
POSTER ABSTRACT

An analysis of the lived experiences of parents and care providers involved in care navigation for children with complex needs using an intersectionality health equity lens.

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Background: The experiences of parents and care providers offer valuable insight into the inequities that exist in navigating care for children with complex needs (CCN). Care services for this vulnerable population are provided within fragmented health, social services, and education systems. Navigating care remains predominantly women's work with both parents and care providers facing significant barriers accessing care for CCN.

Who is it for? CCN and their families use a high volume of resources across multiple sectors requiring a coordinated effort by parents (often mothers) and care providers (often women) involved in their care.

Who did you involve? This paper provides new insight into the work related to care navigation for CCN by applying an intersectionality health equity lens to a secondary analysis of data collected from semi-structured interviews of parents (n=33) and care providers (n=83) involved in care for CCN in two Maritime Canadian provinces.

What did you do? In this secondary analysis, data grouped into ten dominant themes related to care navigation were viewed through an intersectionality health equity lens to identify tensions arising from intersecting relations of inequality with a focus on the implications of sex/gender, geography, and income-level in shaping the lived experiences of parents and care providers navigating care for CCN.

What results did you get? This study found that care for CCN continues to be provided in a context of siloed health, social services, and education sectors perpetuating the difficulties experienced by parents and care providers needing to identify and access care services available to CCN within and beyond their community. Parents of CCN initially planned to share caregiving responsibilities equally, but only mothers reported leaving their jobs or not pursuing their careers to care for their CCN. Mothers researched available services, organized care appointments, arranged logistics (e.g. transportation, paperwork, care for other children), and advocated for their child. However, not all parents were equally able to navigate care for CCN due to differences in literacy rates, financial or geographic barriers, and care burdens, contributing to perceived inequities in access to care for CCN. Care providers reported trying to support parents in navigating care for CCN but these professionals experienced a lack of dedicated time, navigation training, and adequate remuneration during their efforts to provide the necessary assistance.

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What is the learning for the international audience? A dedicated role for paid patient navigators could help ensure meaningful access to care for CCN and their parents but this alone is not sufficient.

What are the next steps? In addition to supporting the women involved in care navigation work for CCN, it is essential to address interconnected systemic issues related to a lack of health human resources, unequal access to care in rural areas, and financial barriers to accessing care that falls outside of the publicly insured care mandated in national legislation.