

Transitioning From “Sick Kid” to Community Health Worker: Building Better Bridges to Adult Care

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The term “transition to adulthood” is used to describe the process that adolescents and young adults (AYAs) with special health care needs experience as they become adults. This process includes not only the often complex transfer of care from pediatric to adult health care systems, but also dynamic changes in social situations, education, employment, recreation, and more. The National Center for Health Care Transition Improvement (Got Transition) outlines 6 core elements for the safe and effective transition to adulthood and transfer of care from pediatric to adult health care systems.¹ However, pediatric providers are often wary of transferring their patients to adult care, and adult providers feel unprepared to accept these patients into their practices, leaving patients and families feeling abandoned and confused.^{2–4}

We present a model at Children’s Hospital of Philadelphia (CHOP) for embedding the patient perspective into a multidisciplinary team tasked with addressing transition to adulthood. We fully integrate a former patient at CHOP with personal experience with chronic illness and transition to adulthood as the youth community health worker (YCHW) into a team of physicians, a nurse practitioner, a nurse coordinator, and social workers. The YCHW is tasked with generalizing personal experiences with chronic illness to encourage goal-setting for AYA patients and viewing AYA patients, especially those with special health care needs, in a holistic

way for providers. Our transition team coordinates care for patients with medically and socially complex backgrounds to transfer their medical care to adult providers safely while also addressing psychosocial needs such as insurance, post-high school planning, and medical decision-making support. The team also works to improve and support transition practices across the institution. The YCHW brings a patient voice to institutional resources (such as transition policies), educational tools for providers and patients, and hospital-wide psychoeducational events that are used to integrate peer mentors for youth and their families to address important topics for transition to adulthood.

TRANSITION: PATIENT PERSPECTIVE (K.W.)

I was introduced to the world of pediatric specialty care at age 10. Despite needing an intestinal surgery, I viewed my adolescence as relatively healthy, granted with additional exposure to the medical world. During my senior year of high school, I celebrated my 18th birthday on a Monday. On Tuesday, I came home from school, ate dinner, went to my piano lesson, and discovered that I could not keep down my dinner. The symptoms I attributed to a minor virus persisted and escalated until 3 weeks later I found myself, after >1 trip to my general pediatrician, in the gastroenterology waiting room at CHOP. A week later, I was having

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a feeding tube placed, canceling a college visit, missing homecoming, and dropping out of 2 classes. Amid all of this, I received care in both pediatric and adult health care systems because, at age 18, this collaboration was recommended by my providers. Although I had talked to doctors alone for part of my appointments starting around age 13, once in adult care I quickly realized that I still relied heavily on my parents when I felt unsure or unprepared. It was surprising to have an adult provider stop me when I looked to my father to validate and elaborate on an answer I gave by saying, “No, I don’t want to know what *he* thinks you feel.”

Straddling the pediatric and adult medical worlds, I finished my senior year chronically ill, but stable. I was accepted into college, went to prom, graduated from high school, and moved into my freshman dorm. Halfway through my first college semester, my symptoms worsened. I kept in steady contact with my physicians and parents, but it was hard to judge and easy to deny how sick I had become because the change was relatively gradual. After completing my final examinations and returning home, my winter break turned into a diagnostic whirlwind that culminated with the decision that surgery and a semester medical leave of absence was necessary.

Returning to “normal” life for my sophomore year 7 months later was simultaneously a relief and a challenge. During my leave of absence, returning to college was my core motivation to learn how to manage my health. However, once I achieved this goal, I felt isolated because my classmates’ lives had moved on without me. My normal was also different because I had new symptoms and medications to chronically manage. Over the course of my sophomore year, I grappled with how having a chronic illness fit into my identity. On the one hand,

I wanted to be proud that I was overcoming new challenges, whereas on the other hand, I did not want to be defined as a “sick kid” any longer.

TRANSITION: PHYSICIAN PERSPECTIVE, PEDIATRICS (D.S.)

In 2002, the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine published guidelines on when and how to transition adolescents to adult care.⁵ Yet, how these guidelines can be operationalized best in busy clinical settings is unclear. As an internal medicine–pediatrics trained pediatric subspecialist who runs a transition program, I am constantly thinking about how to prepare my AYA patients for adult-focused care. In our cancer survivorship program, patients may be medically complex, have intellectual and developmental disability, and/or complex psychosocial situations. Guidelines and tools are useful, but each patient is an individual with his or her own story and timeline for transition, and a thoughtful and tailored approach is often needed. At the same time, transition cannot be delayed because it is difficult. Although it may be just as hard for a medical provider to “let go” as it is for a patient and family to navigate new roles and systems, the many aspects of transition to adult medical care and adult life are an opportunity for pediatric providers to play another important role for their patients in partnering with them and their families to help them balance becoming medically savvy self-advocates while maintaining a sense of normalcy as young adults.

TRANSITION: PHYSICIAN PERSPECTIVE, INTERNAL MEDICINE (S.J.)

Being an internal medicine–pediatrics trained general internist, I am referred many young adult patients with chronic conditions from

local pediatricians to establish adult primary care. Many of my young adult patients have had multiple hospitalizations, endured multiple surgeries, and juggled a myriad of medications and therapies. Some are severely impaired and/or living with family caregivers for the rest of their lives. Others are starting college or trying to figure out how to support themselves after graduation. Often, I find myself without previous medical records or in front of young adults who are unable to tell me their current medications or basic medical history. The hardest part of my job is trying to help these patients develop the skills to manage their chronic illnesses independently or the confidence to communicate their concerns to their providers. “Will you recognize when you need to call me?” “Do you know how to reach me or your other doctors?” “How do I allay your (or your parents’) fears about going to your new adult doctors or an adult emergency department?” “How can we make sure that you have health insurance while in school or finding a job?” “How will you pay for your therapies now that school no longer provides them?” For those young adults with intellectual disability, I ask “Who can legally help you make medical decisions?”

TRANSITION: SOCIAL WORK PERSPECTIVE (S.T.)

As a social worker, my role is to encourage self-care and self-advocacy to the greatest extent possible. Valuing AYA patients’ strengths and abilities rather than focusing on their illnesses or areas of challenge underscores their personal value and skills to manage their lives as adults. Often the process of preparing and supporting families through the process of transition to adulthood involves not only encouraging a young adult to move forward toward independence, but also helping parents and/or caregivers to take an appropriate

step back from their child's care. In my experience, patients and families experience 3 stages in transition, that of "getting ready," "on my way," and "we made it!"

DEVELOPING A PARTNERSHIP: SHIFTING FROM PATIENT TO YCHW (K.W.)

During my sophomore year in college, I mustered the courage to mention my leave of absence to another student. Unexpectedly, she responded by telling me about her own experiences with chronic illness. What followed was an honest conversation about how our chronic illnesses impact the way we look at the world, interact with our peers, and plan our futures. Months later, I learned that this student had been volunteering at CHOP's transition psychoeducational events as a peer mentor for many years and that she recommended me for the YCHW role on the transition team at CHOP.

When I started as the YCHW, I realized quickly that despite my own journey through pediatric care, there are many aspects to transition that I had not previously considered. With guidance from my social work supervisor, I reflected on my own experiences and shifted my perspective from that of a patient to that of a provider. I consider the following 3 aspects of my personal experiences when sharing with patients and families: (1) why I am sharing an experience (ie, to be helpful, rather than to complain), (2) if the experience is appropriate (ie, not too graphic or scary), and (3) if I am truly comfortable and confident in sharing the experience. These 3 considerations help me to frame my experiences in a manner that lends itself to appropriate and constructive discussion aimed at helping AYA patients determine their own goals for their health and their future. Overall, there are 4 aspects

to the YCHW role, described in the following sections:

Building Rapport and Trust Based on Shared Experiences

This is not about having the exact same experiences, but rather using shared experiences of having a chronic illness to establish myself as a nonjudgmental peer resource. For example, considering my own challenges with keeping diet diaries may help me to empathize with a patient struggling with logging sugar levels to manage diabetes.

Building Specific Skills

The concepts of "transitioning to adulthood" and "becoming a self-advocate" are important; however, they can be abstract and overwhelming. Using the Transition Readiness Assessment Questionnaire and recommendations from patients' care teams, we identify 2 or 3 specific skills to improve and practice.⁶ These topics often include practicing making phone calls to make appointments, connecting with vocational rehabilitation, and signing up for patient portals.

Modeling Effective Problem-Solving Strategies

During appointments, I often help patients search for information online or practice making phone calls. Over the course of these interactions, patients can see that I personally do not know "everything," but rather that there are effective ways to find information. For example, after spending an hour during an appointment signing up for an online portal through an employer to choose insurance, a patient e-mailed me a few days later excited that she found a place to sign up for tax-exempt bus passes within the portal on her own. Ultimately, the goal is for our patients to feel empowered to problem solve and advocate for themselves not only in their health care, but also in all aspects of their emerging adult lives.

Communicating With Providers

The final aspect is communicating efficiently and effectively with the other health care providers involved in patients' care. This includes contributing to weekly patient reviews, communicating patients' progress toward their goals, and relaying information that patients share with me about their successes and obstacles landing in adult care to providers.

CONCLUSIONS

Although we seek to define and refine best practices for transition preparation and transfer of care for patients and for pediatric and adult providers, we also strive to incorporate and validate the individual experiences of our patients. Medical providers and social workers trained in AYA care offer innovative solutions to help move patients from pediatric to adult care, and a YCHW with personal transition experience can enhance those solutions by helping to bridge the gap between patients and providers. A partnership between patients, families, providers, health systems, and community resources offers hope of writing a unified narrative in the transition from pediatric to adult care.

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ABBREVIATIONS

AYA: adolescent and young adult
CHOP: Children's Hospital of Philadelphia
YCHW: youth community health worker

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