



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

Parental quotes that represent each of these categories are as follows:

“I think there is a degree of reasonableness of how far those parental responsibilities are expected to extend” Father 10

“I’m a carer and that’s my job so I should be entitled to a holiday.” Mother 14

“I think half the battle knows who to approach. The sign posting isn’t clear.” Mother 7

“Services are available but they are not broadcast. You have to find out yourself.” Mother 12

“Our house is unsuitable; we can’t have helped at home because health workers aren’t insured to carry her about. It’s ok that we carry her though.” Mother 14

It is easy to see that Fair play does not unfold as it should or could for parents who are caring for children who require complex care. I believe we need to think about the expectations we place upon parents and the supports that are in place to assist them. Parents take on a huge responsibility because they love their children but as health care professionals we need to think about the parents’ health as well as the health of the child.

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