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The Experience of Being a Parent of a Child with Medical Complexity: A Case Study Approach

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The Experience of Being a Parent of a Child with Medical Complexity: A Case Study Approach

Parental caregivers of children with medical complexity(CMC) experience the overwhelming role of being not only a parent but also their child's primary advocate. Their experiences have been mentioned in current literature solely in relation to child health interventions and wellbeing and have not been specifically examined in different contexts. This qualitative single-case study aimed to 1)examine experiences of parental caregivers of CMC as they navigate healthcare and social systems; and 2)examine the role of geography on these experiences. This study utilized an online questionnaire followed by a semi-structured phone interview. An intersectional lens was used throughout and the role of power and powerlessness in parental interactions was analyzed. Using the Conceptual Model of Health-Related Quality-of-Life(HRQoL), this study revealed that during times of transition, parental decision-making is driven by their need to improve their child's HRQoL despite negative impacts on their own HRQoL that may result from prioritizing their child's wellbeing.