



Topical review: The role of psychologists in healthcare transition

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ABSTRACT

Objective: Adolescents and young adults (AYAs) with chronic medical conditions often face significant challenges while transitioning from pediatric to adult healthcare (healthcare transition, HCT). Although some guidelines exist on how to facilitate this process, the specific role of psychologists in promoting successful HCT is not clearly defined. In this topical review, we propose a conceptual framework integrating the role of psychology within HCT. We also provide an agenda for behavioral health researchers investigating ways to improve transition services/care for emerging adults.

Method: We first review existing standards of care and HCT guidelines. Using existing literature and the Got Transition model as a theoretical foundation, we developed a conceptual framework to outline the specific roles and recommendations for integrating psychologists in the HCT process, including recommendations for future research in this area.

Results: Limited research has systematically examined the efficacy and effectiveness of HCT services, which vary widely across institutions and populations. Further, existing HCT guidelines/recommendations largely exclude the role of psychologists during this process. There are many opportunities for psychologists to provide essential services as part of an interdisciplinary HCT team and to better understand how to improve these models of care. **Conclusions:** Psychologists offer a unique and specialized element essential to fostering effective HCT. These professionals can take a more active role in promoting successful HCT from both clinical and research perspectives.

Introduction

The critical and formative developmental period of emerging adulthood is characterized by significant neurobiological and psychosocial changes.¹ During this time, adolescents and young adults (AYAs) often face new challenges, including navigating the transition from pediatric to adult healthcare services. The healthcare transition (HCT) process is the purposeful, planned movement of emerging adults with chronic health conditions from pediatric to adult health care systems.² Although there are currently several guidelines/recommendations available for how to support AYAs through the HCT process, there are gaps in their implementation and limited attempts to systematically examine their efficacy and effectiveness.^{3,4} Further, institutions vary in their application of these approaches, including 1) when, if at all, to initiate the HCT process, 2) whether and how services are transferred to adult settings providers, or both (with transfer being a discrete event and only one part of the HCT process),⁵ and 3) the specific role of providers across disciplines in managing HCT. Several real and perceived

individual, systemic, and environmental barriers exist to facilitating successful HCT. As a result, many AYAs are not receiving these essential services and are subsequently underprepared or inadequately equipped to competently engage with the healthcare system in adulthood.⁶ This of course is problematic for youth in general, but understandably even more detrimental to AYAs with chronic medical conditions, given the unique healthcare needs for these populations.

Many AYAs with chronic health concerns tend to experience comorbid/co-occurring mental health problems such as depression and anxiety, difficulties around parent-youth communication, suboptimal treatment engagement, and similar rates of substance use to AYAs without chronic health conditions.⁷ These concerns can compound the challenges associated with HCT,⁸ but can improve with appropriate mental health support. Though there is some evidence that psychologists currently serve in different roles in HCT, many report facing challenges in these efforts, and the type and level of involvement varies greatly.^{9,10} Moreover, psychologists are commonly involved with research examining how to improve the HCT process and outcomes, but the role that

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they should play as clinicians working with AYAs transitioning to adult care is unclear. As the evidence supporting integrated subspecialty care continues to grow, inclusion of mental health providers (both psychologists and social workers) as part of the medical team is now recommended in the standards of care for many chronic health conditions. Ideally, integrated subspecialty care continues through the HCT and there is a need for psychologists to be actively involved in supporting, closely following/monitoring, and in some cases initiating HCT with youth, their families, and treatment teams. Indeed, Schwartz and colleagues (2011; 2013) developed and validated the social-ecological model of adolescent and young adult readiness for transition (SMART) to define points of intervention for AYA preparing for transition and found that assessment of AYA's psychological functioning is a central construct in successful transitions.^{11–14} However, there is little guidance on the specific roles that psychologists play in HCT and more training and recommendations in this area are needed.

In this review, we summarize recent attempts to examine the utility of HCT guidelines in AYAs with chronic illness, with a focus on psychosocial and integrated care recommendations. We also propose a conceptual framework to highlight the urgent need to systematically address the integration of psychology in HCT recommendations as they apply to AYAs with chronic medical conditions. Finally, we provide a research agenda for future work that psychologists can be involved with aimed at improving HCT in AYAs with chronic illness and psychosocial concerns.

HCT guidelines for AYAs with chronic medical conditions

Evidence based guidelines around HCT for AYAs with chronic medical conditions are emerging. Standards of care typically include current clinical practice recommendations for a specific disease or medical condition and are intended to provide clinicians, patients, researchers, payers, and other stakeholders with the components of care, general treatment goals, and tools to evaluate the quality of care.¹⁵ Since evidence-based transition practices are in their infancy, many standards of care do not provide specific transition recommendations, especially regarding the role of mental health providers. However, some disease-specific groups recognize the valuable role that psychologists can play in the HCT. For example, the 2023 American Diabetes Association Standards of Care state that diabetes care teams addressing transition should include social workers, psychologists, and other mental health providers given the behavioral, psychosocial, and developmental factors that relate to healthcare transition.¹⁵

Perhaps the most established guidelines for implementing a structured transition program are Got Transition's Six Core Elements of HCT.¹⁶ Got Transition is a national resource center on HCT that aims to improve transition from pediatric to adult healthcare using evidence-based strategies. Through an iterative process of development and testing with extensive stakeholder input, Got Transition published the Six Core Elements of HCT in the 2018 Clinical Report on Healthcare Transition from the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians. The Six Core Elements define the basic components of a structured transition process and includes a set of steps and tools for transition planning in pediatric care, transfer to adult care, and integration into adult care. Clinicians and scientists have implemented the Six Core Elements in many different subspecialty care settings in youth and young adults with a variety of chronic medical conditions.^{17–20}

The Six Core Elements emphasize the importance of including at least one "motivated and respected" representative from each discipline and practice area involved, but do not specifically mention the roles that psychologists can play in their implementation. Indeed, integrated transition clinics (e.g., young adult clinics or joint pediatric/adult provider clinics) that provide specialized care to young adults during the HCT are an opportunity for mental health providers to become involved in the HCT and address the psychological barriers to successful HCTs. In

type 1 diabetes, two studies that examined the impact of an integrated transition clinic on HCT outcomes and included a psychologist as part of the integrated care team found that attendance rates were high (68 % and 84 %) and HbA1c decreased between the first and last visits in the clinics.^{21,22} In gastroenterology, the use of joint transition clinics with multidisciplinary team members (e.g., pediatric and adult gastroenterologists, psychologists, and nurses) are associated with improved outcomes, including better adherence to care, disease-specific measures, improved quality of life, improved self-care skills, higher satisfaction with care, and improved health care utilization (e.g., higher rates of adult clinic attendance, reduced hospital length of stay).^{23,24} Among youth with cystic fibrosis (CF), participants who engaged in the formal transition process had higher satisfaction with both CF programs, higher perceived health status, and higher independence in CF care.²⁵ Taken together, there is emerging evidence to support the inclusion of a psychologist as part of a structured transition program. Unfortunately, detailed information regarding the specific contributions of psychologists embedded within the multidisciplinary teams/HCT programs described in these studies was limited. In general, psychologists broadly assessed and/or addressed psychosocial factors related to HCT within these respective populations. Some of these areas included assistance with improving disease self-management and adherence to treatment. Importantly, 75 % of patients assessed within one of the type 1 diabetes integrated transition clinics described above opted to receive continued psychological treatment (beyond an initial assessment), highlighting the need and interest in/desire for mental health support for AYAs during HCT.²¹

Incorporating psychologists into Got Transition's Six Core Elements

Arguably, psychologists can play a crucial role across all Six Core Elements of the Got Transition model by lending expertise to creating transition of care services. This is best accomplished by partnering with and coordinating between providers across pediatric and adult healthcare settings. Psychologists are also uniquely positioned to be an essential asset during the HCT process, especially as part of an integrated team. For example, psychologists are uniquely qualified to help allay fears and/or build confidence and effective communication, address uncertainty about seeing a new, adult focused healthcare provider, practice/role play ways to approach concerns, and build health literacy skills. Moreover, behavioral health visits are often longer in duration and providers typically follow-up more regularly with patients and families, compared to other specialists who may only be able to follow-up every 6 to 12 months. Consistency and timing of visits can promote greater accountability and regular support for AYAs, making psychologists ideal for guiding many aspects of the HCT process.

In Table 1, we propose some of the specific contributions psychologists can make during each stage of the HCT process, as delineated by the Six Core Elements of the Got Transition model. Psychologists' role in HCT models can vary, but most often include providing clinical care as part of a multidisciplinary medical team.¹⁰ The specific role that psychologists fill may also be determined by the setting in which they practice (integrated care, referral based, etc.). Psychologists should be involved in policy development and/or modifications to existing policies surrounding HCT within their systems/institutions. Specifically, psychologists possess the skills needed to collaborate with key stakeholders (e.g., administrative professionals, nursing staff, physicians) to develop policies and guidelines around transition. Incorporating stakeholder perspectives during the initial policy/guide phase will enhance feasibility and success of an HCT transition program. Psychologists can play an important role in monitoring AYA readiness for transition throughout their development and providing support to ensure AYAs are prepared for successful transition. In particular, psychologists are familiar with readiness assessment measures, such as the Transition Readiness Assessment Questionnaire,²⁶ which can be a useful tool to identify areas in which AYAs need more support in preparation for HCT transition.

Table 1

Proposed roles and contributions of psychologists during the healthcare transition and transfer process using the Six Core Elements Got Transition model.

Core Element	Role of Psychology
POLICY/GUIDE Develop, discuss, and share transition care policy/guide	<ul style="list-style-type: none"> • Develop and implement systematic training for clinicians to reduce variability • Engage key stakeholders to develop a transition policy with unique clinic needs in mind • Develop and share transition guide with providers and families, including developmental expectations and guidelines for AYAs • Incorporate consideration of sociocultural and diversity factors in transition policy development
TRACKING & MONITORING Track progress using a flow sheet registry	<ul style="list-style-type: none"> • Track and monitor progress (e.g., level of AYA autonomy for illness management, transfer of care) using a developmental perspective.²
READINESS Assess self-care skills and offer education on identified needs	<ul style="list-style-type: none"> • Help multidisciplinary team recognize developmental differences and cultural considerations in transition readiness.³ • Adapt/develop and validate transition readiness assessment measures and interventions.⁴ • Utilize evidence-based strategies for improving treatment engagement (i.e., adherence or self-care) and healthcare communication.⁵ • Conduct consultation and brief intervention ≥ annually to assess transition readiness. • Assess MH needs prior to transitioning and provide brief intervention as needed. • Assess areas of growth and challenges for the AYA (e.g., psychosocial functioning, illness management) and adapt care plan as needed. • Assess competing demands of education, work, social life, cultural practices, and disease self-care and provide brief intervention as needed.¹
PLANNING Develop HCT plan with medical summary	<ul style="list-style-type: none"> • Support ability to identify need for community MH referrals.⁶ • Support parents/caregivers by answering questions or providing resources.⁷ • Help demystify the process of what adult care is like; help set appropriate expectations.⁸ • Provide resources and time to process concerns or questions related to other areas of transition (e.g., educational/vocational, financial, cultural, social relationships).^{4,31}
TRANSFER OF CARE Transfer to adult-centered care and to an adult practice	<ul style="list-style-type: none"> • Ensure AYA transfer to an adult MH provider via warm hand-off if needed. • Identify potential gaps in continuity of care between pediatric and adult care and problem solve issues that might arise.¹
TRANSITION COMPLETION Confirm transfer completion and elicit consumer feedback	<ul style="list-style-type: none"> • Partner with social work to ensure successful transfer to adult MH and medical providers by following up with AYA and their families. • Adapt/develop and validate measures of transition success, especially to be used to solicit feedback, share this feedback with other providers, and improve HCT processes.⁹ • Conduct stakeholder engaged research to define successful HCTs across chronic medical conditions.^{10,11}

Note: The Six Core Elements of Health Care Transition™ are the copyright of Got Transition®. Here, we summarize the original goals of the Six Core Elements. For a more detailed explanation, readers may refer to the Got Transition website (www.gottransition.org). This version of the Six Core Elements has been modified and is used with permission. MH=mental health

Throughout the transition process, psychologists can assess for specific areas of functioning, including markers of psychosocial functioning, behavioral/mental health, or illness management.^{11–13,30} Psychologists can meaningfully provide support, guidance, and skill development throughout the six core elements, though the impact of psychologists may be most apparent during the readiness and planning stages as this is a time that is rich for psychoeducation and the development of skills necessary for successful transition and transfer. Moreover, partnering with social workers during the planning phase can be beneficial in helping AYAs and families prepare for and obtain resources necessary for successful transition. In contexts in which social workers are not available, psychologists may require additional training in, and protected time for, care coordination to ensure successful transition. During the transfer of care, psychologists can facilitate warm hand-offs, connect AYAs with resources for adult mental health services, and continue to monitor transition success using validated tools such as the Health Care Transition Outcomes Inventory.²⁷

An agenda for future research on HCT

Alongside the clinical role of psychologists during the HCT process, many psychologists are qualified scientists with the unique knowledge and skills necessary for conducting well-designed studies within this area. In fact, some of these professionals are currently engaged with research aimed at understanding and improving HCT for youth with various chronic medical conditions.^{28–30} However, several opportunities for psychologists to make meaningful contributions to these inquiries still exist. Here, we offer recommendations for facilitating involvement of psychologists in future HCT research.

1) Engage stakeholders to evaluate HCT programs.

- Psychologists can partner with AYAs with lived experience when conducting both qualitative and quantitative research focused on HCT. These efforts can include development and validation of HCT (e.g., process and outcome) specific measures. This would allow better understanding of the specific needs, challenges, and resources relevant to AYAs with a variety of chronic medical conditions. Input from these individuals should be considered and included at each level/stage of inquiry (i.e., research idea generation through publication).
- Collaborate with psychologists working in existing HCT clinics to understand barriers and facilitators in current transition programs. This can help identify additional research gaps and/or inform intervention trials, among other benefits.

2) Conduct rigorous intervention trials

- Identify key roles/contributions of psychology in HCT (including those discussed within the framework proposed above) to design interventions/transition readiness programs that include these specific components.
- Although many descriptive studies on HCT exist, there is currently a paucity of methodologically sound clinical trials within HCT research. Psychologists should work to design randomized controlled trials that include control groups (e.g., treatment as usual, waitlist) when assessing transition readiness programs to enhance rigor of research in this area.
- Psychologists can spearhead implementation studies to promote dissemination of these interventions/programs, as well as help adapt these to specific populations (e.g., diabetes, chronic pain) as needed.

3) Leverage longitudinal studies

- Employ longitudinal examination of psychologists' role in HCT by tracking progress and meaningful biomedical outcomes (e.g., glycemic level, acute hospitalizations) and behavioral outcomes (e.g.,

treatment engagement, self-care/adherence, quality of life) over time of AYAs who received care from these psychologists compared to those who did not.

- b. Engage AYAs using qualitative and quantitative methods throughout the HCT process to understand their perspective of challenges/successes encountered and beliefs/attitudes held during this time. Continue to follow these individuals into young adulthood to further monitor progress.

4) Incorporate provider insight and needs across disciplines and settings

- a. Engage psychologists working in different settings to better understand specific ways to implement HCT guidelines and measure outcomes within those environments, including adult health psychologist counterparts.
- b. Partner with physicians and other health professionals to understand provider needs and barriers across disciplines. This should be pursued with providers in both pediatric and adult healthcare settings.

Conclusion

While existing HCT guidelines largely overlook the role of psychologists during the transition process, psychologists are well-equipped to provide essential services as part of an interdisciplinary HCT team. Our conceptual framework, guided by the Six Core Elements Got Transition model, highlights the unique roles psychologists can play in the transition process. Future research should systematically examine the efficacy and effectiveness of psychologists in HCT services.

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Ethical statement

All contributing authors have reviewed the content of the final manuscript and approved the submission of this topical review article to Health Care Transitions. This original work has not previously been published, nor is it under consideration for publication in any other journal. All authors take full responsibility for the work presented herein. The authors have no conflicts of interest to disclose.

CRediT authorship contribution statement

Jessica Pierce: Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Conceptualization. **MaryJane S. Campbell:** Writing – review & editing, Writing – original draft, Investigation. **Shreela Palit:** Writing – review & editing, Writing – original draft, Methodology, Investigation, Conceptualization.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

No data was used for the research described in the article.

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