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Challenges and Opportunities of Epidemiological Studies to Reduce the Burden of Cancers in Young Adults

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Abstract

There are >1.9 million survivors of adolescent and young adult cancers (AYA, diagnosed at ages 15–39) living in the U.S. today. Epidemiologic studies to address the cancer burden in this group have been a relatively recent focus of the research community. In this article, we discuss approaches and data resources for cancer epidemiology and health services research in the AYA population. We consider research that uses data from cancer registries, vital records, healthcare utilization, and surveys, and the accompanying challenges and opportunities of each. To illustrate the strengths of each data source, we present example research questions or areas that are aligned with these data sources and salient to AYAs. Integrating the respective strengths of cancer registry, vital records, healthcare data, and survey-based studies sets the foundation for innovative and impactful research on AYA cancer treatment and survivorship to inform a comprehensive understanding of diverse AYA needs and experiences.

Keywords

Cancer; epidemiology; adolescent & young adult; surveys; cancer registries; healthcare utilization

Introduction

More than 70,000 adolescent and young adults (AYAs) are diagnosed with cancer in the United States (U.S.) each year, and cancer is the leading disease-related cause of death for AYAs [1, 2]. Defined by the National Cancer Institute (NCI) as cancers diagnosed in the 15- to 39-year age range, AYA cancer incidence has increased steadily over the past 25 years [2]. Today, more than 85% of AYA cancer patients survive at least 5 years after diagnosis [3–5]. In 2013, there were >1.9 million survivors of AYA cancer living in the U.S. [6], many with a lifelong elevated risk of medical problems as a consequence of curative cancer therapy [5]. Further complicating survivorship, AYAs have a high likelihood of healthcare gaps due to changes in education, employment, marital status, and insurance coverage [7–9]. Further, no standard approach exists for referral to pediatric vs. adult providers for teens [10, 11], and treatment and monitoring of AYA cancer patients are marked by care delays [12, 13], underinsurance [9, 14], and loss to follow-up [15]. The challenges faced by AYAs are exacerbated by the unique financial, social, educational, employment, and family concerns at this life stage [4, 5].

Despite these unique challenges, little clinical and survivorship research has focused on AYA compared to childhood cancers, for which the Children’s Oncology Group (COG) forms a nexus of research. COG provides opportunities for most pediatric patients to enroll in clinical trials [16]. In the context of epidemiologic and health services research, the Childhood Cancer Survivor Study (CCSS) has been a pioneer and longstanding resource, providing important information on late effects in cancer [17]. While there is overlap of the adolescent age range of AYA cancers with pediatric cancers, COG and CCSS studies focus on cancers where the active treatment phase occurs under parental or guardian care. Further, the mix of pediatric cancers differs substantially from the cancers of AYAs, particularly in the age range that does not overlap with COG.

In addition, most adult oncology clinical trials do not consider the unique circumstances that distinguish younger adults diagnosed with cancer. Health services research in cancer survivors frequently uses resources such as the Surveillance, Epidemiology, and End Results (SEER)-Medicare linked databases, which are limited to adults >65 years. From an epidemiologic perspective, only in the past decade or so have prospective cohort studies of survivors of AYA cancers been initiated [18].

AYA cancer survivors require dedicated research because they are in a phase of life that is distinct from that of children, middle-aged- and older adults [5]. Health insurance coverage may be episodic with a lack of continuity because of frequent changes in residence and employment [9]. Insurance gaps may also be precipitated by policies such as the end of parental health plan coverage and result in significant out-of-pocket costs for healthcare utilization. The transition of care from pediatric to adult oncology and primary care may result in discontinuity and splintered care, with lack of communication among providers. Cancer or cancer therapies may compromise fertility [19] or increase the likelihood of late effects, including cardiovascular disease (CVD), kidney disease, endocrine disorders, and second cancers [5], and may have differential effects on developing, compared to mature, organ systems. For AYAs with other medical conditions, the management of these conditions may not be well coordinated, and presents further challenges for AYA survivors who still have most of their lives ahead of them.

In this article, we discuss approaches and data resources for cancer epidemiology and health services research in the AYA population. We consider research that uses information from cancer registries, vital records, healthcare utilization data, and surveys, and the accompanying challenges and opportunities of each. To illustrate the strengths of each data source, we present example research questions or areas salient to AYAs. Linkage across data sources can provide a powerful platform for research on important questions in AYA cancer survivorship.

Research using cancer registries and vital records

Cancer registries are a mainstay in research, including in AYA cancer survivors. In the U.S., federal law mandates cancer diagnosis reporting to central cancer registries. These reports have uniform data standards governed by the North American Association of Central Cancer Registries (NAACCR); some registries additionally adhere to standards of the CDC’s National Program of Cancer Registries (NPCR) and/or the SEER program. The quality of data collected by individual registries is evaluated annually by NAACCR based on completeness of case ascertainment, accuracy of key variables (e.g. cancer type, sex, race, age), and timeliness of data reporting. First course cancer treatment information is also collected in standardized formats, although these variables do not contribute to NAACCR’s evaluation of data quality [20]. However, detailed cancer treatment characteristics (e.g., agents, doses, radiation field) are not available.

A growing body of research has worked to validate cancer registry treatment fields in concordance with administrative insurance claims, medical record abstraction, and patient report [21, 22]. For example, the Intensity of Treatment Rating Scale estimated with cancer treatment data from the Los Angeles SEER registry had 94% agreement between registry and self-reported data for pediatric acute lymphoblastic leukemia [23]. Using public and private administrative insurance claims as the gold standard, North Carolina Central Cancer Registry data had a positive predictive value >80% for chemotherapy receipt among women diagnosed with common AYA cancers [24]. Two major advantages of using cancer registry data are that all reportable cancers within a catchment area can be identified and information on diagnosis and treatment should be available regardless of where care was received.

Cancer registry-based research also face key challenges. Cancer recurrence and therapies to treat recurrence or progression are not recorded. Some cancer registries do not release geographic units smaller than state or identifiers to enable data linkage with other sources. Where linkage is possible, it must be pursued on a state-by-state basis, but not with SEER/NPCR data as a whole. Finally, privacy concerns are paramount and linkage under the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule are complex. Research collaborations are best formed in partnership between statewide agencies and investigators to ensure that the public’s data are linked and analyzed appropriately to preserve confidentially and maintain public trust.

Statewide cancer data can be linked with other statewide vital records systems to capture information from birth and death certificates. Birth certificates provide information on reproductive outcomes that are relevant for studies concerning reproductive potential and birth outcomes of AYA cancer survivors. Most AYAs have not completed their desired family size when diagnosed with cancer [25, 26], and future reproductive potential is a leading patient concern [19, 27, 28]. Fertility counseling informs patients of potential threats to fertility from cancer treatment (including structural changes and gonadotoxicities from pelvic surgery, radiation, or systemic chemotherapies) and available strategies targeted at preserving fertility. The American Society for Reproductive Medicine, National Comprehensive Cancer Network (NCCN), and American Society of Clinical Oncology (ASCO) guidelines recommend patients receive fertility counseling as soon as possible after cancer diagnosis and before receiving cancer treatments that may compromise reproductive outcomes [29–32].

Infertility risk estimates used by providers for counseling are most often based on cancer treatment associations with amenorrhea at specific time intervals after cancer diagnosis. However, amenorrhea is an imperfect surrogate for future reproductive potential—women may resume menses beyond the specified time interval or conceive without menses, while menstruating women may have difficulty conceiving due to depleted ovarian reserve or other late effects. Linked, population-level data on cancer and birth records provide the opportunity to observe livebirths years after cancer diagnosis, arguably a more relevant outcome from the patient perspective than earlier surrogate markers of reproductive potential.

In other countries, particularly Scandinavian nations, the United Kingdom, Canada, and Australia, national data on cancer history is available for linkage with information on livebirths and other health outcomes. These linkages have been instrumental in documenting lower livebirth rates and higher prevalence of adverse birth outcomes such as preterm birth and low birth weight for AYAs with cancer compared to those without cancer [33–43]. Ultimately, this research contributes to professional recommendation statements on, "Counseling and surveillance of obstetrical risks for female childhood, adolescent, and young adult cancer survivors" [44].

Linked cancer registry and vital records analyses also offer the potential to examine trends over time, and in relation to key practice changes or changes in national guidelines or policy. Birth rates among cancer survivors can also be compared between geographical locations to evaluate the impact of state level policies, such as mandated insurance coverage for fertility preservation. As of 2021, 10 of 50 U.S. states mandate coverage for iatrogenic infertility [31]. State differences in healthcare coverage have potential to exacerbate inequities in cancer care and access to fertility preservation or other assisted reproductive technologies in minority and low-income groups [38, 39].

However, vital records-based research cannot separate the biological effects of cancer and its treatment from other contributors along the cancer control continuum, or subsequent changes in survivors' reproductive goals and intentions. For example, fertility counseling appears to be provided more often to patients who are younger [25, 45, 46], have earlier stage disease [47], who have specific cancer types [48, 49], and are non-Hispanic white [12, 49]. Even in the absence of biological effects, differential counseling around the potential for future childbearing could result in subsequent variation in birth rates. Other challenges of using population-level cancer registry data linked with vital records to understand reproductive potential and birth outcomes include limited information on relationship status, reproductive intentions or pregnancy attempts, maternal behaviors that could influence fertility and birth outcomes, and the potential for AYAs to move out of state between diagnosis and giving birth.

Research using healthcare utilization data

Cancer registry data can be linked to healthcare utilization data, such as health insurance claims or electronic health records (EHRs). Insurance claims provide records of services that were submitted for payment to insurers, and include information such as diagnoses or procedures, or whether a billable test was completed. EHRs typically include details on patient diagnoses, procedures, medical and treatment history, medications, laboratory tests ordered, and test results. Integrated healthcare systems often have both EHR and claims data, along with other administrative data, such as information on providers or health benefit plans. These data can facilitate studies of associations among cancers, treatments, care received, and other health conditions.

In the US, cancer research that uses health claims has benefited from the SEER-Medicare data linkage [50]. However, these data are generally not relevant for studies of AYA cancer, as Medicare provides coverage for adults age 65 years or older. To address this gap, some cancer centers have developed resources that incorporate claims from other insurance providers (e.g., the UNC Cancer Information Population Health Resource or the Utah Population Database). Increasingly, insurers and data brokers also make health claims available for research purposes, resulting in a potential source of AYA health care-related data [51]. We and others have linked cancer cases to inpatient and emergency room data that are maintained by many states [52]. These data have limitations, however, such as not including claims by all insurers or lacking information on outpatient care and prescription medications. Finally, regardless of comprehensiveness of population coverage, health claims do not provide the level of detail available from EHRs.

EHR data provide detailed information on most aspects of clinical care. EHR data from an oncology care provider, such as Flatiron Health, provides an example of the use of such data for cancer research [53], although AYA cancers have not yet been a focus of such research. In an integrated health care setting, such as Kaiser Permanente in which the health system is both provider and insurer, data are available from the EHR, health claims, and other administrative sources. This provides additional strengths, including the ability to identify a defined population and to capture essentially all health care received [54]. For studies of cancer outcomes, integrated health care settings also have relatively high retention of members for both health insurance and care after diagnosis [54, 55].

Research on late effects of cancer demonstrates the potential use of healthcare utilization data in AYAs with cancer. To date, most research on late effects of cancer come from childhood cancer survivors [56–64] or studies with a broad age range of AYA and older adult patients [65–72]. Information on late effects among AYA cancer survivors remains limited due to study challenges, including difficulties and costs associated with long-term follow-up of a mobile population, low participation of AYAs in research studies, and accruing sufficient sample sizes [73–75].

Cancer registry data illustrate the high absolute excess risk of subsequent primary malignancies among AYAs [76], and worse survival after their subsequent cancers compared to older adults [77], but do not provide data on other outcomes. Studies that have linked to hospitalization data demonstrate that AYA cancer survivors experience an increased risk throughout the lifespan for a broad range of diseases requiring in-patient hospitalization [78], including cerebrovascular disease [79], CVD [80, 81] and respiratory events [82]. Population-based studies of AYAs with cancer have documented disparities in cancer-specific survival by race/ethnicity, neighborhood socioeconomic status and health insurance [83–89] and cancer-registry data linked to hospitalization data in California suggests that these sociodemographic factors are associated with the occurrence of late effects [52, 90–95].

EHRs allow a more granular examination of the effects of specific treatments, including doses and number of administrations, in relation to conditions diagnosed in both inpatient and outpatient settings. For example, a study based in Kaiser Permanente Southern California found that AYA cancer survivors had a 2- to 3-fold increased risk for heart failure, stroke, premature ovarian failure, chronic liver disease, and renal failure than those without a history of cancer, with significant associations between chemotherapy and radiation therapy exposures and chronic health conditions [96]. Furthermore, 2-year AYA cancer survivors in this integrated healthcare system had an over 2-fold increased incidence of CVD compared to AYAs without cancer [97]; this finding was confirmed in statewide California cancer registry linked with hospitalization data for nearly 80,000 AYA cancer survivors [52]. In both settings, the increased incidence of CVD was observed starting 2 years after cancer diagnosis with no apparent change in the slope of the curve over time [52, 97], demonstrating the need to investigate emergent health problems even in the first few years after therapy completion. Statewide, AYA cancer survivors who were uninsured or publicly insured, of Black/African American race, or who resided in lower socioeconomic status neighborhoods had elevated risk of CVD [52].

Conducting studies in AYA cancers using health care utilization data, whether from claims or EHRs, may limit analyses and inferences to the insured. Thus, the important role of health care access is not readily addressed in such studies. In addition, despite the strengths of research using utilization data from integrated healthcare systems, there are limitations for AYA cancer research. Even with a large membership base, such as over 4.5 million members in Kaiser Permanente Southern California, the sample sizes of AYA cancer survivors defined by cancer type, treatment and sociodemographic factors is limited, especially when assessing associations with uncommon chronic health conditions. Moreover, even though patients with cancer remain in such health insurance programs at relatively high rates, AYAs are more likely to disenroll [9, 75, 98], compromising utility of such data sources and long-term follow-up of AYA cancer survivors. Linkages to other resources may efficiently minimize this limitation. For example, for AYAs diagnosed and treated in Kaiser Permanente Northern and Southern California, two large integrated health systems covering ~25% of the California AYA population, it is possible to follow those who disenroll or seek care elsewhere in California through linkages to statewide hospitalization, emergency department and ambulatory surgery databases, maximizing long-term follow-up for these types of healthcare encounters.

Research using surveys

While existing data from cancer registries, vital records, and healthcare systems have many advantages, cancer survivors can provide information on events and exposures that are not well-measured or available from these sources. Even more importantly, survivors can report on their experiences with healthcare, symptoms and quality of life, health beliefs, financial burden, and gaps or disruptions in their care or life goals due to cancer. For some of these areas, the survivor is the only source of information.

Surveys are key to obtaining information directly from survivors. For example, there are multiple measures of patient-provider communication and patient-reported outcomes in studies using national data sources, such as the Medical Expenditure Panel Survey (MEPS) Experiences with Cancer Supplement [99–108]. One study using MEPS data among cancer survivors age ≥18 years identified communication gaps during survivorship care, with fewer than half of participants reporting detailed communication about emotional needs, treatment effects, or lifestyle recommendations [100]. Communication gaps have not been evaluated specifically in AYA cancer survivors who have unique needs, such as fertility and family planning concerns, financial burden, and distinct psychosocial impacts from cancer compared to older cancer survivors. AYA survivors also have distinct psychological development needs and experiences around cancer diagnosis relative to children [109]. Therefore, age-appropriate care requires a better understanding of AYA concerns (e.g., patient-provider communication, psychosocial health, unmet needs) and reinforce the need for survey research in this area.

Survey data can be collected in person, by phone, or electronically, and in a variety of formats. Obtaining valid and meaningful survey results requires consideration of many factors, including coverage, sampling, non-response, and measurement [110]. Several large surveys focused on AYA cancer survivors have been conducted in the U.S. in the past 15 years [74]. For example, the AYA Health Outcomes and Patient Experiences (HOPE) study identified cancer survivors using information from SEER cancer registries and invited survivors by mail to complete an online survey and follow-up survey and to consent for medical record review. The study attempted to reach non-respondents through a second mailing and then by phone. The study achieved an initial survey response rate of 43% and has published widely on AYA survivorship topics including health-related quality of life, healthcare and support service and information needs, and the impact of cancer on healthcare use and barriers, insurance, work and education, psychosocial and sexual function, and fertility preservation [73, 111–116]. Other AYA cancer survivor surveys that recruit from cancer registries include the Furthering Understanding of Cancer, Health, and Survivorship In Adult (FUSCHIA) Women’s Study and the AYA Horizon study [117, 118].

Because cancer is a reportable condition, recruiting from cancer registries can help ensure that a broad group of AYA survivors are reached. In theory, all survivors diagnosed within a certain area and time frame can be invited to participate (if they can be reached). And, since basic characteristics of all invitees are known (e.g., age, sex, cancer type), it is possible to assess the generalizability of survey respondents and conduct analyses using weighting to adjust for non-response [73, 119]. These are distinct advantages of surveys with a defined sampling frame.

However, open recruitment of AYA survivors through social media offers a unique way to identify patients relatively quickly who have a broad spectrum of cancer care experiences beyond region, healthcare system, and diagnosis [120]. As an example, some AYAs join social media sites for the first time after they are diagnosed with cancer and are identifiable through their Twitter handles or tweets about their cancer [121]. Twitter is potentially useful for recruitment into surveys or to collect qualitative data [122–124]. Further, certain hashtags (e.g., #ayascm) are used by AYA communities to facilitate ongoing discussion. Advantages of social media recruitment include the efficiency in reaching a broad population nationally and internationally. Potential disadvantages are the lack of sampling frame and representativeness of the study population (U.S. Twitter users represent a younger and more educated demographic, but are similar to the U.S.) and resources to maintain active social media presence [125].

Survey data, while valuable on their own, become even richer when combined with other data sources. Data from cancer registries or health plans can provide information on diagnoses and patterns of care that may help explain patient self-reported experience [118].

It is also important to note that structured surveys are not the only way to collect information from patients. Qualitative research gives voice to patient perspectives, enables survivors to discuss their unique stories and journeys with cancer, and can uncover aspects of patient care and illness experience that are not visible to the healthcare system or present in medical records, and not easily elicited through surveys or other quantitative modalities. Qualitative data can also help inform analysis and interpretation of quantitative data, inform the development of new quantitative measures for constructs missing from existing surveys, and form a pillar of data triangulation, resulting in a richer understanding of the research question and patient experience [126].

Future directions

The life stages of AYAs present unique challenges of coping with cancer diagnoses and issues of future childbearing or childcare and financial stress related to seeking economic independence, pursuit of higher education, job loss, and episodic health insurance coverage. The interplay of these challenges and how they influence cancer care and survivorship manifests itself across the cancer care continuum in ways that are typically not examined in cancer epidemiology studies. The impact of AYA-specific factors may begin before treatment, when fertility counseling is an important consideration, or after active treatment, when lack of care coordination or formal transition between pediatric and adult providers or specialists and primary care may result in care discontinuity. These impacts may differ by healthcare settings and patient subgroups.

In the next decade, new research in support of AYA survivorship will emerge and inform comprehensive understanding of diverse AYA needs and experiences for new interventions for AYA care. With the passage of the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act of 2018, NCI has committed more than $50 million to several AYA cancer research initiatives [127, 128]. These new investments promise to expand research tackling some of the most relevant AYA survivorship issues:

- The development of AYA cohorts in diverse care settings is particularly relevant in examining trends, needs, and outcomes. To date, very few large cohorts of AYA survivors exist outside of COG or tertiary cancer centers to assess receipt of health services, appropriate surveillance care, and long-term effects particularly at ages not covered by pediatric research.
- Research focused across the age spectrum and life course adds to the context of adolescence, emerging adult, and young adult needs. Many funded studies have focused on 15–24 year-olds, representing a critical subgroup. However, this age restriction does not span the 15–39 year-old AYA age range as defined by NCI and during which major biological and social developmental life stage transitions occur, thus limiting our scientific understanding of the population.
- As many AYAs live decades after a cancer diagnosis, large-scale studies should aim to better understand, screen for, and prevent and/or treat late effects of their initial cancer treatment. Data from integrated healthcare systems and population-based resources provide opportunities to characterize the incidence and timing of late effects after cancer treatment [129].

- Finally, the development of patient-centered research within AYA communities offers an opportunity for patients' voices to be integrated into research questions posed, methods selected, and interpretation, dissemination, and implementation of study results. AYAs are active within social media, offering a research opportunity to understand current issues. Active engagement through Twitter or with online resources (e.g., LacunaLoft or The SamFund) allows researchers to better understand patient care, experiences, and survivorship needs.

In conclusion, integrating the respective strengths of cancer registry, vital records, healthcare, and survey-based studies sets the foundation for innovative and impactful research on AYA cancer treatment and survivorship. By employing multiple data sources and methods, these studies will provide the necessary evidence on knowledge gaps for intervention studies and future research, and can contribute directly to improving outcomes for AYA cancer survivors.

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