What Care Models Have Generalists Implemented to Address Transition from Pediatric to Adult Care?: a Qualitative Study

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BACKGROUND: The transition from pediatric to adult care is a critical period for young adults with childhood-onset conditions. General internists are tasked with participating in the care of this vulnerable population. Existing guidelines regarding transition do not fully address structural or organizational characteristics of practices that facilitate transition. Moreover, literature regarding transition has focused on pediatric subspecialty settings, leaving internists with little guidance after transfer.

OBJECTIVES: To better understand post-transfer transitional care by describing care models that primary care providers have implemented, and examining common features of generalist physicians' experiences providing transitional care.

DESIGN: Qualitative methods, semi-structured interviews.

PARTICIPANTS: Nineteen generalist-trained physicians from across the USA, engaged in transition-focused and/or ongoing care of adolescents and young adults with childhood-onset conditions.

APPROACH: Content and grounded theory analyses.

KEY RESULTS: Participants included nineteen physicians from seventeen institutions. Most (89%) were from academic medical centers. About 80% had completed a combined internal medicine-pediatrics residency. About 70% worked with clinic staff who were dedicated to transition. Practice structures fell into four main care models: (1) primary care in adult settings; (2) transition support and primary care in pediatric settings; (3) a blend of pediatric and adult care elements forming a bridge during transition; and (4) a transition consultative service. Most provided primary care for adults with childhood-onset conditions within larger adult-oriented primary care practices. Common features across interviews included taking extra time with patients both during and between visits and an interdisciplinary team-based approach. Shared practice strategies and philosophies emphasized care coordination, focus on the whole patient beyond immediate health concerns, and willingness to learn from practice and from families.

CONCLUSIONS: Participants used disparate care models. Common features and strategies among interviews highlight key functions and attributes of transitional care across settings, suggest important elements of care post-transfer, and clarify the role of generalists.

KEY WORDS: transition to adult care; young adult health; care models; qualitative research.

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BACKGROUND

The transition from pediatric to adult-oriented care is a vulnerable period for adolescents and young adults with childhood-onset chronic illness. Teens and young adults experience higher rates of loss of transplant,[1,2] more diabetes-related hospitalizations,[3] and complications and morbidity from sickle cell disease compared to younger teens and children.[4,5] Young adults with asthma[6] and young adults in general[7] utilize the emergency department at higher rates than other age groups. Young adults are less likely to receive preventive care than other age groups.[8] Each year in the USA, 500,000 children with special health care needs reach age 18[9] and thus will be facing a transition to adult care.

Health care transition from pediatric to adult-oriented care includes a period of preparation for leaving pediatric care, transfer to adult providers, and ensuring patients are established with appropriate adult-oriented health services.[10] Patients and families report concerns with the current approach to health care transition. The pediatric approach to care feels personalized and welcoming to patients and families,[11] and they have concerns about moving away from that. Youth report difficulties engaging with adult-oriented providers and navigating the adult health care system.[11–13] They feel they must advocate more strongly for themselves with adult providers than pediatric ones.[13,14] Both patients and parents report feeling as though they are being asked to leave pediatric care too quickly,[13–15] and that adult providers are inadequately trained in providing care to young adults with childhood-onset conditions.[11,13,16] These health concerns are exacerbated by the unique needs of young adults, who are in the process of moving toward greater independence in many facets of life and also continuing to develop cognitively, particularly with regard to judgment and decision-making.[8]

To assist providers with addressing the challenges of transition, clinical guidelines have been developed and are endorsed by the American Academy of Pediatrics, the American College of Physicians, and the American Academy of Family Practice,[17,18] and have been reinforced by other professional groups including the Society of Adolescent Health and Medicine[19,20] and the National Academy of Medicine.[8] In accepting young adult patients and caring for them after transfer, general internists are positioned to play a central role in transition. Nonetheless, internists report discomfort in providing care for adults with childhood-onset conditions.[21–24] General internists are working with relatively limited guidance regarding how to approach transition and the care of young adults with chronic illness because guidelines emphasize the preparation and transfer aspects of transition on the pediatric side over the period after transfer on the adult side[17,18,20] and the literature has thus far been largely focused on specialty settings.[25–27]

We sought perspectives of generalists with first-hand experiences providing transitional care to better understand how generalists are adapting their practices to meet the needs of patients during transition. The first aim was to describe transitional care models that primary care providers have implemented. The second aim was to clarify key functions and attributes of transitional care on the adult side, and understand the role of primary care physicians in caring for young adults with childhood onset illness.

METHODS

We used qualitative methods to explore the study aims.

Participants and Recruitment

We conducted semi-structured interviews with primary care-trained physicians who make transition a particular focus of their practices. We used a purposive recruitment and sampling strategy to select participants who provide transitional care along with typical primary care, as well as those who practice exclusively transition-focused care, with an emphasis on transfer and post-transfer. We included med-peds physicians, family physicians, internists, and pediatricians. We emailed physicians known to the first author through professional organizations' transition interest groups or identified from a listserv for physicians interested in pediatric complex care. We then expanded the participant list through snowball sampling, asking participants to refer us to colleagues in their professional networks. Participants received a $25 gift card. We continued recruitment until we reached thematic saturation. This study was deemed exempt by the University of North Carolina at Chapel Hill IRB.

Data Collection

We collected demographic and clinic information (e.g., type of training, years in practice, proportion of time providing transitional care, appointment length) through an online questionnaire. We developed a semi-structured interview guide informed by previously published guidelines and models regarding transition,[10,17,28] to elicit perceptions on providing transitional care. We probed for details on clinic structure and practice strategies. We asked participants what made their practices successful and their advice for establishing new programs. We asked whether other staff members were involved in transitional care in their practices and about their roles. We also asked about partnering with outside organizations. Interviews were conducted by phone by one or more of the authors (LCH, MM, RT) and lasted 30 to 60 min. They were audio-recorded, transcribed, and de-identified for analysis.

Analysis

We iteratively developed a topical and thematic codebook. To categorize and describe participants' care models, we used content analysis.[29,30] We also employed grounded theory techniques for a more interpretive analysis of key concepts in primary care transition.[29,31] We managed data using qualitative analysis software (Atlas.ti 7.5.18, Berlin). Two authors (LCH, MM) coded interview transcripts individually, then reviewed each transcript together to ensure consistent use of codes and to compare and contrast interviews. Lastly, we generated code output matrices for segments of text tagged with the topical codes *models of care*, *tangible strategies*, and a predominant emerging code, *maximizing patient function*. We used these analytic products to examine prominent ideas common to the various models and interviews, in order to distill key concepts.

RESULTS

We present descriptive and interpretive results in turn. Results of the descriptive analysis include participant and patient characteristics and care models. In the interpretive analysis, five ideas emerged as common characteristics of these generalists' approaches to transitional care.

Participants

Out of 25 physicians invited, 19 (from 17 institutions across the country) participated in interviews and 17 completed the questionnaire (Table 1). Most (79%) had completed a combined internal medicine-pediatrics residency, and about half had done fellowship training in adolescent medicine, medical education, or research. The majority (89%) were from

Table 1 Characteristics of Providers Interviewed

Provider characteristics (*n* = 19)	*n* (%) or range
Residency training	
Med/peds	15 (79)
Pediatrics	2 (11)
Family medicine	1 (5)
Internal medicine	1 (5)
Fellowship trained	9 (47)
Years of experience	7–30
Region of the country	
Northeast	8 (42)
Midwest	5 (26)
Southeast	4 (21)
Western USA	2 (11)
Practice setting	
Academic center	17 (89)
Free-standing clinic	1 (5)
Managed care system	1 (5)

academic medical centers. Many clinics (> 70%) employed dedicated support staff for transition. Most scheduled visit times that were longer than the standard 15 to 20 min allotted in primary care (Table 2). Extended visit times were frequently available for both new and returning patients.

Patient Characteristics

The patients these providers considered to be their transition patients often fell into one of three categories. One group had intellectual or developmental disabilities but were otherwise fairly healthy. Another group was those with intellectual or developmental disability (IDD) as well as comorbidities which ranged from psychiatric diagnoses like anxiety to complex conditions requiring care from multiple specialists. An example would be a patient with cerebral palsy who used a G-tube for nutrition and a wheelchair for mobility. A third group of patients did not have intellectual or developmental disabilities, but had medical diagnoses like type 1 diabetes, management of which was complicated by concomitant psychiatric illness or difficult social situations such that straightforward transfer between specialists was insufficient. Some of the providers had set out to care for patients with IDD. A significant proportion of patients had IDD even when providers had not specifically recruited that population.

Table 2 Features of the Transition Programs

Clinic characteristics (*n* = 17)	*n* (%)
Has dedicated support staff	12 (71)
New patient appointments (min)	
≤ 40	5 (30)
60	8 (47)
120	3 (18)
Unsure	1 (6)
Follow-up appointments (min)	
15–20	6 (35)
30–60	8 (47)
> 60	2 (12)
Unsure	1 (6)

Models of Care

Participants' transition work fell into four broad models (Table 3), based on the site of care (adult, pediatric, or both) and whether care was consultative, ongoing, or both:

1. Primary care for adults with childhood-onset conditions, within adult-oriented primary care practices
2. Mix of transition support and primary care in pediatric settings
3. Bridge program consisting of pediatric and adult-oriented components
4. Consultative transition support service based in an adult-oriented health care setting

Model 1: Primary Care for Adults with Childhood-Onset Conditions, Within Adult-Oriented Primary Care Practices. Eleven participants (from ten institutions) described this care model. They provided primary care to young adults after transfer. Four participants using this model worked in settings with practice and/or system-level adaptations specifically for transitional care. Interestingly, more (seven participants) worked in clinics without any practice or system-level focus on transition.

Practice and system-level arrangements that facilitated transitional care varied. Two participants led complex care programs for young adults with childhood-onset conditions. Their programs had care coordination support and a dedicated team for patients and families to contact when they had concerns between visits. One participant described a program within a program within a practice: in a larger general med-peds primary care practice, transitional care for young adults with childhood-onset conditions was embedded within a larger young adult program that focused on ease of access. Another worked in a comprehensive clinic designed for adults with IDD that offered primary care and numerous specialty services in a common space.

The seven participants who incorporated young adults with childhood-onset conditions into their day-to-day schedules without any practice- or system-level focus on transition generally described themselves as primary care doctors who care for such patients as a piece of the work that they do. They leveraged regular clinic staff and system resources (e.g., social

Table 3 Models of Care

Model number	Setting of care		Care provided	
	Pediatric	Adult	Consultative	Ongoing
Adult primary care (1)		x		x
Transition support and pediatric primary care (2)	x		x	x
Bridge program (3)	x	x	x	x
Consultative transition support (4)		x	x	

worker, same-day clinic) rather than dedicated transition resources to address their transition patients' needs. Some of them had made scheduling and procedural adaptations for transition on an individual level. Extended appointments and more frequent visits were often discussed. Before even scheduling a new patient appointment, several required that the patient's main pediatric provider (not always a PCP) first send a transfer summary with a succinct history, problem list, medications, vaccinations, and recommendations for working with the patient and family. They said these strategies helped incorporate these young adults into their patient mix, even though the larger practices and clinics were not specifically designed for them. Embedded programs kept costs down by utilizing the larger clinics' resources for handling phone triage, patient rooming, and administrative tasks.

Model 2: Mix of Transition Support and Primary Care in Pediatric Settings. Four participants (from three institutions) worked in pediatric clinics that provided intensive transitional support for adolescents and young adult patients and their families, and also primary care services. Interestingly, two of these clinics started as solely consultative programs focused on transition, but later incorporated primary care because they struggled to find adult-oriented providers to take transferring patients.

Transition support consisted of helping youth build self-management skills and identify adult-oriented providers. It also included helping families navigate other changes and needs that arise as adolescents reach adulthood such as guardianship and other medical-legal issues, planning for life after high school, and maintaining health insurance. Some clinics offered group classes specifically for youth on salient topics such as insurance and healthy eating.

Model 3: Bridge Programs, with Pediatric and Adult-Oriented Components. Three participants (from three institutions) described a model that served as a bridge from pediatric to adult-oriented care. Bridge programs pulled in components from adult-focused and pediatric-focused health systems. In two cases, providers saw patients in both pediatric and adult settings, and kept many of the patients after transfer to adult care within their practices. In the third case, both a pediatric and adult provider saw patients within a transition program that was primarily housed in an internal medicine clinic. Patients were seen by one or the other provider, but they worked in the same area of clinic at the same time, which facilitated collaboration. This model was designed to allow patients to begin to adapt to adult care while still working with a team that included pediatric providers. The long-term intent was for patients to transfer from the transition program to a different primary care provider in the internal medicine clinic.

Model 4: Consultative Transition Support Service Based in an Adult-Oriented Health Care Setting. One participant worked in a purely consultative model where patients were referred for assistance with transition support needs. Most referrals came from pediatric specialty clinics in the provider's system. Adolescents and young adults were seen in this program while still following with their pediatric providers, and for one or two appointments after transfer to adult care. This program provided services similar to model 2, but without ongoing primary care. The consultative model also offered post-transfer support for the adult *providers*, including guidance through unfamiliar paperwork and processes and information on rare pediatric-onset diseases.

Common Practices and Practice Philosophies

Three common strategies were tangible practices: efforts to take more time for the care of this population, a team-based approach, and an emphasis on care coordination. Other recurrent themes were more conceptual attributes of care reflecting providers' practice philosophies: a focus on the whole patient and a willingness to learn from practice and learn from families.

Efforts to Take More Time for Patient Care. Participants felt effective transitional care of young adults with childhood-onset conditions required more time than the average patient both during and between visits. During visits, providers needed time to get to know patients and families and to assist patients with navigating systems and to address psychosocial barriers to care. The increased inter-visit time needed was due to a generally high level of medical complexity as well as administrative tasks required for group homes, home health services, and durable medical equipment. Many participants scheduled longer appointments than typically seen in primary care practice both for the initial visit and follow-up (Table 2). Longer initial appointments were especially important, as many patients and families brought lists of concerns to the first visit. Some participants noted that after the first few appointments, less complex patients could eventually be seen in standard visit lengths. Some participants increased time face-to-face with patients by having them follow-up more often, especially early-on, to build the physician-patient relationship.

Team-Based Approach. Transitional care models were interdisciplinary. Participants worked with social workers, nurse care managers, nurse practitioners, pharmacists, dieticians, and respiratory therapists. Staff who could not bill insurance were variably funded through resources including grants, direct health system support, or specialized contracts with Medicaid. In many cases, a percentage of nurses' and social workers' time was dedicated solely to transitional care. In smaller programs and in most programs embedded within larger clinics, interdisciplinary staff supported the broader clinics, but were available for transition patients so that specific staff need not be hired. Participants emphasized how much they relied on the team for the extra administrative work. Three programs had youth advocates or youth community health workers. One clinic employed a community health worker who was a college student with chronic illness. Through sharing her personal experience, the community health worker was able to collaborate effectively with youth. Participants from these programs said young adult patients benefitted from learning from a peer with first-hand experiences of transition.

Importance of Care Coordination. Care coordination was central to these practices. Several participants said their young patients with multiple comorbidities often had multiple specialists, but no one provider had taken the lead with the care coordination and quarterbacking their patients needed. Participants felt that among clinicians, generalists are most comfortable in this role. Even the smallest programs with dedicated support (i.e., a physician working with just one other transition staff member) included a care coordinator, showing the importance of care coordination. Programs without dedicated transition staff support had other mechanisms for care coordination. For example, one relied on payor-based care coordination through the state Medicaid program. Care coordinators were generally nurses and social workers. They maintained care plans and transfer letters, scheduled appointments, and assisted with durable medical equipment and paperwork. Other tasks beyond these core activities varied depending upon their training (Fig. 1). Social work-trained care coordinators tended to focus on referrals to outside agencies (e.g., Office of Vocational Rehabilitation), insurance, and issues around guardianship and surrogate decision-making. Nursing-trained care coordinators focused on patient education, disease exacerbation management, and phone triage.

In a few cases, care coordinators arranged for multiple procedures to be accomplished at one surgery event. In the most striking example, admittedly an outlier, they had coordinated eye, dental, and gynecologic exams, phlebotomy, and an ENT procedure to occur together for a patient who otherwise would have required repeat sedation for each. Participants emphasized such scheduling was worth the effort, with less anesthesia exposure for patients and less time off work for family caregivers. One participant pointed out combining procedures in this way also had the potential to reduce costs for payors or a health system's accountable care organization.

Care coordination for this population was complicated by two factors. The first was the added need for team members to understand and work across both pediatric and adult systems of care. For example, one program tracked down the individualized education plan (IEP) from the school system for their transitioning patients and reframed the information in that plan to help health care providers understand the patient's needs for communicating new information. Doing this required knowledge about how IEPs work, a distinctly pediatric skill, and knowledge of how to present this to adult providers in a useful fashion. The second complicating factor was the strict dichotomy of the health care and social services provided into pediatric or adult, when patients may in fact require services that are somewhere in between what the traditional dichotomy offers. Providers also needed to be aware of changes to Medicaid coverage as patients reached 18 or 19 years old.

Focus on the Whole Patient. Collectively, interviews reflect a shared belief that health care is about quality of life, as well as disease control:

> Of course when you talk about medical care, medical care is never complete without social support and structure and so forth.

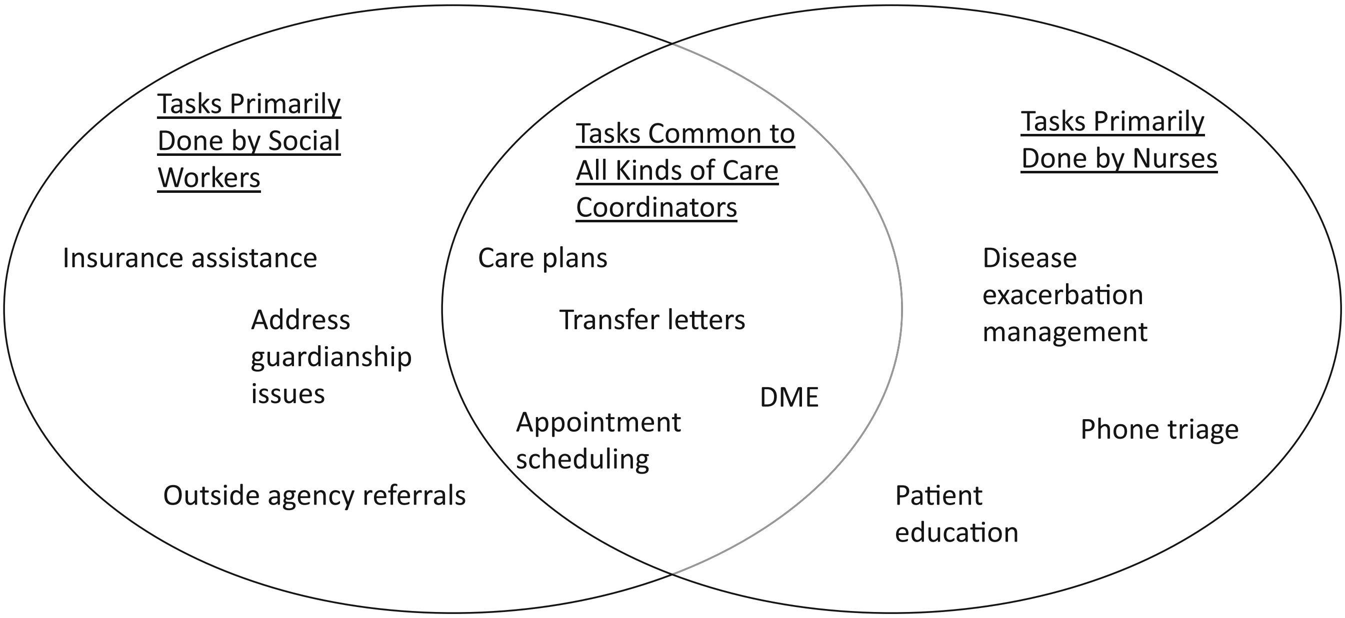

Figure 1 Division of care coordination tasks based on care coordinator's training.

> The young people that we've seen succeed are really the ones who are doing well outside of their illness. And then it's because they're thriving in the rest of their life, and they're getting a job, and they're having a strong social connection, and they're thriving in their personal interests. It's almost because of those things that their illness does well as well, versus just kind of honing in just on the illness.Participants often talked about patients' social contexts. They saw their patients' health as being deeply connected to education, work, play, goals, and independence. Care was aimed at maximizing function and lifting life trajectories and considered the patient's development, including where the patient needed further development. One participant talked about how patients "had been through major developmental milestones," as part of their care in the transition program. To support a patient's development, education might focus on helping patients critically think and problem solve, something older adults might be expected to do more independently.

Maximizing patient function often meant linking patients with community programs. Our interview question about partnering with community organizations was answered enthusiastically:

> ...Bringing in those community partners...opens doors. You don't have to be a social worker, but you have to know a lot about the social needs inherent to transitions, and be willing to network with people and programs within and external to one's healthcare system in order to provide adequate health care to this population.A few participants met with government agencies, local non-profits, home health services, and other clinical departments to learn what they could offer patients.

Learning from Practice and Learning from Families. Finally, many interviewees acknowledged their formal training did not prepare them to care for young adults with chronic medical problems so much as their *practice* prepared them to do so:

> I had a little bit of adolescent training now almost 30 years ago in residency, really no specific young adult. ...I realized to be better at it, I had to invest in learning more about it.
> I said to patients as they came in, like, 'Look, I have no training in this. I'm learnin' with you, and you're gonna teach me.'Participants were eager to work with patients' families. One said:

> I use the parents as experts on their child, and I try to get everybody else to listen.Several mentioned how much they had learned about caring for youth with complex conditions from listening to family members. They emphasized the need to work collaboratively with patients and families.

DISCUSSION

We described a variety of approaches to transitional care of young adults with childhood-onset conditions. The transition literature thus far has focused on youth with one major medical problem such as type 1 diabetes, congenital heart disease, or a rheumatologic disorder.[32–35] For such patients, specialists often direct the transition process.[26, 36] In contrast, our participants saw patients with multiple problems and a high prevalence of IDD. For these patients, participants noted that specialists had not been directing the transition, a finding consistent with patients' and families' reported experiences.[13,14] Participants and their teams addressed multi-morbidity, mental health, assistance with insurance, and connecting patients with available resources, which are needs patients and families have identified as critical.[13,14,37] These findings suggest generalists have a vital role in transition, serving patients with multiple comorbidities and those who most need interdisciplinary support and care coordination.

Guidelines recommend that transitions occur inside the Patient Centered Medical Home (PCMH).[17,18] Our findings support that recommendation. While participants had a variety of clinic structures, team compositions, and practice strategies, the common ideas across interviews that stood out (a team-based approach focusing on care coordination, considering multiple domains of a patient's life, and a patient and family-centered orientation) are also key components of the PCMH model.[38] The alignment between our participants' approaches and PCMH components suggests that primary care providers in practices with or seeking PCMH certification may already be set up to do many of the things transition patients need. The PCMH offers a familiar, workable conceptual framework for incorporating transition care into general medicine practices. These findings suggest that a *transition-friendly* PCMH model would add systems to assess and support patients' cognition and development, and augment care coordination capacity to respond to differences in, and gaps between, pediatric and adult systems.

A known challenge of the PCMH approach is that smaller practices can become overwhelmed with complex patients,[39, 40] and the patients coming to our participants tended to be complex. Participants needed more time than the US average 21-min primary care visit.[41] The frequency with which they talked about strategies to spend more time with patients suggests that longer appointment times may be a necessary component of high-quality transitional care. Scheduling frequent return visits in the immediate post-transfer period was a helpful strategy when youth arrived in adult care with a myriad of needs.

Knowledge gaps about childhood-onset conditions are another challenge for adult-trained primary care physicians.[21–24] Without our asking, many participants talked about having encountered medical conditions and complexity they had no prior experience managing. They emphasized their successes came from listening to families and continuing to read. The high prevalence of IDD among their practices suggests that providers interested in transition can focus their learning on that population to start. Several tools are available for learning about recommended care of adults with childhood-onset conditions,[42–45] such as the book *Care of Adults with Childhood Onset Conditions*[42] and the GeneReviews website, which provides management guidance to providers for patients with genetic disorders. The Got Transition website (www.gottransition.org) offers recommendations for practice changes to improve transition and tools to help providers implement and measure those improvements.[46]

Small sample size is a limitation of this study. We recruited participants from a variety of settings, however, and continued interviews until we had reached thematic saturation. While our decision to purposively sample providers actively engaged in transition elicited rich information, these participants may not be representative of most primary care physicians. Future work could expand to a larger set of providers to better understand experiences of providers who have not made transition a focus in their practices. Most participants practiced in academic medical centers, and thus, our findings may not be generalizable. However, we expect staffing considerations and strategies pertaining to transition embedded within a general practice, the most common model we encountered, to be relevant in non-academic systems.

These providers' experiences and reflections are ground-level information about managing youth as they transition from pediatric to adult care, where internists will need to be ready to assist them. Findings provide insight into strategies and care models that facilitate transition for patients and physicians, an issue of growing importance as more and more children with serious illnesses reach adulthood.

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Compliance with Ethical Standards:

This study was deemed exempt by the University of North Carolina at Chapel Hill IRB.

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