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Impact of Videotaped Information on the Experience of Parents of Children with Acute Lymphoblastic Leukemia

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Abstract

Videotaped information has been shown to be effective in reducing parental anxiety and facilitating knowledge transfer in various clinical settings. There is lack of literature on the use of videotaped information during the pediatric oncology initial family disclosure meeting. The purpose of this study was to deliver an informative DVD, highlighting information on childhood acute lymphoblastic leukemia (ALL), to parents of children with newly diagnosed ALL and to assess if the DVD provided increased levels of satisfaction and decreased levels of anxiety in parents around the time of diagnosis. We surveyed 24 parents of children on active treatment for ALL, diagnosed between the ages of 1 and 18 years from 2008 to 2016 at The Hospital for Sick Children, Toronto, Canada. Parents were provided a survey questionnaire assessing levels of satisfaction with information communicated by the healthcare team and anxiety following verbal disclosure and were asked to report satisfaction and anxiety levels immediately following viewing the DVD intervention. Twenty-three/24 (95.8%) parents surveyed reported seeking information from additional resources after disclosure. Of the 24 parents who watched the DVD, 12 (50.0%) watched it once, while 12 (50.0%) watched it twice or more. All parents were satisfied with DVD information, and there was a significant decrease in anxiety after viewing ($P = 0.03$). All 24 parents felt that the DVD was a useful educational tool. Videotaped information after verbal disclosure is an effective educational resource and is associated with reduced anxiety among parents of children with ALL.

Keywords Childhood leukemia · Cancer diagnosis · Videotaped information

Introduction

The diagnosis of cancer in a child precipitates a state of crisis for a family. Parents must deal with their sick child, the new diagnosis and its implications, and the need to make treatment decisions in a relatively short period of time. Studies have demonstrated high stress levels among parents of children with cancer, particularly around the time of diagnosis and early treatment [1–3]. Information-seeking is a common coping strategy for parents [4] and may provide a sense of control important for engagement with the healthcare team around treatment decisions and in planning for the rest of the family [5, 6].

Oncology teams have established long-standing approaches to delivering information at the time of diagnosis. Providing patients with cancer and their families with an audiotape of the initial consultation has been shown to enhance satisfaction and improve information recall [7–9]. Videotaping of healthcare team family meetings in pediatrics have also been shown to be effective in increasing parental knowledge of infant vaccinations and pain management, to aid in providing informed consent for healthcare trials, and to facilitate parental education and reduce anxiety before pediatric preoperative anesthesia [10–12]. There is a paucity of literature on the use of videotaped information by parents of children with newly diagnosed cancer.

The objective of this pilot study was to provide a professionally produced DVD that included practical disease information and treatment side effects to parents of pediatric patients who were newly diagnosed with acute lymphoblastic leukemia (ALL), the most common childhood malignancy [13], and assess changes in levels of

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satisfaction and anxiety around the time of diagnosis measured pre- and post-exposure to the DVD intervention.

Methods

Ethics board approval was obtained from the Hospital for Sick Children, Toronto, Canada. Eligible participants were English-speaking parents of children with standard-risk or high-risk precursor B or T cell ALL, aged > 1 and < 18 years, diagnosed between 2008 and 2016 at the Hospital for Sick Children. Children were on active induction treatment at the time of parental recruitment for this study. Parents of children with very high-risk ALL (Philadelphia-positive, Hypodiploidy), infant ALL, and mature B cell ALL were excluded due to the DVD not covering disclosure elements, such as therapy-specific components, required for these specific high-risk disease types. A pre-post survey design was utilized to measure satisfaction and anxiety levels around the time of diagnosis disclosure.

Intervention Development

Standard practice of diagnosis disclosure at our institution consists of a verbal discussion between the attending staff oncologist and the affected family of the child with cancer. There is slight variability in the attendance of additional members of the healthcare team at the disclosure discussion, which can include the nurse practitioner or social worker. The DVD was designed as an educational aid for parents of children with newly diagnosed leukemia to supplement verbal information received from the attending physician at the time of diagnosis disclosure. To assist with the intervention development, caregivers of children with newly diagnosed standard or high-risk ALL were approached within 1 month of their child's diagnosis to complete a semi-structured interview with a Clinical Research Assistant (CRA) using the "Pre-Production Parental Information Needs and Satisfaction Survey" shown in Online Resource 1. Twelve English-speaking caregivers consented to participate over a 12-month period. The survey was completed with the CRA over 20–30 min. The CRA took notes and transcribed comments for the open-ended questions included. Parent demographics, patient treatment protocols, and a 5-point Likert scale [14] were used to measure satisfaction with communication at disclosure and the level of anxiety at diagnosis. As part of this survey, parents were asked if they sought out additional disease information from tertiary resources, and what specific information about ALL would they want to see in an educational DVD.

Using the needs assessment feedback from these survey results and available literature at the time, an interactive DVD was developed by a professional production team with direction from two pediatric oncologists (OA and AP), a pediatric psychologist, a pediatric oncology nurse, and two parents as key informants. Two pediatric oncologists (OA and AP) composed the storyboard for the DVD based on the needs assessment of the parent population used in the DVD development process. Revisions were implemented using feedback from physicians, nurses, allied health professionals, and parents. This interactive DVD addressed information needs including, but not limited to, an introduction to ALL with animation figures of the leukemic cells, treatment plans, chemotherapy drugs, and most common side effects; procedures; behavioral changes and emotional reactions related to diagnosis and treatment in the sick child, siblings, and parents; interviews with long-term survivors and parents, as well as support systems and day-to-day activities during and after therapy. The DVD video is 23 min in length, in English with no subtitles, and is now readily available on YouTube (https://www.youtube.com/watch?v=_Mls5TViEhg).

DVD Intervention Assessment

Parents of children with newly diagnosed ALL were monitored for study eligibility and approached by the attending staff oncologist (OA and AP) for participation. Given the nature of this pilot study, a convenience sampling method was used by the staff oncologist for participant recruitment. Staffing changes in the research team during the study recruitment window resulted in participant accrual delays. Upon obtaining written consent, the DVD was provided to parents after the verbal disclosure by the attending staff physician to view at their leisure. Parents were asked to complete a "Post-Production Parental Needs and Satisfaction Survey" (see Online Resource 2) within 1 month of their child's diagnosis. This paper survey was given to parents to take home and was mailed back or submitted in-person to the oncologist in the clinic once completed. Parents were asked the language spoken at home, if they had spoken with a social worker or oncologist at verbal disclosure, and to identify the use of any other tertiary resources used to learn more about ALL at the time of diagnosis. Before viewing the DVD, parents were asked to self-report the levels of satisfaction with the information provided and anxiety experienced following verbal disclosure using a 5-point Likert scale [14]. Satisfaction was measured using the following scale: 1 = "not at all satisfied," 2 = "unsatisfied," 3 = "somewhat satisfied," 4 = "satisfied," 5 = "very satisfied"; whereas anxiety was measured as: 1 = "increased a lot," 2 = "somewhat increased," 3 = "not affected," 4 = "relieved somewhat," 5 = "relieved a lot." Parents were then asked to complete the DVD intervention section of the survey questionnaire after watching the video. Information gathered in this section included the number of times the DVD was watched, overall satisfaction with the information provided on the DVD, topics not covered by the DVD that they wanted to be covered, the usefulness of the DVD, and how the information in the DVD affected anxiety levels. The latter part of the survey was completed after the verbal disclosure section was finished so that each participant acted as his/her own control in determining the effectiveness of the DVD on information satisfaction and anxiety after viewing. Pre- and post-intervention anxiety and satisfaction levels following verbal disclosure and viewing the DVD were measured using the same Likert scale to ensure consistent measurements.

Statistical Analysis

Given the nature of this study, data analysis was predominantly descriptive. Counts and proportions were used to describe categorical data. Due to the relatively small number of subjects in this study, Fisher's exact test was used to test the association between categorical data. The two main outcomes of interest were (1) satisfaction with the information provided in the diagnosis disclosure conversation and DVD intervention and (2) self-reported anxiety levels following verbal disclosure and viewing the intervention. Survey responses from the 5-point Likert scale for satisfaction and anxiety were dichotomized into ≥ 3 and < 3 groupings. Satisfaction scores of 1 or 2 were classified as "unsatisfied" and a 3, 4, or 5 were considered "satisfied." Similarly, anxiety level scores of 1 or 2 were grouped as "heightened" anxiety and a 3, 4, or 5 were considered "relieved." Dichotomization was performed due to the small study sample and to capture the overall change in sentiment for our outcomes of interest, as we were less interested in the degree of response change. McNemar's test using exact methods was then used to test the association between these paired dichotomous data. All *P* values reflect two-sided tests. Analyses were performed using SAS version 9.4.

Results

Thirty-six families of children with newly diagnosed ALL at our institution were approached to participate, of which 30 agreed to take the survey home. A total of 24 of the 30 parents that agreed to take the survey home returned completed intervention assessment surveys (Online Resource 2), representing an 80% response rate. Patient and parent demographics, as well as the informational needs of parents following a child diagnosed with ALL, are shown in Table 1. English was the primary language spoken at home in 17/24 (70.8%) interviewed parents, although all were fluent in English. Primary language spoken at home had no significant influence on the level of satisfaction with the information provided during verbal disclosure ($P = 1.00$) or during the viewing of the DVD ($P = 1.00$), nor on anxiety after verbal disclosure ($P = 1.00$) or after viewing the DVD ($P = 0.46$).

Almost all parents (95.8%) sought information from tertiary resources after verbal disclosure. Among these resources, information from other healthcare team members (83.3%), such as oncologists, nurses, social workers, dieticians, and pharmacists, was most frequently reported. Additional resources include the internet (79.2%), printed materials (75.0%), and families of other children with ALL (62.5%). Information detailing the side effects of chemotherapy (87.5%) and simple explanations of medical terms (83.3%) were most frequently requested as additional information. Reported sources of other resources and the informational needs of parents are shown in Table 1.

After receiving the DVD intervention following verbal disclosure, all parents reported watching the DVD; 12 parents (50.0%) reported watching the DVD once and 12 (50.0%) watched it twice or more. Responses to the survey pre- and post-viewing the DVD are described in Table 2. Immediately following disclosure, a total of 8 of the 24 parents (33.3%) reported that the verbal disclosure heightened their anxiety level (Likert scores of 1 or 2). After viewing the DVD, only 2 of 24 parents (8.3%) reported continued

Table 1 Characteristics of the 24 caregivers who were recruited

Characteristic	Survey responses *N* (%)
Number of patients	24
Caregiver interviewed	
Mother	15 (62.5)
Father	4 (16.7)
Both	3 (12.5)
Information not available	2 (8.3)
Language spoken at home	
English	17 (70.8)
Other	6 (25.0)
Information not available	1 (4.2)
Full verbal disclosure at child's diagnosis	23 (95.8)
Meeting with social worker at diagnosis	23 (95.8)
Use of other resources following disclosure	
Internet	19 (79.2)
Printed materials	18 (75.0)
Other healthcare team members	20 (83.3)
Other families of children with ALL	15 (62.5)
Other	1 (4.2)
Topics requested for additional information	
Visual aids	12 (50.0)
Simple explanations of medical terms	20 (83.3)
More information on the side effects of chemotherapy	21 (87.5)
Changes in daily activities during treatment	17 (70.8)
How to deal with emergencies during treatment	17 (70.8)

Table 2 Parental survey responses following verbal disclosure and DVD viewing

Response	Survey response after verbal disclosure *N* (%)	Survey response after viewing DVD *N* (%)
Number of times viewed DVD		
Once	–	12 (50.0)
Twice	–	7 (29.2)
≥ Three	–	5 (20.8)
DVD Viewed by other family members		
Yes	–	19 (79.2)
No	–	5 (20.8)
Anxiety following receiving information		
Heightened	8 (33.3)	2 (8.3)
Relieved	16 (66.7)	22 (91.7)
Satisfaction with information provided		
Unsatisfied	–	–
Satisfied	24 (100.0)	24 (100.0)
DVD information type		
Worrying	–	–
Not helpful	–	–
Not sure	–	–
Helpful	–	11 (45.8)
Very helpful	–	13 (54.2)
Level of information provided in DVD		
Too much	–	1 (4.2)
Too weak and basic	–	1 (4.2)
Not enough	–	2 (8.3)
Just the right amount	–	20 (83.3)

heightened anxiety levels ($P = 0.03$). Of these two survey respondents who reported no decrease in anxiety levels after DVD viewing, one parent initially reported that anxiety "increased a lot" after verbal disclosure which then decreased to "somewhat increased" after the DVD viewing, while the other parent reported anxiety score remained unchanged after the DVD viewing. All 24 parents reported satisfaction with the information received following verbal disclosure, and all were satisfied with information after viewing the DVD ($P = 1.00$).

All surveyed parents felt that the DVD was a useful tool, with 11 (45.8%) classifying the enclosed information as "helpful" and 13 (54.2%) as "very helpful" (Table 2). Twenty parents (83.3%) thought that the level of information within the DVD was "just the right amount," two thought it was "not enough," one as "too basic/weak," and one as "too much/technical." Six parents (25.0%) hoped for some information that was not included in the DVD, such as "whether cord blood cell storage was useful or not," or "proper handling of all drugs and diapers at home," "more detailed information about treatment protocols, especially after the induction phase," and "more information about coping mechanisms for my child to the medication and anxiety."

Discussion

Our pilot study showed that using a supplemental DVD, which contains important information on various aspects of pediatric ALL, was a useful educational tool for the small group of parents who participated in this study. All parents reported satisfaction with the information provided in the DVD. Anxiety levels reported following verbal disclosure were reduced after viewing the educational DVD ($P = 0.03$), suggesting a positive impact on the emotional distress frequently seen in parents of children with cancer. However, 2 of 24 (8.3%) parents maintained heightened anxiety levels even after watching the DVD intervention. This observation highlights the importance of maintaining an open dialog throughout the clinical course of treatment between the healthcare team and impacted families, ensuring resources are available to assuage the emotional distress of parents during this time.

Using tertiary resources to seek additional disease information was reported by 94% of parents in our study, further supporting the notion that the informational needs of parents are not always met from verbal disclosure alone [15–17]. These needs include information on the diagnosis of ALL, treatment and diagnostic tests, cure rates, caring for their child, emotional impact, side effects, physical impact, coping with painful procedures, and impact on the family [18, 19]. Pacing, consistency, and information provided in a reassuring manner have been identified as important for how information is provided to parents at the time of their child's cancer diagnosis [20]. Providing families of children with ALL with a copy of the DVD allows for the opportunity to view it at their own leisure, in a familiar and comfortable environment. Half of the families watched the DVD twice or more. This flexibility may assist parents' recall of the content of the verbal disclosure, especially during the emotionally stressful time immediately following diagnosis, and may address different learning style preferences of parents and families [21]. Although parents are generally satisfied with the information they receive from their oncology team, many report feeling overwhelmed and have difficulty recalling or assimilating all the information [22–24]. Some studies suggest that more information giving may lead to increased parental anxiety due to information overload [24, 25]. However, parents still consider detailed knowledge at the time of verbal disclosure to be important for decision making [26] and providing an educational DVD video can facilitate knowledge transfer for parents.

Six (25%) of the parents surveyed felt that the DVD intervention was missing information which they hoped would have been included. These topics included the usefulness of cord blood cell storage, handling of drugs and diapers at home, more detailed information about the specifics of induction treatment, and coping mechanisms for their child. Interestingly, these detailed comments suggest that parents had already mined social media and other web-based resources for information and knew what questions needed to be addressed. These observations support the phenomena of an Internet-informed patient in the twenty-first-century which has been well established [27].

Videotaped information for educational use in adult cancer patients has been well studied to enhance patient knowledge, improve satisfaction, and aid in decision making [28, 29]. Previous randomized controlled studies have assessed the impact of a pre-treatment educational video in adult cancer patients and found that participants who watched the video reported lower scores of anxiety and depression, higher information recall of self-care and side effects, while also reporting higher satisfaction with information provided compared to those who did not watch it [30, 31]. However, the use of videotaped information in the pediatric oncology population is limited. Hazen et al. [32] developed a brief 20-min informative DVD for parents of children with newly diagnosed ALL outlining leukemia and explaining informed consent for pediatric randomized clinical trials. Although with only a sample size of 12, 92% of parents reported that the DVD aided in understanding concepts the physician later provided and acted to stimulate them to ask more questions during informed consent conferences [32]. Pediatric cancer disease information is readily available on popular social media platforms, such as YouTube; however, content is typically created by patients or families and seldom is it created by medical professionals or contained useful information [33]. In this study, we present a collaborative effort between physicians, nurses, social workers, and parents to provide an effective informative DVD tailored to caregivers facing their child's cancer diagnosis. Videotaped information grants the opportunity for patients and families to review material as often as is required, aiding in the facilitation of disease knowledge and processes. In pediatric oncology, this videotaped information can also be shared with the patient and family and friends, as an educational tool to explain the illness.

Our study illustrates that the use of an educational DVD about ALL given at the time of verbal disclosure can be an effective ancillary resource for parents of children diagnosed with leukemia. To address the small sample size, conservative statistical tests using exact methods were implemented to prevent type I errors in our analyses. However, the small number of participants and the lack of a control group are limitations of this study and should be considered for future research. In addition, only English-speaking parents were eligible for participation in this study and the socioeconomic status (SES) of each family was not measured. A low SES has been previously linked to a decreased understanding of information during informed consent [34]. If further research is to be done, a more generalized approach must be implemented to include families from diverse backgrounds.

Despite these limitations, our study provides valuable information about the benefits of videotaped information in pediatric oncology and supports the use of digital information to supplement information provided during verbal disclosure.

Compliance with Ethical Standards

Ethics board approval was obtained from the Hospital for Sick Children, Toronto, Canada.

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