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FAIR Play: Respite for parents caring for children requiring complex home care

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Advances in nursing and medical care augmented by developments in pharmaceutical and health technologies have led to an increasing number of children who require complex care at home. Parents are their caregivers. In an attempt to learn more about this caregiving role and how the parents accessed respite an ethnographic study consisting of 47 participants: 19 mothers; 4 fathers; 7 grandparents, 13 nurses; and 4 social workers was undertaken. One of the key categories that emerged from the data was Fair Play. Data collection included in-depth interviews, participant observation, and a document review. All of the participants were interviewed using a question guide that resulted in a conversational approach. Participant observation occurred in the homes of the children as well as in respite facilities. Documents such as respite policies and the carers Act were reviewed in detail. Four themes emerged from the data: Parents Caring; Caring and the Impact on Parental Identity; The Nature of Respite; and Fair Play. Fair Play will be discussed here. According to the Oxford Dictionary Fair play means “reasonable treatment or behavior.” To the parents in this study Fair play was “a sense of give and take.” Fair play is a desired outcome in the struggle to provide respite care in an environment in which the rules are not only unspoken, but vary between the players; and where breaking the rules may provide more gains than being cooperative.

The key categories within Fair play are:

- Care Obligations
- Feelings of Entitlement
- Respite Information Needs
- Ongoing Support Needs
- Negotiating the System
- Equity

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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