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Palliative care for children with cognitive disabilities and their caregivers challenges

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Intellectual and developmental disabilities are a lifelong challenge with a considerable effect on the lives around them. The high quality of care needed by a mentally handicapped child can become psychologically, emotionally and physically stressful to parents and/or caregivers. Although there have been numerous studies conducted to determine the burdens of families with a mentally retarded member around the globe, little was known about the association of the caregivers care-related constraints and their quality of care. This study aimed to determine the practical, emotional and psychological constraints that exist in caring mentally disabled children and its relationship to caregivers' quality of palliative care. The respondents were the primary caregivers of the mentally disabled children studying at Iligan City SPED Center, selected through random sampling technique. Data generated by the questionnaires were analyzed and interpreted using SPSS. High quality care was positively associated with caregiver's capability in responding to practical concerns such as providing constant supervision to the mentally retarded child. Caregivers' emotional constraints like being embarrassed with the mentally retarded child and having a sense of inadequacy in caring the child can adversely affect their quality of care. Being able to manage generalized anxiety disorder in the part of caregivers has a positive impact in their quality of care to mentally retarded children. These findings may shed light on the struggles that caregivers face as well as to ascertain the need for awareness and support for such challenged families in order to provide quality care to mentally retarded children.

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