Transition Practices in Wisconsin Health Care Systems: What Do We Know?

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ABSTRACT

Background: The transition from youth to adult health care is a complex process, and only 25% of all youth and less than 35% of youth with special health care needs in Wisconsin receive support.

Objectives: This article describes the process and results from the Wisconsin Youth Health Transition Initiative's assessment of transition support provided in health care.

Methods: Key informant interviews were undertaken with clinicians from several Wisconsin health care systems.

Results: Fifty percent of health care systems interviewed had a formal policy or guideline supporting health care transition. Additionally, several barriers consistent with national trends were confirmed.

Conclusions: Health care transition for Wisconsin youth remains suboptimally supported in practice. Continued funding and work towards this important maternal and child health objective are needed.

BACKGROUND

Transitioning from pediatric to adult health care can be complex for youth and their families, along with their clinicians. Health care transition (HCT) is defined as the process of an individual moving from a pediatric to an adult model of health care with or without a transfer to a new clinician.[1]

According to the 2020-2021 National Survey of Children's Health, only 34.6% of Wisconsin youth with special health care

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needs and 25% of youth without special health care needs receive adequate HCT assistance from their health care providers.[2] In this survey, parents of youth ages 12 to 17 responded to questions related to whether the health care professional (1) spent time alone with the youth, (2) discussed the HCT process (skills and changes at age 18), and (3) discussed the need to transfer to clinicians for adults.

To address the problem that less than half of all youth are getting the help needed for successful transitions to adult care, best practices have been defined and endorsed by White and coauthors, including the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians.[1] These best practices include structured implementation processes for HCT called the Six Core Elements. The Six Core Elements are intended to be customized depending on patient population and practice type and include: (1) transition and/or care policy, (2) tracking and monitoring, (3) transition readiness and/or orientation to adult practice, (4) transition planning and/or integration into adult approach to care, (5) transfer of care and/or initial visit, and (6) transition completion/ongoing care. Policy development is the first step, with consideration for starting HCT planning as early as age 12 when changes in confidentiality occur.

Clinician barriers to HCT most often reported in the literature include not being given enough time for transition,[1] lack of available clinicians,[1] lack of current knowledge/awareness of available resources,[3] having transition resources but not using them,[4] and hesitancy to transfer patients with active care or disease.[5] Although current literature promotes best HCT practices (eg, the Six Core Elements), there is little evidence for improved out-

comes using a common set of strategies for all clinics/systems.

Families and youth may experience HCT barriers with respect to accessing HCT support, including feeling alone in the process;[3] lack of anticipation/awareness of HCT;[6] difficulty trusting new clinicians;[4] and reluctance to transition.[7] Those achieving HCT frequently reported increasing awareness as being helpful for transition.[7] Two models of HCT described that the use of a care navigator facilitated successful transitions.[8] In a 2023 scoping review, Markoulakis et al[9] described 5 themes that support HCT, including holistic supports, proactive preparation, empowering youth and families, collaborative relationships, and systemic considerations.

In 2021-2022, the Wisconsin Youth Health Transition Initiative (YHTI), funded by the Wisconsin Department of Health Services Maternal and Child Health Block grant on a contract with the Waisman Center University Center for Excellence in Developmental Disabilities at the University of Wisconsin-Madison, was asked to report on HCT practices, which included identifying those Wisconsin health care systems with HCT policies or practice guidelines, the extent of HCT implementation, and the facilitators and barriers of that implementation. This report reflects "what we know" about HCT in Wisconsin during the COVID-19 pandemic.

METHODS

Using a systematic approach, the YHTI chose to conduct interviews with informants from selected Wisconsin health care systems. The YHTI identified the number of hospital beds as the most readily available measure to capture those systems serving the largest population and utilized a state-based database cross-referenced with a national hospital directory for this measure. While the focus of the YHTI is youth with special health care needs, the team sought key informants in the 10 largest systems providing primary and specialty care to pediatric and adult patients. This project met the criteria for "quality improvement" utilizing the University of Wisconsin-Madison Quality Improvement/Program Evaluation Self-Certification Tool and did not require institutional review board approval.

Conducting Interviews

Interview questions were generated to identify the extent of HCT implementation utilizing the Six Core Elements, with a focus on whether the interviewee knew if there was an existing system-wide HCT policy or practice guideline. All interviews (20-60 minutes each, 2 of which included more than 1 respondent in the interview) were conducted over a 15-month period via Zoom by an adult nurse practitioner with lived experience as a parent of a child with a disability. Three pilot interviews, conducted with 3 clinicians known to the YHTI, finalized 19 questions. Seven subsequent interviews involving 10 clinicians were conducted (Table 1).

The YHTI encountered significant challenges in identifying,

Table 1. Description of Interview Sample

	No.	(%)
System size (n = 8)		
Top 10 largest	5	(62.5)
Other	3	(37.5)
Interviewee system size (n = 13)		
Top 10 largest	8	(61.5)
Other	5	(38.5)
Interviewee credential (n = 13)		
Physician	5	(38.5)
Advanced practice provider[a]	4	(30.8)[a]
Registered nurse	1	(7.7)
Social worker	2	(15.4)
Bachelor of Science	1	(7.7)
Interviewee primary role (n = 13)		
Administrative/non-direct patient care	4	(30.8)
Direct patient care	9	(69.2)
Interviewee primary population served (n = 13)		
Adult	1	(7.7)
Medicine pediatrics	3	(23.1)
Adolescent	1	(7.7)
Pediatrics	8	(61.5)

[a]Due to rounding, percentages may add up to more than 100%.

contacting, and interviewing key informants in 5 of the 10 largest Wisconsin health care systems. Therefore, additional interviews with smaller health care systems with known contacts, as well as the 3 pilot interviews, were included in the analysis.

Performing Data Analysis

Interview recordings were transcribed verbatim by one of the authors. A qualitative codebook was developed based on literature review and a seminal HCT article.[1] A single experienced coder performed a thematic analysis of the interview transcripts in QSR NVivo 12 Software (Lumivero). Themes were reviewed by all authors and confirmed that saturation was achieved.

RESULTS

Analysis began with the first of the Six Core Elements (ie, having a HCT policy or guidelines in place) and then focused on facilitators or barriers of additional elements. Four out of the 8 (50%) systems interviewed met the criteria of having a policy or guideline in place. The Six Core Elements further recommends the policy or guideline be consistently communicated and supported by administration, with funded time for implementation, and shared in an accessible format. All 4 systems with a HCT policy or guideline in place indicated limited policy or guideline communication, administrative support, or additional time for HCT. Table 2 includes quotes from interviewed clinicians.

The Six Core Elements includes the availability of electronic medical record (EMR)-embedded tools as a facilitator of HCT implementation. Examples of these tools include the ability to identify, track, and monitor patients during transition; transi-

tion readiness assessments; HCT report queries; clinician registries; shared plans of care or summary statements, and transfer of care materials. Interviews identified that few systems had any of these tools embedded into their EMR. Those that did have access to some EMR-embedded tools indicated their usefulness in HCT implementation and quality improvement initiatives (Table 2).

HCT practice leaders are included as important factors in HCT implementation.[1] Those interviewed indicated both the importance of having system or clinical leadership to keep focus and momentum on HCT, as well as being able to identify clinicians willing to see adults with different conditions. Staff indicated challenges when HCT leaders retired and in identifying enough adult clinicians to transition patients.

DISCUSSION

The YHTI identified that systems were more likely to have met the primary measure of having an HCT policy or guideline if there was previous HCT support, including grant funding, access to targeted training or technical assistance, financial support for professional continuing education opportunities, or the presence of HCT practice leaders within the health care system.

The interview results indicate that HCT continues to occur within practice silos, primarily by clinicians (physician/nurse practitioner/physician assistant) with intermittent evidence of nursing, social work, or other professional support and, typically, without identified system-wide supports. HCT supports were more prevalent in specialty care than primary care settings. There was evidence that HCT work often was initiated and carried out by individual leaders with a passion for the work, which subsequently floundered when the clinician left or retired.

The timing of the COVID-19 pandemic had an impact on both the interview process and HCT practices within health care systems. While the use of virtual platforms facilitated the interview process, the pandemic disrupted the project timeline. With time and efforts saturated by the day-to-day care of patients, it was difficult for clinicians to have time for interviews.

Table 2. Quotes Illustrating Reported Facilitators and Barriers of Health Care Transition Implementation

THEME/Representative Quotes

ADMINISTRATIVE SUPPORT OF HCT POLICY/GUIDE

"I think there's the intention, so the theoretical support [for HCT], but not the time and dollars support."

"We did write a transition policy, which I don't know that anyone is really necessarily supporting that or making it something that teams need or have to follow. From my perspective, we really don't have a whole lot of support just from a system-wide standpoint."

"We do have a policy in place that states that we will be doing this. However, that's as far as we've gotten...I think there's a lack of awareness beyond a few people in the organization, especially in the management and higher level... I think there's a lack of resource allocation to even move forward with the project."

"I think that grant opportunities and the connections that I've had with the [CYSHCN] regional center for many years have both really helped with this whole process...to serve as a catalyst for some of the work that we've done in our health systems."

COVID

"I know with COVID too, you know, that that's kind of putting a lot of regular work that we're doing to the side while we're just trying to manage that weekly changes as you know."

"...So, we work those lists. It's supposed to be every 3 months unless you're in a pandemic or unless you're in a surge of pediatric respiratory cases like right now."

"COVID has changed a lot of our protocols."

HCT LEADER

"We had a couple departments that were doing it ... very well. Now those providers, the two that were kind of our headstrong for leading the transition project have now retired...and I really feel like the transition work has kind of just fizzled out."

"[Many adult] medical providers have no education on this [YSHCN] population. And that's [why there is] really no formal system like a welcome center that has 'okay, these are providers who are interested and willing'."

"I feel like you always need a clinician, a chair cheerleader...but I think it's taking on a lot for someone who is already busy."

"We latch onto somebody that's taking a few [transition patients] and keep adding to their pile."

EMR-EMBEDDED TOOLS

"There is no way to identify them as they're making the appointments as someone who has special needs or complex care. They get slotted into the same 30-minute appointment that all of my new patients would get slotted into. If I happen to preview them enough in advance then I may be able to move them around in my schedule, find them a little more time, some of those sorts of things."

"But I think that we do in this day and age have many opportunities with our EMR's and our systems that we have in place that we could do that. We just don't have the resources to make it happen right now."

"I think the only thing that we really have at a system level right now as we have a process that we send out a letter to all patients 17 years, 9 months. And then we have like a brochure turning 18."

"Yes [we have tools in EMR]. That [HCT readiness] checklist. And then ultimately the shared plan of care will reflect that transition."

"I can do manual audits to see like how often the transition checklists are being used and the questionnaires are being used because those get scanned into the medical record under a specific content type."

Abbreviations: HCT, health care transition; EMR, electronic medical record; YSHCN, youth with special health care needs; CYSHCN, children and youth with special health care needs.

Additionally, many of those interviewed reported the pandemic severely affected HCT work and progress in their system. These impacts on HCT implementation are likely to persist for many years beyond the pandemic.

The interviews were limited to 1 or 2 clinicians within a health care system, and it was difficult to find an individual within an organization that could speak to HCT implementation on a systems level. Nonetheless, interviewees were able to identify HCT facilitators in their organization. Two contacts reported that the recent systemic focus on diversity, equity, and inclusion offered a renewed avenue of conversation regarding equitable care of indi-

viduals with disabilities within their organizations. This has the potential to elicit change in the delivery of health care to youth with special health care needs and to be a potential source of quality improvement for systems to implement HCT practices for all patients. Another positive outcome of these interviews was the identification of leaders with potential to expand HCT implementation. These interviews confirmed Wisconsin has similar barriers to those reported nationally, and this knowledge provides a focus for future work in the state.

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