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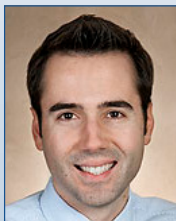
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Perspectives and Approaches to the Dynamic and Developmental Issues in Adolescent Health Care

PATRICIA FLANAGAN, MD
GUEST EDITOR

In this and next month's issue of the *Rhode Island Medical Journal* (RIMJ) we have the privilege of sharing topics in Adolescent Health with readers. Adolescence is generally a very healthy stage of life. Youth aged 10-24 years have the lowest rates of morbidity and mortality in the US and Rhode Island has the lowest teen death rate in the country.¹ Many of the health issues faced by teens are keenly linked to the developmental dynamics of adolescence and behavioral decision making. The leading causes of death in this age group include accidents, primarily motor vehicle crashes, but also unintentional overdoses, homicide, and suicide.

It is important to note that health behaviors beginning in adolescence continue into adulthood, making this a unique time in a life-course for interventions that will have a lasting impact.

Three-quarters of adults with severe and persistent mental illness experienced their first symptoms prior to age 18. Most adult tobacco smokers began smoking as teens. The majority of young people engage in sexual activity by age 21. Rates of chlamydia and gonorrhea are highest among teens and young adults. While rates of teen pregnancy continue to fall, in 2015 we still had 509 young women under the age of 20 give birth in RI.

Providing health care for teens requires an understanding of adolescent psycho-social, psycho-sexual, and cognitive development. Brain maturation from age 10 to age 24 is dramatic, is variable in timing and tempo, and is not always in synchrony with the dynamic physical maturation that happens throughout adolescence. The capacity of a 12-year-old to communicate his or her concerns and symptoms, to understand the ramifications of actions or behaviors, and to fully engage in healthcare decision making certainly can vary widely but is also drastically different from a 16-year-old or a 21-year-old. Helping young people navigate adolescence with the tools, knowledge and motivation to stay healthy requires building a developmental scaffolding. Partnering with parents, schools, and communities allows teens to experiment, to grow, to take risks and make good choices.

This issue of RIMJ opens with **Dr. Susan Duffy's** paper on the very important and difficult topic of adolescent confidentiality. This is a topic that is central to caring for youth yet is complex. Understanding confidentiality and its limits and communicating this to youth and their families is essential to providing high quality effective health care. **Dr. Joanna Brown** and colleagues discuss the very important topic of youth engagement. They present three different

initiatives in Rhode Island that have successfully engaged youth to participate in their own care and to help build a health care system that works for teens and young adults. **DR. SUZANNE MCLAUGHLIN** and colleagues present the proceedings of a panel discussion on transitioning youth to adult care systems that was part of a learning collaborative held by The RI Care Transformation Collaborative (CTC). The transitioning of youth from pediatric care systems to adult care systems is a transition that is often fraught with discontinuity, miscommunication and gaps in care. This is most significant for youth with special health care needs. We then present a case study of a young man whose transition was not smooth and point out multiple opportunities for systems improvement.

Next month, we will look at specific conditions and the health needs of specific populations of youth. **DR. ABIGAIL DONALDSON** and her team will present an update on the care of individuals with eating disorders. **DR. DIANE DERMARDEROSIAN** and colleagues write about an integrated approach to psychiatric care for children and youth with medical conditions. She describes a unique, team-based integrated care model provided both in an in-patient setting and in a partial hospital setting. **DRS. KRISTYN GERGELIS, JONATHAN KOLE** and **ELIZABETH LOWENHAUPT** write about the healthcare needs of incarcerated youth and **DRS. AGNIESZKA JANICKA** and **MICHELLE FORCIER** discuss transgender and gender non-conforming youth. **DR. CHRISTINE BARRON** and colleagues present their research on RI pediatricians and their training, screening, and knowledge about domestic sex trafficking of minors.

Quality health care that recognizes the dynamic developmental nature of adolescence can help youth stay safe and make good behavioral choices. It can be attuned to some of the potential pitfalls and roadblocks to healthy adolescence as well as motivations for positive health-affirming decisions. It can be a great opportunity to cultivate a strong foundation for adult health.

Reference

1. Heron M. Death: leading causes for 2013. National Vital Statistics Reports. Feb. 16, 2016; 65(2).

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Providing Confidential Care to Adolescents in Healthcare Settings

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KEYWORDS: Adolescent Confidential Care, privacy

INTRODUCTION

An unaccompanied 15-year-old girl presents to a local emergency department (ED) with abdominal pain, but at triage does not reveal her concern that she may have a sexually transmitted infection (STI). She is seeking care in the ED instead of her primary care medical home because she believes her visit will be confidential. Upon ED arrival, the youth explains her symptoms to a nurse, who orders urine testing for pregnancy and STIs. Registration staff obtains her insurance and contact information. If she were an adult, this would be a typical ED visit for an acute complaint. Since she is a minor, the situation is complicated by the complexities of providing confidential care to an adolescent.

Based on the patient's symptoms suggesting a possible STI, this minor has the legal right to confidential care in all 50 states. Privacy, however, even if mandated, is not always guaranteed because of the many ways confidentiality can be breached during a health care encounter.¹ In addition, the adolescent may not be in the best position to advocate for her rights. She may be unfamiliar with the laws created by the state and the Federal governments to decrease barriers to care for specific conditions as well as the general workings of the healthcare system.² Hospital staff may also be unaware of the laws, fail to inquire about confidential conditions or inform adolescents of their rights. By not recognizing that a minor is seeking confidential care, healthcare staff may unwittingly inform parents.¹ Unless informed, minors may be unaware that their parents' insurance company will be billed for visits and parents may receive financial statements as well as explanation of benefits (EOB) notifying them of the visit.³ Minors may not know that their parents may have access to confidential lab results through electronic health record (EHR) portals.^{4,5} Or, that healthcare providers may decide it is in the youths' best interest to notify parents of their conditions.¹

PRIVACY IN ADOLESCENT MEDICAL PRACTICE

One of the tenets of adolescent medical practice is to provide confidential care and privacy to minors that align with their evolving autonomy. Medical professionals who care for adolescents practice with an appreciation for their developing cognition and limited life experiences that sometimes, but not

always, limits their capacity to make fully competent decisions.⁶

Since parents are responsible by law and culture for most of the medical decisions involving minors, medical professionals routinely broker with both parents and adolescents about the allocation of medical decision-making. In many adolescent practices, minors, parents and physicians sign formal contracts, agreeing to confidentiality between adolescents and their medical providers as long as it is within the boundaries of professional practice and the law.^{7,8}

In most situations, parents are in the best position to help their adolescents make decisions. They typically know their children best and place the highest priority on their welfare with an appreciation for their evolving capacity for decision-making. Adolescents often welcome their parents' input and look to them for guidance.^{1,7,8,9}

It is faulty to assume however, that because parents are adults they always make competent decisions for their children. Or, that minors lack the capacity to make thoughtful decisions. In fact, sometimes there is conflict between parents' priorities and those of their adolescent children, especially in areas of reproductive health and substance abuse. Such conflict can create barriers to adolescents accessing appropriate healthcare.^{1,7,8,9}

POLICIES RELATED TO ADOLESCENT HEALTHCARE DECISIONS

Out of concern for adolescents and the public health, most states have adopted minor consent and privacy laws that allow certain minors to consent to confidential care in specific areas. Services supported by statute include those for family planning, pregnancy care, STI and HIV testing and treatment, substance abuse treatment, outpatient mental health care, emergency care, sexual assault evaluation and less frequently abortion. Laws differ in each state and define the limits of confidentiality and consent.^{10,11}

A few states have specific statutes that outline criteria for mature minor and emancipated minor status. Most states, including Rhode Island (RI), do not have laws and rely on individualized judicial decisions to make determinations.^{10,11}

At the federal level, protection for reproductive rights, including for adolescents, dates to 1970 when Congress added Title X of the Public Health Service Act that established federally funded programs to allow access to family planning services to everyone. The act was subsequently amended to insure that adolescents have confidential access to care in specific situations.^{1,8,11}

The Supreme Court has also ruled in favor of the

constitutional right to privacy of adolescents in the context of decision-making related to reproductive health and allows them autonomy in decisions to obtain contraception without parental consent.¹

The Supreme Court decision in *Roe v Wade* in 1972 led the way for legalized abortion, including for adolescents. State statutes that followed have consistently limited access to abortion for adolescents without parental consent in all but 2 states. Federal rulings have countered state regulation and supported protection of adolescent decision-making with a “judicial bypass” where a judge determines a minor’s capacity to make the decision to have an abortion without parental consent.^{1,12}

In 1996, Federal health care privacy regulations were issued under the Federal Health Insurance Portability and Accountability Act (HIPAA). These rules were designed to safeguard health information, and facilitate patients’ access to their health information. HIPAA rules closely align with state minor consent laws and other established laws to assure that when a minor can legally consent for care, their health information must be protected, including from their parents.^{3,5,13}

In addition to HIPAA protections, state privacy laws also direct healthcare providers to maintain confidentiality of information. In RI, like most states, if a minor has the authority to consent for care, information cannot be released, even to parents unless the minor consents.¹⁴

There are specific federally funded healthcare programs that protect adolescent confidentiality. Title X Health Centers administered through the Department of Health and Human Services are purposed to assure access to confidential family planning services regardless of age or ability to pay. Medicaid programs are also required to support family planning services for beneficiaries. A few state public funds also support specific abortion services allowed by law.^{1,10}

There are a variety of other state specific laws and policies that help safeguard adolescent confidentiality and direct healthcare professionals. Included are laws that address healthcare providers’ rights to care for adolescents within the boundaries of professional practice and rely on good faith information provided by a minor about their status.^{1,9,11}

A joint statement issued by the the American Academy of Family Physicians (AAFP), the American Academy of Pediatrics (AAP), the American College of Obstetricians and Gynecologists (ACOG), and the Society for Adolescent Medicine (SAM), support the principles of protecting adolescent privacy and respecting confidentiality when the adolescent has the legal right to give consent, while making reasonable efforts to encourage adolescents to involve their families in their healthcare decisions.⁷

STI TESTING AND TREATMENT, CONTRACEPTION AND PREGNANCY

In all states, youth ages 12 and older can consent to confidential care related to STIs. In RI, the law includes confidential testing and treatment of all reportable communicable diseases including HIV. There is no legal requirement to report pregnancy to a parent.^{10,11}

In many states there are laws defining the age of consent for contraceptive and pregnancy related services. In RI there are no statutes but Federal privacy and Title X mandates allow all minors access to confidential family planning services and sets a precedent for access to adolescent confidential contraception and pregnancy care.^{10,11} Title X language encourages but does not require minors to involve their parents in their decisions. Medicaid programs in RI also support payment for adolescent contraception and pregnancy related services.^{10,11} Adolescents who consent for treatment but are not insured by Medicaid are financially responsible for services. The Affordable Care Act (ACA) mandates that private insurance cover contraceptive services with some exceptions.¹¹

ABORTION

Per RI Law, abortion for a minor requires consent of one parent except for medical emergencies. There is an allowance for judicial bypass.^{10,11,14} Connecticut is one of two states that allow adolescents to make the autonomous decision to have an abortion.¹¹ Many private insurers cover abortion services. A recent ruling related to the ACA however, mandates that insurers offer plans that do not offer coverage abortion services.

In RI, public insurance or programs for public employees cover abortion only in cases of life endangerment, rape or incest.¹⁵ Massachusetts Medicaid programs support specific abortion services.

EMERGENCY CARE

Adolescents in RI ages 16 years or older or married may consent to “routine medical or surgical care” and the health information from these visits is confidential. Since “routine emergency care” may fall outside of typical specific confidentially protected care, without safeguards in place in the EHR, this information may be vulnerable to disclosure.^{1,16} In general, minors are financially responsible for treatment for which they consent. In every state, laws support treatment of minors for emergency conditions without parental consent.¹⁶

SUBSTANCE ABUSE TREATMENT

In RI, as in many states, adolescents are allowed to seek treatment for drug or alcohol abuse without parental consent if a qualified professional agrees contacting a parent would not be helpful to the care. There is also no legal requirement to report substance abuse to parents. Parental participation is required for minors to enter a substance abuse treatment program.^{14,17,18}

ELECTRONIC HEALTH RECORD

The establishment of EHRs has increased the exchange and accessibility of health information, but has also resulted in dilemmas related to the protection of adolescent confidential health information.^{19,20}

Most commercial EHRs, including those in RI medical practices, do not have automatically instituted privacy controls for adolescent confidential information. Very few provide point of care access to medical professionals that allow them to segregate or highlight confidential information within the record.^{3,4,5} HIPAA and state privacy laws require

that confidential medical information of minors can only be released after their written consent. Without privacy controls, determining what constitutes confidential information requires an inspection of the record by trained personnel without guarantee that all confidential information will be identified.³ Some EHR vendors have customizable features that can be adapted to meet privacy standards.^{19,20} Patient portals, for example can be configured to allow minors of a specified age and their medical providers access to their personal health information (PHI) while parents are allowed access only by proxy.^{19,20} Each institution must determine how options for privacy are implemented in the EHR and inconsistency across systems may compromise confidentiality.

HEALTH INFORMATION EXCHANGE

The Health Information Exchange in RI called Current Care include policies that support the privacy of enrolled minors that aligns with HIPAA and privacy regulations.²⁰ The PHI related to confidential care of minors between the ages of 10 and 18 years is released only to the minor’s authorized health care providers. The PHI of “routine emergency medical or surgical care” of minors between the ages of 16-18 years is released only to them or their authorized healthcare provider.

INSURANCE

Adolescents are typically insured as their parents’ dependents. One of the most common ways adolescent confidential information is breached is when parents receive insurer provided explanation of benefits (EOBs) or financial statements.^{4,18,20} Each insurer sets the standard for what information is included in their EOBs. Some provide detailed information related to testing and treatments while others, including EOBs from Medicaid programs, are less specific. Some states have developed regulations around EOBs to protect the confidentiality of minors insured as dependents.^{1,3,5}

Respecting the evolving autonomy and privacy of adolescents aligns with best medical practices. Healthcare professionals and their staff are obligated to know and integrate the laws and standards related to adolescent confidentiality and privacy into their practices. Medical professionals will best serve their patients by becoming educated about programs supported by the federal and state governments and other organizations to safeguard adolescent confidentiality, reduce barriers to care and promote adolescent health and wellbeing.

References

1. US Congress of the United States, Office of Technology Assessment Adolescent Health - Volume III: Crosscutting Issues in the Delivery of Health and Related Services. Chapter 17. Consent and Confidentiality in Adolescent Health Care Decision Making. June 1991. III-123-155.
2. ACOG Educational Bulletin. Confidentiality adolescent health care. Number 249, August 1998. American College of Obstetrics and Gynecologists. *Int J Gynaecol Obstet* 1998; 63:295.
3. Bourgeois FC, Nigri DJ, Harper M. Preserving Patient Privacy and Confidentiality in the Era of Personal Health Records. *Pediatrics*, May 2015, Vol 135, Issue 5.

4. Rosenbaum S, Abrasom S, MacTaggart P. Health Information Law in the Context of Minors. *Pediatrics*. 2009. (suppl2) s116-s121.
5. Council on Clinical Information and Technology. Policy Statement. Using personal Health Records to Improve the Quality of Health Care for Children. *Pediatrics*. 2009: 124:403-407.
6. Moon Margaret, MD, MPH. Adolescents Rights to Consent to Reproductive Medical Care: Balancing Respect For Families with Public Health Goals. *AMA Journal of Ethics*. Available at <http://journalofethics.ama-assn.org//2012/10/msoc1-1210.html>
7. Confidential Health Services for Adolescents. Council on Scientific Affairs, American Medical Association, JAMA. 1993; 269:1420
8. American Academy of Family Physicians, American Academy of Pediatrics, American College of Obstetricians and Gynecologists, and Society for Adolescent Medicine. Protecting adolescents: Ensuring access to care and reporting sexual activity and abuse. *J Adolesc Health*. 2004;35:420.
9. Ford C, English A, Sigman G. Confidential health care for adolescents: Position paper for the Society for Adolescent Medicine. *J Adolesc health*. 2004;35:160-7.
10. Guttmacher Institute. Boonstra H, Nash E. Special Analysis: Minors and the Right to Consent to Health Care. August 2000. Available at: www.guttmacher.org.
11. Guttmacher Institute. State policies in Brief. An overview of minors’ consent law. Available at: www.guttmacher.org/state-center/
12. English A, Bass L, Boyle AD, et al. State Minor Consent Laws: A Summary, 3rd ed. Center for Adolescent Health and the Law, Chapel Hill, NC. 2010.
13. The adolescent’s right to confidential care when considering abortion. American Academy of Pediatrics. Committee on Adolescence. *Pediatrics*. 1996; 97:746.
14. American Academy of Obstetrics and Gynecologists. Committee on Adolescent Health Care. Adolescent Confidentiality and Electronic Health Records, Vol. 123, No. 5, May 2014.
15. <http://law.findlaw.com/state-laws/medical-records/rhode-island/>
16. <http://www.rules.state.ri.us/rules/released/pdf/DOH/>
17. Consent for Emergency Medical Services for Children and Adolescents, Committee on Pediatric Emergency Medicine and Committee on Bioethics. *Pediatrics*. Aug 2011; 128(2);427-433.
18. Weddle M, Kokotailo P. Adolescent Substance abuse. Confidentiality and Consent. *Pediatr Clin North Am*. 2002;49:301.
19. Testing for Drugs of Abuse in Children and Adolescents. American Academy of Pediatrics Committee on Substance Abuse. *Pediatrics*. 1996;98:305.
20. Anoshiravani A, Gaskin GL, Groshek MR, Kuelbs C, Longhurst CA. Special requirements for electronic medical records in adolescent medicine. *J Adol Health*. 2012; 51:409-414.
21. Standards for Health Information Technology to Ensure Adolescent Privacy, Committee on Adolescence, Council on Clinical and Information Technology. *Pediatrics*. Nov. 2012;Vol. 130/ issue 5.

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Patient Engagement for Youth in Multiple Facets of Healthcare in Rhode Island

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ABSTRACT

Health reform strives to be patient-centered but often emphasizes institutional and financial well-being at the expense of patient responsiveness. Rhode Island is a pioneer, with innovative youth engagement programs in health care. The Youth Advisory Board of the Adolescent Patient-Centered Medical Home (PCMH) Initiative at Brown Family Medicine has brought together adolescents to gather feedback about participants' preferences for their health care and bring that feedback to health care providers. The Adolescent Leadership Council (TALC) of Hasbro Children's Hospital is comprised of adolescents with chronic medical illnesses and serves as an advisory group. The Rhode Island Department of Health's Office of Special Needs offers Dare to Dream, a youth leadership development program, a youth advisory council and a healthy lifestyles program. These youth engagement programs allow youth to help shape the health care system to meet their needs and contribute to youth empowerment in the state.

KEYWORDS: patient engagement, Patient-Centered Medical Home, special needs, adolescent health transition, positive youth development

INTRODUCTION

Engaging youth in their health care is critical to shaping care in a way that benefits them as patients and consumers. The programs described in this article originate from a variety of sources that have shaped, and are currently shaping, health and health-related programming for adolescents and young adults. These include Positive Youth Development (PYD), the Patient-Centered Medical Home (PCMH), and efforts to enhance patient and family-centered care across the health care system.

Positive Youth Development (PYD) represents an approach to youth engagement that strives to support the "growing capacity of a young person to understand and act on the environment."¹ Key to this approach are inclusiveness and a focus on strength and on positivity.¹ PYD has a rich and extensive literature, some of which focuses on community programming that helps youth build personal and social assets to enable them to make a successful transition to being competent adults.¹

The "Joint Principles of the Patient-Centered Medical Home" were published in 2007 by the main U.S. primary care societies; well before this time, however, medical homes were adopted in pediatrics as a way of achieving coordinated, high-quality care for children and youth with special health care needs.²⁻³ The PCMH model includes comprehensive, coordinated, team-based care, patient centeredness, continuity of care over time, quality, safety, enhanced access to care and payment reform.² Rhode Island has demonstrated a focused commitment to PCMH, forming the Care Transformation Collaborative (CTC, formerly CSI-RI) to promote PCMH adoption in primary care, and PCMH Kids, which focuses on primary care transformation for the state's children.

Patient engagement in medical homes can be implemented at three main levels: engagement of patients and families in their individual care, engagement of patients and families in practice improvement, and engagement of patients and families in policy, as discussed in a white paper published by the Association for Healthcare Research and Quality in 2010.⁴ Self-management support and motivational interviewing are examples of methods used at the individual level. With regard to practice improvement, techniques have been used such as patient and family advisory councils, informal suggestion books or patient "walk-throughs" to assess practice design. Regarding policy involvement, consumer representation in advisory groups on medical home projects is one example.

Substantial programmatic work has focused on engaging patients and families as advisors in health care improvement. The Institute for Patient and Family-Centered Care offers resources including conferences, tools and pamphlets such as "Families as advisors: a training guide for collaboration" and "Creating Children's Advisory Councils."⁵ The University of Michigan's Adolescent Health Initiative has maintained a Teen Advisory Council and published a guidebook to help others implement such groups.⁶ Here we describe three such programs in Rhode Island.

The Youth Advisory Board of the Adolescent Patient-Centered Medical Home (PCMH) Initiative

The Youth Advisory Board (YAB) of the Rhode Island Adolescent Patient-Centered Medical Home (PCMH) Initiative, or APCMH, was designed to engage local youth in offering input about adolescent healthcare to a larger project focused on patient-centered, community-based health-care delivery.

The APCMHI spanned five health care sites, five schools and five community agencies and was designed to improve primary health care quality and access for adolescents. To develop the YAB, project staff conducted outreach to youth at participating organizations. Meetings were held in easily accessible locations at convenient times. The youth participants were provided with gift cards for a set stipend and refreshments. Transportation was arranged for youth if needed. Project staff developed agendas and lesson plans for each meeting with input from participating agencies and chose topics based on youth interest. In addition to monthly meetings, youth were invited to offer input at larger project meetings, such as the APCMHI steering committee and other health care reform events.

The YAB met for nine sessions and covered such topics as nutrition and exercise, sexual health, behavioral health, transitions to adult care and substance abuse. At each meeting, project staff took notes and condensed findings into five to six key themes. Sample feedback from YAB meetings included statements such as, “Tell parents and guardians to leave the exam room when discussing certain topics;” “Environment matters! Think about what posters and magazines are in the waiting room,” and “Future plans, work, school, family and body image are major sources of stress.”⁷ In addition to offering comments at meetings, youth advisors made a video offering “Do’s and Don’ts” as to how providers should communicate with them about sexual health and used the video as a teaching tool at a CTC event.

While the advisory board was initially designed as a resource for the project and its participating health care sites, the youth participants reported that meetings were valuable to them as well. Meetings offered an educational venue where youth could learn health information in a way that was accessible to them. Several reported they then felt empowered to educate peers about how to better care for themselves.⁸

The Adolescent Leadership Council of Hasbro Children’s Hospital

The Adolescent Leadership Council (TALC) of Hasbro Children’s Hospital is a healthcare transition and support program for adolescents ages 13 to 18 who live with chronic medical illness. TALC provides year-long programming through monthly meetings, periodic social and art related events, an annual overnight summer leadership camp, and an annual team-building retreat. The overall goals of TALC are to decrease isolation, empower patients and their families to self-advocate, educate teens and their parents about healthcare transition, and educate providers about the experience of illness in adolescence. TALC achieves this through a PYD model that emphasizes mentoring and employs a strengths-based approach to support adolescents in successfully transitioning to adulthood.

College-age students who live with chronic illness serve as mentors to the teens, providing adult-youth relationships. Mentors assist in the design of agendas and help facilitate

meetings. Medical residents and other hospital staff help lead the program and act as “mentors to the mentors.”

The largest piece of TALC programming is the monthly leadership council meetings for youth and, separately, for their parents. At the beginning of each year, the adolescents work with mentors to develop a curriculum for their meetings that includes discussion topics and skill building activities. Participants identify topics pertinent to their experiences, such as: diagnosis, school, college, doctors, independence, relationships and “living outside the illness box.”

TALC has many demonstrated benefits. Youth with chronic illnesses are able to interact with peers who understand their experiences and can look to the mentors and staff for guidance. Physicians who refer to the program regularly report that their patients are more confident, more likely to self-advocate, and more involved in their care. TALC’s outcomes research indicates that participants become significantly less lonely, have a better attitude towards illness, and have increased transition-readiness skills after one year of participation.⁹ The youth themselves report satisfaction with the program and being better able to cope with illness. They also report increases in a variety of PYD-related measures. TALC provides one example of how the PYD model can be effectively used to help a specific adolescent population succeed as they transition to adulthood and to adult health care settings.

The RI Department of Health (RI DOH), Office of Special Needs (OSN)

The RI DOH OSN, also builds on the foundation of PYD through on-going youth engagement focused on youth potential as a means to promote adolescent health transition. In 2008 the OSN began engaging transition-age youth through a collaborative process with state and community partners. The OSN provides a framework for youth leadership and development called the Dare to Dream Initiative, convenes a Youth Advisory Council and offers workshops for adolescents and young adults promoting health and well-being.

The Dare to Dream Leadership initiative culminates with the Dare to Dream Student Leadership Conference, held annually since 2008 at the University of Rhode Island in Kingston. The day-long event is planned and led by students, for students. Workshops are presented in a relaxed, engaging, and creative environment that encourages learning, sharing, and connections with others.

More than 900 students, teachers, support staff and volunteers of all abilities attend from across Rhode Island.

Technical assistance is provided for schools and community groups who would like to participate.

The Youth Advisory Council is comprised of adolescents and young adults who have demonstrated leadership through Dare to Dream or other statewide youth initiatives and have an interest in working with their peers to improve their school and communities. The council advises and collaborates with the OSN on activities, programs, policies,

and resources affecting the health, wellness, and transition of youth in our state. The group is open to ages 14–26 and meets September through June.

The Healthy Lifestyles Workshops offer a free, fun, and interactive evidence-based curriculum co-taught by certified youth health coaches and adult mentors. Participants learn what it takes to live a healthy, balanced life and the program concludes with creation of a personal action plan for participants.

The Office of Special Needs Internship Program places transition-aged students in office-based, entry-level internships throughout the Department of Health. Intern tasks include mailings, filing, data entry, meeting preparation, outreach assistance, organizing, preparing health fair materials, presentations and providing youth input. These unpaid internships are open to students affiliated with other DOH transition programs and have resulted in a number of paid positions.

Through these initiatives, the RIDOH is creating an environment where students with diverse abilities can explore their potential, identify their unique capabilities for growth and development, and feel empowered.

DISCUSSION

Due to the efforts of these varied and innovative projects and programs, Rhode Island has been an important forerunner in the movement to engage and empower youth in their health-care experiences. The programs described in this article demonstrate that there are many ways to involve youth in their own health care, to harness their input to improve the care they receive and empower them to be more active participants in the health care system. In addition, outcomes of these programs suggest that participating youth may become more activated with regard to their own care, which has the potential to improve their own health behaviors.¹⁰ Each youth engagement program has been tailored to the sector of health care in which it has been built and to the youth patient or consumer population the program serves. Each program has been highly attentive to outreach and recruitment, to youth-friendly design, to leadership and skills development and to supporting and building on youths' strengths and capacity. These models of youth engagement can offer guidance to others who would like to continue to create youth-responsive health care in Rhode Island and elsewhere. Youth engagement in health care needs to be an ongoing priority, can be achieved, and can have a number of beneficial effects for the health care system and the youth themselves.

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References

1. Hamilton, S.F., Hamilton, M.A., & Pittman, K. Principles for Youth Development. In S.F. Hamilton & M.A. Hamilton (Eds.) 2004, *The Youth Development Handbook: Coming of Age in American Communities*, pp 3-22. Thousand Oaks: Sage Publications, Inc.
2. American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, American Osteopathic Association. Joint principles of the patient-centered medical home. Washington, DC: Patient-Centered Primary Care Collaborative; 2007.
3. What is the Medical Home? National Center for Medical Home Implementation. Available at <https://medicalhomeinfo.aap.org/overview/Pages/Whatisthemedicalhome.aspx>. Accessed 6-6-2016.
4. Scholle SH, Torda P, Peikes D, Han E, Genevro J. Engaging Patients and Families in the Medical Home. (Prepared by Mathematica Policy Research under Contract No. HH-SA2902009000191 TO2.) AHRQ Publication No. 10-0083-EF. Rockville, MD: Agency for Healthcare Research and Quality. June 2010.
5. Institute for Patient- and Family-Centered Care. <http://www.ipfcc.org>. Accessed 6-3-2016.
6. Creating and sustaining a thriving youth advisory council. Adolescent Health Initiative. Available at <http://umhs-adolescenthealth.org/wp-content/uploads/2014/12/Manual-for-Website.pdf>. Accessed 6-8-2017.
7. Big Lessons from a small state: Youth engagement in various facets of health care in RI. Presentation at Annual Meeting of Society for Adolescent Health and Medicine, March 2016.
8. Oral comments by youth panel at Adolescent PCMH Initiative Celebration, June 2015.
9. Maslow, G., Adams, C., Willis, M., Neukirch, J., Herts, K., Froehlich, W., Calleson, D., & Rickerby, M. An evaluation of a positive youth development program for adolescents with chronic illness. *Journal of Adolescent Health*. 2013; 52:179-185.
10. Hibbard JH, Green J. What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs. *Health Affairs*. 2013; 32:207-214.

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Transitions to Adult Care for Rhode Island Youth with Special Healthcare Needs

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ABSTRACT

The transitioning of youth from pediatric to adult care systems is often fraught with discontinuity, miscommunication and gaps in care. This is most significant for youth with special health care needs. A panel discussion on transitioning youth to adult care systems that was part of a learning collaborative held by The RI Care Transformation Collaborative (CTC) is presented here, illustrated by a pertinent case of a youth with type 1 diabetes.

KEYWORDS: Health care transition, Children with special health care needs, Adolescent transition

INTRODUCTION

Moderator: Joanna Brown, MD MPH

RI Adolescent Patient Centered Medical Home Initiative

I'll briefly review the panel's purpose. The Care Transformation Collaborative is a collection of primary care practices seeking to improve primary care in Rhode Island. The transition from pediatric to adult care is a challenge to many practices, whether transitioning from a pediatric to adult-care practice or transitioning the approach to care within a practice to become more autonomous (e.g. a family medicine or combined medicine-pediatrics practice). As more children with complex, childhood-onset conditions survive to adulthood, there is a statewide need for more health care providers who care for adults to accept these adolescent/young adult patients with special health care needs. Panel members will use the following case to illustrate best practices in transition.

JD, a 17-year-old with type 1 diabetes presents to your office for the first time, with his mother. He has additional diagnoses of ADHD and depression, and complains of poor sleep. He takes methylphenidate and fluoxetine. He wears a Foo Fighters T-shirt and black jeans and pays more attention to his smartphone than you. His mother reports she's always scheduled his appointments and refilled his medications. She says they argue daily about checking blood sugars. He's had 2 recent DKA admissions. "He just says he's sick of taking insulin." She worries about losing her job over taking time off to care for him, and hopes it might help to go to a doctor's office that's "not just for little kids and babies."

Suzanne McLaughlin, MD

Medical Director, The Medicine Pediatrics Primary Care Center & the Transition Consultation Clinic, Rhode Island and Hasbro Children's Hospitals

The case may understate the challenges. I've added our experiences to the scenario. JD is seen mid-morning, overbooked into a follow-up slot after a recent hospital discharge. Although I'm listed as his primary care doctor, he has not yet been seen in our office. A future physical is scheduled, but I do not have his pediatric records yet. I find 16 EMR documents from recent admissions. After a brief effort seeking responses from JD, his mother opts to answer my questions to move the visit along. I provide requested prescriptions for current medications, and ask about his most recent hemoglobin a1c, ophthalmologic exam, and endocrine care. His mother replies they were just told they need to find an adult endocrinologist to take over his care by his 18th birthday.

Does it have to be like this? No.

I have a better-case scenario: Our office was contacted at hospital discharge to book a follow-up appointment for JD. The nurse noted he was enrolled in our practice with an upcoming visit, but had not yet been seen. The needed post-discharge visit was scheduled for end-of-session, and with the visit-reminder call, his mother was asked to bring his immunization record. Prompted at morning huddle, our nurse called the pediatric office and had the record of a recent visit faxed to our office.

In meeting with JD and his mother, I note our office policy that anyone age 11 and up has time with the doctor on their own as a part of each visit. The policy preserves confidentiality, often improves the history, and offers an every-visit opportunity for an emerging-adult to develop skills in conveying their own needs and concerns when interacting with health care professionals. JD, on his own, is able to relay information regarding insulin dosing and his annoyance at how his diabetes care disrupts his school and social activities. He endorsed smoking cigarettes, but denies alcohol, illicit drugs and sex.

When his mother re-joins us, she pauses more to listen for JD's responses. But at the conclusion of the visit, she repeats her frustration about his not monitoring blood sugars, connecting this behavior to the DKA admissions. JD is again silent. I ask: "Wow, you really stepped out of the conversation when we came to that – what happened?" JD and his mother acknowledge they fight almost daily about whether he is "responsible enough." She says, "I wish he'd take care of it, but if he doesn't, I have to!" He wants "to do it my way

and not be hassled.” I ask for a compromise: “How can we allow some level of responsibility and risk, but avoid the extremes you find scary or frustrating?” We set up a plan to trial JD being responsible to check his sugars, without nagging. They agree to review his meter together nightly, and if there is at least one check, no comments are allowed. If there are no checks, he has to check immediately, without argument. The plan stays in place until he goes a full week with at least one daily check. Neither get exactly what they want, but it’s framed as: “What could you each live with in exchange for not having the daily fights?” I acknowledge limits; “this is the small step we can take in today’s allotted time,” but plan for the next step. We book a longer physical slot for JD’s next visit, and I ask them to complete an online transition screening to give us all a better idea of how the process is going and what next-steps are needed, and give them information about a peer-based transition program for RI adolescents.

The transition process can be overwhelming to a patient and family, but also to us as physicians. There are long-standing dynamics within families, and the issues of the medical condition are superimposed on the age-appropriate adolescent struggle for independence. See **Table 1** for helpful resources, which can be used to inform, engage and guide families in their efforts. I continually remind families, and myself, that transition is a process and won’t be accomplished in one over-long visit. Ultimately, transition is intended to help someone realize their potential and can be incredibly rewarding for patients and providers.

Jodie Neukirch, LCSW

The Adolescent Leadership Council (TALC), Rhode Island and Hasbro Children’s Hospitals

As a hospital-based social worker, I sometimes meet with a patient as a consultant during an admission, or make an arrangement to see them at the time of a primary care or specialty visit if these are at Hasbro Children’s Hospital (HCH). This case is typical in that our service is often asked by a physician, family or patient to enter the picture after things are well off-track.

Chronic medical illness often co-exists with mental health issues, like depression and anxiety. I’ll focus on framing JD’s experience. He is resentful of his diabetic regimen interfering with his life. Part of his frustration is that even when he follows his insulin regimen, that doesn’t always keep his blood sugar in range. As a result, he may not fully trust his care team. Irritability, sleep disruption and poor concentration may be symptoms of uncontrolled depression. Chronic illness can be an isolating experience for adolescents and contribute to depression and anxiety. Untreated, depression can interfere with his judgment and motivation. Striving for more independence is a normal adolescent behavior and brain capacity for logical reasoning and future thinking is still developing through early adulthood. All of these factors help us understand why he is upset and non-adherent.

It’s also important to consider the perspective of JD’s mother. She has spent years managing his diabetes. It is difficult for her to relinquish the role of caretaker and entrust him with self-care, but equally concerning if he does not move into this role.

Our service’s approach incorporates both the patient and parent. I try to identify past issues, without laying blame, and help the patient to develop a plan. Plans must incorporate patient suggestions, and should use a stepwise approach, allowing the patient some autonomy as an opportunity to build trust. The graduated independence, and hopefully success, will build confidence for later tasks. I encourage parents to share their concerns with their child in a non-accusatory way and to understand their developing role as an

Table 1. Transition resources for practices and providers

<p>GotTransition.org is a national clearinghouse, run by the National Alliance to Advance Adolescent Health. Their nationally recognized transition model is aligned with professional organization recommendations and includes 6 core elements of health care transition support: policy, tracking and monitoring, readiness assessment, transition planning, transfer of care and transfer completion.</p> <ul style="list-style-type: none"> • A tip sheet to start the transition process: www.gottransition.org/resourceGet.cfm?id=331 • A validated tool providing a framework for conversation about transition: www.gottransition.org/resourceGet.cfm?id=126 • Information regarding Billing and Coding for Transition!: www.gottransition.org/resourceGet.cfm?id=353 • The QuickGuide Transition Tool with guidance on health insurance and career goals: www.gottransition.org/resourceGet.cfm?id=372
<p>New guidelines and tools for transition for internists, from the American College of Physicians’ Pediatric to Adult Care Transition Initiative:</p> <ul style="list-style-type: none"> • https://www.acponline.org/clinical-information/high-value-care/resources-for-clinicians/pediatric-to-adult-care-transitions-initiative.
<p>Local resources for transition services are listed at the bottom of the Rhode Island Department of Health’s Pediatric to Adult Healthcare Transition Guidance, along with a checklist for families and patients to plan and track progress:</p> <ul style="list-style-type: none"> • http://health.ri.gov/programs/detail.php?pgm_id=89 • http://www.health.ri.gov/publications/brochures/specialneedschildhoodtransition/Ready.pdf
<p>RI Department of Education, Office of Student, Community and Academic Supports has 4 Regional Transition Centers:</p> <ul style="list-style-type: none"> • http://www.ride.ri.gov/StudentsFamilies/SpecialEducation/SpecialEducationProgramming.aspx#1239631-secondary-transition-services.
<p>A community-based organization, the Rhode Island Parent Information Network (RIPIN), has a Transition Coordinator who can help families start the process.</p> <ul style="list-style-type: none"> • Phone: (401)270-0101, or on-line: www.RIPIN.org or http://www.startingpointsforparents.org/content/transition-school-adult-life.

advisor in their child's care. This can open up new ways to communicate around transition issues.

Sometimes a single visit or a series of visits during an admission are sufficient, and JD and his family may be ready to move forward on their own. For more support, I'd encourage JD and his mother to participate in our transition program. The Adolescent Leadership Council (TALC) is a transition program offered at Hasbro Children's Hospital for youth age 13–18 with chronic medical illness (www.TALCProgram.org). College-age mentors with chronic illness and Hasbro staff lead monthly meetings. There is a concurrent parent group. JD and his mother would have peer support and opportunities to address transition issues on an ongoing basis.

Deborah Garneau and Deb Golding
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JD and his case highlight challenges faced by adolescents as they transition care in Rhode Island. Our office supports a wide variety of programs to help. JD and his family can learn more about our programs on our website. See Table 1 for links to on-line RIDOH materials including: youth-friendly patient handouts with prompts for transition geared towards different levels of readiness, a youth transition workbook, and transition checklists for providers.

We'd encourage JD to sign up for our Dare to Dream Conference, where he'd have the option to train as a peer teacher. These programs can help adolescents realize real growth and achievement. Our perspective is that health affects all aspects of life. School, community, and job success are all associated with health. We emphasize ensuring inclusion and full participation of individuals with disabilities and chronic health conditions in education, meaningful employment, and community living. Our positive youth development interventions include the Dare to Dream Conference, Healthy Lifestyle Classes, and a Youth Internship Program especially geared to supporting an activated patient. The programs cover a wide range of special needs, including those of patients with cognitive disabilities and disabilities that may qualify for SSDI and other programs.

We'd also ask JD and his mother if they had explored any of the resources available through the RI Department of Education. Their Office of Student, Community and Academic Supports ensures children with diverse learning needs and children requiring special education services are provided equal access to a public education, and that schools develop effective strategies for meeting the needs of these unique learners. There is programming focused on transition; Table 1 includes links to their 4 Regional Transition Centers.

Early contact with a community support, such as the Transition Coordinator at RI Parent Information Network (RIPIN), can help families start the process. Table 1 includes a link to the Rhode Island Parent Information Network.

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Almost 1 in 5 US youth ages 12–18 have a special health-care need. Their health care transition has become a focus of

professional organizations, insurers, policy makers and providers over the past decade. Despite these efforts, the 2009–2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) demonstrated no significant improvement in transition preparation nationwide versus a 2005 survey.¹ Four transition goals were measured, asking parents if their child's doctor had discussed a shift to an adult provider, future health care needs, future insurance needs or if their child was encouraged to take increasing responsibility for their own health care needs. Fewer than half (40%) met the 4 national transition outcomes. Rhode Island performed slightly better, reaching 44% overall (a 6% increase over the state's 2005–2006 result). A local survey identified specific areas in need of improvement: only 13% of providers had written practice policies on transition. ² Consistent with the national trends, 97% of providers reported that health care plans and insurers did not help in the transition process.

Rhode Island has committed to focus on transition objectives and strategies in their Title V State Action Plans for fiscal year 2016.³ There are many resources for providers and practices to improve transition; Table 1 highlights links to several useful options.

References

1. McManus MA, Pollack LR, Cooley WC, McAllister JW, Lotstein D, Strickland B, Mann MY. Current status of transition preparation among youth with special needs in the United States. *Pediatrics*. 2013;131:1090-1097.
2. Burke R, Spoerri M, Price A, Cardosi AM, Flanagan P. Survey of primary care pediatricians on the transition and transfer of adolescents to adult health care. *Clinical Pediatrics*. 2008;47(4):347-354.
3. McManus M, Beck D, White P. State Title V Health Care Transition Performance Objectives and Strategies: Current Snapshot and Suggestions. Washington, DC: Got Transition/The National Alliance to Advance Adolescent Health, February 2016.

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Here, There and Nowhere: Following Adult Survivors of Childhood Cancer A Case Report of Recurrent Osteosarcoma in a Young Adult

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ABSTRACT

Approximately 1 in 285 children in the United States (US) will be diagnosed with cancer before the age of 20.¹ More than 80% of children diagnosed with cancer will become long-term survivors.² As of January, 2010, there are more than 380,000 adult survivors of childhood cancer in the US.³ More than two-thirds of survivors will develop chronic conditions.⁴ Professional organizations have advocated for specialized risk-based care of survivors.⁵ Locally and nationally, lack of transition services and insurance coverage are barriers to care of these adult survivors.⁶ We describe one such case to illustrate these challenges and their impact.

KEYWORDS: Cancer survivorship, healthcare transition, adult survivors of childhood cancer, emerging adults

CASE REPORT

A 15-year-old boy was diagnosed in November, 2005, with osteosarcoma of the right distal femur. He underwent two cycles of chemotherapy in his home country, the Dominican Republic, and travelled to Rhode Island (RI) for surgery and further treatment. He continued treatment in RI according to Pediatric Oncology Group (POG) protocol 9754, undergoing 2 cycles of chemotherapy, an amputation to mid-femur with rotationplasty of the lower extremity and 4 additional cycles of adjuvant chemotherapy completed in October, 2006. His treatment was complicated by typhlitis, febrile neutropenia and hemorrhagic cystitis. He was discharged from his final treatment with follow-up with the brace shop, orthopedics, physical therapy and hematology/oncology, and his port was removed 5/2007. He reported having no primary care physician. He was not seen in oncology follow-up from 11/2008 at the time of a negative CT scan for metastatic disease, until re-presenting in 8/2010 with report of skin breakdown at his prosthesis site, fever, pain, swelling and drainage from his right great toe. He received podiatric care and screening x-rays and echocardiogram for late-effects, but no additional follow-up. He re-presented 3/2011 to an oncologist, reporting a 3-day history of facial pain and swelling, with concern for tooth abscess. He next presented to the Emergency Department (ED) in 11/2011, for pain and swelling of his right leg stump. An ultrasound showed deep

venous thrombosis of the femoral vein, and he underwent drainage of a paronychia of his right great toe. He received cephalexin, warfarin and low dose molecular heparin in the ED but reported being able only to purchase the warfarin due to cost. He presented 5 days later to the pediatric oncology clinic. Social work was involved to facilitate insurance coverage, medications, follow-up with orthopedics and podiatry, audiology for previously recommended hearing aids and primary care visits. He was scheduled for follow-up with the late effects clinic, and seen in Transition Consultation Clinic in 11/2011. Routine screening indicated learning disabilities, poor nutrition, limited physical activity, clinical depression and overweight. He lacked insurance coverage, a functioning prosthesis and a vocational plan. His pain and swelling were attributed to thrombosis and infection, but failed to improve over the following 4 weeks. He denied fever or night sweats, but endorsed more focal right thigh pain, fatigue and daily vomiting with an unintended 30 pound weight loss in the two weeks preceding the visit. He underwent a bone scan at a survivorship clinic visit 1/2012 for possible osteomyelitis, given persistent erythema of the right great toe and an elevated white blood cell count. The scan indicated "a large, round, markedly hypervascular mass in the right thigh, predominantly extraosseous in appearance with more focal intense areas of uptake within the soft tissues of the right side with possible involvement of the right proximal femur in the area of internal fixation hardware, highly suspicious for recurrence of osteosarcoma."

The patient was admitted for a CT-guided biopsy of the right thigh mass, which confirmed recurrent osteosarcoma. He underwent a right hip disarticulation. With no evidence for metastatic disease at that time, no adjuvant chemotherapy was pursued. However, subsequent 5/2012 surveillance chest CT demonstrated pulmonary nodules consistent with metastatic disease. The patient was treated with neoadjuvant chemotherapy consisting of methotrexate, doxorubicin and cisplatin, with subsequent decreased size of nodules and then underwent a right thoracotomy with wedge resection of metastatic nodules in the right middle and lower lobes in 7/2012. This was followed with an individualized adjuvant chemotherapy protocol, including methotrexate, doxorubicin, carboplatin, cyclophosphamide, etoposide and zoledronic acid completed in 12/2012. He next presented to the survivorship clinic in 8/2014, reporting cough and intermittent chest pain, after a period of lost-to-follow-up. A chest

CT and bone scan did not show new disease and his echocardiogram was normal. He was again advised to establish primary care. He presented to primary care in 9/2014, and returned for a health maintenance visits 12/2014 and 1/2016. At his most recent well adult visit it was noted that he had not had interim care with the survivorship program, and was encouraged to follow-up. He presented for survivorship follow-up 1/2016, and had negative surveillance imaging and a normal echocardiogram.

DISCUSSION

Our patient experienced multiple secondary effects of chemotherapy, including hearing loss, learning disabilities and infertility. In addition, he experienced recurrence of his osteosarcoma. Adherence to routine monitoring and care coordination might have mitigated some of these conditions and allowed for earlier detection. Importantly, adherence to recommended off-therapy tumor surveillance imaging may have detected this patient's tumor recurrence earlier. Early detection followed by early treatment of relapsed disease may have also decreased this patient's risk for pulmonary metastatic disease, for which he required a substantial amount of additional chemotherapy. In the past 35 years, the 5-year survival rate for localized osteosarcoma improved from 40-76% for children <15 years, and from 56-66% in adolescents ages 15-19 years.⁷

Our patient sought care primarily to evaluate acute conditions, and engaged in primary preventive and survivor-related follow-up only when prompted by other providers. Among the more than 10,000 adult survivors in the Childhood Cancer Survivor Study (CCSS), more than 62% reported one or more chronic conditions.⁸ However, although 87% reported general medical contact and 71% a general physical exam within the prior 2 years, only 19% had a visit at a cancer center.⁹ Thus, the majority of adult survivors of childhood cancer are getting care from providers who are not oncologists. Encouraging routine care and developing and maintaining an awareness of secondary effects and screening recommendations are important steps for primary care providers. Yet, in a survey of internists, only 12% stated that they felt at least "somewhat familiar" with available guidelines.¹⁰ The Children's Oncology Group's Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers summarizes secondary effects of treatments, surveillance recommendations, and provides sample treatment summaries. <http://www.survivorshipguidelines.org/>¹¹

Our patient identified cost of care and lack of insurance as significant barriers. Uninsured survivors in the CCSS cohort had lower utilization of both survivor-focused and general preventive health care than privately or publicly insured survivors.¹² Fewer than 14% and 10% of survivors, respectively, have ever been enrolled in the supplemental security income (SSI) or social security disability insurance (SSDI) federal disability programs providing income and insurance

support for disabled adults.¹³ The 2010 Patient Protection and Affordable Care Act (ACA) established provisions intended to increase access to affordable health insurance, including requiring employer-sponsored health insurance plans to cover enrolled members' children up to age 26 and limiting exclusions for pre-existing conditions. During the first full two years following the passage of the ACA, young adults (YA) ages 19-25 per capita health care spending grew at a rate nearly double that for the non-YA adult population.¹⁴ However, in a 2011-12 survey of survivors, only 27% reported familiarity with the ACA.¹⁵ And most recently, a comparison of adult childhood cancer survivors to adults without cancer found fewer CCS were insured (76% vs 81%), and were more likely to report delaying medical care (25% vs 13%) and to report needing but not getting medical care in the previous 12 months (20% vs 10%).¹⁶ A regional review of all of the academic pediatric oncology programs in New England found that funding for resource intense programs and transitioning care to adult clinical services were common challenges.¹⁷

Hasbro Children's Hospital's Comprehensive Health Assessment and Management for Pediatric Cancer Survivors (CHAMPS) Program is a local resource that includes monitoring for late-effects, as well as social work support that can assist patients seeking coverage and resources: <http://www.hasbrochildrenshospital.org/Programs.html>.

References

1. American Cancer Society. Cancer Facts and Figures, 2014. <http://www.cancer.org/acs/groups/content/@research/documents/webcontent/acspc-042151.pdf>. Accessed 5/4/2016.
2. American Cancer Society. Cancer Facts and Figures, 2016. <http://www.cancer.org/research/cancerfactsstatistics/cancer-factsfigures2016/>. Accessed 5/4/2016.
3. National Cancer Institute. Child and Adolescent Cancer Fact Sheet. <http://www.cancer.gov/types/childhood-cancers/child-adolescent-cancers-fact-sheet>. Accessed 5/4/2016.
4. St. Jude's Children's Research Hospital, The Childhood Cancer Survivor Study, Public Access Data Tables. <https://ccss.stjude.org/public-access-data/public-access-data-tables.html>. Accessed 5/4/2016.
5. American Academy of Pediatrics Section on Hematology Oncology Children's Oncology Group. Long-term follow-up care for pediatric cancer survivors. *Pediatrics*. 2009;123:906-915.
6. Kenney LB, Bradeen H, Kadan-Lottick NS, Diller L, Homans A, Schwartz CL. The current status of follow-up services for childhood cancer survivors, are we meeting goals and expectations: A report from the consortium for New England childhood cancer survivors. *Pediatr Blood Cancer*. 2011;57:1062-1066.
7. National Cancer Institute. Osteosarcoma and malignant fibrous histiocytoma of bone: Treatment. <http://www.cancer.gov/types/bone/hp/osteosarcoma-treatment-pdq>. Accessed 5/10/2016.
8. Oeffinger KC, Mertens AC, Sklar CA, Kawashima T, Hudson MM, Meadows AT, Friedman DL, Marina N, Hobbie W, Kadan-Lottick NS, Schwartz CL, Leisenring W, Robison LL. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med*. 2006;355:1572-82.
9. Oeffinger KC, Mertens AC, Hudson MM, Gurney JG, Casillas J, Chen H, Whitton J, Yeazel M, Yasui Y, Robison LL. Healthcare of young adult survivors of childhood cancer: A report from the

- Childhood Cancer Survivor Study. *Ann Fam Med*. 2004;2:61-70.
10. Suh E, Daugherty CK, Wroblewski K, Lee H, Kigin ML, Rasinski KA, Ford JS, Tonorezos ES, Nathan PC, Oeffinger KC, Henderson TO. General internists' preferences and knowledge about the care of adult survivors of childhood cancer. *Ann Intern Med*. 2014;160:11-17.
 11. Children's Oncology Group. Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers. October, 2013. <http://www-survivorshipguidelines.org/>. Accessed 5/10/2016.
 12. Casillas J, Castellino SM, Hudson MM, Mertens AC, Lima ISF, Liu Q, Zeltzer LK, Yasui Y, Robison LL, Oeffinger KC. *Cancer*. 2011;117(9):1966-1975.
 13. Kirchhoff AC, Parsons HM, Kuhlthau KA, Leisenring W, Donelan K, Warner EL, Armstrong GT, Robison LL, Oeffinger KC, Park ER. Brief Communication: Supplemental Security Income and Social Security Disability Insurance coverage among long-term childhood cancer survivors. *J Natl Cancer Inst*. 2015;107(6):djv057.
 14. Health Care Cost Institute. 2012 Health care cost and utilization report. HCI, September 2013. http://www.healthcostinstitute.org/files/IB8_YA_09242014.pdf. Accessed 5/4/2016.
 15. Park ER, Kirchhoff AC, Perez GK, Leisenring W, Weissman JS, Donelan K, Mertens AC, Reschovsky JD, Armstrong GT, Robison LL, Franklin M, Hyland KA, Diller LR, Recklitis CJ, Kuhlthau KA. *J Clin Oncol*. 2015;33:764-772.
 16. Kuhlthau KA, Nipp RD, Shui A, Srichankij S, Kirchhoff AC, Galbraith AA, Park ER. Health insurance coverage, care accessibility and affordability for adult survivors of childhood cancer: A cross-sectional study of a nationally representative database. *J Cancer Surviv*. 2016.epub ahead of print. <http://www.ncbi.nlm.nih.gov/pubmed/27072683>. Accessed 5/10/2016.
 17. Kenney LB, Bradeen H, Kadan-Lottick NS, Diller L, Homans A, Schwartz CL. The current status of follow-up services for childhood cancer survivors, are we meeting goals and expectations: A report from the Consortium for New England Childhood Cancer Survivors. *Pediatr Blood Cancer*. 2011;57:1062-1066.

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