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Perceptions of transition from pediatric to adult care for youth with chronic and rare diseases: A participatory health research project

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Background: Children with the chronic and rare disease have challenges in transitions into adult care.

Purpose: To understand physician perceptions of current protocols for the transition of pediatric patients with a history of childhood disease into adult care and expand future research to include the perceptions of youth.

Methods: 1) 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 Pediatrics National Conference & Exhibition. 2) 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 participants were medical providers (MD, DO), 17.17% were students/residents/fellows and 6.06% were researchers (PhD, MS/MA), as seen in Table 1. 57% rated current processes of transitioning from pediatric to adult care mean 5 out of 10 on a 10 item scale with no participants rating 9 or 10. The top obstacle was a lack of communication between pediatric and adult doctors (68%), The top-ranked strategy for improvement was to provide formal transition guidelines (68%). In Phase 2, 66.67% of respondents were pediatricians, with 60% of interviewees were in public healthcare and 40% were in private healthcare. There are evident unmet needs in the transition process as identified by healthcare personnel. Creation of general transition guidelines or formalized transition models (66.67%), tools to navigate insurance processes (66.67%) and increased access to adult specialists interested in adolescent medicine (46.67%), were reported to be among the most needed additions to supplement the transition process.

Conclusion: Continued assessment and research are necessary to establish trends in pediatric hospitals internationally and to share best practices on this issue. Currently, ongoing work is taking place to interview youth at the same pediatric institutions to ask them how models of transition can be improved.

Biography

Vivian Tsang is a medical student at the University of British Columbia, Canada where she was also completed her undergraduate degree in Public Health and Therapeutics. Vivian is heavily involved in paediatric patient advocacy through her positions as Team Lead of KidsCan at BC Children's Hospital in Vancouver, co-lead on the national Child-Bright Youth Advisory Panel Steering Committee and on the Board of Directors on the International Children's Advisory Network- an advisory group that collaborates with researchers and clinicians around the world to improve paediatric research. Since starting medical school, Vivian has taken the lead as Co-Chair of the Medical Undergraduate Society's Political Development Committee and recently represented the Faculty of Medicine in advocating for improved youth mental health with the Minister of Health in BC. Along with her role on Vancouver City Council's Children, Youth and Families Advisory Committee, she is working on advocating for improvements to mental health resources for BC youth.

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