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An Interpretative Phenomenological Analysis: Exploring the Experiences of Hospice Healthcare Workers Caring for Adolescents and Young Adults with Advanced Cancer

Nadine Persaud

Executive Director of the Kensington Hospice, Canada

Adolescents and young adults living with advanced cancer are a distinct population who require specialized care from healthcare workers. A thematic synthesis was conducted to better conceptualize the emotional experiences of healthcare workers who care for children and young adults living with life-limiting illnesses. The thematic synthesis resulted in eight themes and three analytic themes and highlighted that little is known about the experiences of hospice healthcare workers who care for adolescents and young adults. The aim of this study is to understand the lived experience of hospice healthcare workers who provide palliative care to adolescents and young adults living with cancer.

Methods: Hospice healthcare workers from four paediatric hospices across Canada were recruited and semi-structured in-person interviews took place, and all interviews were transcribed verbatim. Interpretative phenomenological analysis was used to analyse all of the data.

Findings: 18 Hospice healthcare workers participated. Two superordinate themes were generated. First, balancing on the tightrope of uncertainty, and second acting as a proxy. Within the superordinate theme balancing on a tightrope, the subordinate themes were related to healthcare workers doing their best and being a hero with an emphasis on uncertainty and the fear of failure. The role that time does not play in the development of attachments as well as the role that healthcare workers play in decision-making. There was also a focus on healthcare workers taking the path of least regret while sometimes having to be comfortable with being uncomfortable with the decision being made. The focus on supporting families when caring for adolescents and young adults is also highlighted. Within the second superordinate theme acting as a proxy, the subordinate themes were focused on the importance of having honest and transparent conversations and the cycle of protection between adolescents and young adults, families, and healthcare providers. This theme also highlights the role that hope plays when caring for this population and the experiences of adolescents and young adults dying in a hospice versus a hospital.

Conclusion: The lived experiences of hospice healthcare workers supporting adolescents and young adults demonstrate doing for rather than being with, protecting rather than showing emotion, the critical need to make attachments, and the importance of involving adolescents and young adults in advance care planning.