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An institution-wide mixed methods assessment of healthcare transition

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ABSTRACT

Background: Healthcare transition (HCT) is the process of moving a patient from pediatric, parent-supervised care to an independent, adult-centered model. This study assesses current HCT activities and explores the educational and system-based needs for effective HCT processes in a single institution.

Methods: We interviewed division/care program leaders at one academic tertiary-care children's hospital regarding HCT practices. We evaluated these groups using an interview guide and rubric scoring from the "GotTransition Current Assessment of HCT Activities" (scoring range from 8 [low HCT] to 32 [high HCT]). We audio-recorded and transcribed interviews. We calculated each group's score on the rubric. Two coders qualitatively analyzed interview transcripts using a thematic analysis approach with deductive and inductive strategies.

Results: We interviewed 28 participants, each representing one division/care program. The institutional mean on the HCT assessment was 15.5 ± 4.5 (median 17.5, range 8–28). Key interview themes included: 1) Significant heterogeneity in the HCT process exists within most divisions/care programs; 2) While some groups have their own HCT practices, there is no coordinated institutional HCT approach.; 3) Participants find HCT difficult if they perceive the lack of an equivalent adult specialist for a patient's specific medical condition; 4) There is a lack of coordinated handoffs from pediatric to adult providers. 5) Participants desire ancillary staff to support HCT. Conclusion: Despite known benefits of a structured approach, most leaders report heterogeneity in current HCT practices and a lack of institutional resources and adult provider partners to support optimal HCT. We present a reproducible methodology to evaluate HCT within a single institution, as well as baseline assessment data that may inform interventions.

1. Introduction

Healthcare transition (HCT) is the process of an individual moving from pediatric, parent-supervised care to an independent, adult-centered model. HCT is an important aspect of adolescent and young adult healthcare, especially for those individuals with medical complexity or chronic health conditions. Lapses in care during the transitional period have been associated with adverse health outcomes for patients. Interventions promoting high-quality HCT have been associated with reduced loss to follow up and improved transition readiness among patients. Such HCT interventions may also promote better health outcomes among youth with chronic diseases, though

evidence is limited. 10

The American Academy of Pediatrics, American College of Physicians, American Academy of Family Physicians, and the American College of Obstetrics and Gynecology all have provided best practice recommendations for HCT. ^{11,12} GotTransition.org is a program of the National Alliance to Advance Adolescent Health and is a web-based clearinghouse of tools and information about ideal HCT, including the Six Core Elements of HCT. ¹³ The Six Core Elements include development of a transition policy/guide, tracking and monitoring adolescents and young adults, evaluating patient transition readiness, transition planning, transferring care, and completion of transfer. ¹³ Despite these existing best practice recommendations, pediatric healthcare providers

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endorse gaps in their understanding of HCT and voice additional needs for education and resources to optimize HCT. 14,15

While prior research has focused on individual provider educational needs and barriers, ^{14,15} we sought in this study to assess current HCT activities, system-based needs, and barriers to effective HCT processes on an institution-wide level throughout the divisions and care programs of a single academic tertiary-care children's hospital. We hypothesized that, while there would be programs with strong HCT activities, the majority would report suboptimal HCT for their patient populations. Importantly, in qualitative interviews, we explored the challenges and facilitators to implementing HCT programs that adhere to current guidelines. We hope the results of this study will ultimately inform HCT policymaking, determine key areas of intervention, and serve as a framework for HCT needs assessment and practice improvement at our institution and beyond.

2. Materials and methods

We interviewed division or program leaders at one academic tertiary-care, free-standing children's hospital regarding HCT practices. Each division leader represented one pediatric division or care program. We evaluated groups using an interview guide and rubric scoring from the "Current Assessment of HCT Activities" publicly available on the GotTransition website [13]. This rubric assesses eight domains capturing the six core elements of HCT (Transition Policy/Guide, Tracking and Monitoring, Transition Readiness, Transition Planning, Transfer of Care, Transfer Completion, Youth/Young Adult and Parent/Caregiver Feedback, and Youth/Young Adult and Parent/Caregiver Leadership). ¹³ Each domain is scored from Level 1 ("low adherence with HCT guidelines") to Level 4 ("high adherence with HCT guidelines"). 13 Total scoring on this rubric ranges from 8 ("low HCT") to 32 ("high HCT"). 13 For the qualitative component of the study, the study team developed the interview guide and based its flow and questions off the rubric described above (Supplement 1: Interview Guide). The interview guide also explored barriers and facilitators to optimal HCT.

We obtained verbal informed consent from all participants prior to the interview. Each interview lasted from 25 to 90 min. We audio-recorded each interview and transcribed interviews verbatim using Zoom videoconferencing technology. Two interviewers (AM, AA) conducted all interviews. At the time of the interviews, the two interviewers were a female general pediatrics resident (AM) and a male pre-medical student / non-profit organization employee (AA). Both were trained in qualitative methods by a senior co-investigator (TMK). The interviewers discussed findings and summaries after interviews with TMK after approximately every five interviews. The University of Pittsburgh Institutional Review Board deemed this study exempt.

We calculated each participant division's/group's rubric score on the GotTransition assessment upon completion of the interview. We utilized descriptive statistics to analyze results. For the interviews, two independent coders (AM, AMC) created a preliminary codebook based on the interview guide. AMC is a female medicine-pediatrics resident and was trained in qualitative methods by a senior co-investigator (TMK). AM functioned as an interviewer in the study and as a coder and received training in these methods as described above. The coders independently analyzed all transcripts upon completion of all interviews using Braun and Clarke's thematic analysis approach with deductive and inductive strategies. 16 The coders used deductive coding based on the initial codebook and centered on the GotTransition "Current Assessment of HCT Activities". Coders used Dedoose software (SocioCultural Research Consultants, Los Angeles, CA) to complete coding. Both coders added codes progressively as they deemed appropriate during the coding process using an inductive coding approach. Using a consensus coding approach, the two coders met three times to reconcile codes and review their work until they established a final codebook. The coders documented notes from these meetings. The coders then used the final codebook to code all transcripts. Senior co-investigators (LK, TMK) were available to resolve discrepancies in the analysis process as needed. AM and AMC engaged with coding the data for approximately five months. Upon completion of coding all transcripts, the two coders chose illustrative quotes to support emergent themes.

2.1. Results

2.1.1. Participants

We interviewed 28 divisional or program leaders. Table 1 summarizes the divisions/programs represented.

2.1.2. HCT Rubric Scores

The institutional mean on the HCT assessment was 15.5 \pm 6.1 (median 17.5, range 8–28). Table 2 depicts scores by domain across participating divisions/programs. Mean domain scores (out of a maximum of 4) ranged from 1.4 \pm 0.78 for Patient and Parent Leadership to 2.5 \pm 0.96 for Transition Planning as well as 2.5 \pm 1.1 for Transfer of Care.

2.1.3. Qualitative Themes

Five themes emerged from analysis of the interviews relating to the HCT process and barriers and facilitators to improving transition care. Table 3 summarizes the themes and provides representative quotations.

Theme 1. Significant heterogeneity in the HCT process exists within most divisions/programs.

Almost all participants reported the overall lack of a systematic, unified HCT process within their respective divisions/programs. This theme was especially highlighted through provider-to-provider variation in practice. One participant reported, "We don't have anything formal or in writing or anything like that outlining transition. We have four attendings in our department, and each one does it a little bit differently. (Participant 14)" Another participant commented, "We write it [HCT] in our notes if it's a discussion that we've had. But beyond that, we really don't have an organization around that process. (Participant 17)". Providers also noted that they do not know what their colleagues' HCT practices are. One such participant expressed, "I personally don't know what my colleagues' transition policies are, but we don't have one [HCT policy] within the division that is universally used. (Participant 26)".

Most participants recognized significant gaps in HCT within their group's practice and expressed that their respective divisions/programs remain in the early stages of developing an appropriate HCT process. One participant reported, "I think that there is just a lot of variation and we're kind of at very beginning stages. (Participant 13)" Another participant said, "So that [HCT] is haphazard. So, there is no consistent approach and that could definitely be improved across the clinic. (Participant 19)" Many participants also endorsed that HCT discussions with pediatric patients are rare. A participant stated, "I would say we are discussing transition with our patients less than 10% of the time. (Participant 26)".

Table 1Participating pediatric divisions or care programs.

Allergy and Immunology Dental Oncology Asthma Clinic Down Syndrome Clinic Orthopedics Plastic Surgery Adolescent and Young Adult Endocrinology Otolaryngology Clinic Medicine Pulmonology Behavioral Health General Surgery Sickle Cell Clinic Child Advocacy Clinic Genetics Solid Organ Cerebral Palsy/Spina Bifida Gastroenterology Transplant Heart and Lung Clinic Cystic Fibrosis Center Transplant Chronic Pain Management Hepatology Complex Care Clinic Nephrology Congenital Cardiology Neurology Neurosurgery

Table 2Current Assessment of HCT Activities Scores, Overall and by Domain.

Domain	Score Mean (SD)
Transition and Care Policy Guide	1.8 (1.0)
Tracking and Monitoring	2.0 (0.88)
Transition Readiness	1.7 (1.1)
Transition Planning	2.5 (0.96)
Transfer of Care	2.5 (1.1)
Transfer Completion	2.1 (1.3)
Patient and Parent Feedback	1.6 (0.88)
Patient and Parent Leadership	1.4 (0.78)
Overall	15.5 (6.1)

Theme 2. While some groups have their own HCT practices, there is no coordinated institutional HCT approach.

In addition to heterogeneity in HCT practices within groups, participants also report the lack of a coordinated institutional HCT approach. While providers within a division may have differing HCT practices, participants reflected that HCT fragmentation is further compounded by practice differences between divisions/groups. For example, one participant said, "Many subspecialists here will graduate patients at the age of 18. Some will see them past 18 and work to transition them. We and some other subspecialists will see patients up to the age of 26. So that's something that poses a lot of difficulty - the lack of a formal age for transition. It would be nice if there was a standard policy within the hospital about when kids should be transitioned and how. (Participant 16)".

Most participants desire an overall formalized HCT process across the institution. One participant expressed, "First and foremost, the providers in the clinic, the nurses in the clinic, we need to have a better handle on what or a better understanding of what needs to be involved. We need a process. We need a checklist. Here's what we do when we start, here's what we talk about when you turn 16. Here's what we talk about when you turn 20. (Participant 13)".

Some participants note that, without an institutional HCT approach or policy, they do not transition patients to adult care. Pediatric providers have continued to care for patients well beyond their pediatric years and reported being unequipped to navigate adult-related health problems or concerns. A participant stated, "We actually did a terrible job of transitioning patients...we were caring for patients into their 30 s. We were caring for patients who had children. We were trying to deal and all right, it [HCT] happened. The process happened quickly and haphazardly when a patient called and said, 'I'm 28 and pregnant, what do I do?' We'd say, 'Oh, we don't know. We're not going to deal with that, go to the adult side.' It was kind of just like there was an external circumstance that suddenly forced us to transition before we really went through the process with the families. (Participant 18)".

Participants from the groups with the highest HCT rubric scores highlighted key facilitators to optimal HCT. Key facilitators include a written HCT guideline or policy, a standardized tool or checklist for assessing HCT readiness and progress, and uniform HCT provider practices within a division. Participants from these higher scoring divisions noted their "team does a really strong job of consistently using a standard transition readiness assessment questionnaire. That's sort of like a checklist that we look over with patients. (Participant 1)" They also emphasize the significance of leaning on a written HCT policy or guideline as a framework to guide not only their patients and caregivers through the process, but to guide the providers' practice. "We have a transition policy that we have developed....we really work with that document consistently within the overall division. (Participant 18)".

Theme 3. Participants find HCT difficult if they perceive the lack of an equivalent adult specialist for a patient's specific medical condition.

Many participants endorsed that a perceived lack of equivalent adult

Table 3Themes and illustrative quotations by pediatric division or care program leaders regarding HCT.

Illustrative quotations

Theme

Theme	mustrative quotations
Theme 1. Significant heterogeneity in the HCT process exists within most divisions/programs.	"Practice within my division is extremely heterogeneous, meaning that there's wide variation in practice." -Participant 21 "I think it's case by case and provider by provider. We don't have like a formal
	"It is incredibly variable and there's not a system in place per se. We write it [HCT] in our notes if it's a discussion we've had. But beyond that, we really don't have an organization around that process." -Participant 26 "There's a lot of variation and we find
Theme 2. While some groups have their own HCT practices, there is no coordinated institutional HCT approach.	that to be an issue." -Participant 18 "There's not a policy that says by age X you need to be transitioned." -Participant 19 "But the patients with the more unusual or rare conditions I tend to continue to see on the peds side, despite age." -Participant 1
	"I think that we all recognize that this is a very vulnerable period for patient populations when they go to the adults. And so I do think having formal processes in place for chronic care kids, which is really what we're talking about, would be
Theme 3. Participants find HCT difficult if they perceive the lack of an equivalent adult specialist for a patient's specific medical condition.	incredibly beneficial." -Participant 12 "I have one patient who's in their thirties that they have a rare genetic disorder, and there's no adult Genetics Department. So they have asked that they keep coming back to see me so that they can have their care coordinated here." -Participant 16
	"We need to identify providers that are willing to care for these folks. I don't know who is available to care for these medically complex young adults. Many providers say, 'No,' they won't accept the patient. They're too complex. So it's very difficult to find. It can be difficult to find even a PCP." -Participant 9 "I struggle to find providers to treat autism symptoms like sleep problems, behavior problems, ADHD, anxiety, depression. There are very few adult providers out there, and there are very limited resources, so that's a struggle." -Participant 21 "The one that limits me from transitioning patients on the adult side is
Theme 4. There is a lack of coordinated handoffs from pediatric to adult providers.	the lack of [adult] physicians who have an interest or knowledge of how to care for these patients." -Participant 6 "The communication between the adult world and the pediatric world is not great. So I'm left struggling with patients." -Participant 9 "No, we don't necessarily have a formal, like, written sign out. And again, I think it's case by case and provider by provider." -Participant 5 "We have the process of filling out a release form, but we don't necessarily have a warm hand off or other established forms of sign outs. I think on a case by case basis, we will sometimes
	reach out to the new provider if we know where a child will be establishing care." -Participant 23 "I think where this falls apart is if a young (continued on next page)

Table 3 (continued)

Table 3 (continued)

Theme 5. Participants desire ancillary

staff to support HCT.

Theme

Illustrative quotations

adult never tells us where they're going.'

"Some people do a different note when they are ready to transfer. Some people use their last clinic visit note and summarize everything in that note. They can do it in the last note, or they can do a different note - different people do different things." -Participant 13 "More people, more manpower. And at one point, again, before COVID, we had a nurse that joined our transition program. The health plan allowed her to do that, to come to the clinic because I think it was part of her responsibilities to make sure that young adults would transition safely and would follow with all the things that are part of the standard of care. She was fantastic because not only would she talk to the patients in clinic, but then she would follow [up] with them on the phone. But that person then had to leave. So again, it's manpower. We were able to do a lot with her." -Participant 13 "That's the other aspect. How much we can invest in a little bit of more mannower to do these things that take a little bit of follow up and that we cannot do right on our own. I think we have a lot to improve that we could do with more manpower," -Participant 17 "This process requires involvement from a lot of people." -Participant 6 "We're all so busy. That's another entire initiative that takes staffing and building and money, and we don't have that." -Participant 28 "The coordinators are really the key

person for continuing this transition."

-Participant 27

subspecialists for particular conditions in pediatric patients is a barrier to HCT. One participant described, "In [our] world there is not a separate adult clinic and there's not an adult level provider who has that interest. I think this is a major barrier. The one that limits me from transitioning patients on the adult side is the lack of [adult] physicians who have an interest or knowledge of how to care for these patients. (Participant 21)" Another participant stated, "Similar to the kids with congenital heart disease, there are metabolic liver diseases that are unique to kids that the adults really don't know anything about because they've never really seen [them]. (Participant 19)".

Providers noted that this gap may delay the HCT process itself. A participant commented, "I think not having a physician who has expressed a significant interest in taking care of adults ...is the rate limiting step for me. (Participant 6)" One participant further described how this may pose an ethical dilemma for many clinicians, "The one that limits me from transitioning patients on the adult side is the lack of physicians who have an interest, even if they don't have the specific training. If I don't have somebody who has that interest, it makes it hard. It makes it hard for me to in good conscience refer people to them when I know it's not their focus (Participant 16)."

Theme 4. There is a lack of coordinated handoffs from pediatric to adult providers.

Many participants endorsed a lack of coordinated handoffs or transfer of patient information from pediatric to adult clinicians. Participants reported wide variation in the methodology of how this transfer of information occurs, including over the phone, email, or transition documentation in the electronic medical record by the

pediatric provider. One such participant described "I would say it's probably less actual, like verbal communication. It could definitely be an email if it's a thicker patient. If not, then typically it's a release of information type and you have a summary page for them. (Participant 15)" Similarly, another participant reported, "We don't necessarily have a formal, like, written sign out. And again, I think it's case by case and provider by provider. (Participant 17)".

Participants reported that there is often no intentional transfer of information from clinicians and the onus of information transfer is placed on the patient or caregivers. One participant noted, "I think lots of times people [adult clinicians] probably will look at the last note and kind of figure, 'Okay, I guess that's my transition note. (Participant 26)".

Theme 5. Participants desire ancillary staff to support HCT.

Most participants stated that an effective, streamlined approach to HCT is rooted in interdisciplinary care and increasing the number of healthcare professionals can allow them to adequately manage HCT. One participant expressed, "So, we struggle. This [unified HCT transition] has worked when we do it with a limited number of kids. But how do we translate this to our whole clinic population? Because that takes many resources also. We need to have an educator, we need to have a social worker, we need to have nursing coordinators. We need a full team that helps run it. (Participant 13)".

Participants highlighted the need for an interdisciplinary team whose focus is to manage HCT. Participants identified decreased staff availability as a leading barrier to creating such a team. As one participant discussed, "That's the thing I think we need more of - staffing support. There are more things we could do if we had more staff, but there's not a lot of openings for us to bring those other multidisciplinary people in. We could go further beyond just checking organ functions but also start to look at other aspects for each patient, including better transitioning. (Participant 23)" Most participants noted that without adequate interdisciplinary staff, the onus of coordinating HCT falls solely on clinicians. While clinicians are interested in improving this process, a participant expressed there is a "...Big barrier when it comes to time. When you can only have a 20-minute visit with a patient and you need to see about 60 patients in a day, the level of investment that you can have on each of these [coordinating HCT for each patient] is naturally just going to diminish itself. Not that you're not invested. It's simply just a barrier. (Participant 13)".

3. Discussion

Our institutional assessment of current HCT activities highlighted clear areas for improvement. Many divisions or care programs achieved suboptimal scores on our rubric derived from the GotTransition website. Division and care program leaders emphasized the heterogeneity of HCT practices across the institution. The leaders also described barriers and facilitators to optimal HCT which may inform key interventions for creating a unified, cohesive HCT experience for patients and families.

Poor institution-wide performance on quantitative scoring and reported heterogeneity in practice within and between divisions/care programs suggest an institutional need for standardization of the HCT process. Our study adds to the literature on barriers to HCT by emphasizing the fragmentation of care that results from a lack of standardized practice throughout an institution. One strategy to address such a lack of standardization is an institutional HCT policy. The Six Core Elements of HCT featured on GotTransition.org begin with implementation of a HCT policy. In a recent survey of pediatric healthcare providers, the most preferred facilitator for improving HCT was creation of a formal transition policy. Such policymaking might include: (1) age-specific guidelines for developmentally appropriate anticipatory guidance on HCT throughout adolescence and young adulthood, (2) suggested age of transfer, and (3) evidence-based tools for assessing and tracking patients' transition readiness and progress. Ideally, a HCT policy would

also be informed by feedback from patients and families who are undergoing or who have completed the HCT process.

Concerns raised in our study, as well as in prior literature, about individual providers lacking sufficient resources (i.e. in terms of time, space, and staffing support) suggest that development of an institutionwide policy should be accompanied by an institution-wide investment in HCT infrastructure to make optimal HCT processes feasible. 17,18 One example of such infrastructure that has been reported in the literature is a multi-disciplinary clinical team that tracks and promotes HCT across the institution. 19 Functions of such a team may include development of institutional HCT tools (such as clinical decision support tools in the electronic health record including standardized transition readiness assessments, a registry template, and a transfer note template) and clinical consultations for medically complex patients requiring care from multiple specialties. 19 Other features of successful institutional programs have included designated transition care coordinators and multi-disciplinarity (with particular emphasis on the incorporation of social work support to address patient/family social determinants of

In addition, institutional initiatives must account for difficulties, as reported in our study, in identifying adult healthcare providers with appropriate expertise and interest in caring for patients with pediatriconset chronic diseases. Difficulty identifying appropriate adult providers is among the most commonly reported barriers to optimal HCT by both patients/families and healthcare providers in previous research. ^{17,} 18,21–24 Pediatric institutions seeking to improve HCT should attempt to cultivate relationships with adult providers and health systems to facilitate transition and transfer. However, the onus cannot be on the pediatric institution alone – the adult providers and health systems also need to buy into this process. Graduate medical education systems, and potentially also payors, may be able to support and incentivize the development of adult providers who are both qualified and interested in caring for transitioning patients.

This study's limitations include that participants were from a single academic children's hospital, which may impact generalizability. However, our methodology is reproducible for investigators seeking to understand current practices, barriers, and facilitators within their own institutions as baseline assessment prior to intervention development and implementation. Another limitation may be that solely interviewing division or programs leaders may not provide the fullest, most in-depth information about their divisions and programs, as compared with also interviewing other clinicians and multi-disciplinary providers. However, our goal in this study was to interview leaders to obtain a high-level snapshot of HCT within and between divisions/programs institutionally, rather than deeply explore any individual division/program. Future work should also include youth and family perspectives on experiences of HCT within our institution, whose perspectives are critical to ensuring the success of any transition-related initiatives. Finally, this study focused only on HCT and did not address other aspects of the transition to adulthood that are crucial in the lives of young people, such as educational, legal, social, and employment transitions, which are rich potential areas for future inquiry.

Regarding next steps, we presented these results to hospital executive leadership and discussed future initiatives with program and divisional leaders. Our institution sponsors a HCT task force, who leads educational opportunities for patients, families, and multidisciplinary providers on HCT and serves in an advisory role for condition-specific HCT programs. In line with the results of this study, the task force and hospital leadership are partnering on clinical effectiveness guidelines related to evidence-based HCT care and considering the value of a larger infrastructure investment in HCT across the institution.

4. Conclusions

Despite widely available best practice recommendations for a structured HCT approach from multiple medical organizations and the

GotTransition.org website, most leaders within our single academic tertiary-care children's hospital reported heterogeneity in current HCT practices and a lack of institutional resources, as well as adult provider partners, to support optimal HCT. This baseline assessment of HCT will inform institution-wide interventions to standardize and improve HCT and positively impact the health of youth. We also present in this article a reproducible methodology for other investigators or institutional leaders seeking to understand, assess, and improve HCT on an institution-wide level.

Ethics in Publishing

The University of Pittsburgh Institutional Review Board deemed this study exempt (STUDY21030018).

Competing interests statement

The authors have no competing interests to disclose.

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Maheshwari Anisha: Data curation, Formal analysis, Project administration, Validation, Visualization, Writing – original draft, Writing – review & editing. Coronata Anna Maria: Data curation, Formal analysis, Writing – original draft, Writing – review & editing. Kirkpatrick Laura: Formal analysis, Methodology, Supervision, Visualization, Writing – original draft, Writing – review & editing. Abdul-Al Ahmed: Data curation, Project administration, Writing – original draft, Writing – review & editing. McCormick Andrew: Conceptualization, Visualization, Writing – original draft, Writing – review & editing. Matheo Loreta: Conceptualization, Visualization, Writing – original draft, Writing – review & editing. Kazmerski Traci M: Conceptualization, Methodology, Resources, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing.

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

Data will be made available on request.

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