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Respite for Parents of Children who require Complex Care

Current literature states that advances in nursing and medical care and developments in pharmaceutical and health technologies, have led to an increasing number of severely disabled children who require complex health care. These children who require complex care are being cared for in their homes by their parents. The purpose of this study was to better understand parents' caregiving experiences and to explore the values, beliefs, and practices that influence parents' use and satisfaction with respite services.

An ethnographic study involving 19 mothers, 4 fathers, and 4 grandmothers and 3 grandfathers of children between the ages of 8 and 16 years of age who required complex care and their respite providers, including 13 nurses, and 4 social workers from 3 counties in Northwest England was conducted. Data were collected through in-depth interviews, participant observation and document review.

The context of caring for a child with complex care needs was described and four broad themes were identified in the data. These themes include: parents caring, caring and the impact on parental identity, the nature of respite, and fair play. These themes will be discussed in the presentation.

Biography

Heather L MacDonald completed a Master's degree in Nursing at the University of Toronto, Canada and a PhD at the University of Manchester in the UK. Currently she is a Professor in the Faculty of Nursing at the University of New Brunswick (Canada). Dr. MacDonald's doctoral work examined respite for parents who were caring for children who required complex care. This paper comes from that work. Dr. MacDonald has three children of her own.

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