The Experiences of Rural Family Caregivers of Cancer Patients in Newfoundland and Labrador and Their Challenges and Needs in Relocating to Urban Settings for Treatment

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Abstract : Background: Newfoundland and Labrador (NL) has rapidly aging population and is characterized by its vast geography with high proportion of dispersed rural communities when compared to other provinces in Canada. Structural, demographic and geographic factors have created big gaps for rural residents across NL with respect to accessing various health and social services. While the barriers are well documented for patients' access to cancer care in rural and remote areas, challenges faced by family caregivers are not fully recognized. Caregiving burden coupled with challenges associated with relocation and frequent travels create situations where caregivers are vulnerable physically, emotionally, financially and socially. This study examines the experiences of family caregivers living in rural NL through a social justice lens. It is expected to identify the gaps existing in social policy and support for rural family caregivers. It will make a novel contribution to the literature in this regard. Methods: Design: This qualitative study adopted the hermeneutic phenomenology to best describe and interpret rural-based family caregivers' living experiences and explore the meaning, impact, and the influence of both individual experience and contextual factors shaping these experiences. Data Collection: In-depth interviews with key informants were conducted with 12 participants from various rural communities in NL. A case study was also used to explore an individual's experience in complex social units consisting of multiple variables of in-depth understanding of the reality. Data Analysis: Thematic analysis guided by the Voice-Centred Relational (VCR) method was employed to explore the relationships and contexts of participants. Emerging Themes: Six major emerging themes were identified, namely, overwhelming caregiving burden on rural family caregivers, long existing financial hardship, separation from family and community, low level of social support and self-reliance coping strategies, and social vulnerability and isolation. Conclusion: Understanding the lived experiences of rural-based family caregivers is critical to inform the policy makers the gap of health and social service in NL. The findings of this study also have implications for family caregivers who are vulnerable in other similar contexts. This study adds innovative insights for policy making and service provision in this regard.

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Keywords : family caregivers, policy, relocation, rural

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