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The Impact of Psychosocial Needs of Adolescent and Young Adult Cancer Patients: An Analysis
of Clinical Trial Participation and Adherence

by

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Abstract

The treatment of Adolescent and Young Adult Oncology patients requires a comprehensive understanding of the psychological and social complexity of this group. Psychosocial support is often coupled with clinical treatment, but there are still unmet needs within this population regarding relevant information, mental health counseling, practical resources, and others. A significant gap in available clinical trials and participation in clinical trials has prevented progress in clinical treatment of Adolescent and Young Adults with cancer. A review of pertinent literature on psychosocial needs and oncology clinical trials was conducted in order to examine any relationship between unmet needs and clinical trial participation. Adolescent and Young Adults with cancer who have symptoms of unmet psychosocial needs experience a lower participation rate of clinical trials. This suggests that an increase in available psychosocial resources and delivery of these resources to patients will increase clinical trial participation, furthering the clinical treatment capabilities of Adolescent and Young Adult Oncologists and increasing survival rates.

Cancer is one of the leading causes of death in both developed and underdeveloped countries and receives a substantial amount of attention and effort from the medical field. In oncology, the medical study of cancer, these advances have increased survivorship of pediatric patients aged one to fourteen from 28% to nearly 80% over the past 40 years.¹ The following population of adolescents and young adults (AYAs) between the ages of 15 and 39, however, have not benefited from medical advancements to the extent of older and younger populations; five year survival rates of AYAs diagnosed with cancer have increased minimally between 1975 and 1997, despite having 8 times the incidence of cancer than the pediatric population.² Due to the gap in survival rates between these populations, a new subspecialty in oncology has emerged: Adolescent and Young Adult Oncology (AYA). Specialists in this field are conducting research that addresses the unique and markedly heterogeneous psychosocial needs of the population, and the duration and quality of life of AYA cancer patients via biological understanding.^{2,3,4} In this analysis, I will examine the relevant literature and address the following question: How can AYA providers use information on the psychosocial needs of AYAs to increase survival rates for the population? By addressing the unmet psychosocial needs of the population, oncologists will be able to increase adherence rates, participation in clinical trials, and quality of life both during and after treatment.

BIOLOGY

One distinct challenge in treating AYA cancer patients is that the biology of disease is different in AYAs than in other age groups.⁵⁻⁸ The array of cancers that affect AYAs are not similar to any other age range and do not respond to treatment in the same manner as pediatric or adult cancer patients.⁵ More research must be conducted to better understand the etiology of cancers in AYAs. There are several barriers in advancing AYA biology including a deficit of

tumor banks, lack of a standardized care model, and difficulty tracing environmental carcinogens and family history of an AYA cancer patient.^{2,6,7} Most important is the lack of clinical trials available and utilized to study the biology of AYA cancers.^{1-3,9-11}

Significant evidence demonstrating the biological benefits of age specific clinical trials is seen in the increased use of randomized clinical trials in childhood Rhabdomyosarcoma (RMS).¹ Survival rates for the pediatric age group with high clinical trial participation have improved substantially over the past 25 years. Adult populations have not had clinical trials available to them and survival rates for RMS in adults have decreased.¹ Other sarcomas such as non-Rhabdomyosarcoma soft-tissue sarcomas (NRSTSs) have received little to no study through clinical trial and none stratified for age. As a result, little is known about the treatment of these tumors and limited knowledge of their biological functioning in all age groups.¹

This same phenomenon is seen with the AYA age range of most cancers. Several oncologists have written articles dictating the importance of tissue sample collection and banking in order to make research on the biology of AYA cancers more viable.^{2,6,7} Specimen banks are particularly beneficial because research is conducted without the added complication of patient participation. Without a broad sample collection of both malignant and benign AYA tissues, research is significantly limited and contained within institutions. Most cancers in young adults are spontaneous carcinogenic mutations. There is a less conspicuous relationship to environmental carcinogens or family history making it more difficult to predict incidence or response to treatment.¹¹ By increasing AYA tissues in tumor banks, researchers will have access to an array of samples and can conduct research independently of one another.

The distinct lack of clinical trials available for AYA patients paired with the minimal participation of AYAs in clinical trials is one of the most common topics in the field. The low number of available trials for this age group stems in part from the use of strict age ranges due to pediatric protocols.³ In recognition of this, the upper age limit for pediatric group protocols has been increased to 30 or 40 years and new adult pediatric cooperative group trials have been established for research in several cancers, a marked success of collaboration efforts thus far.³ However, the participation of AYA cancer patients in clinical trials remains a distinct barrier in learning about the unique pathology of their cancer. There are several practical and personal reasons that AYAs do not enroll in clinical trials: diagnosing physicians do not refer patients to current trials; high unemployment of this population results in limited funding for health care and often no insurance coverage to cover cost of treatment; the highly transient nature of this age range limits the number of participants who successfully commit to the duration of the trial; and the emotional distress experienced by AYAs fosters an indignant attitude toward any association with their diagnosis.^{1,2,3,9,11,12} Identified as unique challenges to the AYA population, these needs are being addressed by both psychosocial and clinical professionals.

PSYCHOSOCIAL

Several distinguishing social, developmental, biological, and psychological trends in AYAs have prompted scholars from many fields to research discrepancies for this population. Even before their cancer diagnosis, AYAs are at a disadvantage. This age range is associated with perceived invulnerability; few cancer prevention measures are targeted at this population and there is a distinct delay in accessing a physician for a medical concern.² Once the AYA sees a primary care physician, their symptoms are often attributed to fatigue or stress and no further testing is conducted.² If the patient is successfully diagnosed, there is no standardized referral

pattern or treatment regimen for cancers in this age range; the patient may be referred to a pediatric oncologist, gynecological oncologist, or radiation oncologist who then decide how to treat the patient.² A call for more structure in how to clinically treat AYAs is unanimous in all related disciplines.

Relative to older and younger populations, AYA adherence rates are lower both in cancer and other chronic illnesses.¹² Definitions of adherence vary between fields. Formerly described as compliance, the term adherence in nursing is seen as an active responsible role taken by the patient in the interest of their care.¹³ Other medical fields consider adherence to be valued strictly by compliance with medical advice such that non-compliance is the tardiness or absence of treatment when prescribed.¹³ In this analysis, adherence to medical advice will be used as the working definition. Adherence to treatment is often disrupted due to the same barriers of enrolling in clinical trials and significantly impacts the quality of life the patient experiences in survivorship.¹⁴ Non-adherence is of particular concern for cancer patients because it greatly decreases the efficiency of treatment and chance of survival.¹² Limited communication between the patient, their oncology team, and their primary care physician both during and after treatment results in lessened adherence to follow-up testing and care, in addition to increased incidence of relapse.^{12,15}

More recent literature has eluded to a relationship between the unmet psychosocial needs of this population to their adherence to treatment and follow-up care.^{13,14} Psychosocial needs that have been identified by AYAs include: credible, relevant information specific to this age range available online; mental health services; socializing opportunities with other AYAs; and practical services such as transportation and childcare.^{14,16,17} Addressing these needs is the focus of social

workers, psychologists, and oncologists alike. By increasing available resources to meet these needs, both quality of care and quality of life will be augmented for AYAs with cancer.

Adolescents and young adults are all at unique milestones in their maturation and psychological development. At a time of life that is meant to be for exploration, experimentation, and self-discovery, a cancer diagnosis is devastating. Exploration is replaced with confinement and fatigue, experimentation is replaced with adherence, and self-discovery takes place in an environment of anxiety, fear, and various treatments. AYAs often experience severe emotional and physical distress after their diagnosis as well as in survivorship.¹⁶⁻¹⁸ Not only are their lives disrupted at one of the most critical stages in identity development, but their survival rates are lower than average due to stigma surrounding health status in this age group. This population is at the crux of medical and psychosocial disadvantage, and increasing awareness is not enough. More research and evaluation is necessary to improve the quality of life and survival rates for this population.

LITERATURE REVIEW

Literature surrounding the medical study of AYA oncology and the developmental process of AYA cancer patients has developed dynamically since first emersion in the late 1970s. The field of nursing initiated study of psychosocial and developmental challenges of this population and has remained a strong and consistent voice in advocacy for this group.¹⁸⁻²¹ Early published works focused on how different nursing methods could aid the patient and improve quality of life during treatment.¹⁹ Other publications note how difficult young adult patients can be to treat due to disrespectful behavior and share best practices.²⁰ In 1991 a team of nurses published an article identifying two areas of development that needed to be researched further:

the impact of cancer on development during adolescence; and the various coping strategies and styles of the adolescent cancer patient.²¹

In 1980, a team of medical doctors conducted a study of 23 patients ages 5 to 35 to investigate the distinctive clinic-pathology of specific carcinoma in liver found in adolescent and young adult patients.²² This was one of the first acknowledgements of differing biology in adolescent and young adult cancers. In the mid-1990s, a call for an interdisciplinary team of providers was made by an oncologist in Britain due to the physical, educational, and emotional needs of this group; increasingly, psychosocial needs of the patient were being addressed by medical doctors.¹⁹ A noted oncologist wrote: “In contrast to the broadly accepted view of adolescence as a 'time apart' somewhere between childhood and adulthood, it should be viewed as containing elements of both of these. Adolescents are both adults and children”.¹⁹ Treatment must address both the conflicts of adults and children, that psychosocial care must anticipate adult and pediatric needs. At this point, research in AYA oncology was limited to the fields of nursing, medicine, and psychology.

AYAO continued to gain momentum around the globe. In Scotland a literature review was conducted by oncology nurses examining the current work in psychosocial needs.²³ During this evaluation, the authors identified five themes of pertinent support to AYA cancer patients: “Parents and siblings, Psychosocial issues, School and social life, Information and support, Sexuality and Hopefulness”.²³ During this same year, Archie Bleyer MD enters the discussion of AYA oncology and discusses the age range used to define this population.¹⁰ Bleyer continues to make a unique impact on the field. Since his early AYAO publications, Bleyer has published as part of an interdisciplinary team of authors and offered comprehensive evaluations and direction

for medical and psychosocial needs. He remains a key player in discussion and promotion of AYAO with interdisciplinary management strategies.

Concern surrounding patient compliance to treatment solidified in 2000 with a published study on adolescent and young adults with various chronic diseases.¹³ In this study, only 23% of adolescents reported full compliance with health treatment and 17% reported poor compliance, the rest on a spectrum in between.¹³ In high compliance cases, adherence was promoted by motivation, positivity, and support in continuing normal social activities.¹³ One year later, the same lead author published a report stating that the most powerful predictor of compliance was support from nursing staff.²⁴ The field of nursing steadily increased publications on AYA cancer patients, and called for meaning based models of research for qualitative findings.²⁵

A pivotal year for AYAO was in 2006 when the National Cancer Institute (NCI) and the Lance Armstrong Foundation (LAF) collaborated to create the Adolescent and Young Adult Oncology Peer Review Group (AYAO PRG).² A large group of contributors were chosen from various fields that encounter oncology patients, including public health professionals, social workers, pediatric and adult oncologists, nurses, pharmaceutical specialists, public administration specialists, and others. The creation of the PRG solidified AYAO as a specialty of its own within oncology. A shift in conversation surrounding AYA cancer patients and treatment began with this publication; research was more focused and suggestions and criticisms direct. Specific topics within AYAO were defined and clear measures of improvement were set. With expectations set and awareness increased, this marked a new wave of participation from other disciplines outside of oncology and psychology. Three distinct areas of concern emerged as the most frequent and debated topics in AYAO: clinical trial participation and availability; differences in biology; and psychosocial needs.

One of the co-chairs of the psychosocial/behavioral factors committee of the PRG was esteemed Dr. Brad Zebrack of the School of Social Work at the University of Michigan.^{2,26} Zebrack was the first resilient interdisciplinary voice in the field of AYAO and published many articles on information and psychosocial needs of AYA cancer patients.^{14,16-18,26-29} Awarded a doctorate of Social Work and Sociology, Masters of Social Work, and Masters of Public Health, Zebrack researches matters of psychosocial durability and quality of life in young cancer patients. His work encompasses pediatric and AYA age ranges and comments on the social and identity formations of young adult cancer survivors.²⁷

Brandon Hayes-Lattin, MD is the leading voice in biological differences between adult and pediatric cancers. As a co-chair of the awareness breakout group at the PRG, Hayes-Lattin advocated that AYA cancer patients be accepted as a distinct population with unique needs.² This publication also addressed the descriptive nature of published works up to that point and called for more evidence collection and research.² Hayes-Lattin is an AYA cancer survivor and is an advocate for AYA cancer patients. He brings a personal light and lens to the study of a population that is plagued by exaggerated symptoms and side effects. His dedication to AYAO has led him to start an AYA Oncology Program at Oregon Health and Science University that specifically targets this population's medical and psychosocial needs. Hayes-Lattin's contributions to AYAO have lent a realistic view of the trials that these patients face when confronted with a chronic disease. Specifically, he has become an advocate for the study of differing biology between adult and AYA cancers. His work supports the claim that oncologists can better the lives of their patients by better understanding the specific biological functioning in addition to addressing the psychosocial needs of each patient. Hayes-Lattin offers person consultations with AYA cancer patients at Oregon Health and Science University in an effort to

better explain their treatment and/or offer advice and resources on how to cope with other issues attached to a cancer diagnosis. The work of Hayes-Lattin has shaped further research for this group and increased awareness throughout the clinical and social services.

The majority of authors are in agreement that increased collaboration between adult and pediatric oncologists is needed in addition to addressing the psychosocial needs of the population. Both adult and pediatric oncologists call for increased collaboration between the two fields to decrease the “no man’s land” many AYAs find themselves in. One example of this is the improvement in collaboration is the reconsideration of age restrictions for pediatric clinical trials.³ Many advocates concentrate all resources on improving psychosocial needs of patients, but the majority of oncologists weighing in on the conversation identify clinical trials as the primary concern for the AYA population. Distinct need for biological research and clinical trials remains the highest urgency found in AYAO literature as a whole due to the origin of this defined population which has decreased or plateaued five year survival rates.

The route to increase biological data on this population is debated, as the cause of low clinical trials is a plexus of systemic barriers. Several authors attribute low clinical trial data to poor physician recruitment, availability of trials for patients in the AYA age range, low adherence rates from patients once enrolled in a trial, or a combination of these causes. Physician interest in initiating research on AYA cancers is still relatively low due to the recent emergence of the specialty; increased awareness of this population may assist in increasing attention. Current AYA providers face protocol and financial barriers to completing a clinical trial due to age restrictions and lack of grant funding.^{1,2,12} Trial eligibility and referral patterns to those trials remain convoluted and exclusive to older and younger cancer patients.^{1,2,10} One example is in the study of germ cell tumors in adolescents; male patients with testicular or extragonadal germ cell

tumors are excluded from pediatric trials once they reach the age of 15, yet females with ovarian germ cell tumors may enroll in pediatric trials until the age of 21.¹ Butow describes two general frameworks of thought surrounding adherence behaviors in AYAs: interactions between the patient and their medical team and the patient's personal cognitive-motivational processes.¹² Both frameworks address adherence as a dynamic process relative to each individual patient.

CONCLUSION

In recognition of the body of literature surrounding AYA circumstance, an additional category of psychosocial and practical needs must be included in the discussion surrounding adherence. Many studies on adherence to cancer treatment and other chronic illnesses between the ages of 15 and 39 point to a distinct correlation between psychosocial needs met and adherence to treatment and clinical trial participation.^{1,3,11,12,13,23,24} Autonomy, relationships, education, employment, and social maturation can all affect adherence of adolescent patients.^{1,12,14,13,24} Functional needs such as transportation, childcare, employment, and insurance coverage are direct barriers to adherence in clinical trials and treatment.^{1,3,12,14,17,13,30-32} However, emotional and psychological needs also effect patient engagement and adherence. Increased stigma and anxiety surrounding the stress and physical pain of cancer treatment is often a deterrent for patients to interact with their medical providers and engage in any research or clinical trial.^{1-3,33} Confidence, family relationships, friendship, support from medical staff, and autonomy deprivation can all significantly alter the motivation and cognitive processes of the patient.^{2,14,21,24,31,33}

Lack of psychosocial support both during and after treatment increases risk of nonadherence. A proposed solution to the deficit of care for AYA cancer patients echoes much

of what has already been discussed in the field: there must be a clear clinical referral pathway between pediatric and internal medicine; increased awareness and urgency must be conveyed to the public to stimulate grant funding; psychosocial needs must be addressed; benign and malignant specimen banking must increase; and AYA specific clinical trials must increase. But in addition, the manner in which AYAs are treated must be evaluated. Psychosocial needs must be met at the forefront of a patient's treatment to increase adherence. Psychosocial services must become an integral part of AYA cancer treatment, and clinical trials must be intentionally designed to overcome common barriers for AYAs including practical, emotional, and social support. Only when the entirety of a patient's needs are met can the oncology community increase survival rates for the population. Utilizing a holistic approach with AYA patients is necessary to stimulate clinical trial participation and increase survival rates for this population.

References

1. Burke ME, Albritton K, Marina N. Challenges in the recruitment of adolescents and young adults to cancer clinical trials. *Cancer*. 2007;110(11):2385–2393. doi:10.1002/cncr.23060.
2. Adolescent, Group YAOPR. *Closing the gap: research and care imperatives for adolescents and young adults with cancer (NIH Publication No. 06-6067)*. Department of Health and Human Services, National Institutes of Health, National Cancer Institute, and the LIVESTRONG Young Adult Alliance Bethesda, MD; 2006.
3. Ferrari A, Montello M, Budd T, Bleyer A. The challenges of clinical trials for adolescents and young adults with cancer. *Pediatr Blood Cancer*. 2008;50(S5):1101–1104. doi:10.1002/pbc.21459.
4. Hayes-Lattin B, Mathews-Bradshaw B, Siegel S. Adolescent and Young Adult Oncology Training for Health Professionals: A Position Statement. *J Clin Oncol*. 2010;28(32):4858-4861. doi:10.1200/JCO.2010.30.5508.
5. Bleyer A. Adolescent and Young Adult (AYA) Cancers: Distinct Biology, Different Therapy? 2009. Available at: <http://search.informit.com.au/documentSummary;dn=076867674244230;res=IELHEA>. Accessed April 10, 2014.
6. Bleyer A, Barr R, Hayes-Lattin B, Thomas D, Ellis C, Anderson B. The distinctive biology of cancer in adolescents and young adults. *Nat Rev Cancer*. 2008;8(4):288-298. doi:10.1038/nrc2349.
7. Tricoli JV, Seibel NL, Blair DG, Albritton K, Hayes-Lattin B. Unique Characteristics of Adolescent and Young Adult Acute Lymphoblastic Leukemia, Breast Cancer, and Colon Cancer. *J Natl Cancer Inst*. 2011;103(8):628-635. doi:10.1093/jnci/djr094.
8. the AYA HOPE Study Collaborative Group, Harlan LC, Lynch CF, et al. Recruitment and follow-up of adolescent and young adult cancer survivors: the AYA HOPE Study. *J Cancer Surviv*. 2011;5(3):305-314. doi:10.1007/s11764-011-0173-y.
9. Bleyer WA. Cancer in older adolescents and young adults: Epidemiology, diagnosis, treatment, survival, and importance of clinical trials. *Med Pediatr Oncol*. 2002;38(1):1–10. doi:10.1002/mpo.1257.
10. Bleyer WA, Tejeda H, Murphy SB, et al. National cancer clinical trials: Children have equal access; adolescents do not. *J Adolesc Health*. 1997;21(6):366-373. doi:10.1016/S1054-139X(97)00110-9.

11. Ferrari A, Bleyer A. Participation of adolescents with cancer in clinical trials. *Cancer Treat Rev.* 2007;33(7):603-608. doi:10.1016/j.ctrv.2006.11.005.
12. Butow P, Palmer S, Pai A, Goodenough B, Lockett T, King M. Review of Adherence-Related Issues in Adolescents and Young Adults With Cancer. *J Clin Oncol.* 2010;28(32):4800-4809. doi:10.1200/JCO.2009.22.2802.
13. Kyngäs H. Compliance of adolescents with chronic disease. *J Clin Nurs.* 2000;9(4):549-556. doi:10.1046/j.1365-2702.2000.00368.x.
14. Zebrack BJ, Block R, Hayes-Lattin B, et al. Psychosocial service use and unmet need among recently diagnosed adolescent and young adult cancer patients. *Cancer.* 2013;119(1):201-214. doi:10.1002/cncr.27713.
15. Nathan PC, Hayes-Lattin B, Sisler JJ, Hudson MM. Critical issues in transition and survivorship for adolescents and young adults with cancers. *Cancer.* 2011;117(S10):2335-2341. doi:10.1002/cncr.26042.
16. Zebrack B. Information and service needs for young adult cancer survivors. *Support Care Cancer.* 2009;17(4):349-357. doi:10.1007/s00520-008-0469-2.
17. Zebrack B. Information and service needs for young adult cancer patients. *Support Care Cancer.* 2008;16(12):1353-1360. doi:10.1007/s00520-008-0435-z.
18. Zebrack B, Butler M. Context for Understanding Psychosocial Outcomes and Behavior Among Adolescents and Young Adults With Cancer. *J Natl Compr Canc Netw.* 2012;10(9):1151-1156.
19. Caring for the young adult with cancer: Cancer Nursing. Available at: http://journals.lww.com/cancernursingonline/Fulltext/1978/10000/Caring_for_the_young_adult_with_cancer.5.aspx. Accessed April 26, 2014.
20. Lewis IJ. Cancer in adolescence. *Br Med Bull.* 1996;52(4):887-897.
21. Ma R. Psychosocial functioning of adolescents with cancer: a developmental perspective. *Oncol Nurs Forum.* 1991;19(10):1497-1501.
22. Craig JR, Peters RL, Edmondson HA, Omata M. Fibrolamellar carcinoma of the liver: A tumor of adolescents and young adults with distinctive clinico-pathologic features. *Cancer.* 1980;46(2):372-379. doi:10.1002/1097-0142(19800715)46:2<372::AID-CNCR2820460227>3.0.CO;2-S.
23. Whyte F, Smith L. A literature review of adolescence and cancer. *Eur J Cancer Care (Engl).* 1997;6(2):137-146. doi:10.1046/j.1365-2354.1997.00022.x.
24. Kyngäs H, Rissanen M. Support as a crucial predictor of good compliance of adolescents with a chronic disease. *J Clin Nurs.* 2001;10(6):767-774. doi:10.1111/j.1365-2702.2001.00538.x.

25. Haase JE, Phillips CR. The Adolescent/Young Adult Experience. *J Pediatr Oncol Nurs*. 2004;21(3):145-149. doi:10.1177/1043454204264385.
26. Zebrack B, Isaacson S. Psychosocial Care of Adolescent and Young Adult Patients With Cancer and Survivors. *J Clin Oncol*. 2012;30(11):1221-1226. doi:10.1200/JCO.2011.39.5467.
27. Zebrack BJ. Cancer Survivor Identity and Quality of Life. *Cancer Pract*. 2000;8(5):238-242. doi:10.1046/j.1523-5394.2000.85004.x.
28. Zebrack B, Bradley J, Zebrack. 2014. Available at: <http://ssw.umich.edu/faculty/profiles/tenure-track/zebrack>. Accessed May 5, 2014.
29. D'Agostino NM, Penney A, Zebrack B. Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. *Cancer*. 2011;117(S10):2329-2334. doi:10.1002/cncr.26043.
30. Abrams AN, Hazen EP, Penson RT. Psychosocial issues in adolescents with cancer. *Cancer Treat Rev*. 2007;33(7):622-630. doi:10.1016/j.ctrv.2006.12.006.
31. Evan EE, Zeltzer LK. Psychosocial dimensions of cancer in adolescents and young adults. *Cancer*. 2006;107(S7):1663-1671. doi:10.1002/cncr.22107.
32. Harlan LC, Lynch CF, Keegan THM, et al. Recruitment and follow-up of adolescent and young adult cancer survivors: the AYA HOPE Study. *J Cancer Surviv*. 2011;5(3):305-314. doi:10.1007/s11764-011-0173-y.
33. Roberts CS, Turney ME, Knowles AM. Psychosocial Issues of Adolescents with Cancer. *Soc Work Health Care*. 1998;27(4):3-18. doi:10.1300/J010v27n04_02.