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Background and aims

Approximately 15% of children have a complex health condition that impacts their health and causes limitations in their lives. Children with complex health conditions have one or more chronic physical, emotional, developmental or behavioural condition(s) that require health and other services from multiple care providers in multiple locations. Caring for a child with a complex health condition is challenging for the whole family, but even more so when services are not available or challenging to navigate to meet their needs. Our team was awarded a four-year grant to implement a navigation centre for children with complex health conditions and their families. This paper integrates together the pieces of the puzzle of the needs assessment phase before pilot-testing the navigation model.

Methods

We conducted semi-structured focus group and individual telephone interviews with healthcare providers, social service providers, and educational stakeholders, as well as telephone and home interviews with children and their parents. We analyzed the data using the inductive thematic analysis.

Results

In total, 165 stakeholders participated in this study. Emerging overarching themes were: increased complexity of cases in a system with decreased resources, making use of what is available to meet the children's needs, incongruence between policies and patient/family needs, lack of cohesion and knowledge to effective service delivery, child/family circumstantial challenges, and a shift toward patient/family engagement/self-management.

Conclusions

The study implications for children with complex health conditions and their families will be discussed, including the potential of a navigation centre to overcome the barriers to care.

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CHILDREN WITH COMPLEX HEALTH CONDITIONS: LINKING THE PIECES OF THE PUZZLE PRIOR TO THE CREATION OF A PATIENT AND FAMILY NAVIGATION CENTRE (NEW BRUNSWICK, CANADA)

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