

The challenges of providing palliative care for people with intellectual disabilities: a literature review

Dunkley S, Sales R. The challenges of providing palliative care for people with intellectual disabilities: a literature review. *International Journal of Palliative Nursing*. June 2014; 20(6): 279-284. Available from CINAHL with Full Text, Ipswich, MA. Accessed June 28, 2017.

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ABSTRACT

People with intellectual disabilities are often marginalized from mainstream health-care services because of the complexities of their disability. They are under-referred to specialist palliative care owing to a limited understanding of its role and little collaborative working. Furthermore, professionals caring for people with intellectual disabilities and palliative care services often lack knowledge about and confidence in their ability to meet the needs of people with an intellectual disability who require palliative care. This literature review explores the challenges of providing palliative care for people with intellectual disability. It highlights that training requirements need to be effectively identified, referrals between professional groups made, and the perspectives of patients understood to overcome the marginalization of people with intellectual disability. There is a need for ongoing staff development focusing on staff confidence, collaborative working between professionals, and the empowerment of people with intellectual disability to be involved in decisions about their end-of-life care. Further research is needed to examine the most effective way of capturing the perspectives of those with intellectual disability and of enabling people with intellectual disability to access and engage with health surveillance, cancer screening, and palliative care services.

STRENGTHS

- Literature search selected from a broad area including nursing, mental health, medicine, and social care.
- Included research from UK, North America, and Europe giving more broad review of the existing research on an international level.
- Summarizes the existing research and gives insight into the limited amount of research in this area

WEAKNESSES

- Only 90 publications, and very few involved primary research regarding the challenges of providing palliative medicine to this population.
- The primary publications were largely from the same group.
- Although the authors identified three main themes found in the literature review, the commentary was quite repetitive within and between each of the themes identified.

RELEVANCE TO PALLIATIVE MEDICINE

- Brings awareness to the importance of palliative and the unique challenges faced when providing palliative care in this population.
- Reinforces the importance of strong communication skills and the inclusion of patient in discussions around end-of-life issues regardless of their intellectual ability.
- Supports the interdisciplinary approach that is well established in palliative care.