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Journal of Adolescent Health ■■ (2017) ■■-■■



JOURNAL OF ADOLESCENT HEALTH

www.jahonline.org

Original article

Primary Care Physicians' Decision Making Regarding Initial Oncology Referral for Adolescents and Young Adults With Cancer

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Article history: Received February 1, 2017; Accepted September 5, 2017 *Keywords:* Young adult; Adolescent; AYA; Cancer; Decision making; Pediatric oncologist; Referral patterns; Primary care physician

ABSTRACT

Purpose: The objectives of this study were to determine whether pediatricians are more likely than other primary care physicians (PCPs) to refer newly diagnosed adolescent and young adult patients with cancer to pediatric oncological specialists, and to assess the physician and patient characteristics that affect patterns of referral.

Methods: A cross-sectional vignette survey was mailed to PCPs to examine hypothetical referral decisions as a function of physician characteristics and patient characteristics, including diagnosis, age, gender, race/ethnicity, family support, transportation, insurance, and patient preference for site of care. Pediatrician PCPs and nonpediatrician PCPs (family medicine, internal medicine, and emergency medicine physicians) practicing in North Carolina and in Washington State participated in the study. **Results:** A total of 406 surveys were completed (35.8% response rate). Sixty percent of pediatric PCPs referred their hypothetical patients with cancer to pediatric specialists (PSs), compared with only 37% of nonpediatric PCPs. Patient age also influenced referral patterns; 89% of 13-year-olds, 74% of 16-year-olds, 25% of 19-year-olds, and only 9% of 22-year-old patients were referred to a PS. Multivariate logistic regression demonstrated that diagnosis and physician practice setting also were associated with referral patterns.

Conclusions: Both patient age and PCP specialty were significant predictors of referral patterns in hypothetical vignettes of newly diagnosed adolescent and young adult patients with cancer. Pediatricians were more likely than nonpediatrician PCPs to refer patients to a PS. Referrals to PSs decreased dramatically between ages 16 and 19. Because the site of oncological care can impact outcomes, these data have the potential to inform awareness and education initiatives directed at PCPs.

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IMPLICATIONS AND CONTRIBUTION

Adolescents and young adults with cancer may receive oncological care from pediatric or adult specialists. Care varies by provider and, for some diagnoses, outcomes vary. These data elucidate the patient and provider factors influencing referral patterns to oncological care and should inform primary care provider education.

Conflicts of Interest: Dr. Johnson is on the speaker's bureau for Shire Pharmaceuticals and Jazz Pharmaceuticals, and is a consultant for Shire Pharmaceuticals. Dr. Albritton is a consultant for Shire Pharmaceuticals. The other authors have no competing financial interests.

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In the U.S., there are no uniform or mandated age criteria that determine whether an adolescent and young adult (AYA) is referred to a pediatric or adult health-care facility, or to a pediatric or adult specialist. Yet studies have shown variation in care according to site or provider specialty in the management and outcomes of, for example, end-stage renal disease [1,2] and congenital heart disease [3,4]. Likewise there are outcome differences for AYAs with cancer associated with whether they are referred to either pediatric specialists (PSs) or adult specialists. Yet, the decision process of primary care physicians (PCPs) making these referrals is not well understood.

Population studies reveal that only one third of 15- to 19year-olds with cancer are seen at pediatric centers. In a Utah cancer registry study [5], referrals to a pediatric center decreased by age starting at 14; only 34% of 15- to 19-year-olds and <1% of patients over 19 were cared for at a pediatric facility. A NCI population-based Surveillance, Epidemiology, and End Results (SEER) cohort survey of newly diagnosed AYAs found that only 23% of patients aged 15–21 and <1% of patients aged 22–39 were treated by PSs [6].

Does treatment site matter [7]? The first outcome determined to dramatically differ by site of care was enrollment on clinical trials; AYAs are more likely to be enrolled at pediatric than adult cancer centers [8,9]. Although enrollment on a clinical trial may not benefit the individual patient, clinical trials are felt to be responsible for the systematic improvements in pediatric cancer survival and essential to similar progress for AYAs.

Of course, choice of site or specialist matters if overall survival varies. There are clear data that AYAs with acute lymphoblastic leukemia (ALL) [10,11] and suggestive data that AYAs with sarcoma [12–16] and Burkitt lymphoma [17,18] have better survival when treated on pediatric protocols and/or at pediatric sites. AYAs with malignancies that primarily affect adults, such as carcinomas, germ cell tumors, and non-Hodgkin lymphoma, may have superior survival when treated at adult cancer centers [19,20]. Indeed, utilization of pediatric facilities varies by tumor type. In the Utah study, 15- to 19-year-olds with sarcoma and leukemia were much more likely to be seen at the pediatric center, whereas virtually all adolescents with epithelial cancers were treated elsewhere. Nevertheless, increasing age exerted a strong influence, as still only half of the leukemia and sarcoma and one third of the brain tumor and lymphoma adolescents were treated at the pediatric center [5]. In the SEER AYA cohort, a diagnosis of ALL or sarcoma also strongly correlated with treatment by a PS [6].

The choice of specialist or site is likely made by a referring physician who may be unaware of these data and yet have the potential to critically impact patient outcomes. Data are lacking regarding which characteristics of patients or their PCPs might influence referrals of new AYA patients with cancer. We utilized a vignette-based survey to systematically investigate PCPs' decision making about AYA cancer patient referrals. Although one could posit that only patient characteristics should influence referral, we hypothesized that pediatricians would be more likely than nonpediatricians to refer AYAs to PSs. Understanding the current referral patterns of PCPs will inform the development of continuing education programs and elucidate barriers to appropriate care.

Methods

We conducted a mail-based survey to assess the referral choices of PCPs randomly selected from physician databases in two states, using hypothetical vignettes about AYAs newly diagnosed with cancer. The North Carolina (NC) sample was chosen from the North Carolina Health Professions Data System, an annually updated comprehensive database of licensed physicians maintained in collaboration with the state's professional licensing boards [21]. The Washington State (WA) sample was purchased from Medical Marketing Services, Inc., a licensed American Medical Association distributor that maintains the database. The study was approved by the institutional review boards of the University of North Carolina and Seattle Children's Hospital. Eligible participants were pediatric, internal medicine (IM), family practice (FP), general practice, or emergency medicine physicians actively practicing in NC or WA. The NC cohort also included gynecology and adolescent medicine physicians. Physician specialty was determined by selfreport. If respondents endorsed more than one specialty and one was pediatric, they were counted as pediatricians.

Sampling of primary care physicians

The NC study used a stratified random sample of 300 pediatric PCPs (of 1,318 eligible) and 300 nonpediatric PCPs (of 6,983 eligible); the percent chosen in each nonpediatric specialty matched the distribution of the overall database. Forty physicians were surveyed in a 2007 pilot study, after which the remaining 560 surveys were mailed. In the WA study, 1,000 PCPs (500 pediatricians and 500 nonpediatricians), the minimum number one could purchase from the database, were randomly selected by a computer from 16,841 eligible entries. The percent chosen in each nonpediatric specialty matched the distribution of the Medical Marketing Services, Inc., database. A total of 572 questionnaires were mailed in 2009.

Survey follow-up for nonresponders

In both cohorts, reminder postcards were mailed 2 weeks after the questionnaire. After another 2 weeks, a second identical survey was mailed to those who had not yet responded. Additionally, we attempted to locate nonresponders via the Internet and called physician offices for surveys that were returned undeliverable to obtain correct addresses. NC completers received a \$20 Amazon.com gift card, whereas the WA cohort received a \$2.00 bill in the initial mailing.

Questionnaire format

The survey began with questions that assessed the demographic and professional characteristics of the PCPs: year born, gender, race/ethnicity, board certifications, medical specialty, year graduated from residency training, type of residency setting (e.g., community hospital, university hospital, or a combination), and type of practice setting (e.g., private office, university clinic or hospital, and public health facility). We asked whether they had a first-name relationship with an oncologist (pediatric, medical, or other) and whether they had diagnosed cancer in a patient aged 12-24 in the last 2 years. Next, physicians received variable, hypothetical case vignettes describing AYAs with symptoms resulting in a diagnosis of cancer. A statistical design called "Latin squares" created systematic variation of eight patient characteristics: age of patient (13, 16, 19, or 22 years), gender (male or female), race/ethnicity (Caucasian, Black, or Hispanic), cancer diagnosis (ALL, Hodgkin lymphoma, Ewing sarcoma, or germ cell tumor-ovarian cancer for females and testicular cancer for males),

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