

Families' experiences of caring for technology-dependent children: a temporal perspective

Janet Heaton BA (Hons)¹, Jane Noyes RGN RSCN Cert Ed MSc PhD², Patricia Sloper BA MA PhD¹ and Robina Shah MBE, MSc BSc (Hons)³

¹Social Policy Research Unit, University of York, York, ²School of Nursing, Midwifery and Social Work, University of Manchester, Manchester and ³Independent Researcher, Manchester, UK

Correspondence

Janet Heaton
Social Policy Research Unit
University of York
Heslington
York YO10 5DD
UK
E-mail: jh35@york.ac.uk

Abstract

In the present study, families' experiences of caring for a technology-dependent child were examined from a temporal perspective. This involved exploring the multiple 'technological', 'social' and 'natural' rhythms and routines around which the families' lives were variously structured. A purposive sample of 36 families with technology-dependent children who used one or more medical devices on a daily basis was recruited. Devices included feeding pumps, suction machines, dialysis machines and ventilators. Using mainly qualitative methods, children, parents and siblings were interviewed to establish what the care routines involved and how these impacted on family members. The authors found that the rhythms and routines of care varied across the sample, depending on the type and number of devices used, the individual child's needs, and who provided technical care during the day and/or at night at home and in other settings. While the children's health and quality of life benefited from the technology, the time demands of the care routines and lack of compatibility with other social and institutional timeframes had some negative implications for the children and their families, limiting their participation in school, employment and social life in general. The need to use and oversee the use of some medical technologies at night also meant that many parents suffered regular disruption to their sleep. In conclusion, the authors argue that the care of technology-dependent children at home places considerable time demands on families. Families have little or no access to suitably trained carers who can provide technical care required in the home or away from the home to give parents and the whole family a break from caring where required. More trained carers and short-term care provision, better coordination of services and improvements in the design of devices would all help to reduce the negative effects of the care routines on families.

Keywords: complex care, disability, home care, medical devices, technology-dependent children, time

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Introduction

In 2001, it was estimated that there may be up to 6000 'technology-dependent' children living in the community in the UK (Glendinning *et al.* 2001). These children (the term includes young people aged up to 18 years) are so-called because of their reliance on medical tech-

nologies which compensate for the partial failure or loss of a vital body function (US Congress, Office of Technology Assessment 1987). Examples of such technologies include assisted ventilation, artificial nutrition, intravenous drug therapies, oxygen therapy and renal dialysis. Some children rely on a number of medical devices to support or replace the loss of more than one

body function. Various secondary devices may also be used to monitor their condition.

Previous research has explored the experiences of families of technology-dependent children living at home in North America (e.g. Aday & Wegener 1988, Doyle *et al.* 1992, Petr *et al.* 1995, Spalding & McKeever 1998, Wilson *et al.* 1998; see also reviews of the literature by Kirk 1998, Murphy 2001), and to a lesser extent, the UK (e.g. Mohammed & McDowell 1998, Kirk & Glendinning 1999, Noyes 1999a,b, Noyes *et al.* 1999, Manns 2000, Townsley & Robinson 1999a,b, 2000, Watson *et al.* 2002). This literature has highlighted limitations in service provision for this group, including problems with the availability, coordination and reliability of services (Kirk & Glendinning 1999, Watson *et al.* 2002). It has also provided evidence of the social, emotional and financial effects on parents, and to a lesser extent, the children and their siblings (e.g. Kirk 1998, Wilson *et al.* 1998, Noyes 1999a,b, Noyes *et al.* 1999). Negative effects include exclusion from work, social isolation, loss of privacy in the home and sleep disruption. While this literature has provided examples of the time demands and effects of caring for a technology-dependent child at home, no studies have explicitly set out to examine the temporal organisation of the care routines involved for children using a range of medical devices and the effects on families.

In this paper, the present authors report the results of a qualitative study that was designed to examine the social organisation and effects of the home-care regimes for technology-dependent children and their families from a temporal perspective. The theoretical context for the study was developed from the literature on the sociology of time, and in particular, work exploring the ways in which social life is structured around multiple temporalities (Gurvitch 1964, Zerubavel 1979, 1981, Giddens 1984, Young 1988, Young & Schuller 1988, Adam 1992, 1994/1990, 1995, Nowotny 1994). In this literature, various concepts of time and rhythms of natural and social life have been distinguished (including biological rhythms, 'clock' time and institutional timetables). The present study adds to this work by describing the rhythms and routines of 'technological' time (including how long it takes devices to perform their functions and the associated technical care routines), and examining how these relate to other 'social' and 'natural' time frames (e.g. the institutional timetables of work, schools and health service providers, and the 'artificial', as opposed to the 'natural', biological, rhythms of the technology-dependent body). The authors consider how the incompatibility of these time frames contributes to the social exclusion of families with technology-dependent children from aspects of social life. The implications of the findings for future policy and

practice concerning families of technology-dependent children are discussed.

Subjects and methods

The overall aim of the present study was to examine the temporal organisation and time consequences of the care regimes for technology-dependent children and their families. Families with technology-dependent children who were aged up to 18 years, living at home, and reliant on one or more medical devices on a daily basis, were invited to take part in the study. Children using the following devices or technologies were included: ventilators, feeding pumps, dialysis machines, oxygen therapy, intravenous drug therapies, tracheostomies and suction machines. A purposive sampling strategy was used to ensure that a minimum of six lone-parent families and six families from minority ethnic groups were included, and that a minimum of 12 technology-dependent children and 12 siblings were among those interviewed.

Families were recruited via hospitals, a hospice, the Family Fund and a previous study based in the North of England. These different sources were used to ensure that a target sample of 36 families could be recruited who met the study criteria and who satisfied the purposive sampling strategy. Invitations to take part in the study were sent out to families via consultants or staff they knew on a rolling basis. As recruitment progressed, staff were asked to target particular types of families who were proving more difficult to recruit sufficient numbers of, such as families where the technology-dependent child had siblings who were old enough to be invited to take part in the study, in order to achieve the purposive sampling framework targets. Staff were asked to keep a record of how many families were invited to take part but not all did and, hence, it is not known how many families declined to take part. Where records were kept, the response rate did appear to be low and it took some time to achieve the sample targets. However, all the targets were eventually achieved (see 'Results' below).

Various qualitative methods were used to obtain the perspectives of the children, their siblings and their parents. Face-to-face semistructured interviews were carried out with one or both parents from all the families, depending on whether one or both parents chose to take part. Technology-dependent children and their siblings were interviewed if they were able and willing to take part; they were invited with the agreement of their parents if they were aged 8–18 years. In a few cases, younger or older children and siblings were interviewed where their parents informed us that they were also keen to be included along with other members of

the family and the children/siblings assented. The interviews lasted between one and 2 hours, and took place in the family home over one or two visits. Parents and children/siblings were generally interviewed separately. Some children and siblings chose to be interviewed together, whereas others elected to be interviewed individually. The majority of the interviews were recorded on audiotape, except where permission was refused ($n = 7$) or the tape recorder failed ($n = 1.5$), and notes were used.

Interviews with children and siblings were facilitated by the use of time-line drawings. In the drawings, the children and siblings described an example of a 'good' and a 'bad' day in their lives on a 24-hour chart. This included space for them to describe where they were, what they were doing, who they were with and why that part of their day was good or bad. Parents, children and siblings were also given the option of keeping written and/or photographic diaries over a week after the interviews. Structured data on the socio-demographic characteristics of the families, the children's devices and services received were also collected via a questionnaire completed by parents immediately prior to the interviews.

Interviews were transcribed in full (where recorded). Transcripts and notes of interviews were anonymised and entered on to computer for analysis using the ATLAS.ti software package. These data were analysed in conjunction with the children's time-line drawings. Only a few families completed and returned the diaries, and hence, these data were used to supplement the main analysis of the transcripts and drawings. Data from the questionnaire were entered into a spreadsheet for descriptive statistical analysis. Qualitative data analysis was carried out using the 'framework' approach (Ritchie & Spencer 1995). This involved developing a coding framework made up of categories reflecting the content of the data (both a priori and emergent themes) and relating to the aims of the study. These codes were jointly developed by all the researchers and applied by the two researchers who had carried out the majority of the interviews (J.H. and J.N.). Many of the codes related to temporal themes, including time spent using a device, the routines associated with using different devices, the time spent by family and formal carers in providing technical care, and the extent to which families were able to combine caring with work, holidays, education and social activities.

Ethical approval for the study was obtained from four National Health Service local research ethics committees. Consent was obtained from all participants who took part in the study. In the case of children aged under 16 years, consent was obtained from both the child and a parent.

Results

Following a description of the sample, the findings are divided into three sections. First, the paper describes the rhythms and routines of care relating to the various devices used by the children in the study. Secondly, it examines the time demands of the associated care routines, and the respective roles of parents and formal service providers in performing the technical care required during the day and/or at night at home and in other settings. Finally, it considers the effects of the care regimes on the children, their siblings and parents, and in particular, the extent to which they were able to participate in education, employment and social life in general.

Characteristics of the sample

Thirty-six families took part in the study, including eight families from ethnic minority groups and seven lone-parent families. A breakdown of where the families were recruited from is shown in Table 1.

Seventy-five family members were interviewed, including 46 parents, 13 technology-dependent children, 15 siblings and one grandparent. One family had three technology-dependent children. The gender and age profile of the interviewees and family members living at home is shown in Table 2.

The sample comprised a range of family configurations, including seven lone-parent families and five families where one of the parents was not the biological parent of the technology-dependent child(ren). It also included families with between one and seven children living at home (see Table 3).

There was a clear gender division in terms of which of the parents was in paid work. Twenty-one of the 30 fathers in the sample were in paid work compared to just eight of the 35 mothers. Both parents in eight, two-parent families were involved in full- or part-time work, while the same number of couples were without work. None of the seven lone-parents were in paid work. Total household income varied across the sample. At the extremes, nine of the families had an annual income of under £10 000, while four families had incomes of

Table 1 Sources of recruitment

Source	Number of families
National Health Service trusts/primary care trusts	20
Hospice	7
Family Fund	4
Previous study	5
Total	36

Table 2 Gender and age of the interviewees and the family members living at home

Group	Female	Male	Average age (years) (range)
Parents:			
number interviewed 46	34	12	37.3 (22–52)
total number in sample of families 65	35	30	37.3 (22–52)
Technology-dependent children:			
number interviewed 13	5	8	10.1 (4–19)
total number in sample of families 38*	22	16	7.8 (0.9–19)
Siblings:†			
number interviewed 15	7	8	14.3 (7–22)
total number in sample of families 52	15	37	11 (2–27)
Total:			
number interviewed 75‡	46	28	
total number in sample of families 156‡	72	83	

* One family had three technology-dependent children living at home.

† Includes only siblings living at home.

‡ Includes one grandmother who also took part in the joint interview with her daughter and son-in-law.

Table 3 Number of children living at home

Total number of children per family (living at home)	Number of families (total sample = 36)
1*	9
2	15
3	6
4	2
≥ 5	4

* The technology-dependent child.

over £30 000. All the families received Disability Living Allowance, and several received additional benefits including Invalid Care Allowance (now called the Carer's Allowance), Income Support and Housing Benefit. Twenty families owned their own homes; the remainder lived in rented accommodation.

The children had various, and in several cases, multiple impairments relating to their medical conditions. Their primary and secondary medical diagnoses are summarised in Table 4. In some cases, their condition had not been diagnosed. All of the children were currently using one or more medical devices on a daily basis, apart from one who had recently had his tracheostomy removed. There was considerable variation in the number and type(s) of devices used by each child (see Tables 5 & 6). Thirty children attended a special or mainstream school or nursery, while three were home educated; five did not go to school or nursery.

Rhythms and routines

Parents, children and siblings were asked to describe how often and where the children used their devices,

Table 4 Primary and secondary diagnostic groups ($n = 38$)*

Type of disability	Primary	Secondary	Total
Neuro-disability (e.g. cerebral palsy)	9	0	9
Respiratory	4	5	9
Renal	8	0	8
Neuro-degenerative (e.g. spinal muscular atrophy and muscular dystrophy)	5	0	0
Gastrointestinal	2	3	5
Cardiac	3	0	3
Metabolic	2	0	2
Congenital abnormality	2	0	2
Haematological	2	0	2

* Some of the children had very rare syndromes which have not been named to protect the anonymity of the families.

Table 5 Main medical technologies/devices used by the children ($n = 38$) in the sample

Technology/device	Number of children*
Artificial nutrition	21
Tracheostomy and/or suctioning	10
Renal dialysis	8
Assisted ventilation	6
Oxygen therapy	4

* Some children used two or more of these medical technologies and associated devices.

what this involved, and who provided technical care, if required. Analysis of the data showed variations in the patterns of usage of different types of devices and changes in usage over time. All of the children used (or

Table 6 Number of devices used

Number of devices	Number of children*
1	11
2	9
3	5
4	6
≥ 5	5

* All data were not collected for two of the three technology-dependent children in one of the 36 families in the sample.

had recently used) one or more medical devices on a daily basis, and several also used a number of other devices less frequently. Three basic patterns of usage were discerned. A ventilator was used constantly, i.e. 24 hours a day, by one child, who could not survive without it. Other devices, particularly dialysis machines, gastrostomies and other forms of tube-feeding, tended to be used at regular times during the day and/or at night. For example, eight children were on peritoneal dialysis at home for around 10 hours 5–7 nights a week. Finally, several devices were used on a more irregular basis, as and when required. This could range from several times a day (e.g. suctioning machines) to a few times a year in the event of a medical crisis (e.g. oxygen therapy).

For most children, the patterns of usage shifted over time with changes in the children's medical conditions and as they physically grew. Usage also tended to increase when the children were ill, and technology-dependent children – who are also sometimes described as 'medically fragile' – are often unwell; for example, 29 children in the study had been hospitalised within the past 12 months because of illness or for procedures to be undertaken.

The time scales of the devices also varied in the extent to which they artificially replicated the natural rhythms of the body, and had to be regulated by users and carers. While some devices, such as pacemakers (which were not featured in the study) more or less replicate the natural rhythms of the body and work relatively automatically, those used in the present study tended to work at different time scales and/or had to be regulated by users and carers. The design of the devices also varied in the extent to which they restricted children's and carers' movements in time and space when the former were 'plugged in' or otherwise using these machines, or where both the device and a technical carer had to be readily accessible in case they were needed.

Variations in the natural and artificial rhythms of the technology-dependent body are illustrated by the technologies of dialysis, tube-feeding and assisted ventilation. Eight children using dialysis machines, all receiving peritoneal dialysis at home for 9–10 hours a night for six

or seven nights a week. Some of the children had previously been on haemodialysis, which was provided at hospital on 3 days a week over 3 hours, and/or continuous ambulatory peritoneal dialysis (CAPD) where fluid constantly dwelled in the body and was exchanged in three or four bag changes during the day, taking around 30 minutes. Of the 22 children who received artificial nutrition, some were totally dependent on this while others also fed normally. Some children were fed by tube at intervals of up to every 2 hours a day and/or continuously overnight for 10–12 hours a night for between 5 and 7 nights a week; one child had a short supplementary feed while asleep. One of the six children who had assisted ventilation was totally dependent on this technology for 24 hours a day, while the others mainly used the ventilator to supplement their own breathing patterns at night while sleeping or when unwell.

These artificial processes were often programmed to reflect the needs and characteristics of the children (e.g. their physical size and tolerance to the rates at which fluids and foods could be pumped through the body). At the same time, they were, to varying degrees, set around the social schedules of the family and other institutional timetables. Thus, peritoneal dialysis was generally programmed to start at a time that allowed the requisite number of cycles to be completed in time for the children to get up and go to school. These schedules were adjusted at weekends and other non-school days. A few families had been given permission to suspend feeding and/or dialysis on special occasions, such as on holiday. Conversely, social schedules were also adapted around the technical routines. For example, use of short-term care and babysitters was mainly on those nights when the children were not using their devices, and families found it difficult to access technically competent carers on the nights when the devices were being used. In addition, as previously noted, many of the children also used devices on a more irregular and unpredictable basis which could not be scheduled, and hence, families found it difficult to commit themselves to regular activities such as paid work and to plan ahead for holidays.

Time demands of technical care

Care relating to the devices (or 'technical care') was mainly provided by the children's parents, particularly mothers, with varying levels of support from other family members (mainly fathers and older siblings) and formal service providers. Parents and other family members also provided a variety of personal, practical and other types of care linked to the children's medical condition, in addition to the kinds of care associated

with parenting in general. This study focused mainly on the technical care that was provided as part of the overall care regime.

Technical care involved a range of activities, namely: assisting the child when she or he was using a device; monitoring the child by close visual observation and/or use of secondary devices; managing the equipment (e.g. cleaning and preparing it for use, ordering supplies, and managing stocks); maintaining the interface between the device and the body [e.g. care of entry and exit sites (re)placement of tubes]; accessing technical support from service providers (including hospitals, community services, companies who supply equipment and consumables); and providing technical support to others through training formal or informal carers, or preparing equipment for use by other carers. The above medical tasks had to be performed following strict protocols by parents or other informal carers who had been trained in how to manage the devices.

Formal technical care was provided in a variety of settings. At home, eight families had help with technical care from professionals such as Diana nurses, district nurses, community nurses and specialist outreach nurses. Four families had a trained carer through the night. For two families, this was allocated every night, but in one case, it was not always provided in practice. The other two families had overnight carers for two nights per week: one during the week, which enabled the parents to get some sleep on two out of five work nights; the other at weekends, when all the family were at home. Seven families had packages of care where hours of paid care were allocated during the day. This ranged from one hour a week to 8 hours a day, but again, the latter was not always provided. Some families found it particularly difficult to get help from formal technical carers during the 'twilight' hours to enable them to go out in the evening, either because the service was not available, or because it had to be booked well in advance – which parents were reluctant to do since they did not know if the child would be well enough to leave with another carer, or if they would be feeling too tired to go out after having a bad night.

Twelve families had received short-term care away from the home over the past year for between a minimum of one weekend a year and a maximum of 2 weeks a year plus one weekend a month; four children stayed with relatives occasionally through the year. The remaining 20 families received no break from care away from the home. During care at hospices, where usually the whole family would stay and be looked after, technical care was provided by a mix of the hospice staff and the children's parents; in one case, the child's own formal carers also assisted at night. Three families received short breaks through a family placement scheme, where

these carers had been trained to provide the technical care required while the parents had a break.

Twenty-seven families received equipment and supplies on a regular basis from commercial companies who deliver medical equipment and supplies to the home, and from community nurses, surgeries and hospitals. Parents were generally happy with how this was organised, including those who had made special arrangements to ensure that supplies were delivered in their absence, although some reported 'teething' problems at first. Few parents had to collect large quantities of supplies themselves, but some had to make regular visits to pharmacies for prescriptions which was not always easy to do (e.g. when a child is at home unwell and looked after by a lone parent).

Twelve children received technical care at school or nursery from individual members of staff (e.g. carers, teachers and/or escorts) who had been trained to assist the children to use their devices and/or by school nurses. This support generally enabled the children concerned to attend nursery or school, although parents reported difficulties accessing places because of a lack of trained carers, as well as problems with children being unable to attend school when their carers were not available and with coordinating some technical care around school timetables (e.g. the timing of a feed at lunchtime).

Finally, when the children were in hospital, parents preferred to continue to provide the technical care related to their devices because of a lack of staff who had been trained to use the devices and concerns about the quality of the care provided, usually based on problems previously experienced.

Effects of care regimes on children, siblings and parents

In general, the children's use of medical devices was recognised to have benefited their health and quality of life and made lives easier for their parents because their children were healthier, and in some cases, the children had transferred to technologies which were relatively easier to manage (e.g. in moving from haemodialysis carried out at hospital to peritoneal dialysis performed overnight at home). However, as one parent said, it was not an 'easy' life.

In the interviews, the children talked about what the care routines involved and how they affected their everyday lives. Although there was great variation in the complexity of care regimes between individual children and their levels of dependency on medical technology, the children invariably gave prominence to the activities concerned with their medical devices and health in their drawings. They consistently identified 'good' days

as days when they were well, their care regime 'worked' and there was more time for social activities. 'Bad' days tended to be the reverse of good days, and could also involve contact with hospitals for operations or tests.

All but one of the 13 children interviewed liked school because of the social contact with other children. However, almost all children described school days as 'worse' than non-school days because they had less time to deal with their medical devices and health needs. The day started earlier (at around 05:00 hours for some) and children described the 'race' to get everything done (as did some parents). Two children said that the school bus picked them up early, which added to the pressure. The children's education was disrupted by a number of factors. Children talked about: missing school because of hospital appointments ($n = 11$); missing a lot of school because they were frequently unwell ($n = 8$); missing lessons because they received medical therapy ($n = 4$), although it was appreciated that therapies were coordinated around key lessons where possible; and having difficulties fitting their homework around medical routines ($n = 2$). Almost all children said they got very tired on school days, which was exacerbated for some by getting up too early, and/or by interrupted sleep caused by machines alarming or the need for turning or other interventions at night.

In terms of impact on their social lives, three children reported that having artificial feeding increased their energy and enabled them to participate more fully in social activities. Conversely, six older children who had a greater dependence on medical technology described having limited social lives, and wanted more opportunities to meet friends and go out.

Living in a family with a child dependent on technology conferred a different type of childhood for brothers and sisters whereby the focus and routines were planned around the child using the technology. Siblings described the divisions of labour that dictated their individual roles and responsibilities in the home. Roles and responsibilities varied between families, changed in nature over time and increased with age. For example, most siblings started off with considerable domestic responsibilities (e.g. cleaning, washing and cooking), and some progressed to taking on aspects of technical and nursing care, as well as supervising their technology-dependent sibling; some also cared for other siblings in their parents' absence or when they were busy with the technology-dependent child. Two older siblings were able to drive, and contributed by taking their brothers and sisters to school and hospital appointments. One sibling was able to care fully for her sister so that her parent(s) could have short breaks. Some siblings felt that their considerable responsibilities in the home limited time for social activities outside the home.

In addition, around half of the siblings said that their attendance at school/college was often affected by the care regimes. For example, one 6-year-old was frequently late for school in the mornings because he had to wait for his father to take him. Another older sibling frequently took time off to take her brother to hospital appointments or look after other siblings; she felt that her examination results had been adversely affected by her absences. Others found it impossible to complete homework or examination revision if their technology-dependent brother or sister was unwell.

Concerns emerged about siblings' mental health and well-being. Seven siblings described the atmosphere at home as being tense and said they witnessed arguments between their parents, which they disliked. The atmosphere could be exacerbated by a lack of personal space within small, cramped homes. Three siblings said they were stressed and depressed by the unpredictable nature of life at home and the impact it had on them, especially at times of increased pressure, such as during school examinations and when their sibling was ill. Almost all siblings talked about the need for a holiday or break to lift their spirits (but not all families managed to go away on holiday). Five siblings who spent periods of time at a hospice appreciated the break from their responsibilities and enjoyed the social opportunities provided; all returned feeling better and said they wanted to go more often. Two siblings talked about the value of attending young carers' groups; although, in one case, the group had closed because of a lack of resources (but not clients).

As the main provider of technical care, parents, and particularly mothers, were affected in various ways by the rhythms and routines and time demands of technical care outlined above. For example, some parents reported difficulties combining caring and paid employment. As noted, 21 of the 30 fathers in the sample were in paid work compared to just eight of the 35 mothers. Eight of the fathers worked shifts and two had their own businesses; all but one of the mothers had part-time employment. These patterns of work generally suited families who combined working and caring. Of those parents who were not working, some were content with this situation and two were not medically fit to work. However, others reported that there were few employment opportunities that would fit with the children's patterns of usage of medical devices and general care needs, as well as allowing time off for medical appointments. Several parents had lost or changed their jobs because they were incompatible with the care needs of their children. The finances of families had been adversely affected where parents were unable to return to work and because of the increased costs of looking after a technology-dependent child with disabilities.

In addition, a large proportion of the families ($n = 22$) reported regular sleep disruption (getting up in the night at least 2 nights a week), and others reported periods of sleep disruption when the children were unwell ($n = 5$) or on the occasions when overnight carers were not provided ($n = 1$). Parents were getting up between one and 10 times a night (increasing when the child was unwell). One parent stayed awake five nights per week to monitor her child for when his airway needed suctioning. Parents' sleep was disrupted for various reasons. A major cause was dialysis machines and feeding pumps alarming when the tubes kinked or were blocked when the child laid on them; they could also be blocked by a build up of fibrin (dialysis) or the thickness of the liquid food (tube feeding). 'Flow error' alarms were also triggered when tube-feeding connections leaked, or when dialysis fluids were not draining properly. Parents also got up during the night in order to turn the children, check the machines, and to attend to the children when they were in pain or vomiting as a consequence of the dialysis or tube-feeding. For families whose child had short-term care away from the home, they reported that a major benefit was getting a good night's sleep.

Finally, the time demands of being a technical carer, and lack of formal or other informal technical carers who were available to provide care in the home, limited the opportunities many couples had to engage in social activities together and as a family. This had adversely affected some parents' previous relationships, but equally, some of the established couples in the study felt that their relationship was stronger as a result of their experiences. However, lone parents and some of the mothers from ethnic minority groups were particularly socially isolated, having little social life and no employment.

Discussion

Advances in the design of medical devices and the development of government policy promoting home-based care for children with disabilities have enabled more children to live a more normal life at home. While the children's health and quality of life has benefited from these advances, at the same time, the family has taken on the brunt of the care responsibilities required, and this has placed considerable time demands on families.

The present study has shown the technical care routines of technology-dependent children are complex and variable. Devices may be used constantly, regularly and/or on an ad hoc basis, depending on the child's medical needs. The time taken for devices to artificially perform particular functions of the body varies from that performed naturally and may be carried out during the day and/or at night. While some devices, such as suctioning machines, may be relatively easily

fitted into everyday life, when used occasionally through the day, other technologies, such as tube-feeding and dialysis, are more disruptive. In addition, because children often need assistance or supervision when they are using their device(s), they are not only 'technology-dependent', but also reliant on having a suitable trained carer present or easily accessible throughout the day and/or night, and in different settings. Since families, and particularly mothers, provided most of the technical care required for their children when they were not at school, this placed considerable time demands on them. The incompatibility of these 'technological', 'social' and 'natural' time frames creates difficulties for families, limiting their inclusion in school, work and social life in general.

There are two major implications for policy, practice and future research arising from this work. The first is for services to be developed in ways which reduce the time demands on families who care for technology-dependent children and that provide appropriate breaks from care for families. The present study found that, while children who went to school were generally assisted by trained carers where required when they were there, there was little such support for families outside school or when the children were off school because of illness. In common with previous work (Olsen & Maslin-Prothero 2001, Robinson *et al.* 2001, Jackson & Robinson 2003), the present study identified a lack of appropriate respite care in the home, especially in the evenings to give parents a break, and at night where required to enable parents to get a good night's sleep. Provision of care at these times would require additional resources since these are the most expensive times to provide staff.

The present study has also shown the value of breaks from care away from the home for the whole family. Where this was provided, it was greatly valued (not least because it enabled parents to get a good night's sleep) and families would have liked more of it. However, while a number of families in the sample used a children's hospice, they were recruited to the study through the hospice, so the proportion accessing this service is probably greater than in a general population of technology-dependent children.

Lack of coordination of services and multiple appointments with professionals and hospitals also exacerbated the time demands on families. Children reported missing significant amounts of school for such appointments, and mothers reported these as limiting opportunities for employment. Coordination of assessments and appointments between different professionals and agencies, through multi-agency care planning and a single key worker to liaise with and support the family, is badly needed (Townsend & Robinson 2000, Sloper *et al.* 2003).

Attention should also be given to the needs of siblings. Some families relied heavily on help from siblings and the siblings reported limitations to their education and social lives, and in some cases, effects on mental health. Although the *Framework for the Assessment of Children in Need and Their Families* (Department of Health 2000) takes a more holistic approach to assessment of need than previously, there is still an emphasis on the capacity of parents to provide care for the 'child in need', rather than on assessment of how services can support families in which parents provide care that is much over and above the norm (Sloper 2000, Roberts & Lawton 2001). In such families, assessment should encompass how these demands on parents impact on siblings, and what support is needed to reduce effects on siblings. In this sample, siblings appreciated the breaks provided for the whole family at children's hospices, and in two cases, they valued attendance at young carers' groups. More consideration should be given to the provision of resources for siblings, such as breaks from care and social opportunities.

Secondly, the present study also has implications for future research aimed at improving the design of medical devices. The transfer of technology from hospital to home has gathered pace over the past 25–30 years and designs have changed; indeed, some of the families had used different devices and commented positively on the design changes. However, it may be that technologies and associated devices could be further refined to help ensure that they are less disruptive of and more easily fitted into the rhythms and routines of everyday life. In particular, research on how the incidence of false alarms at night (related to tube connections failing, and kinking in dialysis and artificial feeding) could be reduced to minimise sleep disruption, and ensuing tiredness for parents and children, would be useful.

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