Pediatric Cancer CareLink™ –
Supporting home management of childhood leukemia

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Abstract

We conducted a descriptive evaluation of an Internet-based system designed to support home management of childhood leukemia (Pediatric Cancer CareLink™). Twenty-five parents of children with ALL and thirty-four clinicians were interviewed to identify functional requirements and to demonstrate the system's potential to improve the experience and outcomes of children with acute lymphoblastic leukemia (ALL). Parental interviews focused on: medication and side effect management in the home; communication with the health care team; and the use of a computer for ALL home management. Results from these interviews provide strong evidence that parents of children with ALL are struggling to manage the complexity of their children's care in the home. Parents revealed an urgent need for tools that would help them to safely organize the medicines that their children receive while on ALL protocols. Forty percent of parents needed to know more about what to expect during their child's therapy and how to be prepared for it. Clinician interviews focused on the clinical impact and workflow issues associated with such a system. Decision support, prescription refill management, and educational and emotional support functions were considered key components. Clinicians were concerned that such a system would increase their already overburdened workload. Conversely, parents believed that access to such a system would eliminate unnecessary phone calls to the care team. Our findings show that parents would embrace collaborative, Internet-based tools that would help with the home management of their child's leukemia.

Introduction

Acute lymphoblastic leukemia (ALL) accounts for about 80% of the childhood leukemias in the United States and approximately 2500 new cases of ALL are diagnosed in the US each year. [1] The development of effective therapy for children with ALL is one of the undisputed successes of modern clinical hematology-oncology. Fifty years ago, ALL was uniformly fatal, but currently over three-quarters of children with ALL are cured.[2] Current regimens for the treatment of childhood ALL result in high proportions of patients achieving complete remission and long-term, event-free survival.[2,3,4] This extraordinary therapeutic progress resulted from a series of clinical trials that utilized combinations of anti-leukemia drugs, radiation, and supportive measures.

Improvement in outcomes over the last 40 years can be attributed to the development of complex chemotherapeutic regimens. Patients generally receive treatment for two to three years and a significant portion of this therapy is now given while the patient resides at home. Parents who participate in home chemotherapy report that administering the chemotherapy treatments themselves helped them to cope, feel more in control, and encouraged them to learn more about their child's illness and treatment.[5] However, the proper administration of these potentially life-saving medications in the home is a safety issue. Patients and families must learn to manage medications, mitigate side effects, and watch for potential complications while adhering to treatment protocol. Close monitoring and follow-up with the health care team are required for years.[6,7]

In this study we evaluate an Internet-based system, Pediatric Cancer CareLink™, which was designed to support the home management of children with ALL. Our objective was to demonstrate the system's potential to improve the experience and outcomes of children with ALL and their families.

Methods

The Jimmy Fund Clinic at the Dana-Farber Cancer Institute (DFCI) in Boston was our study site. We conducted structured interviews using a convenience sample of volunteers. Eligible subjects were English-speaking parents of the first 50 children with ALL, still alive and in first remission, enrolled on ALL Consortium protocols at DFCI/Children's Hospital

beginning in January 1999. Also included were pediatric oncology clinicians currently practicing in the Jimmy Fund Clinic.

Structured interviews with parents focused mainly on the management of medications administered in the home and the management of corresponding side effects. Essential functional requirements for an Internet-based system to support home management of childhood leukemia were identified. Parents and clinicans were asked whether or not they would be likely to use such a system and whether or not they believed it would provide benefits and advantages to them and their child. In addition, we identified potential barriers to its implementation and use.

Results

Invited parents who choose to participate were contacted by telephone. Table 1 describes the results of our recruitment efforts.

Table 1: Participant recruitment

Parents Invited to Participate	N = 50
• parents using opt out method	N = 18 (36%)
• parents unable to be reached by telephone	N = 7 (14%)
• parents who agreed to participate	N = 25 (50%)
Clinicans Invited to Participate	Clinic staff
• physician participants	N = 15
• nurse participants	N = 17
• psycho-social clincian participants	N = 2

Of the 25 parents who agreed to participate in this study 72% were mothers who stayed at home to care for their child. None of the parents interviewed had less than a high school education, while most of the parents had 4 or more years of college. (Table 2)

Table 2: Parent study participants

Gender		
• Female	N= 18	72%
• Male	N= 7	28%
Educational background		
• Grade School	N= 0	0%
• High School	N= 5	20%
• 2 years College	N= 5	20%
• 4 years College	N= 12	48%
• Graduate School	N= 3	12%

All parents reported having a computer in the home, and 92% of those computers were connected to the Internet. The majority of parents (80%) described themselves as having average or better computer skills. (Table 3)

Table 3: Parent computer skills

Computer in the home	N= 25	100%
Internet access in the home	N= 23	92%
Reported Computer skill		
• No skill	N= 1	4%
• Beginner	N= 4	16%
• Average	N= 12	48%
• Above Average	N= 3	12%
• Expert	N= 5	20%

Parental Interviews
Telephone interviews were conducted with parents whose children were currently enrolled (N=22) in a DFCI ALL protocol, or who had just recently completed the protocol (N=3). The following content areas were discussed during the interviews:
• Medication management in the home
• Side effects management in the home
• Communication with the health care team
• Using the computer for ALL home management

Medication Management in the Home
Parents were asked whether or not they experienced any problems with managing their child's medications in their home. The majority (84%) of parents initially answered no to this question and then went on to elaborate the creative methods that they employed to assist with this rather complex challenge. They described a scenario in which the first few months were particularly difficult as they developed the skills and tools to manage the medication schedule. Many described creating a schedule calendar to help them remember when to take which medicine.

Thirty-six percent of parents reported being less than extremely satisfied with the help they received concerning medication management in the home. (Table 4) We did identify some inconsistency between how clinicians and parents felt about the medication information they received. Clinicians felt good about having provided patients with a comprehensive booklet on medications and side effects during the first clinic visit. They communicated to patients that they should not hesitate to ask if they had any questions at all. While parents were satisfied with the information they were provided, they did express a desire to be better

prepared by the clinical team as to what to expect. One parent exclaimed:

"The doctor would tell me all this stuff about what to watch out for, then I'd get home and it would be 3am and I couldn't remember what he'd said".

One father described his need to take control of the situation soon after his son was diagnosed:

"My wife took charge of the physical needs of our son and I felt like I needed to do something to help. So I used the computer to create a template for the medication schedule. Basically what my wife and I needed was something in a calendar format, so that we could make sure that we gave our son all the medicines he needed and at the right time. We would put this calendar on the refrigerator to double-check what we were supposed to give and then cross it off after we gave it. This way there were no mistakes or missed doses."

This theme, the need to have a visual aid of the schedule, was repeated many times in our interviews. One mother looked at it from another perspective:

"Basically my life took on meaning in 3 week chunks. I managed day to day, but thought ahead in three-week chunks. What did I need to do, what did [my son] need to do in the next three weeks? What would have been helpful to me was each time my son entered a new cycle if I could have had a calendar of what to expect and what to do in those three weeks"

Table 4: Parental level of satisfaction with help received for medication management in the home

Not satisfied at all	1	N=0	0%
	2	N=0	0%
Satisfied	3	N=2	8%
	4	N=7	28%
Extremely Satisfied	5	N=16	64%

Side Effects Management in the Home
Parents seemed to have more difficulty managing the side effects of medication than with the administration of the medicine. Forty percent of parents reported being less than extremely satisfied with the help they received with managing their child's side effects in the home. (Table 5) Parents expressed the need to know more about what to expect while taking certain medicines and then how to be more prepared with dealing with whatever occurred. Comments such as "kind of wish I knew what to expect", "no one told us what to expect when we first came home from the hospital", and "I referred to a book to see if she was having a side

effect or if she was getting sick" were the most commonly heard themes.

Parents purchased reference books in addition to the teaching sheets that were provided by the care team. One mother explained, "There was not enough instruction. I needed more than the basic information; I felt it was up to me to learn what I needed to know. If you wanted to know, you needed to read it for yourself". Some parents said they would benefit from a reference about potential side effects with commonly asked questions and answers, perhaps developed by "veteran" parents.

While some parents felt "bad" about calling the clinic with questions, most described needing to be proactive with staff around side effects. When asked how managing side effects of medications in the home might be made easier one parent suggested, " a list of all the types of supplies that you could possibly need. Its frustrating to find out your child needs something that isn't available until the stores open in the morning." The notion that veteran parents impart their experiential knowledge in some way to the newcomers was repeated many times. One parent stated:

"The doctors and nurses know their part so well that sometimes I think they forget that we are new to this and don't know anything. They know how to prescribe the medicines, but they can't help me get my child to take it when it tastes bad and she's nauseous anyway"

Table 5: Parental level of satisfaction with help received for side effects management in the home

Not satisfied at all	1	N=0	0%
	2	N=0	0%
Satisfied	3	N=6	24%
	4	N=4	16%
Extremely Satisfied	5	N=15	60%

Communication with the Health Care Team
The current method of communicating with the health care team is phone and voice mail based. Depending on the acuity of the problem, parents reported that a physician or nurse would call them back within minutes or hours. Forty-four percent of parents described this method as less than extremely satisfactory. When asked to describe how communication with their care providers might be improved, some parents suggested that email would be very helpful for those questions that did not require an immediate response. In this way they could reserve phone calls for urgent situations

One parent explained that she would call the doctor, who would call back "right away", but felt that if the information were available in some other way she wouldn't have had to "bother" the doctor. Many other parents echoed this theme: that they often had questions that they did not want to "bother" the doctor with and that email would be more appropriate for this type of inquiry.

Using the Computer for ALL Home Management

Parents were asked how often they used the Internet to find ALL related information. Thirty-eight percent of parents said they used it at least weekly in the few months after diagnosis and that this frequency diminished with time. Of the 25% of parents who did not use the Internet to locate ALL information, they reported either not understanding the information or being frightened by the negativity of what they found. When asked if they had concerns about the privacy or security of their information on the Internet, 20% of parents said they did.

Parents were asked if they thought they might use the computer to perform such tasks as keeping a diary related to the management of medications and side effects and 56% reported that they would. Of the parents who said that they would not use such a tool, the reasons ranged from a lack of time, to feeling overwhelmed with what they already have to do.

Clinician Interviews

Interviews with clinicians were done using both individual and focus group methods. The following content areas were discussed with clinicians.
- Using the computer for ALL home management
- Work flow issues
- Integration of web based tools with existing CIS

Using the computer for ALL home management

Clinicians were asked to describe their functional requirements for an Internet based system to support home management of childhood leukemia. Clinicians identified three areas of clinical importance; decision support, prescription refill support and educational and emotional support.

Decision support was seen as an essential component. An online patient assessment, which could result in the early detection of side effects, was considered to have the potential to improve clinical outcomes for these patients. One clinician suggested that collecting information through a patient's daily journal or through a structured assessment might also help to identify a newly recognized side effect. Barriers to successful implementation of decision support would be the inconsistent use of the system by the parents.

Prescription writing and refill management was identified as very desirable in this type of system. The physicians suggested that prescription writing be tied to the entry of a new medication into the patient's medication list and that this would insure the integrity of the medication list.

Educational support was considered by all clinicians interviewed to be the strength of an Internet based support tool for ALL home management. Having credible, timely, and relevant ALL content delivered from DFCI to the patient was considered a positive benefit by all clinicians interviewed. It was suggested that using Cancer CareLink to deliver information on upcoming tests might help parents and patients to be better prepared. There was some concern as to how to fit the work of delivering this content into the current processes, but no one denied that it would be beneficial to the patient.

Emotional support was discussed during interviews with the psychosocial clinicians. These clinicians suggested that Pediatric Cancer CareLink might enhance emotional support services by improving communication of upcoming programs. They also suggested that using this system to help evaluate pain management in the home would be invaluable.

Workflow issues

Interviews with physicians and nurses revealed concern for how their current workflow process might be affected by adding a new communication media into the clinic. Their concerns included finding the time to log onto the computer and the generation of additional work.

Finding time to log onto a computer seemed to be a universal concern. Clinicians were concerned that there would not be enough time in their day to "check the computer for patient emails". The current voice mail system, in their view, was sufficient to meet their communication needs. Clinicians were also concerned about the potential for an unacceptable time delay between electronic messages arriving and clinicians reading them. There was also concern from clinicians that this type of an application would increase contact from families thereby increasing their already overburdened work schedule.

Integration of web based tools with existing CIS

Clinicians expressed the need to have Pediatric Cancer CareLink integrate with the existing Clinical Information System (CIS). In this way medication information updated in the CIS would automatically be updated in CareLink. Also lab data in the CIS could be made available to the patient's CareLink.

Discussion

The results of our study have provided very strong evidence that parents of children with ALL are struggling to manage the complexity of their children's care in the home. Our interviews demonstrated that parents have been very creative in finding ways to adapt and cope with the challenges with which they are faced. They clearly expressed an urgent need for tools that would help them to organize the care needs of their child in the home. Parents are also very concerned about the early and appropriate detection of medication side effects.

Parents and clinicians were forthcoming concerning the functional requirements of an Internet based ALL support system. Parents requested up-to-date, personally relevant, easily accessible information. Most parents agreed that having relevant information on their child's personal Cancer CareLink, to be available to them at the time when they were ready to hear it and when they most needed it, would be highly beneficial. This is consistent with previous work, which demonstrated that web based education used by patients at a time that was most convenient and relevant to them would in fact improve their clinical outcomes.[8,9,10,11] Clinicians in this study agreed that educational support for patients was a major benefit of an Internet based support system.

In addition to educational support, access to protocol driven, personalized, medication schedules; a medication administration record; and decision support tools that recognize and report medication side effects, was highly valued by both parents and clinicians.

In this study our sample size was small and potentially non-representative. Parents in this study were better educated and had greater computer access than does the general population.[12] Gustafson has shown that computer and Internet based information in cancer care can have greater measurable effects on health outcomes in less educated populations.[13] However, our study population, while well educated, was still information needy and their information needs were not totally served by the clinical staff.

While both parents and clinicians agreed on the benefit of Internet based educational support and protocol driven medication schedules, there was a disconnect concerning the consequences of using an Internet-based support system. Clinicians voiced concern that Pediatric Cancer CareLink would increase their workload by increasing contact with, and information from, their patients. Our parent interviews suggest just the opposite. By providing parents with alternative information sources, such as a secure messaging center, FAQs written by veteran parents, and up-to-date educational support, parents felt they could reserve phone contact for more urgent situations, thereby reducing unnecessary phone calls to clinicians.

Businesses outside of healthcare embrace "collaborative technology" to improve customer relations and business performance. [14] Our findings demonstrate that parents would embrace tools of collaboration that would help them with the home management of their child. However, it is important that particular attention be focused on clinician workflow in order to gain widespread professional acceptance.

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