

Palliative Care and Persons with Intellectual Disabilities

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Abstract : Background: Patients with intellectual disabilities have specific palliative care needs, which can affect how resources and services are planned for this type of patient population. Aim: The purpose of this practice review is to assess the indications for, numbers of and outcomes of care for adults with intellectual disabilities referred to a specialist palliative care service over a two-year period. Service utilization aspects considered included the frequency of home visits by a specialist palliative care doctor or clinical nurse specialist and the number of hospice admissions that occurred for the patients. Method: A retrospective review was carried out of persons 18 years and older with intellectual disabilities referred to a specialist palliative care service. A manual review was carried out of the register using the place of residence and diagnosis in addition to the patients known to the clinicians who had intellectual disabilities. Results: 16 persons with intellectual disabilities were identified as being referred during that time. However, this may be an underestimate. 8 women and 8 men were referred with an age range of 50 to 81 years old. 4 patients referred did not have home visits from the specialist palliative care team. A range of 2 to 12 phone calls per person occurred by the specialist palliative care team regarding this cohort of patients. For some patients, the care is ongoing. Sadly, other patients died. Conclusion: Providing specialist palliative care for adults with intellectual disabilities is an important element of palliative care. Further research is necessary, and education to inform, support and empower specialist palliative care professionals in optimizing palliative and end-of-life care for persons with intellectual disabilities and to inform service development and provision.

Keywords : palliative care, intellectual disabilities, service planning, practice review

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