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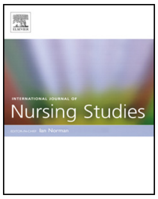

Childhood cancer-parenting work for British Bangladeshi families during treatment: An ethnographic study

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ABSTRACT

Objective: To detail the day to day management experiences of a specific group of parents from a minority ethnic group who lack representation in many studies.
Background: Studies of parental experiences during their child's treatment for cancer have revealed a considerable burden of care related to intensive treatment regimens and the uncertainty of prognosis. In the context of UK paediatric cancer services there is limited research on how parents manage their daily lives and no published studies detailing the experiences of parents from minority ethnic groups.
Design, setting and participants: This ethnographic study used participant observation in the home, community and clinical settings, to follow eight families of British Bangladeshi children undergoing cancer treatment over an extended time period (22 months). Focused interviews with parents (7) were conducted. Data were analysed concurrently during fieldwork with themes identified, defined and refined, maintaining context whilst comparing within and across data sets.
Results: Parental roles and responsibilities are reconceptualised in this study as a form of 'work' that parents (and children) undertook to achieve and manage cancer treatment. Five themes describing parental work were identified: Managing Competing Knowledge, Vigilance, Advocacy, Balancing Parental Work and the Burdens of Treatment. Analysis revealed that cancer-specific knowledge was more highly valued by professionals than child-specific knowledge. A good deal of their 'work' related to being vigilant about their child's condition and care and treatment, including acting as advocates. Whilst undertaking caring work for their child, parents had to balance this with a range of other responsibilities. The range of responsibilities placed on parents throughout treatment were acknowledged only rarely by professionals and as a result, parents experienced their input as a burden that lacked recognition and increased a vulnerability, already present through minority ethnic status.
Conclusions: The taken for granted and often unseen aspects of parenting during childhood cancer treatment constituted a considerable workload for this group of parents. The relentless nature of treatment was also a burden, since this took place in the context of on-going uncertainty about their child's recovery. Clinical staff should consider the impact of service organisation and treatments on specific groups of parents including minority ethnic groups in order to recognise and mitigate against burdensome work.

What is already known about the topic?

- Providing care to children with cancer is a significant disruption and potential burden to parents.

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- Despite improved survival rates childhood cancer mortality remains significant and parents are managing this uncertainty alongside demanding treatment regimes.

What this paper adds

- In a context of rapid change in health care this paper confirms the importance of parents as a key resource in effective supportive care in paediatric oncology.
- This paper re-defines parental participation in the care of their child during serious illness as 'work'. Parental work in childhood cancer illustrated as a complex and sometimes burdensome set of obligations.
- This paper provides an example of how one group of minority ethnic parents manage their child's cancer, suggesting additional burdens and vulnerabilities for this group of parents.

1. Introduction

Parental responsibility to protect children from harm is a recurring theme in health and social care literature. During a serious and life threatening illness, such as childhood cancer, this responsibility is expanded to include the acquisition and use of illness-specific knowledge and skills. This additional level of expectation for parents is undertaken primarily in the hospital setting but extends beyond this to include home and school life. The financial burdens of caring work are acknowledged through a complex network of benefits (both statutory and supported by the charity sector) and there is recognition of the emotional and psychological burdens that the diagnosis of cancer evokes (Mitchell et al., 2006). However the day-to-day work, and the responsibility of parents of children with cancer, is seldom detailed and there is limited analysis of how those from minority ethnic groups experience these demands – or how they can best be supported to manage them.

The data presented here are drawn from an ethnographic study of the childhood cancer experiences of British Bangladeshi children and parents. This paper focuses on the implications for parents of childhood cancer treatment and illustrates Mayall (2001) contention that childhood cannot be studied fully without also considering the interdependent concerns of parenthood.

1.1. Parenting in illness

Social scientists and health researchers have highlighted the complexities of health care 'work' often undertaken by parents (Baruch, 1981; Strong, 1979; White, 2002). Parents demonstrate an awareness of the need to present themselves as competent in the context of illness (Kirk et al., 2005) and conforming to health care professionals' expectations of them when parenting in 'public' (Callery, 1995). The acknowledgement of parental expertise and the importance associated with the family unit for children who are ill can lead to an uncritical approach to specific care practices. This can lead to assumptions that they are underpinned by the widely accepted philosophy of family centred care (Franck and Callery, 2004) and therefore unproblematic. As a result there are few critical insights into the impact of taken for granted caring roles for parents (Corlett and Twycross, 2006; Earle et al., 2007).

1.2. Cancer and childhood

Childhood cancer represents a broad spectrum of conditions with a similarly wide range of prognoses. The incidence of cancer in childhood is rare, with one in 600 children in the UK developing the disease during their first fifteen years (Stiller, 2007). Potentially life threatening improvements in treatment have resulted in a survival rate of 78% for most 0–14 year olds (National Registry of Childhood Tumours/Childhood Cancer Research Group, http://www.crg.ox.ac.uk), leading practitioners to reclassify childhood cancer, as a chronic life threatening illness rather than an acute terminal one. The worldwide picture is similarly optimistic in most high income countries (Sankila et al., 2006).

Despite increased survival rates cancer remains a significant cause of death amongst children and young people (Björk et al., 2005; Woodgate, 2006). Moreover, childhood cancer requires complex treatment modalities (Gibson and Soanes, 2008) including life-threatening regimes managed in the UK by highly specialised centres (NICE, 2005), whilst other aspects of care are devolved to local hospital and community services. These care models require parents and children to develop relationships with a wide range of health care professionals and services over the course of the disease (Clarke et al., 2004).

A diagnosis of childhood cancer starts a child and family on an illness trajectory involving complex treatments with an uncertain outcome (Parry, 2003). Although parental experiences of childhood cancer treatment have been studied extensively, the majority of studies focus on psychological outcomes or specific experiences linked to hospitalisation, such as disclosure of diagnosis, experience of invasive procedures and recruitment to clinical trials (Eiser et al., 2005). The social impact of the disease and treatment is also acknowledged in terms of the effect on family income (Dockerty et al., 2003; Eiser and Upton, 2007), relationships (McGrath, 2001), school experience (Noll et al., 1999) and overall cancer experience (Woodgate and Degner, 2002). Family models of care within paediatric oncology place a strong focus on parental participation in care delivery and recognise that support needs exist for parents managing the impact of a life threatening diagnosis (Mitchell et al., 2006). However there has been little critical analysis of the model of 'family care' itself; rather it has become the de facto approach promoted in many UK care settings (Coyne and Cowley, 2007). In addition limited data exists on the day to day lives of families as they manage the practical demands of cancer (Woodgate, 2006) or how they negotiate their parental roles in the face of a potentially life threatening illness (Young et al., 2002). Even less is known about families from minority ethnic groups who face unique demands such as language difficulties, social isolation and stereotyping (Abbe et al., 2006; Gibson, 2008; Pergert et al., 2008).