

Community-Based Palliative Care for Patients with Cerebral Palsy and Developmental Disabilities

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Abstract : Background: Individuals with Cerebral Palsy (CP) and/or IDD face numerous physical and mental health challenges, including difficulty accessing effective palliative care. The aim of this study is to assess the knowledge and comfort of healthcare providers in providing community-based palliative care for patients with Cerebral Palsy (CP) and severe to profound Intellectual and Developmental Disabilities (IDD). Methods: This study includes a mixed methods approach obtaining both quantitative and qualitative data. Quantitative data from palliative care practitioners was obtained through an online survey assessing comfort in symptom management, grief assessment, and goals of care discussion. This survey was distributed to physicians and allied health practitioners across Canada through the College of Family Physicians of Canada Member Interest Groups for Palliative Care and for IDD. Survey results guided the development of a semi-structured interview template, which was used to conduct a focus group on the same topic. Participants were four palliative care providers (3 physicians and one spiritual care practitioner). The focus group transcript is currently undergoing thematic analysis using NVivo 12 software. Results: 57 palliative care practitioners completed the survey. 87% of participants indicated they have provided palliative care services for persons with CP and/or IDD. Findings suggest practitioners are somewhat confident in identifying specific physical symptoms (dyspnea, pressure ulcers) but less confident in identifying physical/emotional pain, addressing grief, and prognosticating life expectancy in this population. 54% of responses indicated they had little/no training on palliating those with CP or IDD, and 45% somewhat or strongly disagree members of their profession can manage symptoms for this population. Focus group analysis is underway, and results will be available at the time of the poster presentation. Conclusion: Persons with CP and IDD are more likely to experience severe health inequities when accessing palliative care. Results of this study suggest further education is needed for palliative care professionals to address the barriers and challenges in providing palliative care to this patient population.

Keywords : palliative care, symptom management, health equity, community healthcare, intellectual and developmental disabilities

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