmila Kamani**[a]

[a]The Degge Group, Ltd., 1616 North Fort Myer Drive, Suite 1430, Arlington, VA 22209

[b]6825 Grenadier Boulevard #1405, Naples, FL 34108

[c]Graduate School and University Center of the City University of New York and Mount Sinai School of Medicine, The Graduate Center, 365 Fifth Avenue, New York, NY 10016

Abstract

To meet the need for an interactive software product to educate children with leukemia, ages 4–11 years, and their families about the disease and its treatment, we developed and evaluated an interactive, comprehensive, multimedia CD-ROM product, *Kidz with Leukemia: A Space Adventure*. The prototype was tested using a randomized controlled experimental design. Children with leukemia and their parents were randomized to receive either the newly developed CD-ROM or the book *You and Leukemia* by Lynn Baker. Health care providers (HCPs) and other content/ technical experts evaluated only the CD-ROM. Data were collected on children's health locus of control, their understanding of leukemia, and the satisfaction of participants with their assigned intervention. Children in the CD-ROM group, compared with those in the book group, showed increased feelings of control over their health. Although there was a high level of satisfaction with the CD-ROM among all users, younger children and their parents were most satisfied. In conclusion, the CD-ROM, *Kidz with Leukemia: A Space Adventure*, was found to be a useful, engaging, and empowering tool for children with leukemia and can serve as a model for developing future health-related educational materials.

Keywords

Childhood cancer; CD-ROM; Leukemia; Patient education; Pediatrics

1. Introduction and review of the literature

1.1. Childhood leukemia

Approximately 8,700 children are diagnosed with cancer each year in the United States [1]. Childhood leukemia represents 30% of these cases with an incidence of 38 per million children per year [2]. Acute lymphoblastic leukemia (ALL) accounts for 80% of childhood leukemia cases. The incidence is highest among four to six year-olds with more frequent occurrence in males. Caucasian children are 20–30% more likely to be diagnosed with this disease than are African-American children. Treatment consists of the use of multiple antineoplastic agents but may also include radiation therapy or bone marrow transplantation.

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[1] This publication was supported by grant number R44 CA71271 from the National Cancer Institute. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the National Cancer Institute.

[*] Corresponding author: Judith K. Jones, MD, PhD Tel: 703 276 0067; Fax: 703 276 0069; jkjones@deggegroup.com.

Regimens extending over several years include invasive procedures such as lumbar punctures, bone marrow aspirates, and venipunctures. Approximately 80% of children with ALL survive long-term [3].

1.2. Educating children about their medical conditions

Little is known about the appropriate depth of information to give children undergoing treatment for a specific illness or participating in research. Increasing evidence shows that children want more information about their bodies, their illnesses, and their treatment, particularly medicines [4–6]. Providing children with information rests on arguments not only related to its effects on children’s behavior and clinical outcomes, but also on children’s “right to know.” Without information, children may form beliefs and attitudes that are often erroneous, cause fear and anxiety, and may adversely affect compliance [4,7–11].

A preponderance of evidence favors giving children information as soon and as completely as possible. In a study by Slavin and colleagues [12], children who were told earlier during diagnosis and treatment about having cancer fared better psychologically than children who indirectly learned about their diagnoses at a later time. Educating children and their parents about the diagnosis and treatment plan helps to establish trust with health care providers (HCPs), reinforces honesty among family members, and enhances adjustment to the illness [12].

Information is the most widely used intervention to prepare children for a painful procedure. The rationale for such an intervention is that unexpected stress provokes more anxiety than expected stress [13]. Over time, children with cancer increase their information-seeking behavior and decrease avoidance behaviors during invasive procedures. As reviewed by Bearison [14], the literature suggests that interventions that actively engage children in seeking information facilitate their adjustment.

1.3. Computer-based multimedia education

In recent years, the health care delivery system has seen an increase in computer-based patient education. Falling prices have made computers widely accessible to a larger market. In 1998, 60% of families with children had computers in their homes [15]. According to current estimates, 95.9% of 6–12 year-olds and 70.3% of children less than six have used a computer [16]. Computer-based education uses games, music, animation, and graphics to engage the user while conveying important information [17].

Multimedia CD-ROM technology provides several benefits over print and video used in educational resource development for children with leukemia: (1) The flexibility of the CD-ROM format permits users to learn at their own pace, choosing the type and depth of information to acquire and review, which may differ from what their HCPs feel is most important [18–19]. (2) The user-driven nature of the CD-ROM format provides children with a sense of control, an optimal format for learning [6,10,20–21]. An interactive program going beyond a preplanned tutorial format maximizes the CD-ROM’s capability to engage, entertain, and educate children. (3) The CD-ROM’s use of graphics and animation with voice-over eliminates some of the obstacles to independent learning encountered by children with limited literacy. This medium is ideal for the translation of medical information into a format more easily understood by children [22].

1.4. Purpose of the study

Educating children about their cancer is consistent with two theories. One, consistent with social learning theory [23], states that children who know more about their illness, feel more in control of their health, which leads to better outcomes [12]. The second states that there is a dynamic relationship between how children cognitively represent and organize their experiences and how they adjust to these experiences [14]. Both of these theories are believed to work through reduction of anxiety [13]. The question remains as to how best to educate children with cancer and how to give them greater feelings of control. Despite excitement over the capabilities of interactive computer technologies for education, there is little research comparing patient education methods using computers with more traditional methods of learning. The present study addresses this gap.

The specific research questions of this project were:

1. Is there a greater increase in feelings of control over their health among children with leukemia, ages 4–6 and 7–11 years, using the CD-ROM than among those receiving a commonly used print educational resource?
2. Is there a greater increase in children's understanding of leukemia among children using the CD-ROM than among those receiving a commonly used print educational resource?
3. How does satisfaction with the CD-ROM compare with satisfaction with a commonly used print educational resource among children with leukemia and their parents?
4. How satisfied are HCPs in pediatric oncology with an interactive educational CD-ROM about leukemia for 4–11 year-olds and their parents?

2. Methods

2.1. CD-ROM educational intervention development

The target audience of 4–11 year-olds was divided into two groups: 4–6 year-olds and 7–11 year-olds. The different developmental levels of preschool and school-age children required focused assessments to determine whether the CD-ROM could meet the needs of both populations.

2.1.1. Phase I—The Phase I script and storyboard content development was guided by feedback from focus groups with 7–11 year-olds with leukemia (N=14), their parents (N=16), and interviews with HCPs (N=24). Participants for these convenience samples were drawn from a pediatric cancer center in Ohio.

The Phase I CD-ROM prototype, with a space hospital theme, was evaluated by a convenience sample of twenty 7–11 year-olds and their parents as well as HCPs. The children enjoyed using the program, continued using the program except when text was not accompanied by voice-over audio, and requested that there be more videos within the program. Parents felt the proposed content areas addressed the areas they discussed in focus groups and were enthusiastic about the prototype. They recommended the addition of "Question and Answer" sections. HCPs (N=21) agreed the program was entertaining, provided an outline for needed information, and could be used independently by 7–11 year-olds.

2.1.2. Phase II—In Phase II, focus groups were used to determine how the prototype should be changed to accommodate the needs of 4–6 year-olds with leukemia and their parents. Focus groups were held with a convenience sample of 4–6 year-olds with leukemia (N=7) and their parents (N=8) from a university-affiliated cancer center in Virginia and a pediatric cancer support group serving the same area. Additionally, structured 20–40 minute telephone interviews were conducted with a geographically diverse group of eight HCPs in pediatric oncology.

Six healthy 4–6 year-olds from a private preschool in Virginia helped establish the ease of use of the prototype for a younger population. Their feedback led to the elimination of complex hierarchical nesting of information and the inclusion of brighter graphics. The format of the CD-ROM was thus changed from a “space hospital” with several floors and rooms on each floor to a planet with 6 major areas to explore.

The Phase II prototype included information for both 4–6 and 7–11 year-olds in one of the six major content areas, the area highlighting things children have some control over during the treatment process. A convenience sample of seven 4–11 year-olds with leukemia who either attended a university-affiliated cancer center in the District of Columbia or a cancer support group in the same area evaluated the prototype. They navigated easily through the program, spontaneously visited nearly all active content areas, listened to the content for the duration of its presentation, and expressed enjoyment in the program.

2.2. Content and format of the CD-ROM

The content and format of the CD-ROM, *Kidz with Leukemia: A Space Adventure*, were continuously revised based on feedback provided by focus groups, questionnaires, interviews, and pilot testing as described above. The script was developed by a certified pediatric oncology nurse practitioner and reviewed by a 14-member multidisciplinary panel including multimedia designers, university-based experts in pediatric oncology, developmental psychology, and children's health promotion, as well as an adolescent with leukemia.

On entering the CD-ROM program, users pick the age group to which they belong: 4–6 years old (no reading ability required), 7 years or older, or adult. Activities often have the same two to three levels of difficulty for each age group. This allows children with more experience, curiosity, or knowledge to have access to more challenging activities, even if they are in the younger age group. For example, a 6 year-old who has had leukemia for two years may know as much as a 10 year-old who is newly diagnosed with leukemia. During the program, a “Space Buddy” is the user’s guide. "Space Buddy" has no identifiable gender or ethnicity in order to help more users identify with the character. Before users explore the planet “Leukator,” they are presented with three main points about leukemia (Figure 1a).

The contents of the program include: *The Get Better Place* (research studies, medicines, treatment, health care team), *Help Yourself* (areas in which children can exert some control, including nutrition, preventing infections, pain control, creative arts, and relaxation techniques), *The Testing Center* (bone marrow tests and spinal taps, blood tests, radiology tests, heart testing, and vital signs), *The Fill and Fly* (red blood cells, white blood cells, and platelets), *The Space Mall* (changes in appearance, central venous catheters, anatomy and physiology, and resource/reference section), and *The Movies* (video hospital tour, living with leukemia, expert explanation of leukemia, and siblings’ views of leukemia). The contents are presented interactively using video, animation, puzzles, and games.

Some sections of the program are designed for children 7 years and older and adults. *Taking Part in Research* is included only for these age groups because assent is not usually obtained from children under the age of 7. Sections with a large amount of written text also were available to users who choose the pathways for children 7 years and older or adults. Sections at the Adult level include *Frequently Asked Questions for Parents*, NCI’s *Physician Data Query*, and the *Resource Section* with hyperlinks to selected sites for those with Internet access.

The contents for children 7–11 averaged at the 7th grade reading level (SMOG Readability Index). The *Frequently Asked Question* section for parents averaged at the 8th grade reading level. Four commonly used multi-syllabic words (leukemia, medicine, chemotherapy, infection), which must be used but increase reading levels, are defined via print and audio in the *Book of Big Words* section, available to all users.

Kidz with Leukemia: A Space Adventure was produced using Authorware® 4.0, Adobe Photoshop® 4.0–5.5, Adobe Illustrator® 7.0, Macromedia Director® 7.0, and Macromedia SoundForge® 3.0 on Micron Pentium II® machines running Windows®95–98. The final version of the CD-ROM is 467 Mb, 2.5 Mb of which is a self-running executable and 347 Mb of which is video. Minimum program requirements are Windows® 95/98/2000 or NT, a Pentium® processor with 24 Mb memory, 8xCD-ROM drive, a VGA 640×480 display with 256 colors, 6.5 Mb free hard drive space, a compatible sound card, and speakers.

2.3. CD-ROM intervention evaluation: children with leukemia and their parents

2.3.1. The setting and sample—The initial study was conducted through four comprehensive pediatric oncology programs in the District of Columbia, Virginia, and Ohio. A support group serving the District of Columbia metropolitan area provided additional participants. This convenience sample was initially recruited from the two institutions that had agreed to be part of the study at its inception. Due to the recruitment of fewer participants than anticipated, three additional settings were used. All relevant Institutional Review Boards approved the study. Most interviews were done at the hospital where the child was treated, but occasionally interviews were done at home, especially during post-testing.

Criteria for selecting participants included: age 4–11 years, a diagnosis of acute lymphoblastic leukemia (ALL) or acute myelogenous leukemia (AML) in first remission, currently undergoing treatment or less than 3 years since the end of treatment, ability to understand spoken English, absence of a severe learning disability, lack of participation in any earlier focus groups about the CD-ROM development, and consent to participate for children 7 years of age and older. Additionally, parents had to understand spoken English and either the child or the parent had to be able to read materials written in English, in case the child was randomly assigned to the control group receiving printed text.

Although only a few institutions required consent from older children, all children approached for this study were told about the study at their developmental level and were told they did not have to participate. Informed consent was obtained from all parents prior to seeking consent from their children. Participating children were given the option of receiving either $25 or a copy of the completed CD-ROM as compensation.

2.3.2. Interviewer training—Six interviewers were trained by an experienced study coordinator in individual and group sessions. The interviewers first viewed a video-taped demonstration interview prepared by the study coordinator. They also received a detailed interview manual that was reviewed during the training sessions. In all, the interviewers received eight hours of training, four for the pre-test interviews and four for the post-test interviews. The same interviewers were used for both testing sessions.

The interviewers were not blind to the experimental condition because they distributed the intervention following the pre-test and asked questions relative to the specific condition at post-test. Also, it would not have been possible to keep the children and parents from telling the interviewer which intervention they had. Interviewers were taught how to avoid biasing subject responses during their training sessions. Special emphasis was given to methods for interviewing 4–6 year-olds.

2.3.3. Research design—Data were collected both longitudinally (i.e., pre- and post-intervention) and cross-sectionally (i.e., experimental and control conditions) by trained interviewers. Participants were randomly assigned to either the CD-ROM or comparison group at the time of registration in a balanced 4-block randomization pattern by age group (4–6 year-olds vs. 7–11 year-olds) and institution. The experimental group received the CD-ROM, *Kidz with Leukemia: A Space Adventure*, to use for approximately three months. The comparison group received the book *You and Leukemia* (1988) by Lynn Baker [24] for the same time period. This book is used as a standard method of conveying information to children who have leukemia and their families throughout the United States.

2.3.4. Data collection instruments—Demographic data were collected at the start of the study. All participants completed pre-test and post-test assessments using the Leukemia Children's Health Locus of Control (LCHLC) scale and Leukemia Event Knowledge Interview (LEKI), described below. Additionally, Satisfaction and Use Questionnaires were administered during post-testing.

2.3.4.1. Demographic data form: Data were collected on children’s gender, age, race/ethnicity, leukemia diagnosis, status of treatment, and access to a computer. Data were collected on parents’ gender, race/ethnicity, and number of years of education.

2.3.4.2. Leukemia children’s health locus of control: The Leukemia Children’s Locus of Control (LCHLC) scale was adapted from the Children’s Health Locus of Control (CHLC) scale, originally developed by Parcel and Meyer [25].

Health locus of control scales measure people’s feelings of having a sense of control over their health. The scales have three dimensions: Powerful Others (PO), Chance (C), and Self (S). Scores range from low (primarily external health locus of control) to high (primarily internal health locus of control). People with an externally oriented locus of control believe people, things, or events outside themselves (i.e., luck or chance) have the greatest control over their personal health. People with an internally oriented locus of control believe that they have the greatest control over their own health.

A 9-item version of the original CHLC scale, consisting of 20 Yes/No questions, achieved Kuder-Richardson-20 (KR-20) internal reliability values ranging from .31–.74 among 60 children in each of grades 1–6 [25]. A picture version achieved a KR-20 value of .57 among kindergarten children compared with only .03 when the version without pictures was used. The shortened version was later administered to 300 children in grades 3–7 and achieved a KR-20 value of .69 [27]. An 18-item version was administered to more than 1,000 children in grades 4–6 and was repeated each year until the children were in grades 7–9. Factor analyses revealed the expected three dimensions with KR-20 values ranging from .65–.71 across the four years [28]. The CHLC scale has been found stable over time, positively correlated with age and socioeconomic status, and negatively correlated with expectations to take medicines for common health problems [26–28].

Some items from the original CHLC version were modified to reflect that children could not do things to prevent them from getting leukemia. For example, an item from the original version, “I can do things to keep from getting sick,” was modified to “I can do things to keep from feeling sick.” A picture version (one for boys and one for girls) was used for 4–6 year-olds.

2.3.4.3. Leukemia event knowledge interview (LEKI): Children’s knowledge of common recurring events in their lives is cognitively organized in the form of event knowledge [29–31]. Event knowledge consists of a temporal sequence of socially mediated activities involving participants and others but expressed from the participant's perspective. In the present study, measures of children's understanding of leukemia were derived from methods employed by Bearison and Pacifici [32] to assess children's event knowledge of routine outpatient clinic procedures in the treatment of childhood cancers. In addition to its theoretical basis, the LEKI was selected because it was the only instrument of its kind known to have been tested with children with cancer as young as four years [31].

Participants in the present study were asked to imagine that they had just learned that another child, much like themselves, had just found out that he or she had leukemia and to tell the interviewer everything that they might tell that child about "What happens when you have leukemia." ("Tell me what happens first and then everything that happens after that. What happens first?") Children were given non-directive prompts ("What happens next? What else?") until they no longer responded with leukemia events. Children were then asked, "What happens when…?" kinds of questions about three particular medical procedures: (1) taking blood, (2) receiving a spinal tap, and (3) getting chemotherapy. Event narratives were audio recorded and then coded from the verbatim transcripts.

Transcripts were broken down into events, consisting of the description of a single activity. Events were coded according to four levels of generality: (1) superordinate, (2) basic, (3) subordinate, and (4) episodic. Superordinate level events were the most general, constituting a segment of related contiguous activities that described the attainment of a goal (e.g., getting chemotherapy). Basic level events consisted of the particular activities necessary to realize the superordinate level events (e.g., inserting a needle into the thigh muscle). Subordinate level events consisted of activities that were not commonly mentioned by the children and episodic level events were those that rarely occurred (i.e., idiosyncratic). The identification and order of basic level events within superordinate level events was obtained from interviews with pediatric oncologists and children with leukemia.

In addition to levels of generality, events were coded as either spontaneous or elicited via prompts, as well as whether or not they were elaborated. Elaborations of four types were coded: (1) explanation of an activity, (2) expression of an emotion about an activity, (3) reference to side effects of treatment, and (4) description of physical setting, objects, and/or people. Finally, events were coded according to whether they were repeated and whether they clearly misidentified or incorrectly described an activity (i.e., were errors).

2.3.4.4. Satisfaction and use questionnaires: Simple parent and child instruments were developed to assess acceptability and feasibility of use of the particular material the child received at randomization. Questions assessed the material's ease of use, whether it would be recommended to others, how often and for how long it was used, the child's need for adult assistance, what was liked best and least, and the user's preferred method of learning. All questions were asked in an individual interview format with responses transcribed verbatim; most were multiple-choice. If participants spontaneously requested to write in their own responses, they were allowed to do so.

2.4. CD-ROM intervention evaluation: survey of health care providers and other experts

2.4.1. The setting and sample—Physicians, nurses, psychosocial personnel, and administrators with expertise in pediatric leukemia were recruited from organizations including the Children's Cancer Group Leukemia Subcommittees, the Association of Pediatric Oncology Nurses, the American Cancer Society, the Leukemia and Lymphoma Society, Candlelighters Childhood Cancer Foundation, and Special Love, Inc.

2.4.2. Procedure—A CD-ROM prototype was sent to interested HCPs and other experts with instructions to review the CD-ROM and return it, with the evaluation, in a prepaid mailer.

2.4.3. Data collection instrument—HCPs completed a different Satisfaction and Use Questionnaire about the number of years they had cared for children with leukemia, their prior use of CD-ROM technology, and their assessment of the current CD-ROM in terms of completeness, likelihood that it could be used independently by 4–11 year-olds, what they liked best and least about the CD-ROM, and any changes they would recommend.

3. Results

3.1. Sample description

3.1.1. Children with leukemia and their parents—Forty-one participants were recruited of 137 approached at five sites. The sample size was limited by institutional factors including fewer children than expected diagnosed with leukemia at one center, and the reticence of staff at another center to approach all eligible families because they were being recruited for multiple studies. Parental factors limiting enrollment included the inability of otherwise eligible parents to understand English and the decision by parents not to expose their children to information from any outside source.

Among the 41 participants enrolled, 31 (14 4–6 year-olds and 17 7–11 year-olds) completed the study. Attrition was due to five families declining post-testing, leukemia relapse in two children, one child who became anxious during pre-testing, a child who lost access to a compatible computer after enrollment, and a child whose learning disability was too severe to complete the instruments.

The racial/ethnic composition of the participants was: 25 Caucasian, 3 Latino, 1 African American, 1 Asian, and 1 Other. All had been diagnosed with ALL and were an average of 2.6 years from diagnosis. Nine children (29%) had completed treatment, and 27 children (87%) had access to a home computer able to play interactive software. The remainder had access to a computer at school, the library, or a friend's home. Primary caretakers had completed an average of 14.6 years of schooling. There was no significant difference between the children randomly assigned to the CD-ROM group and those randomly assigned to the book group on any demographic variable.

3.1.2. Health care providers and other experts—CD-ROM prototypes and evaluation forms were sent to 121 HCPs and other experts. There was a 30% response rate. Thirty-six physicians, nurses, psychosocial personnel, and other experts from all areas of the United States reviewed and evaluated the CD-ROM. Seven physicians – six pediatric oncologists and one palliative care specialist – participated. Almost all nurses participating were Clinical Nurse Specialists or Pediatric Nurse Practitioners specializing in oncology. Other experts included social workers, child life specialists, and organization administrators. Respondents had an average of 14 years experience caring for children with leukemia. Interestingly, 30% of respondents had no prior experience with interactive CD-ROM technology. Nurses represented the highest percent of first-time CD-ROM users (47%); physicians the lowest percent (0%). On average, participants reviewed the CD-ROM for just over one hour.

3.2. Data description: Children with leukemia and their parents

3.2.1. Leukemia children's health locus of control—Fourteen children 4–6 years old and 17 children 7–11 years old completed the 18-itemYes/No Leukemia Children's Health

Locus of Control (LCHLC) instruments at both pre- and post-test. Kuder-Richardson-20 [KR-20] tests for internal reliability indicated 0.73 pre- and 0.85 post-test for the standardized variables, with range 0–18 external to internal control. Table 1 shows the mean LCHLC scores by age group, treatment group, and interview status.

Analysis of Variance (ANOVA) using the General Linear Models (GLM) procedure in SAS on the LCHLC change scores (post-test less pre-test), with main effects treatment group and age group, found a significant change with model $F_{2,28} = 6.38$, R^2 0.33, $p = .004$ and no significant interaction effects. For treatment group, $F = 9.24$, $p = .005$; for age group, $F = 5.45$, $p = .027$. The analyses indicated that in both age groups, compared with the book, the CD-ROM was associated with an increase in LCHLC scores, indicating relatively increased feelings of control over health.

3.2.2. Leukemia event knowledge interview—Interrater reliability was based on the results of two coders analyzing five randomly selected scripts. Agreement [(number of agreements)/(number of agreements + disagreements)] ranged from 84–94%. The number of events ranged from 2–29 in both the pre-test and post-test covering 1–11 superordinate categories. Only two children had an erroneous event statement. Among all children, the ten most commonly stated events accounted for 50% of all stated events (N=701) (Table 2).

There were no differences between the CD-ROM and book groups on the pre- to post-test change scores based on: (1) number of events stated, (2) number of superordinate event categories, and (3) the number of basic level events, erroneous events, spontaneously stated events, and elaborated events. However, for 7–11 year-olds, the changes between pre- and post-test scores were in the expected direction for all variables listed above except the total number of events. In these analyses (ANOVAs with main effects treatment group and age group) both generally and specifically elicited events were entered as data. With only generally elicited events in the model, $F_{2,19} = 2.66$, $R^2 = 0.219$, $p = .096$; for treatment group, $F = 4.93$, $p = .039$. For both age groups, participants in the CD-ROM group had a greater increase in the proportion of basic level events on the post-test than pre-test compared to participants in the book group. This finding supported the comparative efficacy of the CD-ROM by showing that the CD-ROM group had more detailed narratives about leukemia events than the more superordinate, less articulated narratives among the book group.

3.2.3. Satisfaction and use questionnaire: children and their parents—For questions about satisfaction and acceptability, children were asked closed-ended questions such as “Was this computer program easy for you to use?” Only those clearly responding “yes” were counted as an affirmative response. Fisher's exact test was used to determine if differences between subgroups were significant; otherwise, chi square. Of children in the CD-ROM group, 86.7% used their assigned intervention to learn about leukemia compared with 56.3% in the book group (p = .06). Only two children in the CD-ROM group, both 7–11 year-olds, did not use the CD-ROM to learn about leukemia. In the CD-ROM group, 93.3% found their intervention “easy to use,” whereas 68.8% of those in the book group did so (p = .08). Only three of the eight 4–6 year-olds reported they needed help to use the CD-ROM. The groups were similar in their willingness to advise other children with leukemia to use the CD-ROM or read the book.

Parents were asked to respond on a 4-point Likert scale in response to questions about use of their assigned intervention. ANOVA using the GLM procedure found no differences between the CD-ROM and book groups in ease of use for parents, use to get specific information about leukemia, or willingness to recommend their assigned intervention to other parents of children with leukemia. Parents in the book group were more likely to feel that their intervention was not easy for their children to use compared to parents in the CD-ROM group ($p = .01$). The likelihood that the parent received needed information about the child's leukemia, especially general information, was affected more by the age of the child than by the kind of intervention. Parents of 4–6 year-olds in both groups were more likely to get the information they needed about their child's leukemia from whichever intervention they were assigned than were parents of 7–11 year-olds ($p = .04$). More parents of 4–6 year-olds used their assigned intervention to get general information about leukemia than did parents of 7–11 year-olds ($p = .02$).

Children were prompted to answer with a set of responses ("never/once/a few times/many times") to questions about the frequency and length of time they used the CD-ROM or book. More children in the CD-ROM group (93.3%) reported using their intervention independently at least once than did children in the book group (37.5%) ($p = .001$). In the CD-ROM group, only one child, a 4–6 year-old, did not report using the CD-ROM at least once by himself. None of the six children in the book group who reported using the book independently did so "many times" compared with six of the 14 in the CD-ROM group. Overall, parents agreed with their children on how often the children used the materials independently (Spearman's $r_s = .741$, $p < .0001$).

In the CD-ROM group, 73.3% of the children used their assigned intervention for "a long time" each time they used it compared with 12.5% in the book group ($p = .0006$). All eight of the 4–6 year-olds in the CD-ROM group reported that they used the CD-ROM for "a long time" whenever they used it compared with three of the seven 7–11 year-olds in the same group ($p = .026$). Both groups of parents were similar in the duration and frequency with which they used their assigned intervention.

Parents were asked to rank their preferred "methods of getting information about leukemia" and children were asked about their preferred "ways of learning about things." Although these questions address slightly different issues, they were phrased in this manner to elicit the most useful information for designing future educational interventions and validating the choice of a CD-ROM as the medium for this study. The first choice method of learning for 43.3% of parents was being taught by a real person; books were preferred by 30.0%. The first choice method of learning for 41.2% of the 7–11 year-olds was the CD-ROM, but being taught by a real person was chosen by 35.3%. The first choice for 35.7% of the 4–6 year-olds was to learn by video, followed by 28.6% choosing the CD-ROM, and 21.4% choosing audiotapes as their preferred method of learning.

Children and parents were then asked open-ended questions about what they liked and did not like about the intervention they received. Children's positive comments included references to specific content, overall content, and overall format. Their negative comments included references to specific content, aspects of the format (e.g., print size), and inability of the intervention to hold the child's attention. The aspects of the CD-ROM most liked by parents included its user-friendly navigation, appealing format for children, and informative nature. Parents in the book group liked its ease of use and informative nature. The CD-ROM and book were similarly viewed by parents as "very informative." Some parents stated that the games in the CD-ROM were too simple for adults, that graphics needed to be more sophisticated, and that voices used were unappealing to adults. Other negative comments referred to the need for more skill levels and more challenging games for older children. Some parents in the book group thought the drawings were too hard to understand and didn't hold the child's attention. Parents in both groups agreed that the best time to receive educational material is at the time of diagnosis.

3.3. Data description: health care providers

The majority of HCPs agreed that the CD-ROM was an entertaining product, with accurate, complete information about leukemia. They also agreed that it provided useful information for children with leukemia, their siblings, and friends, and agreed, to a slightly lesser extent, that it also provided useful information for parents. Ninety-one percent agreed/strongly agreed that 7–11 year-olds could use the CD-ROM without adult help; only 44% said that 4–6 year-olds could do the same. When asked what they liked and disliked about the CD-ROM, the majority of HCPs described the format as fun and appealing for children, the information on the illness comprehensive and accurate, and navigation user-friendly. Specific positive comments referred to information “given at different age levels in a developmentally appropriate manner,” “reinforced throughout the program,” “presented in a non-threatening manner,” and general enough to be “used by any center in the United States.” Negative comments referred to child-oriented aspects that were unappealing for adults (e.g., voices), not seeing a great deal of difference between user paths, and several content suggested changes based on differing institutional practices.

4. Discussion

4.1. Findings

4.1.1. Significance—This study involved the development and evaluation of a comprehensive, interactive, multimedia CD-ROM to inform children with leukemia and their families about the disease and its treatment. Focus groups were the primary means of defining and refining content and format of the CD-ROM. Involving users in the development process at all stages helped to create a final product that responded to users’ needs and was easy for them to use.

Evaluation used both cross-sectional controls (i.e., CD-ROM vs. book) and longitudinal controls (i.e., pre-and post-testing) to test the effects of the CD-ROM. *Kidz with Leukemia: A Space Adventure* allowed children to self-regulate their use along the dimensions of time (i.e., when used), topic (i.e., type of content chosen to be viewed), and pace (i.e., amount of content viewed at any given time). This interactive multimedia resource was used more often and for longer periods of time than was the book resource.

4.1.2. Children’s feelings of control over their health—Results demonstrated that feelings of control over their health increased relatively more among children who used the CD-ROM compared with those who used a commonly used print educational resource. Older children in both the CD-ROM and book groups showed a more internal locus of control than younger children, a relationship supported by the literature [25–28]. Additionally, internal reliability was excellent even among 4–6 year-olds. In the past, the internal reliability of health locus of control scales among younger healthy children had not been as high as that reported in this study of children with leukemia. Moreover, our findings appear to be the first report of a relative increase in internal locus of control following an educational intervention, in a study using a control group. Some caution must be used in interpreting the findings, however, as inexplicably, the average LCHLC score of the 4–6 year-old children in the book group changed toward the external direction from pre- to post-test, *albeit* not significantly.

4.1.3. Understanding leukemia—There was no significant difference in children’s understanding of events associated with leukemia between the CD-ROM and book groups as measured by the LEKI. However, among the older children, changes in pre- to post-test scores were in the expected direction. Because of the high variance in the small sample of 4–6 year-olds, an increase in sample size should produce more representative findings.

It was hypothesized that an educational intervention that actively engaged children in the process of learning would assist children in actively seeking information about their leukemia from other sources as well. Consequently, the kinds of information assessed by the LEKI may not have been acquired only from the CD-ROM, but from any number of sources, including HCPs, parents, books, or the Internet. Also, no attempt was made to match the information in the CD-ROM to that in the book. Thus, the amount of information is confounded with the intervention medium and may account for differences.

4.1.4. Children's and parents' satisfaction with their assigned educational resource—A higher proportion of the children assigned the CD-ROM were satisfied than were those assigned the book. Four to six year-olds were the most positive in their response to the CD-ROM. Older children may have begun to lose interest in some games or activities in the CD-ROM that did not continue to challenge them. This may have been due to their previous experiences with fast-paced, action-oriented types of CD-ROMs used for games. Even with the possibility of using the book with adult assistance, children used the book for shorter and less frequent periods of time than those who used the CD-ROM. Most children found the content of the CD-ROM to be both accessible and engaging.

A CD-ROM with a flexible information access format can serve as a valuable supplement to traditional methods of informing children about leukemia and complex treatment regimens and need not replace other modes of information. Traditionally, children have been viewed as passive recipients of health care, with little involvement in their treatment and relatively uninformed about their health conditions. Providing independent access to knowledge through CD-ROM technology allows children to become more engaged in the process of learning. When children become more knowledgeable about their conditions, they are empowered and better able to understand and become involved in their treatment. In turn, they may feel a greater sense of control due to their expanded knowledge. As one mother of a 4 year-old participant stated,"[What I liked best about the CD-ROM was] that my daughter loved it and was able to get information about leukemia on her own and be the expert because she could tell me about leukemia."

4.1.5. HCPs' and other experts' satisfaction with the CD-ROM—On all except one item (the ability of 4–6 year-olds to use the CD-ROM independently), HCPs and other experts were very satisfied with the CD-ROM intervention. As one expert stated, "This is a fantastic resource for children with leukemia, siblings, and friends to develop a better understanding of an all too often frightening experience." HCPs underestimated the ability of children, especially those 4–6 years old, to independently use the CD-ROM when compared with the actual independent use described by parents and children in this study. This does not mean, however, that children should always use a CD-ROM like *Kidz with Leukemia: A Space Adventure* by themselves, even if they know how to navigate the program. Based on our findings, we suggest that children use the CD-ROM in the presence of a parent or HCP. This encourages greater exploration of areas of interest or concern and clarification of the child's treatment and reactions to treatment. This may also encourage greater communication between parents and their children, particularly younger children.

4.2. Limitations to generalizability and usefulness

The small sample size and relatively high educational level of the children's primary caregivers (average 14.5 years) are the study's greatest limitations to generalizability. Additionally, the sample may be biased towards families favorably disposed towards using CD-ROM technology. Although families could participate if they had access to a computer at home, school, or a friend's home, home access may have made it more likely that families would consent to be in the study even though they knew they might be assigned the book.

Another potential source of bias might result from interviewers who were not blind to the condition. However, interviewers were blind to the study questions. Also, given the nature of the LCHLC instruments and complex coding of the LEKI, it is difficult to imagine how interviewers biased towards the CD-ROM or the book could have affected the scores.

The study should be replicated in a larger, more diverse sample. The low number of non-Caucasian participants may be due, in part, to a much smaller percentage of Hispanic and African-American households having computers than Caucasian households [33]. Additionally, no children with AML, the less common form of leukemia, evaluated the CD-ROM to determine if it met this population's needs.

4.3. Practice implications

The findings indicate that the CD-ROM is most useful to children and families at the start of treatment. After treatment, however, the CD-ROM can help children recall aspects of treatment they may have forgotten or misunderstood. The CD-ROM uses a variety of media (print, audio, and visual) to meet different learning styles, referring users to additional resources as needed. Although our goal was to meet the informational needs of 4–11 year-old children, the CD-ROM can benefit siblings and peers who would want a better idea of what their siblings or friends are experiencing, as well as school personnel, including school nurses. It may be easier for children with leukemia to share information with siblings or peers in the form of a CD-ROM because this medium is so well received by other children. During development of *Kidz with Leukemia: A Space Adventure*, many healthy children were very interested to see what it contained and to try out the activities.

It has been shown that HCPs tend to overestimate what older children understand about their illnesses and underestimate what younger children understand [34]. During the review of LEKI transcripts, it became clear which children were very aware of what happens to them during treatment, which children specifically avoided answering the questions, and which ones were misinformed. For example, children often used the term “shots” interchangeably as a reference to intramuscular injections, the start of an intravenous line, and needle insertion for a spinal tap. Children, at times, associated “shot” with a procedure using a syringe alone (e.g., a needle-less blood draw from a central venous catheter). Use of the LEKI, as an organized method to help children describe their treatment-related events (e.g., getting chemotherapy, receiving a spinal tap) and their side effects, may be a clinically relevant way of assessing children’s understanding of leukemia to prevent incorrect assumptions by parents and HCPs.

4.4. Recommendations for further research

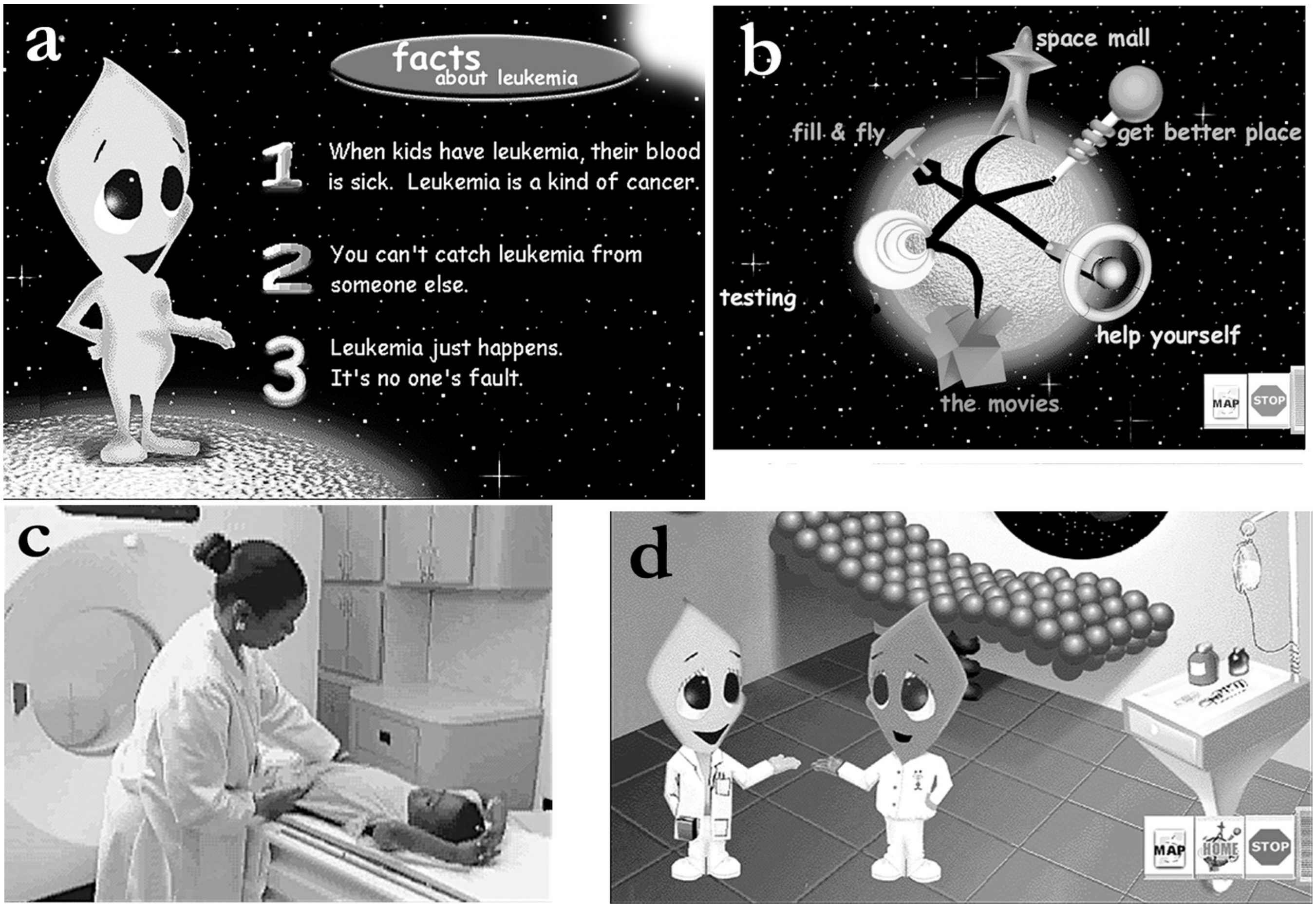
The development of clinically useful educational materials would be enhanced by further studies that systematically track time spent in different sections of an interactive CD-ROM and in the comparison of CD-ROM technology with materials produced by print and video media. It has been assumed, because children might spend more time using a CD-ROM than reading print material on the same subject, those who use computer technology will have greater understanding of the subject [35]. A method tracking use of the CD-ROM was not feasible in the present study, but would have been helpful in evaluating use, format, and content interests.

This study validated effects of the CD-ROM on children’s feelings of control over their health and satisfaction with the learning method. The CD-ROM *Kidz with Leukemia: A Space Adventure* compared favorably with the book, *You and Leukemia*; however, more studies are needed comparing CD-ROM technology with print and video media with regard to how they affect changes in understanding about illness, compliance with treatment, and adjustment. In conclusion, the CD-ROM was found to be a useful, engaging, and empowering tool for children with leukemia that may serve as a model for developing future health-related educational materials.

References

1. American Cancer Society. Cancer facts and figures, 1998. Atlanta: The American Cancer Society; 1998.
2. Miller, BA.; Ries, LAG.; Hankey, BF., editors. SEER cancer statistics review, 1973–1995. Bethesda, MD: National Cancer Institute; 1998.
3. Landis SH. Cancer statistics, 1998. CA Cancer J Clin. 1998; 48:6–29. [PubMed: 9449931]
4. Bush PJ, Davidson FR. Medicines and "drugs": what do children think? Health Educ Q. 1982; 9:113–128.
5. Bush, PJ. Children and medicines. In: Smith, MC.; Wertheimer, AI., editors. Social and Behavioral Aspects of Pharmacy - Implications of Pharmaceutical Care. Binghamton, NY: Haworth; 1996. p. 449-471.
6. Menacker F, Aramburuzabala P, Minian N, Bush PJ, Bibace R. Children and medicines: What they want to know and how they want to learn. J Soc Adm Pharm. 1999; 16:38–52.
7. Bibace R, Walsh ME. Development of children's concepts of illness. Pediatrics. 1980; 66:912–917. [PubMed: 7454481]
8. Perrin EC, Gerrity PS. There's a demon in your belly: Children's understanding of illness. Pediatrics . 1981; 67:841–849. [PubMed: 7232049]
9. Bibace, R.; Schmidt, LR.; Walsh, ME. Children's perceptions of illness. In: Penny, GN.; Bennett, P.; Herbert, M., editors. Health psychology: A lifespan perspective. Langhorne, PA: Harwood Academic Publishers; 1994. p. 15-30.
10. Bearison, DJ. A different approach to medication compliance in pediatric practice; Proceedings of U. S. Pharmacopeia Open Conference, Children and Medicines: Information Isn't Just for Grownups; Reston, VA: 1996 Oct.
11. Vessey J. I've got rocks in my head. Nurs Spectr. 1996; 6:10–11.
12. Slavin LA, O'Malley JE, Koocher GP, Foster DJ. Communication of the cancer diagnosis to pediatric patients: Impact on long-term adjustment. Am J Psychiatry. 1982; 139:179–183. [PubMed: 7055287]
13. Fritz GK, Williams JR, Amylon M. After treatment ends: Psychosocial sequelae in pediatric cancer survivors. Amer J Orthopsychiat. 1988; 58:552–561. [PubMed: 3228162]
14. Bearison, DJ. In: Sigel IE, Renniger KA, volume editors. Child Psychology in Practice. In: Damon W, series editor. Handbook of Child Psychology (5th edition). New York: Wiley; 1998. Pediatric psychology and children's medical problems; p. 635-712.
15. Over 45% of U.S. Homes Had Computers Last Year. Wall Street Journal. 1998 Mar 10.231:B8.
16. You’re Never Too Young To Use A Computer. Youth Markets Alert. 1996; 8:3.
17. Bosworth K, Espelage D, DuBay T, Dahlberg LL, Daytner G. Using multimedia to teach conflict-resolution skills to young adolescents. Am J Prev Med. 1996; 12:65–74. [PubMed: 8909626]
18. Pfefferbaum B, Levenson PM. Adolescent cancer patient and physician responses to a questionnaire on patient concerns. Am J Psychiatry. 1982; 139:348–351. [PubMed: 7058951]
19. Siegler RS. Cognitive variability: A key to understanding cognitive development. Curr Dir Psych Sci . 1994; 3:1–5.
20. Paperny D. Pediatric medical advice enhanced with use of video. Am J Dis Child. 1992; 146:785–786. [PubMed: 1496938]
21. Brown S, Lieberman D. Interactive and video games for health promotion/patient education. Interactive Healthcare Newsletter. 1995; 11:9.
22. Gustafson DH, Bosworth K, Chewning B, Hawkins RP. Computer-based health promotion: combining technological advances with problem-solving techniques to effect successful health behavior changes. Ann Rev Public Health. 1987; 8:387–415. [PubMed: 3555528]
23. Bandura, A. Social Learning Theory. Englewood Cliffs, NJ: Prentice Hall; 1976.

24. Baker, LS. You and Leukemia: A Day at a Time. Philadelphia, PA: WB Saunders; 1988.
25. Parcel GS, Meyer MP. Development of an instrument to measure children's health locus of control. Health Educ Monogr. 1978; 6:149–159. [PubMed: 689889]
26. Bush, PJ.; Parcel, GS.; Davidson, FR. Reliability of a Shortened Children's Health Locus of Control Scale; American Psychological Association Annual Meeting; Washington, D.C.: 1982 Aug. (Poster). (Indexed in ERIC, No. ED 223 354)
27. Bush PJ, Iannotti RJ. A children's health belief model. Medical Care. 1990; 28:69–86. [PubMed: 2296217]
28. O'Brien RW, Bush PJ, Parcel GS. Stability in a measure of children's health locus of control scale. J Sch Health. 1989; 59:161–164. [PubMed: 2785616]
29. Mandler, J. Representation. In: Mussen, P., editor. Manual of child psychology. New York: Wiley; 1983.
30. Nelson, K. Event knowledge: A functional approach to cognitive development. Hillsdale, NJ: Erlbaum; 1986.
31. Schank, RC.; Abelson, RR. Scripts, plans, goals, and understanding. Hillsdale, NJ: Erlbaum; 1977.
32. Bearison DJ, Pacifici C. Children's event knowledge of cancer treatment. J Appl Develop Psychol. 1989; 10:469–486.
33. Pietrucha B. Information, Technology Gaps Widen Among Americans. Newsbytes News Network 7/28/98.
34. Perrin EC, Perrin JM. Clinicians' assessments of children's understanding of illness. Am J Dis Child. 1983; 137:874–878. [PubMed: 6613952]
35. Evans JH, Collier J, Crook I, Garrud P, Harris P, MacKinlay DR, Redsell SA. Using multimedia for patient information - a program about nocturnal enuresis. Brit J Urol. 1998; 81 Suppl:120–122. [PubMed: 9634036]



facts about leukemia

1 When kids have leukemia, their blood is sick. Leukemia is a kind of cancer.

2 You can't catch leukemia from someone else.

3 Leukemia just happens. It's no one's fault.

Figure 1.

Sample screens from Kidz with Leukemia: A Space Adventure. (a) Key facts about leukemia (b) main screen of accessible areas of the program (c) child receiving an abdominal CT scan (d) subscreen for "The Get Better Place" [or treatment area]

Table 1

Mean LCHLC scores by age group, treatment group, and interview status

	Treatment and Interview Status			
	Book		**CD-ROM**	
	Pre-test	**Post-test**	**Pre-test**	**Post-test**
Age 4–6				
N	6	6	8	8
Mean	8.33	6.17	8.25	9.13
SD	2.07	3.87	2.38	3.23
Age 7–11				
N	10	10	7	7
Mean	13.70	13.70	11.14	13.40
SD	2.98	3.53	3.29	3.46

Table 2

Leukemia Event Knowledge Interview: Ten most commonly stated events

Event	**Percent of all stated events (N = 701)**
Administration of sedation prior to lumbar puncture	7.4
Needle insertion for a peripheral blood draw	6.4
Coming to the hospital	6.4
Peripheral blood draw	5.5
Needle insertion during the lumbar puncture	4.7
Staying in the hospital	4.7
Needle insertion for intramuscular chemotherapy	4.5
Administration of intravenous chemotherapy	4.3
Blood draw via external catheter	3.5
Leaving the hospital	2.9