

Electronic Personal Health Records for Childhood Cancer Survivors: An Exploratory Study

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Purpose: Childhood cancer survivors have complex healthcare needs that may be effectively communicated using electronic personal health records. This study explores the knowledge, interest, and attitudes of a sample of survivors and some of their caregivers towards electronic personal health records (ePHRs).

Methods: This descriptive study was conducted in a pediatric hematology-oncology clinic and associated survivorship clinic with a convenience sample of caregivers of survivors who were <14 years old and survivors ≥14 years old along with their caregivers when present. A semi-structured interview was conducted with survivors and some caregivers to understand their knowledge, interest, and attitudes towards adoption of ePHRs.

Results: Interviews were completed with 11 caregivers of young survivors, four survivors alone, and five survivor-caregiver dyads. Survivors ranged in age at diagnosis from 1 to 17 years old. Among the ethnically diverse sample, approximately half of the nine survivors and 25% of 16 caregivers reported having some knowledge of ePHRs. Eighty-nine percent (8/9) of the survivors and 81% (13/16) of the caregivers reported that they were somewhat or very comfortable using the internet. All nine survivors and 75% of caregivers were interested in the adoption of ePHRs. Data security and privacy were the primary concerns expressed.

Conclusions: Interest in adoption of ePHRs to manage cancer survivorship-related health information was high. Most felt that the privacy and security concerns would not prevent adoption. Additional research is needed on larger and more representative samples of survivors to understand what types of support and education are needed to effectively implement ePHRs.

Keywords: survivorship, cancer care continuum, health information technology, electronic personal health records, attitudes

DESPITE GREAT SUCCESS IN THE TREATMENT of childhood cancer, many of the treatments contribute to the development of chronic health problems in early adulthood and beyond.¹ As a result, lifelong risk-based medical surveillance is recommended with the goal of decreasing premature morbidity and mortality. Medical surveillance is ideally guided by an individualized survivorship care plan. Development of a care plan requires access to accurate diagnostic and treatment information. Once treatment exposures are summarized, a knowledgeable healthcare provider can refer to the Children's Oncology Group (COG) Long-term Follow-up Guidelines for screening recommendations that align with each treatment.² Typically, care plans are not generated until survivors visit a specialized follow-up program. The care plan is intended to facilitate communication between survi-

vors and healthcare providers in addition to providing a roadmap for ongoing healthcare.³

Despite recommendations, most pediatric cancer survivors transition from oncology care without a survivorship care plan, adequate knowledge of their health risks, or basic information about their treatment exposures.^{4,5} Too often, this critical health information remains within the pediatric oncology setting and is never communicated to primary healthcare providers.³ Identifying effective approaches to managing and conveying health information across the fragmented healthcare system could facilitate communication between specialists, primary care providers, and survivors, which may translate into improved survivorship care.³

Electronic personal health records (ePHRs) offer one approach to managing the health information of childhood

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cancer survivors.⁶ ePHRs are distinguished from electronic health records in that survivors themselves—rather than the healthcare system—control or personally manage the information and decide with whom to share the information. In addition, ePHRs are available in a secure electronic form accessible through the internet. A final advantage of ePHRs over paper documentation is that they can be maintained as a living document that is updated throughout the survivor's life as health issues arise and/or new knowledge emerges. Currently, only 7% of adults in the United States have an ePHR,⁷ although there is widespread recognition of their potential benefit.

Attitudes and adoption of ePHRs vary by the population studied. For example, a study conducted with low-income elderly individuals found limited adoption of ePHRs when offered without any human support. However, primary barriers to use were low computer literacy, discomfort with the internet, and limited health literacy, which were over-

come for many by offering in-person assistance for using the ePHRs.⁸ In a more general sample, individuals who were physically ill but not disabled utilized medical-related computer resources 19% more often than non-disabled healthy users.⁹ Many studies suggest that ePHRs are well-suited to individuals with chronic illnesses and that satisfaction is high.^{6,9,10}

To our knowledge, the use of ePHRs has not been formally explored in childhood cancer survivors. Exploration is justified by the fact that contrasted with chronic childhood illnesses for which the health problem is often a part of the clinical visit, most childhood cancer survivors do not develop a chronic health problem until years after the cancer treatment is complete. By the time chronic health problems present, most survivors are older and seeking care only in the adult primary care setting, where their cancer treatment is rarely discussed in detail.^{5,11} As a result, we questioned whether or not survivors and their caregivers would be

TABLE 1. DEMOGRAPHIC CHARACTERISTICS OF THE SURVIVORS AND THEIR CAREGIVERS BY PARTICIPANT GROUP

	<i>Survivors only, n=4 Mean ± SD</i>	<i>Survivor and caregiver dyads, n=5 Mean ± SD</i>	<i>Caregivers only,^a n=11 Mean ± SD</i>
Current age (years)	27.0 ± 10.2 range: 18–39	15.8 ± 2.0 range: 14–19	7.3 ± 4.3 range: 2–13
Age at diagnosis (years)	5.5 ± 7.7 range: 1–17	8.7 ± 4.7 range: 4–16	3.4 ± 4.2 range: 0.01–12
	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>
Survivors' gender			
Male	2 (50)	4 (80)	4 (36)
Female	2 (50)	1 (20)	7 (64)
Survivors' race/ethnicity			
African American	3 (75)	0	2 (18)
White, non-Hispanic	1 (25)	2 (40)	5 (46)
White	0	3 (60)	4 (36)
Survivors' education			
Less than high school	0	4 (80)	11 (100)
High school graduate or equivalent	4 (100)	1 (20)	0
College graduate	0	0	0
Survivors' cancer type			
Leukemia	0	3 (60)	4 (36)
Retinoblastoma	2 (50)	0	3 (27)
Sarcoma	0	1 (20)	2 (18)
Lymphoma	1 (25)	0	1 (9)
Wilms tumor	1 (25)	0	1 (9)
Medulloblastoma	0	1 (20)	0
Type of caregiver			
Mother		4 (80)	9 (82)
Father		1 (20)	1 (9)
Other		0	1 (9)
Caregivers' race/ethnicity			
African American		0	2 (18)
Hispanic		2 (40)	5 (46)
White, non-Hispanic		3 (60)	4 (36)
Caregivers' education			
Less than high school		0	3 (27)
High school graduate or equivalent		3 (60)	8 (73)
College degree		2 (40)	0

^aCaregivers' report on their children's demographics.
SD, standard deviation.

interested in ePHRs or perceive that ePHRs provide any direct benefit. Furthermore, caregivers manage much of the health information for younger survivors and little is known about their interest in ePHRs to assist in this process. Successful adoption of ePHRs could significantly diminish the effort required to ensure that survivors' medical records and care plans transition to subsequent care.

This exploratory study aimed to characterize the knowledge, interest, and attitudes of a sample of childhood cancer survivors and their caregivers towards ePHRs. Responses were considered in the context of participants' current internet literacy and access to computers or smartphones.

Methods

Recruitment

A convenience sample of childhood cancer survivors and caregivers of childhood cancer survivors was recruited from a pediatric hematology-oncology clinic and its associated childhood cancer survivorship clinic. Both clinics are located in an academic medical center in the United States. The survivorship clinic, directed by a physician with combined medicine and pediatric training, cares for survivors regardless of age. At the time of the study, patients did not have access to any type of ePHR through the medical center.

Survivors were eligible for this study if they: had been diagnosed with any childhood cancer prior to the age of 18, were at least 3 months post-cancer treatment completion, and provided appropriate consent or assent for those younger than age 18 at study. For survivors who were less than 14 years of age at study, only their caregivers were offered participation with no lower age cutoff. Both survivors and their caregivers were offered participation if a survivor was 14 years or older with no upper age cutoff. Written informed consent or assent was obtained from all participants and the study had approval from the University of Illinois at Chicago's Institutional Review Board. The research assistant was bilingual in English and Spanish, although all participants chose to complete the interview in English.

Interview content

Participants completed a single semi-structured interview, developed for this study, which included demographic questions. Survivor-caregiver dyads completed separate interviews. Caregivers of survivors younger than 14 years old provided demographic information on their child. An initial draft of the interview was pilot tested on three healthcare professionals and two survivors for face validity and clarity. A brief definition of ePHRs was refined with input from four respondents in a pilot phase. For study purposes, we used

TABLE 2. REPORTED USE OF AND ACCESS TO THE INTERNET BY SURVIVORS AND THEIR CAREGIVERS

	Survivors only, n = 4	Survivor and caregiver dyads, n = 5 n (%)		Caregivers only, ^a n = 11
	n (%)	Survivor	Caregiver	n (%)
<i>How comfortable are you with using the internet?</i>				
Do not use internet	0	0	1 (20)	2 (18)
Not comfortable	0	1 (20)	0	0
Somewhat comfortable	1 (25)	1 (20)	1 (20)	1 (09)
Very comfortable	3 (75)	3 (60)	3 (60)	8 (73)
<i>What do you usually use to access the internet?</i>				
Computer	1 (25)	3 (60)	3 (60)	3 (33)
Telephone	0	0	0	1 (11)
Computer and telephone both	3 (75)	2 (40)	1 (20)	5 (56)
<i>Do you have access to the internet on a computer in your home?</i>				
Yes	2 (50)	2 (40)	2 (40)	2 (22)
<i>Do you own a cell phone with internet access?</i>				
Yes	2 (50)	4 (80)	2 (40)	7 (64)
<i>Do you access the internet any places other than home?</i>				
Yes	2 (50)	3 (60)	4 (100)	7 (78)
<i>If yes, where?^b</i>				
School	1	3	2	2
Work	0	0	2	4
Library	1	1	1	1
Other	0	0	0	1
<i>How often do you use the internet?</i>				
Every day	1 (25)	2 (40)	4 (100)	6 (67)
Almost every day	0	1 (20)	0	2 (22)
2-3 times per week	2 (50)	1 (20)	0	1 (11)
Once per week	0	1 (20)	0	0
Less than once per week	1 (25)	0	0	0

^aCaregivers' report on their children's demographics.

^bMore than one response was allowed.

a general definition of an ePHR as “an electronic file with information on you or your child’s health that you can control and get into from the internet.” The final 15-item interview (excluding demographic questions) was comprised of seven closed-ended questions that assessed if the respondent used the internet, and if so, with what level of comfort. Internet users were further queried regarding the locations and frequency in which they accessed the internet, their access to the internet on a home computer, and ownership of a cell phone with internet access (i.e., a smartphone). Knowledge, attitudes, and concerns related to ePHRs were assessed with four closed-ended questions, each followed by an open-ended question asking for further information. Interviews were audio-recorded and subsequently transcribed. Participants were each reimbursed \$10 for their time.

Data analyses

Transcripts were independently reviewed by two investigators (LKS and PC) as each interview was completed to identify problems and evaluate for response saturation. Responses to open-ended items were coded by the two investigators independently and reviewed with no discrepancies. Descriptive analyses were performed on quantitative data using SPSS version 19 (IBM Corp., Armonk, NY). Tables 1 and 2 present results separately for the three groups of respondents, while discussion in the text groups all survivors ($n = 9$) and all caregivers ($n = 16$).

Results

Participants

Interviews were completed with four childhood cancer survivors alone, 11 caregivers of childhood cancer survivors younger than 14 years old, and five survivor–caregiver dyads who each completed a separate interview. There were no refusals. As shown in Table 1, survivors who were interviewed without a caregiver were the oldest, ranging from 18 to 39 years old. Those interviewed with a caregiver were slightly younger, ranging from 14 to 19 years old. Combining the survivors who were interviewed alone and those interviewed with a caregiver, six of the nine were male, and six of the nine self-identified as African American or Hispanic. A range of cancers were represented, and most caregivers were mothers. As reflected in the population served by the medical center, caregivers had limited formal education, with only 13% (2/16) reporting education beyond a high school diploma or equivalent.

Internet literacy and access to the internet

As shown in Table 2, 89% (8/9) of all survivors and 81% (13/16) of all caregivers reported being somewhat or very comfortable using the internet, suggesting high levels of internet literacy in the group. Two Hispanic mothers with less than a high school diploma or equivalent did not use the internet. Similarly, one White, non-Hispanic mother with a high school education did not use the computer and her 14-year-old son (diagnosed with medulloblastoma at age 5) was not comfortable using the internet. None of these three families had internet access. Fifty-six percent (9/16) of caregivers and 67% (6/9) of survivors owned a smartphone.

Knowledge of electronic personal health records

After providing a general description of an ePHR, participants were asked if they had prior knowledge of one. Fifty-five percent (5/9) of survivors reported any knowledge of ePHRs. Fewer caregivers—25% (4/16)—reported any knowledge of ePHRs.

Interest and attitudes toward use of electronic personal health records

All survivors and 75% (12/16) of caregivers expressed interest in adopting an ePHR. Many respondents spontaneously mentioned that they would need someone to show them how to use the tool first. The most common perceived benefit related to confidence that the health information would not be lost or that it would be easier to find because of a centralized location that increased accessibility when needed. Examples of these responses were:

“If an accident happens and they are not able to get here then doctors elsewhere could still have access to his records.” Mother of a 4-year-old son who was diagnosed with acute lymphoblastic leukemia (ALL) at 3 years old

“It would be good because everything is together. I could print things out for the doctor and the communication would be faster. Also, it would provide information for my daughter when she gets older to share with teachers and doctors.” Mother of an 11-year-old daughter who was diagnosed with ALL at 3 years old

“I am not afraid and don’t hide anything. I have two insurances (for my son) and we have to see multiple doctors so it would actually be better to keep all of his records together and updated. My son is going to college and if something happens, it would be much easier to have all of his records.” Mother of a 16-year-old son who was diagnosed with acute myeloid leukemia (AML) at 4 years old

When asked about any concerns regarding the use of ePHRs, 77% (7/9) of survivors and 50% (8/16) of the caregivers denied having any concerns. Among those who offered concerns, data security and privacy were the most common. Examples of these comments were:

“It depends on the security so I would need to have some type of username and password.” (32-year-old female survivor diagnosed with retinoblastoma at 18 months old)

“I know what a personal health record is and I would not want my child to have one—period. I am concerned with all types of hackers and the information they can get. I do not want one period.” Mother of 3-year-old daughter who was diagnosed with retinoblastoma at 3 months old

“I am worried that my computer might crash and I would lose the information because I did not back it up.” Father of a 14-year-old son diagnosed with ALL at 10 years old

“I could see it might be a problem if insurance got into the record and denied future coverage. I would want to look into it first and then proceed with caution.” Partner of the mother of a 13-year-old son diagnosed with osteosarcoma at 12 years old

Among those with privacy concerns, 67% of survivors and 80% of caregivers stated that the concern would not prevent them from using an ePHR, as they felt that the benefit outweighed the risks.

Respondents were asked how they would feel about entering medical information, such as treatments received, into the ePHR. Seventy-eight percent (7/9) of survivors and 88%

(14/16) of caregivers reported that they would be comfortable entering information in their ePHR. Four caregivers commented specifically about the time it might require to enter the information in the record, as expressed by one caregiver:

“I think it might be time consuming to enter the information...but some patients might want to review information in the medical record to make sure everything is there.” (Partner of the mother of a 13-year-old son diagnosed with osteosarcoma at 12 years old)

Despite expressing comfort, 67% (6/9) of survivors and 75% (12/16) of caregivers actually preferred the doctor to enter the information into the record. The most common concern was “difficulty understanding” or “discomfort with medical terms” as expressed by one mother:

“I would feel more secure if all doctors used a centralized record and could see the health information. So I see that benefit but why would a doctor trust what I put in—the information I put in. I am also worried about the medical language and the outcome if I use different terminology.” (Mother of a 4-year-old son diagnosed with ALL at 3 years old)

Discussion

In this exploratory study of childhood cancer survivors and caregivers, roughly half of the participants reported having some familiarity with the concept of ePHRs as a tool for managing health information. Overall, interest in adopting ePHRs was high, with negative attitudes centered most frequently upon safety and privacy concerns. Additional concerns focused upon the ability of individuals to accurately record their own health information in ePHRs and the potential adverse impact of communicating inaccurate information that the patient and/or caregiver may have entered. Only two caregivers reported that their concerns would prevent them from adopting an ePHR.

Similar results were noted in a US survey, conducted in 2009–2010, assessing attitudes toward health information technology in a representative sample of adults. Seventy-five percent of the 1583 ePHR non-users reported privacy concerns as a possible barrier to adoption. Despite those concerns, 57% reported that they “would or might sign up” if they trusted the organization that provided the ePHR.¹² We could not find an empirical study investigating the adoption of ePHRs, however, a study conducted with adult primary care patients in three large healthcare systems showed that expressed concerns regarding privacy at baseline did not prevent patients from accessing their health information online through a hospital-sponsored electronic health record during the subsequent year. In fact, 99% of patients in that study wanted continued access to the electronic health records following the study, regardless of their privacy concerns.¹³

Our finding of participants’ high level of interest in using an ePHR was notable considering the ethnic diversity and limited educational attainment of the sample. Some prior research on ePHRs suggested that underserved populations may be hesitant to adopt these tools because of limited internet literacy.^{14–16} However, the widespread use of smartphones has exponentially increased among ethnic minority groups,¹⁷ making ePHR adoption feasible for many. Over half of survivors in our study had accessed the internet on

both a computer and a smartphone, with somewhat fewer caregivers having similar access.

The potential benefits of patient-managed electronic health records for cancer survivors are appealing. Lifelong medical surveillance begins with the diagnostic details and treatment exposures provided to cure the original cancer. Once a care plan is developed, this information needs to be conveyed to subsequent providers, who may or may not share interoperable electronic medical record platforms. Subsequent test results and health issues may require modification of the care plan, suggesting that a dynamic or “living” document is required. At this time, survivors and their families remain a critical link in transmitting health information across providers and healthcare systems.

Results of this exploratory study must be interpreted with caution as it included a small, non-representative sample of survivors (i.e., age, cancer types, and time since treatment completion) seen within one academic medical center. Retinoblastoma was over-represented because of local specialization in this disease. Despite limitations, our results add to emerging evidence suggesting that childhood cancer survivors understand the potential value of having a treatment summary and care plan when offered appropriate education. A study conducted with 111 privately-insured adolescent and young adult cancer survivors who completed a long-term follow-up visit at Memorial Sloan Kettering Cancer Center found that 83% of participants felt that receiving a paper copy of their treatment summary and care plan was moderately or extremely valuable.¹⁸ In addition, 95% expressed that they understood the information on their treatment summary and care plan. When queried about other formats, 95% of the participants expressed interest in an online or wallet card with their treatment summary and care plan.¹⁸ The results of this study, combined with our current study, suggest that survivors may appreciate the value of having an ePHR. However, having an ePHR is only beneficial if survivors share it with healthcare providers who then in turn integrate the information into the survivor’s care. One may presume that survivors who understand and value the information housed in an ePHR would be more likely to share the information. However, additional research is needed to test the hypothesis that receipt of follow-up care is increased when ePHRs are provided to survivors. Survivors may need additional guidance on how to communicate with physicians who may have little knowledge of survivors’ unique healthcare needs.

Conclusion

In conclusion, ePHRs show promise to facilitate the management and communication of complex health information that is relevant to childhood cancer survivors and their families. This exploratory study is among the first to assess ePHR use in the context of childhood cancer with an ethnically diverse sample. Attitudes and interest in adopting ePHRs in childhood cancer survivors and their caregivers were generally favorable, suggesting that efforts to promote ePHRs among this population may be welcomed. Privacy and security concerns are likely to be a common barrier; although younger survivors may be less concerned. Moving forward, it is important to understand how survivors and their caregivers actually use ePHRs to manage and communicate health information.

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Disclaimer

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