

Children with disability and complex health needs: the impact on family life

Analysis of interviews with parents identified time pressures, the need for carers to adopt multiple roles and being a 'disabled family' as major influences on their lives, as Mark Whiting reports

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Date of submission
April 17 2013

Date of acceptance
November 8 2013

Peer review
This article has been subject to open peer review and checked using antiplagiarism software

Author guidelines
ncyp.rcnpublishing.com

Abstract

Aim To identify consistency and differences in parental perceptions of impact, need for support and 'sense making' in children with a disability, children with a life-threatening or life-limiting illness and children who are technology dependent.

Method A series of in-depth semi-structured interviews were undertaken with parents from 33 families that included one or more child with disabilities. The data arising from these interviews were subjected to a systematic comparative analysis based on three discrete subgroups of children: those with a disability, those with a life-limiting or life-threatening illness, and those with a technology dependence.

Findings There were major areas of consistency in parental experience of impact as related

in three categories that emerged from the data: time, multiple roles and the disabled family.

Conclusion There are many effects of childhood disability on the family. In large part, the effects cannot simply be defined or described in the context of a particular 'medical' diagnosis or prognosis. Many elements of impact do not appear to be related to whether or not a child has a life-threatening or life-limiting illness or by whether or not a child is dependent on specific medical devices or ongoing nursing care.

Keywords Childhood disability, complex health needs, family-centred care, life-limiting illness, life-threatening illness, technology dependence

IT IS ESTIMATED that about 800,000 children in the UK have a disability (Department for Work and Pensions 2012). This can vary from impairments that minimally and infrequently affect the child's ability to participate in a full range of activities to multiple and complex impairments that are ever present and involve many aspects of the child's daily life. In this, the first of three articles, the author considers the effect of disability and complex health problems on the lives of these children and their families, as reported by the parents of a small cohort of children with a range of care needs.

Literature review

Several areas in which childhood disability was reported by parents to affect family life were identified. They included employment, family finances, parental mental and physical health, relationships in the family, loss of social opportunity and time pressures.

Eight broad search terms - disability, life-limiting/life-threatening illness, technology dependence, impact, meaning/sense making, need for help and support, qualitative research methods, and mind maps - and multiple search strings derived from those terms - formed the basis for a literature review

which was last updated in August 2008. The terms were searched on the following databases: Allied and Complementary Medicine, British Nursing Index, Cumulative Index to Nursing and Allied Health Literature, Medline and the King's Fund. Searches were also undertaken, using the same search strings, in the Cochrane Library, Bandolier, the NHS Economic Evaluation Database, and the Health Technology Assessment Database, each of which was accessed through the National Library for Health.

Family finances and employment Studies by Beresford (1995), While *et al* (1996) and Dobson *et al* (2001) identified various additional costs, including expenses related to transport, clothing and feeding, for families of children with a disability due to the child's specific care needs. Harrison and Woolley (2004) reported that 92.8% of families identified some form of financial difficulty arising directly from costs related to their child.

A study by Contact a Family (2004a) reported that 32% of parents of children with complex health needs identified problems at work 'since having a disabled child'. A subsequent study (Contact a Family 2004b) identified several specific issues reported by parents in relation to their work experiences. These included:

- Difficulties in accessing appropriate childcare after school and during school holidays.
- Time needed for hospital and school appointments, and reviews.
- Lack of understanding and flexibility on the part of their employers.

Hewitt-Taylor (2007) reported that parents identified a need for flexible and part-time job opportunities. However, the same parents also acknowledged that they were limited in terms of the hours they were available for work and by their own lack of flexibility.

Parental mental and physical health Several UK studies have considered the effect that caring for a child with disabilities and complex needs has on the physical and mental health of parents. While *et al* (1996) reported the findings of a Department of Health-funded study into the experience of families of 99 children with life-limiting and incurable illness. Of the 72 mothers who identified that their child's illness had affected their health, 55.6% reported a mental health problem, 19.4% a bad back and 18.1% tiredness. In addition, 42 fathers also identified health issues, including mental health problems (64.3%), a bad back (14.3%) and tiredness (16.7%).

In a survey by Mencap (2003), eight out of ten families (total n=76) caring for a child with

learning disabilities in England and Northern Ireland reported that they had reached 'breaking point'. In a larger follow-up study of 353 families, Mencap (2006) found that six out of ten family carers attributed their physical ill health and nine out of ten their mental ill health to the consequence of providing care for their child.

Family relationships Several studies considered the effect of childhood disability on parental relationships. Both the studies undertaken by Mencap (2003, 2006) included anecdotal parental accounts of how the relentlessness of caring for a disabled child had contributed significantly to marital breakdown.

In a study on parental relationships (Contact a Family 2004a), 9% of respondents said that having a disabled child was the reason for family break-up. A further 31% of parents identified 'some problems' and 13% 'major problems' in their relationships as the result of their child's disability. However, 23% reported that it had brought them closer.

Loss of social opportunity Parental concerns about the loss of social opportunity have been widely reported (While *et al* 1996, Kirk and Glendinning 1999, Dobson *et al* 2001, Marchant *et al* 2007, Townsley *et al* (2004) identified parental and familial social isolation as a recurring theme in a study involving 115 professionals that included social care staff, 25 parents and 18 young people.

Time pressures Several studies highlighted the additional time pressures faced by the families of children with disabilities. For example, Roberts and Lawton (2001) and Heaton *et al* (2003, 2005) described how the extra care demands placed on parents in meeting the needs of their disabled children affected the time available for other family activities.

Aim

To identify areas of consistency and difference in parental perception of impact, need for help and support and 'sense making' between three identified subgroups of children: children with a disability, children with a life-threatening or life-limiting illness and children who are technology dependent.

Method

To develop insight and understanding of the effect of disability within the family (Whiting 2009), the parents of 34 children with disabilities (from 33 families) were asked: 'What difference

has your child's disability or complex health needs made to you and to your life as a family?' The study used a qualitative approach to data collection and data analysis, incorporating elements of the grounded theory method as described by Glaser and Strauss (1967).

The children enrolled in the study were identified by the referring professionals (health visitors, school nurses and community children's nurses) as fitting most closely with one of three subgroups (Box 1):

- Children with a disability.
- Children with a life-limiting or life-threatening illness.
- Children with a technology dependence.

Although it was recognised that some children might meet the definitions of two or even all three subgroups (Box 1), one of the study aims was to identify areas of consistency and inconsistency in parental experiences in and between the subgroups (Whiting 2013). With this in mind, parents were asked which of the subgroup descriptors best 'fitted' their child (although the detailed definitions were not shared with parents).

Parental views were largely consistent with those of the professionals who had referred the child (Whiting 2009). It is important to acknowledge, however, that this study did not set out to carry out a systematic or scientific analysis

of the differences between three discretely defined subgroups of children – categorisation of children with disabilities and complex needs is not straightforward.

Ethical considerations Ethical approval for the study was obtained from the local research ethics committee. Formal research governance approval to access professional healthcare staff and research participants was obtained from four NHS trusts and the local children's hospice. Data obtained as a result of the research were stored securely and in accordance with Department of Health guidance. All patient-identifiable information was removed from the data set to ensure anonymity of participants.

Findings

Effect of disability Parents were engaged in a series of one-to-one conversations based on a semi-structured interview schedule. The participants were predominantly mothers, although in some cases both parents were involved. Out of the 33 interviews, 26 were with mothers alone, six were with both parents (including one stepfather) and one with a father. Among the 33 families, the biological parents were together in 27 instances, there were four single mothers, and two families included the biological mother and a stepfather.

The parents were interviewed in their homes, although one interview took place in a health centre. The conversations were recorded on a digital audio recorder and transcribed by the author. The process of data analysis and verification of the study findings has been described in an earlier article (Whiting and Sines 2012).

Analysis of the study data set in relation to the theme impact revealed major areas of consistency between the three subgroups with respect to the categories and subcategories (Box 2). Three main categories emerged from an analysis of the study data:

- Time.
- Multiple roles.
- The disabled family.

Time Parents in all three subgroups consistently reported that the child's disability or complex health needs affected several elements of family life in this category. One issue was the time required to provide for their child's additional care (described by several parents as 'extra care'), leading parents to identify themselves as 'time poor'. Analysis of the interviews highlighted several reasons for this extra care:

- Having to meet the additional needs of a child

Box 1 Definitions of the three study subgroups

Disability The 'outcomes of interactions between health conditions (diseases, disorders and injuries) and contextual factors... disability involves dysfunctioning at one or more of three inter-related levels: impairments, activity limitations and participation restrictions' (World Health Organization 2002).

Life-limiting illness 'A condition for which there is currently no cure available and the likelihood is that the condition will lead to the child dying prematurely' (Sutherland *et al* 1993).

Life-threatening illness 'A condition in which medical intervention may prove successful but by its nature carries a substantial chance of mortality in childhood' (Association for Children with Life-threatening or Terminal Conditions and their Families, Royal College of Paediatrics and Child Health 2003).

Technology dependence Requiring 'a medical device to compensate for the loss of a vital bodily function and substantial and on-going nursing care to avert death or further disability' (Office of Technology Assessment Task Force 1988).

who has not yet developed independence in one or more activities of daily living, which comparable age-equivalent peers have done.

- Providing care of a non-technical nature specifically related to the child's disability or complex health needs, including preparation and administration of medicines and special feeds, application of creams, feeding, bowel washouts, chest physiotherapy, moving and stretching exercises.
- Providing technical care, for example the use of medical devices/equipment, such as suction machines, oxygen delivery systems, ventilators and feeding pumps. This was evident across all subgroups, but particularly in the technology-dependent subgroup.
- Having to attend hospital for routine appointments, or planned or emergency admissions.
- Being available for professional appointments at home – and keeping the house tidy for these occasions.
- Being available to attend school or nursery in case of emergencies.

As a result of the identified need to provide 'extra care' to their disabled child, parents reported that they had less time available for partners, for siblings and 'for a social life' (*participant 1*).

Multiple roles Many parents, in all three subgroups, identified the need to take on multiple roles (parent, partner, taxi driver, diary keeper, nurse, physiotherapist) and graphically described the need for complex planning skills and having to juggle multiple responsibilities. Many of these roles are not materially different from those in other families, however, parents of children with disabilities and complex health needs had to take on a range of additional roles, such as administering enteral feeds, giving medicines and clinical care tasks.

Several parents acknowledged their expertise in relation to their child's care needs, recognising at the same time that this created difficulties in terms of the inability of others to look after their child. This included not only other family members whom several parents described as too scared to take on the responsibility of providing respite/babysitting, but also local hospital staff or potential respite care workers. This especially seemed to be a problem where a child had a relatively uncommon medical condition and if a child was technology dependent.

Parents identified significant elements of role conflict in terms of the dichotomy of undertaking technical care tasks and of simply being a parent to their child. Parents also reported how the demands

Box 2 Categories and subcategories in the three study subgroups

	Study subgroup		
	<i>Disability</i>	<i>Life-threatening or life-limiting illness</i>	<i>Technology dependence</i>
Category	Subcategory		
Time	Need to plan ahead. Time for... 'Extra care'. Juggling.		
		Time wasted waiting for hospital appointments.	
Multiple roles	Different roles. Role conflict. Learning. Juggling.		
The disabled family	Positive impact of child on family. Marriage/relationship with partner. Implications for siblings. Effect on physical and mental health of parents. Working lives of parents. Social disengagement. The future.		
	Simple things become more complex. Disruption to household organisation.		Simple things become more complex. Disruption to household organisation.

of providing 'extra care' for their child affected their ability to fulfil other roles. One parent observed: 'You stop being just a mum... I'm now a mum, and a nurse, and physio all in one' (*participant 2*).

The disabled family Several parents in the study used the term 'a disabled family' to describe their situation. However, in the author's clinical experience, this is a term that many parents would not recognise as applying to their circumstances and is a result of the interplay of a range of social, cultural and personal/personality factors.

Parents related the notion of the disabled family in terms of the effect their child's disability had on aspects of family life, including relationships with other family members in the nuclear and extended groups, social disengagement, loss of work opportunities (and consequent financial problems), and general disruption to household and

family life. This is best illustrated in quotes from two parents:

- 'You become a dysfunctional family, definitely, totally dysfunctional from day one' (*participant 3*).
- 'You know, somebody once said "If you've got a disabled child, you've got a disabled family"... and that is very, very true' (*participant 4*).

Discussion

This article has considered the experiences of parents of children with disabilities and complex health problems, and has focused on how the need to provide extra care to the disabled child affects the family. Such care is often required beyond the age where, in other circumstances, the child might have been expected to become increasingly independent. Childhood disability impacts on families in many ways.

This study identified areas of consistency and inconsistency in the families' experiences across the three subgroups. A systematic comparative analysis led to the identification of a number of categories and subcategories in terms of how having a child with disabilities affected the families. This may help professionals to identify and develop targeted strategies to support families.

Limitations This was a small study that drew on the experiences of 33 families living in one county in England. Although many of the findings, as

described by the participants, are consistent with the author's experience, the extent to which they can be considered to have wider relevance is the most significant limitation of the study.

Conclusion

Three areas of parental experience were reported consistently in the three study subgroups described in this article: time, multiple roles and the disabled family. A second article, to be published next month, will consider how parents experience the need for help and support in caring for children with disabilities and complex health needs.

Implications for practice

- Be aware that time is precious and make every effort to offer appointments at times and places parents find most appropriate. If possible, offer combined appointments, perhaps two or three in the same clinic or hospital on the same morning or afternoon.
- Be aware of the multiple roles parents may have to play in caring for the child. At times of increased healthcare needs, parents often need to focus solely on their role as mother or father.
- Recognise that the child's disability has implications for all the family.

Online archive

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Conflict of interest
None declared

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