Respite care in seven families with children with complex care needs

Study highlights the need for community children’s nurses to act as key workers to help relieve the physical burden, practical difficulties and isolation of mothers of the child and family and not the needs of the professionals providing it (NHS Executive 1998).

Abstract

Aim To evaluate the experience of nursing respite care in families caring for children with complex health needs.

Method Seven mothers took part in semi-structured, in-depth interviews, which were taped, transcribed and coded. Results were categorised thematically.

Findings Families described a positive impact on all aspects of life, the high value of respite care and the preference for more information, flexibility, choice and co-ordination of the different services.

Conclusion Respite care is highly beneficial to family life, but there need to be clearer communication lines and a stable, flexible and adequately resourced workforce. Families value a single point of contact and would prefer more respite care to be available.

Keywords Care at home, children with complex health needs, respite care

DESPITE STRONG recommendations over the past 50 years, development of community children’s nursing (CCN) teams in the UK has been slow (Hughes and Harsburgh 2002). An increasing number of children with complex health needs are surviving (Hewitt-Taylor 2009) and are being cared for in their own home or school by the CCN service. Studies have reflected issues about caring for this group of children. There is also an improved understanding of the pressures faced by the family of a child with complex needs and appreciation that these families require a break from caring if they are to continue with the demands of the role (Noyes et al 1999).

Families’ needs for respite have begun to be addressed through the provision of a nursing respite service (Kirk and Glendinning 2002). Respite care is generally defined as care where the main function is to relieve the family by providing extra support in the home or in an alternative community environment (International Children’s Palliative Care Network 2008).

Little is known about parents’ views on what respite service they may find beneficial. Respite care is most effective when it meets the needs of the child and family and not the needs of the professionals providing it (NHS Executive 1998).

Background

Eaton (2001) described six models of home care delivery based on local need in view of the lack of national strategic direction. A scoping exercise of CCN services in Wales (Davies 2011) showed that the number of teams has grown over the past decade but that there are considerable variations in team size and inequities in service provision. There has been little evaluation of different models of CCN services (Emond and Eaton 2004) and research tends to focus on the acute aspects of CCN delivery (Jennings 1994, Peter and Torr 1996, Sartain et al 2002).

The CCN team in the area where the research described in this article was conducted consists of an even mix of community children’s nurses and healthcare support workers (HCSWs). They deliver respite care in the home and also provide an in-reach service when the child requires acute care in hospital. The HCSWs undertake a competency-based training programme in supporting a child with complex health needs. Following referral of
a child to the CCN service, the nurse co-ordinates a multi-agency continuing care assessment (Department of Health (DH) 2010), develops a care plan and completes a national needs assessment tool (United Kingdom Working Party on Long-Term Ventilation 2004), which will guide the number of hours for which respite is required. The eligibility for continuing care is then discussed and agreed by a panel and is reviewed at least annually.

Literature review
A review of the UK literature over the past ten years shows that a growing number of children with complex health needs are being cared for at home (MacDonald and Callery 2007). Most published data are descriptive or opinion based (MacDonald and Callery 2004, Margolan et al 2004, Eaton 2008, Koshti-Richman 2009) and suggest that more qualitative research is needed on the perspectives of family members in this situation (Murphy 2001, Kirk et al 2005, Hobson and Noyes 2011). The findings should be used to inform service development continuously and guide professional practice (Franck 2004, Thurgate 2005).

Aim
This study aimed to explore parents’ experience of caring for a child with complex health needs and to evaluate whether the nursing respite service at home meets their needs.

Method
Undertaken in an area of Wales, this study took a qualitative approach, with semi-structured in-depth interviews as the method of data generation. Qualitative research is often described as holistic and, like nursing, is patient-centred. Thus most qualitative approaches are suitable for the study of nursing phenomena (Lester 1999).

The study sample included seven families whose children met the eligibility criteria for continuing health care, as defined in the National Framework for Children and Young People’s Continuing Care (DH 2010) (Table 1). The families were recruited via the CCN service, having all met the inclusion criteria of receiving respite care from the CCN service since its establishment, while also having received other forms of respite care.

All seven families had accessed the service since the team’s establishment and had previously received other forms of respite care. Both parents of each child were sent the study information leaflet and invited to contribute, but only the mothers agreed to participate because the fathers’ work situations were too demanding for them to take part.

Ethical considerations Following approval from the local research ethics committee and having obtained written consent from the participating mothers, the study interviews were undertaken in the child’s home while the child was at school and were led by a child health lecturer to reduce bias. The data from the interviews were taped, transcribed and coded to ensure confidentiality. The interview text was coded according to themes identified from mothers’ accounts and categorised.

<table>
<thead>
<tr>
<th>Participant identity</th>
<th>Child’s condition</th>
<th>Age of child (yrs)</th>
<th>Weekly respite provision (hours)</th>
<th>Family setup</th>
</tr>
</thead>
<tbody>
<tr>
<td>M1</td>
<td>Developmental delay Epilepsy Poor mobility Enterally fed</td>
<td>12</td>
<td>50 (1 healthcare support worker (HCSW) and 1 community children's nurse (CCN))</td>
<td>Both parents Four siblings</td>
</tr>
<tr>
<td>M2</td>
<td>Epilepsy Learning difficulties Behaviour problems</td>
<td>10</td>
<td>4 (1 HCSW)</td>
<td>Both parents One sibling</td>
</tr>
<tr>
<td>M3</td>
<td>Signs of birth asphyxia Enterally fed Suctioning</td>
<td>14</td>
<td>20 (1 HCSW and 1 CCN)</td>
<td>Both parents Two siblings</td>
</tr>
<tr>
<td>M4</td>
<td>Tracheostomy Muscular weakness</td>
<td>3</td>
<td>20 (1 CCN)</td>
<td>Single parent No siblings</td>
</tr>
<tr>
<td>M5</td>
<td>Respiratory problems Long-term ventilation</td>
<td>12</td>
<td>50 (1 HCSW and 1 CCN)</td>
<td>Single parent No siblings</td>
</tr>
<tr>
<td>M6</td>
<td>Vision and hearing impaired Developmental delay</td>
<td>8</td>
<td>6 (1 HCSW)</td>
<td>Both parents One sibling</td>
</tr>
<tr>
<td>M7</td>
<td>Wheelchair dependent Enterally fed Muscular spasms Developmental delay</td>
<td>10</td>
<td>30 (1 CCN)</td>
<td>Separated parents Two siblings</td>
</tr>
</tbody>
</table>
Findings

Impact of child's condition on family life The findings suggest that having a child with complex health needs has an overwhelming impact on all aspects of family life. All seven participants described the demands of constant caring and the challenges of enabling their child to undertake routine activities, which resulted in mothers experiencing excessive physical burden and social isolation. This had a negative impact on their ability to work and the family’s income. Holiday times were difficult and, even though play schemes were available, most had access problems. The effects on older siblings were obvious. One mother observed her older children as they saw their sister’s condition deteriorate and associated this with mourning a loved one as they tried to ‘remember X as she was’.

One mother described the emotional turmoil of caring for her children as: ‘I’m very aware that my mind is constantly on ‘A’ and so ‘B’ and ‘C’ start to get pushed to the side and their needs are sort of gone by the way as ‘A’ is constantly in need of care. It’s hard to divide your time between everyone’ (Participant M3).

Respite care provision from the CCN service The parents valued the nursing respite care and viewed the nursing service positively as it benefited both the child and family. They stated that they were reliant on the service and a reduction in service provision would be devastating. All were satisfied and felt confident with staff competence and they viewed the parent-professional relationship positively. They identified that there had been a number of improvements to the service since the establishment of the respite nursing team, including better access to staff, clearer lines of communication and responsibility, a good reporting structure, a degree of flexibility with the respite provision and continued support during hospital admissions.

One mother particularly valued the flexibility the service tried to offer, as this was her only means of support, and stated: ‘The service has restored my sanity, as I can now hang on in there when my child is particularly difficult’ (Participant M2).

Another mother welcomed the consistent support provided by her CCN while her child was in hospital: ‘While he was in hospital and really poorly it was good to have somebody to spend time with me and to give me a break. She really knows my son and so could talk to the doctors and nurses on the ward better than I could’ (Participant M4).

The findings reveal inconsistency in the amount and type of respite provision available to families, and the options are limited as the child’s condition deteriorates. All participants would have liked an increase in their respite care package, accentuating the need for a validated nursing dependency scoring tool to guide the level of appropriate care provision (Escolme and James 2004).

Views on service development All participants asked for flexibility and for a choice of respite provision to be available. Participants M1 and M4 wanted to be able to access respite nursing care away from home and all advocated for an increase in the nursing team to allow consistent cover from a carer known to the child. One participant requested more registered staff to enable the administration of medicines, but most were satisfied with the service provided by the HCSW. Other recommendations included access to short-term respite care during periods of crisis and more involvement of families in the recruitment of carers.

Even though they are appreciative of the services available to them, parents would like agencies to communicate more closely and work more collaboratively with each other on behalf of their child. A particular area of concern is the provision, maintenance and replacement of specialist equipment – participants stated that the delay with provision caused them a considerable degree of stress. All thought that more training in specific aspects of care is needed, such as the safe handling of their child, and suggested that this in particular be addressed because it had affected their health.

Parent-professional relationship Most mothers described a good relationship with the nurses and some commented that staff were like a ‘part of the family’. One mother did not like the current staff rotation to the hospital wards every three months, as she preferred consistency: ‘It’s just like when you get used to someone, and then they’re leaving and then they give you someone else. I prefer to have someone all the time – you know, regulars, even if it’s two or three, but the same ones all the time’ (Participants M7).

One participant noted that the level of respite received was a good balance, supportive to the family but not too intrusive so that they had their own ‘space’ at weekends. Another mother emphasised that it was important to establish boundaries in the parent-staff relationship, as learned from past experience: ‘Occasionally problems can arise if you get too attached to the person, as difficulties can arise when there are issues to deal with. I think it’s important to know how far to take that relationship and try to keep a professional line’ (Participant M6).
Discussion
This study shows that having a child with complex health needs has an impact on all aspects of family life, including physical burden, social isolation and emotional turmoil. The findings reveal inconsistency in the amount and type of respite provision offered to families and indicate that fewer respite opportunities are available to the family as the child’s condition deteriorates. Alternative forms of respite provided jointly, flexibly and adequately by health and local authorities should be considered.

The participants found the respite nursing service to be highly beneficial to family life, but emphasised the importance of clear lines of communication and the need for a stable, flexible workforce. Even though the mothers valued the different services available to them, they identified a lack of co-ordination and communication between those services. Numerous research studies report that parents want a single point of contact, but in reality less than one third of families with severely disabled children have a key worker (Greco and Sloper 2004). A CCN is in a prime position to fill this role, but it is time consuming, potentially stressful and therefore needs to be resourced appropriately.

Limitations
This is a small qualitative study and therefore it is difficult to generalise the findings, which is a recognised weakness of semi-structured interviews (Harvey Jordan and Long 2001). Despite this limitation, much can be learned from the mothers’ rich accounts of their experiences and how these illustrate ways in which professional beliefs and activities need to adapt to the changing nature of care provision.

Conclusion
This study has clarified users’ views of the respite nursing service, with participants acknowledging areas of good practice and areas needing improvement. Further research should define the training and educational requirements of nurses dealing with parents with children who have complex health needs living at home.

Implications for practice
■ Reliable and flexible choice of respite care at and away from home is required.
■ Access to short-term respite care during periods of crisis should be available.
■ The community children’s nurse (CCN) should act as a key worker.
■ The CCN nurse can lead multidisciplinary, multi-agency assessment and regular reviews of the holistic care package.
■ The family should be included in the care plan and in recruitment of carers.
■ Joint funding will promote innovative solutions.

References


Conflict of interest
None declared.

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