

Building Care Networks for Patients with Life-Limiting Illnesses: Perspectives from Health Care and Social Service Providers

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Abstract : Comprehensive and compassionate palliative care and support requires an integrated system of care that draws on formal health and social service providers working together with community and informal networks to ensure that patients and families have access to the care they need. The objective of this study is to further explore and understand the community supports, services, and informal networks that health care professionals and social service providers rely on to allow their patients to die in their homes and communities. Drawing on an interpretivist, exploratory, qualitative design, our multidisciplinary research team (medicine, nursing and social work) conducted interviews with 15 health care and social service providers in the Ottawa region. Interview data was audio-recorded, transcribed and analyzed using a reflexive thematic analysis approach. The data deepens our understandings of the facilitators and barriers that arise as health care and social service providers attempt to build networks of care for patients with life limiting illnesses and families. Three main findings emerged: First, the variability that arises due to systemic barriers in accessing and providing care; second, the exceptionally challenging workload that providers are facing as they work to address complex social care needs (housing, disability, food security), along with escalating palliative care needs; and, finally, the lack of structural support that providers and informal care networks receive. Conclusion: These findings will facilitate and build stronger person-centred/relationship-centred principles and practices between providers, patients, community, and informal care networks by highlighting the systemic barriers to accessing and providing person-centred care. Further, they will have important implications for future partnerships in integrated care delivery programs and initiatives, community policies, education programs, and provincial and national palliative care strategies.

Keywords : public health palliative care, palliative care nursing, care networks, informal care, integrated health care

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