

Transition from Hospital to Home for Children with Medical Complexity

Project Summary

Centre for Leadership in Child Development

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Kids Rehabilitation Hospital

Bloorview
RESEARCH INSTITUTE

SHARING OUR WORK

This project has already been shared at:

- Holland Bloorview's annual Roszel Research Day
- The Hospital for Sick Children's annual Research Day

Following completion of this project, we will share it at:

- Bloorview Research Institute's annual Research Day
- A Lunch and Learn event for Holland Bloorview / CCC staff
- The Canadian Paediatric Society's Annual General Meeting
- Publication in a journal

WHAT WAS THIS STUDY ABOUT?

- “Children with medical complexity” (CMC) are those with one or more serious, long term conditions that require help from medical technology and have significant healthcare needs.
- CMC have higher rates of hospitalization and longer inpatient stays and are at risk for health complications and differences in clinical care during transition from hospital to home
- Little is known about what transition to home is like for CMC from the client / family viewpoint. This project aimed to look at the experience of transition from hospital to home for CMC and their families.

WHAT DID WE DO?

- We interviewed 8 mothers, 2 fathers and 1 client who transitioned from the Complex Continuing Care Unit (CCC) at Holland Bloorview Kids Rehabilitation Hospital (HBKRH) to home during 2012 to 2015.
- Interview questions were based on the World Health Organization's International Classification of Functioning, Disability, and Health framework to help us understand health and psychosocial factors that may impact what it's like to transition home.
- The interviews were analyzed by the project team to identify key themes.

IMPACT FOR CLIENTS, FAMILIES AND CLINICAL PRACTICE

- This study helps us to understand family experiences and the factors contributing to a successful transition from hospital to home through the viewpoints of clients and their families.
- This information will help to improve clinical practices on CCC and other inpatient units.
- Finding areas of potential improvement in the transition process may help to reduce risk of poor health and psychosocial outcomes for clients and promote opportunities for community participation / inclusion following discharge for CMC.

WHAT DID WE LEARN?

- Length of stay on CCC ranged from 6 weeks to greater than 4 years.
- CMC: were 7 months to 18 years in age at the time of discharge; had been in hospital many months prior to leaving hospital with some having spent their entire lives in hospital; and had a variety of medical problems (for example, children with genetic conditions affecting multiple areas of their health and needing support from technology such as tracheostomy, ventilator, feeding tubes, etc. to keep them healthy).
- Data analysis for this project is ongoing; several preliminary themes have been identified. These include: “The Journey” and “Preparation for Transition.”
- Participants talked about:
 - The long journey they had taken to get to the point of being able to “finally” go home.
 - A much longer journey – that of the future and the things they looked forward to.
 - The many steps that needed to happen before they could go home, such as getting people ready (including the client, their parents and family, their health team, and members of the community) and getting environments ready (including the home and places outside the home).
 - Factors at each of these levels could be helpers or obstacles to having a good transition experience.
 - There tended to be more satisfaction with the preparation of immediate people and environments (i.e. how ready the client and their parent(s) were for discharge and how ready the home was), and more problems related to more external factors (i.e. negative experiences with community service providers or barriers to community involvement).

NEXT STEPS?

- Finish data analysis.
- Share findings with some of the participants to check our analysis (“member checking”).
- Complete our knowledge sharing activities.

TO LEARN MORE ABOUT THIS STUDY, PLEASE CONTACT:

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WHO ARE WE?

- Dr. Doig is a Developmental Paediatrics Fellow with an interest in care coordination and service provision for CMC.
- Dr. Penner is a Clinician Investigator in the Bloorview Research Institute (BRI) with research training in health service delivery for young people with developmental needs.
- Dr. Hoffman is the physician director of CCC with clinical expertise in the care of CMC.
- Dr. Lindsay is a scientist in the BRI with experience in pediatric transitions and qualitative research, focusing on participation and inclusion.
- Dr. Ballantyne is the Chief Nurse Executive and a Clinician Investigator at HBKRH with research experience in healthcare transition.

THANK YOU!

The project team wishes to thank the Holland Bloorview clients and families who participated in interviews, without whom this project would not have been possible.

THIS PROJECT WAS FUNDED BY:

The Holland Bloorview Centre for Leadership in Child Development