Perceptions of Transition from pediatric to Adult Care for Youth with Chronic and Rare Diseases: A Participatory Health Research Project

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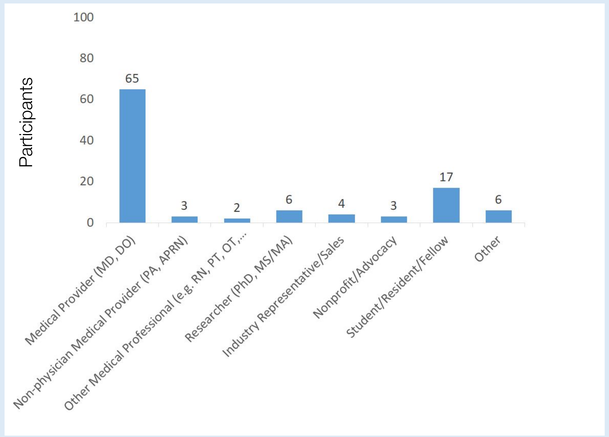
INTRODUCTION

Transition from pediatric to adult care continues to be a growing issue for patients approaching the age of majority. Barriers such as lack of communication, diminishing patient compliance, lack of care teams or specialists, and lack of patient education impede on the successful transition to adult care. Communication remains to be a barrier between different hospital departments as there is a lack of information on patient history. As pediatric patients approach adulthood, parents may be less involved in patient care, leaving the adolescent to be responsible for appointments and taking medication. Entering adult care, patients must re-educate adult care teams and physicians to manage their case, which may be an issue especially for rare diseases. Despite existing transition programs and guidelines available for chronic diseases in select hospitals, there are existing gaps that are not yet met which is detrimental for patient health.

METHODS

Figure 1. Demographics



This study took place in two phases.

I. A survey to investigate physician perception on existing gaps in the transition of care in children's hospitals around the world and to identify the barriers and improvements that can be made was administered by youth to 100 physicians at the 2017 American Academy of Pediatric National Conference & Exhibition.

II. 15 semi-structured, standardized interviews of medical professionals who work with adolescents were created and administered by youth to investigate adolescent transitions in 8 cities across Canada and the United States.

RESULTS

In Phase 1:

- 65% of respondents were medical providers (MD, DO), 17.17% were students/residents/fellows, and 6.06% were researchers (PhD, MS/MA).
- ★ 57% of participants gave the current process of transition from pediatric to adult care a rating of 1 to 5 (poor to average on a 10 item Likert scale), 0% of participants rating a 9 or 10
- ★ Top obstacle selected was a lack of communication between pediatric and adult doctors (68%; Figure 2)
- ★ Top ranked strategy for improvement selected was to provide formal transition guidelines (68%; Figure 3).

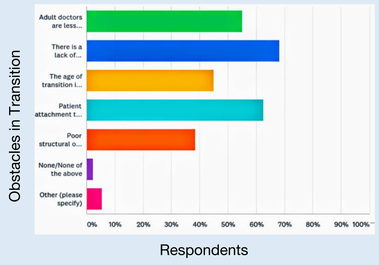
Phase 2:

- 66.67% of interviewees were pediatricians
- 60% were in public healthcare, 40% in private healthcare.
- ★ There are evident unmet needs in the transition process as identified by healthcare personnel.
  - The greatest consensus was over the following obstacles in the transition process:
    - Difficulty of insurance transfer (60%)
    - Lack of physicians (40%)
  - Reported to be among the most needed supplements to the transition process were:
    - Creation of general transition guidelines or formalized transition models (66.67%)
    - Tools to navigate insurance processes (66.67%)
    - Increased access to adult specialists interested in adolescent medicine (46.67%)

Table 1. Rating of current process of transitioning patients with history of childhood diseases from pediatric to adult care (1 being poor, 10 being excellent)

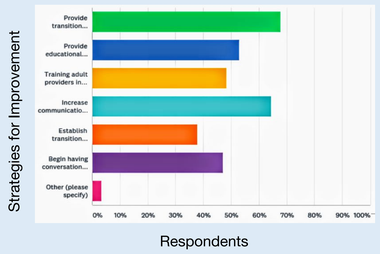
1	2	3	4	5	6	7	8	9	10
5.5%	4.4%	10.0%	12.2%	24.4%	13.3%	16.6%	13.3%	0.0%	0.0%
5	4	9	11	22	12	15	12		

Figure 2. Major issues perceived by survey respondents surrounding the transition of patients with history of childhood illness from pediatric to adult care



Obstacles in Transition	Respondents %	Respondents #
ANSWER CHOICES	**RESPONSES**	
Adult doctors are less prepared for caring for patients with a history of childhood diseases and/or there is a lack of adult specialists for patients with a history of childhood diseases	54.95%	50
There is a lack of communication between pediatric and adult doctors	68.13%	62
The age of transition is not need-based, but chronological; it does not accommodate medical complexities or developmental readiness of the young person	45.05%	41
Patient attachment to pediatrician or current healthcare provider (for example, a fear of letting go, negative views of adult healtcare providers, etc.)	62.64%	57
Poor structural or institutional support (for example, insurance, public versus private healthcare systems, lack of transition guidelines, etc.)	38.46%	35
None/None of the above	2.20%	2
Other (please specify)	5.49%	5
Total Respondents: 91		

Figure 3. Strategies suggested by survey respondents to improve transition of patients with history of childhood disease from pediatric to adult care



Strategies for Improvement	Respondents %	Respondents #
ANSWER CHOICES	**RESPONSES**	
Provide transition guidelines	67.82%	59
Provide educational materials for the patient, parent/guardian/caregiver, and the healthcare provider(s)	52.87%	46
Training adult providers in pediatric care, and training pediatric providers on what patients need to know when transferring to adult care. (the suggested specialties already exist as pediatric specialties)	48.28%	42
Increase communication and collaboration between pediatric and adult healthcare providers, particularly, during the phase of transition	64.37%	56
Establish transition clinics, and employ staff that specialize in aiding patients in the transition phase	37.93%	33
Begin having conversations with pediatric patients earlier to educate and inform them about transitioning from pediatric to adult care	47.13%	41
Other (please specify)	3.45%	3
Total Respondents: 87		

DISCUSSION

Barriers

- There is a disparity between what healthcare professional perceive as barriers for youth in the transition from pediatric care to adult care and what youth are identifying as barriers for their transition to adult care.
- Responses regarding major issues around the transition of patients from pediatric to adult care are indicated in Figure 2.
- Lack of transition models for children with rare diseases.
- Clinicians interviewed in Phase 2 primarily cited difficulty of insurance transfer, the lack of available physicians, poor communication between care teams, and patient immaturity as the biggest obstacles in transition.
- Having a multidisciplinary, integrated team with specialists, primary care physicians, nurses, psychologists can assist in the development of a transition model that can improve patients' transition of care in the future.

Needs

- Patients and families want transparency and improved communication throughout the entire transition process to avoid physician attachment and leaving a structure that they have become accustomed to, in order to have a successful transition of care (Schlucter, 2015).

Suggestions

- Healthcare workers ranked strategies to improve the pediatric to adult care transition process in Figure 3.
- Clinicians acknowledge that starting the transition process early can be beneficial to everyone.
- A possibility to improve the transition process would be to integrate primary care physicians in the transition of care and incorporate transition clinics to not act as silos but to support the overall care of transitioning adolescents.
- Identifying a transitions worker leader for each transition program at healthcare institutions can be beneficial in organizing and informing the patient's care team at the receiving healthcare institution to ensure that all patient information is accurate and up to date regarding the patient's case and history (Vaks et al., 2016).

CONCLUSION

There continues to be gaps as identified by both healthcare workers and youth physicians in the transition transfer of care from pediatrics into adult care. There is a discrepancy between the priorities that healthcare workers believe their youth to have and the priorities identified by the youth themselves in the navigation of resources and support during this transition period. Continued assessment and research is needed to establish trends in pediatric hospitals around the world to share best practices on this issue. It is ultimately essential to smooth the process of transition in order to maintain steady, high quality care for patients who, along with healthcare givers, already have to handle so much.

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