Survivors of pediatric cancers: How much do they know?

As more children survive pediatric cancers, oncology nurses are challenged to learn about past cancer histories from uninformed adult patients.

GETTY IMAGES

SHARIFA AL-QAAYDEH, MS, RN

More than 10 million cancer survivors currently reside in the United States, and 270,000 of these survivors received their diagnosis before age 21 years.[1] Moreover, almost 80% of children who had cancer are still alive 5 years after diagnosis.[1] Successful treatment of childhood cancers has introduced newfound struggles. Many adult survivors of childhood cancers are now at increased risk for numerous physical, emotional, psychological, social, financial, and other long-term effects, known as late effects, of cancer treatment.[2] These late effects increase both morbidity and mortality in adult survivors of pediatric cancers. The three most frequent causes of increased mortality are heart damage, relapse, and secondary neoplasms.[3] The most common effects of treatment that increase morbidity are sexual dysfunction, cardiovascular disease (CVD), psychosocial impediments, financial strain, endocrine difficulties, secondary malignancies, and neurologic dysfunction.[3]

The importance of addressing what adult survivors know about their childhood cancer diagnosis and treatment is magnified because more children are surviving cancer than ever before. These effects are becoming more evident, and an understanding of what adult survivors know about their childhood cancer is crucial to caring for these patients.[4] However, the literature shows a limited number of studies address this aspect of cancer care, and many studies that do failed to investigate what survivors know about the screenings and follow-up care they should be receiving.

THE CLINICAL SITUATION

Adult survivors of childhood cancers are at a unique disadvantage compared with survivors of adult cancers. Children with cancer often do not have control of their care, as decisions are made by their caregivers. In addition, many survivors were too young to understand the diagnosis, medications, or other treatments they received. This limited understanding leads to problems as survivors reach adulthood and seek general practice providers for their health care needs. Many health care providers do not know what follow-up and screenings are needed for this patient population.[5]

The purpose of this review is to evaluate what adult survivors of pediatric cancers know about their medical history, and to determine if adult survivors know what screenings and follow-up care are needed based on their risk for late effects. This article uses the National Cancer Institute (NCI) Dictionary of Cancer Terms definition of late effects:

> **late effects** Side effects of cancer treatment that appear months or years after treatment has ended. Late effects include physical and mental problems and second cancers.[6]

COG GUIDELINES

The Children's Oncology Group (COG) published *Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers* on its website and in various publications.[7] These guidelines provide information about what follow-ups and screenings are indicated based on the survivor's risk. The guidelines not only help survivors, but also general practice providers who may have limited experience with pediatric oncology treatments. The guidelines are evidence-based and were developed by a multidisciplinary team of pediatric oncology experts from around the world. However, if survivors are unaware of their own medical history, they will be unable to find what guidelines they should be following. They will also be unable to relate this information to their health care providers, which is a critical step in preventing complications.[8]

OVERVIEW OF THE LITERATURE SEARCH

The following objectives guided the review process: (1) determine what adult survivors can recall about their medical history, (2) evaluate adult survivors' knowledge about risk-based follow-up guidelines, (3) identify what information is lacking in the literature and propose future research, (4) discuss the implications for nursing.

Databases The electronic databases PUBMED and CINAHL were used to identify which studies meet the inclusion criteria. All date ranges were searched to include any historical articles on the topic. Key phrases were "pediatric cancer survivors and knowledge," "knowledge of late effects," and "adult survivors of pediatric cancer and knowledge."

Inclusion criteria Participants were survivors of childhood cancer and older than 18 years at the time of the study. The survivor was the informant of the medical history and follow-up care. All the articles were English-only and peer-reviewed.

Exclusion criteria Unpublished literature, dissertations, opinion papers, and abstracts were excluded. Studies that utilized parents as the informant were also excluded. Studies that interviewed adolescent cancer survivors were also not included because of the short timeframe between treatment conclusion and the study. These criteria looked specifically at what the survivors themselves could recall about their medical history.

Article retrieval The above inclusion and exclusion criteria were applied to all database searches. The articles were reviewed to determine if they met the defined criteria. The reference lists of selected articles were also reviewed to identify any other articles that met the defined criteria. The selected articles were individually reviewed in detail following a coding sheet developed by the author.

Review of studies A coding sheet was developed to record the goals, purpose, framework, methods, sample characteristics, findings, and implications of each article. The sheet was developed specifically for this review.

Selected studies Five articles met the described criteria. **Table 1** provides a side-by-side comparison of the sample characteristics, measures, and methods of the selected studies. Three of the studies described what adult survivors recall about their medical history; the other two described what adult survivors knew about their future care needs based on their risk for late effects.

Characteristics A wide range in sample sizes was represented by these articles (N = 332 to N = 9,242). Many large sample sizes included participants from the National Childhood Cancer Survivor Study. The participants' ages ranged from 23.7 to 35 years. Although different childhood cancer diagnoses were utilized and none of the studies limited diagnoses, two studies limited its participants based on past cancer treatment received. The Cox study limited its participants to those who had received radiation to the chest.[9] Lansdale and colleagues limited their study participants to those at risk for hepatitis C virus (HCV) based on their transfusion history.[10]

TABLE 1. Summary of reviewed studies

Study	Age and past diagnoses	Characteristics	Types of Measure	Knowledge deficits
Byrne et al[10]	• Mean age: 32 y • Diagnoses: Any childhood cancer except skin cancer	• 1,928 participants with cancer diagnosis before age 21 y • Cancer was diagnosed between 1945 and 1974 • Participants taken from five US cancer registries • Survivors were at least 5 years post diagnosis and older than 21 y	Follow-up interview	• Lower recall of cancer diagnosis in participants who had CNS tumors • Those with lower levels of parental education, nonwhite race, younger age at diagnosis, and diagnosed during earlier years were less likely to recall diagnosis
Cox et al[7]	• Mean age: 30.92 y • Diagnoses: Any childhood cancer with radiation to the chest	• 335 female participants who were at risk for breast cancer based on radiation to the chest as a child • Secondary analysis of data taken from three consecutive surveys within the Childhood Cancer Survivor Study	• Paper and pencil questionnaire from the National Health Interview Survey • Follow-up questionnaires • Comparison of medical records	• 27% of those at high risk never had mammography • Those who were older than 40 y were more likely to have mammography than those younger than 40 y
Kadan-Lottick et al[9]	• Mean age: 29.3 y • Any childhood cancer	635 survivors chosen from 12,156 participants of the Childhood Cancer Survivor Study	• 3-5 min telephone questionnaire • Medical record	• 72% could recall diagnosis • Little worry among most survivors regarding late effects • Only half could recall radiation site and anthracycline therapy • Survivors of CNS tumors and neuroblastoma were less likely to recall accurately
Lansdale et al[8]	• Mean age: 23.7 y • Any childhood cancer with risk for HCV	9,242 participants chosen from the Childhood Cancer Survivor Study who were at risk for HCV based on their transfusion history	Questionnaire	More than 70% reported no HCV testing
Sheen et al[11]	• Mean age: 35 y • Nonhereditary and hereditary retinoblastoma	• 836 retinoblastoma survivors • 35% were survivors of hereditary disease • 47% were survivors of nonhereditary disease • Participants were 18 y and older	Computer aided telephone interview	Screenings positively correlated with higher level of education, contact with healthcare system, and secondary malignancy

Key: HCV, hepatitis C virus.

Quantitative approaches were used in all five of the studies. The Lansdale study reported some qualitative data collected from the participants' medical records.[10] Methodologies used to gather data were telephone interviews, questionnaires, mailed surveys, and review of the medical records.

A REVIEW OF THE FINDINGS

The results of this literature review are summarized based on the reported survivors' knowledge of their diagnosis and the treatment they received for the cancer. Reports of the survivors' awareness of potential late effects and understanding of future follow-up care needs are also discussed.

Knowledge Kadan-Lottick and team found that when adult survivors were prompted with names, 72% knew their diagnosis with detail and 19% knew their diagnosis without detail.[11] *Detail* was defined as knowing the exact type of cancer the survivor had, not just a broad name. Only 75% of survivors of central nervous system (CNS) cancers accurately recollected their medical history, whereas 98% of survivors of Hodgkin lymphoma, Wilms tumor, and bone cancers were able to discuss their diagnosis with detail.[11]

Byrne and colleagues found that 14% of respondents, who were survivors of non-CNS malignancies, reported no childhood cancers when they did in fact have cancer as a child.[12] Seventy-five percent of respondents who had a CNS cancer did not recall having cancer as a child.[12]

Treatment In regard to knowledge of chemotherapy, 94% of participants in the Kadan-Lottick study knew they had received chemotherapy. However, only 33% knew they received doxorubicin (Adriamycin, Doxil, Rubex, generics) and 8% remembered receiving daunorubicin (Cerubidine, DaunoXome, generics). Those with a positive cardiac family history had slightly more accurate reporting. Byrne's study found that 82% of those who remembered they had cancer could recall the treatment they had received.[12] This study conducted no further investigation to determine if survivors knew the specific treatments they received.

Childhood cancer survivors who transition to adulthood now manage their own health care and require accurate information in this role.

Kadan-Lottick found that 89% of adult survivors accurately recalled receiving radiation treatment.[11] However, only 15% with CNS tumors could accurately recall receiving this treatment. Overall, 70% of those who received radiation knew which site was irradiated as a child. Sixty-seven percent of those who underwent splenectomy recalled doing so, whereas 14% of Hodgkin lymphoma survivors recalled undergoing the procedure when they had not.[11]

Late effects When asked if past treatments could have implications for the future even with the passage of time, only 35% of adult survivors responded yes, 46% responded no, and 19% did not know.[11] Moreover, only 44% reported attending a follow-up clinic for their cancer and only 15% reported receiving written copy of information on their disease and treatments.[11]

Future follow-up care Adult survivors of childhood cancers must not only know their past history but also must be aware of their risk for late effects. Follow-up care and screenings based on risk must be maintained to prevent and treat late effects.

Cox looked at female young-adult survivors of pediatric cancers who received radiation to the chest.[9] The researchers reviewed the survivors' current screening practices because many of these survivors carry the same risk for breast cancer as persons with the *BRCA* gene.[9] Cox and team used a questionnaire along with follow-up questionnaires to conduct a secondary analysis of a subset of 335 survivors from the Childhood Cancer Survivor Study. The study revealed that 59% of survivors at low risk and 27% of survivors at high risk had never had mammography screening, and half of those at highest risk had never talked about this with a physician.

Lansdale used data from the Childhood Cancer Survivor Study to identify knowledge of risk for hepatitis C virus (HCV) and if the survivors had been screened for it.[10] More than 70% reported no HCV testing or uncertainty about testing, 29% reported prior testing, and 89% were unsure of their HCV status.

Sheen and colleagues investigated the screening practices of young-adult survivors of retinoblastoma, who are at high risk for secondary cancers such as osteosarcoma.[13] The researchers used a sample size of 836 retinoblastoma survivors who were older than 18 years and had retinoblastoma as a child. Computer-aided telephone interviews were used to determine the prevalence of breast self-examination, clinical breast examination, mammography, Pap test, testicular self examination, and MRI/CT history. Their sample consisted of survivors of both hereditary and nonhereditary retinoblastoma. Eighty-seven percent of female survivors had a Pap test within the past 2 years and 76% reported mammography within the past 2 years. Seventeen percent of males reported performing a monthly testicular examination. A greater number of hereditary retinoblastoma survivors had undergone a CT or MRI in the past 5 years. Higher education, greater contact with the medical system, and having a second cancer were associated with positive screening practices. Survivors of hereditary retinoblastoma were much more likely to report a second cancer (10% vs. 2%) and to have been hospitalized within the past 5 years (33% vs. 21%) than were survivors of nonhereditary retinoblastoma.[13]

DISCUSSION

Research on adult cancer survivors' knowledge and recall of their medical history is an emerging field of study. Very few studies have used the survivors themselves for participants instead of their parents or families. As the survival rates of childhood cancer rise, the number of patients experiencing late effects of their cancer treatment also increases. Furthermore, childhood cancer survivors who transition to adulthood are now responsible for managing their own health care needs and require accurate information to assume this role.

Knowledge of diagnosis Across the studies, no consistent factors identified those survivors with gaps in knowledge about their past cancer history. However, a few differences were seen in two or more of the studies. One factor was differences in knowledge of diagnosis. Both the Kadan-Lottick and Byrne studies found that survivors who had CNS tumors as a child recalled less about their diagnoses.[11,12] In addition, many survivors with CNS tumors did not even accurately report that they had cancer.

Another difference was found among those with Wilms and Hodgkin lymphoma tumors. These two groups were much more likely to accurately report their past diagnoses and history.[11]

Age Differences in the ages of the survivors were seen in some of the studies. Byrne found that those who were diagnosed at an earlier time period and those who were younger at diagnosis could recall less about their diagnoses.[12] Cox found that among survivors who were at high risk for breast cancer, those younger than 40 years were less likely to undergo mammography than those who were older than 40 years.[9]

Inadequate information All the studies identified gaps in medical and historical information given to patients. While some patients reported they had received some information, many did not or could not recall that they had received information. This is significant to nursing because nurses are largely responsible for much of the education in and out of the hospital. Electronic access to past medical records is one way to decrease this deficit.

Kadan-Lottick found that only "74% could provide an accurate general summary" of their medical history.[11] No single survivor could recall all of the following: exact diagnosis, anthracycline treatment, and radiation sites. Furthermore, more than half could not recall receiving anthracycline and radiation therapy.[11] This critical lack of information could substantially increase morbidity and mortality if care is not taken with follow-up.

Late effects Discussions of late effects and past treatments with a health care provider is another crucial element evidenced in some of the studies. Cox reported that almost half of their high-risk participants never reported discussing late effects with their current health care provider.[9] Kadan-Lottick found that only one-third of their participants were worried about experiencing a late effect in the future.[11] This is staggering because the percentage of survivors who will experience a late effect is extremely high. Lansdale found that many survivors were unaware of their transfusion history.[10] Granting survivors and their health care providers access to their cancer histories could empower them with the knowledge they lack, and help facilitate crucial open discussions about survivors' health care needs. Survivors need to be aware of late effects as well as what symptoms they should be looking for to prevent complications.

Other findings Sheen found that a higher level of education, greater contact with the medical system, and the presence of secondary cancers correlated positively with screening practices.[13] Byrne found that survivors who were nonwhite, whose parents had a lower level of education, and who received less aggressive treatment were less likely to recall they had cancer.[12]

SEE THE ONLINE VERSION OF THIS ARTICLE TO LINK TO:

Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers
www.childrensoncologygroup.org/disc/le/

IMPLICATIONS FOR CLINICAL PRACTICE

In the clinical setting, health care teams play an important role in the dissemination of both past and present knowledge. Health care summaries should be made accessible to both survivors and health care providers. Summaries of childhood medical history should be stated verbally as well as in writing. As survivors age, having accessible medical histories becomes crucial, thereby allowing their health care providers to easily determine the necessary follow-up care.

> As the number of survivors increases, health care providers need to be aware of the challenges when caring for these patients.

Long-term or late-effects clinics are available in many states but not in all. Currently, late-effects clinics are available in 25 states. Ensuring clinics are available to all cancer survivors can also help provide the needed education and follow-up care.

IMPLICATIONS FOR FUTURE RESEARCH

More studies that investigate what survivors know and can recall must be conducted. In addition, qualitative types of inquiry should also be conducted to expand on what survivors know. Data on survivors of cancers diagnosed after 1986 should also be conducted to determine if knowledge among survivors is increasing as more children with cancer survive.

Another area future research should attend to is the needs of minority survivors. Minorities are a vulnerable population; therefore, their knowledge of their past and future health care needs warrants study. Whether minorities have access to care or if more knowledge deficits occur because of language barriers or cultural differences should be investigated.

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LIMITATIONS

Although the studies were all descriptive and quantitative in nature, this review had some limitations. Because studies that utilized adolescents and family informants were not included, additional insight into survivors' knowledge may be missing. Three of the five studies relied on data from the National Childhood Cancer Survivor Study; therefore, those informants' recall may be more accurate as a result of study participation. In addition, many of the survivors' cancers were diagnosed between 1970 and 1986, and the education given to patients regarding survivorship and future health care needs at that time was most likely less than it is today. Participants in the National Childhood Cancer Survivor Study may also be more motivated and more knowledgeable than other survivors because of their participation. Therefore, a higher percentage of the reports have accurate past history recall in this study population.

This review is also limited because it was restricted to only published, peer-reviewed articles. No dissertations or non-English articles were included. Finally, it involved only studies that used the survivor as the participant and not the caregiver; therefore, knowledge of disease and treatment information was not verified by a parent or caregiver.

CONCLUSION

Current research findings indicate that adult survivors of pediatric cancers have knowledge deficits. The deficits are seen in recall of the exact stage and type of cancer, and also in recall of treatment received, such as type of chemotherapy and radiation. This information is crucial to survivors' understanding of future risk. Deficits were also seen in knowledge of and adherence to follow-up guidelines based on risk.

Survivors' knowledge of their past cancer history is largely unexplored. As the number of survivors increases, health care providers need to be aware of the challenges in caring for these patients. Survivors need education, access to medical records, and knowledge of resources available to them. Adult survivors of childhood cancer are a distinct patient population because they did not have the role of primary caregiver at the time of diagnosis and treatment. Health care providers and nurses should understand the unique needs of this patient population. Further research, inquiry, and education must be made available to impact and help guarantee their well-being in the future. ■

Sharifa Al-Qaaydeh is a clinical instructor and PhD student at the University of Utah College of Nursing in Salt Lake City. Her research interests include pediatric survivorship, bone marrow transplantation, palliative care, and symptom management in children with cancer.

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