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**TECHNOLOGY AND TIME: HOME CARE REGIMES AND
TECHNOLOGY-DEPENDENT CHILDREN**

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EXECUTIVE SUMMARY

Advances in medical technologies have enabled more children with complex health care needs to survive and increasingly to be cared for at home with their families in the UK and other developed countries. 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). The present study adds to the small but growing literature on the experiences of this group by examining the social organisation and effects of the home care regimes for technology-dependent children and their families from a temporal perspective.

The experiences of 46 parents, 13 technology-dependent children, 15 siblings and one grandparent from 36 families were examined using a variety of qualitative methods, including semi-structured interviews and time-line drawings. All the children in the sample used (or had recently used) one or more medical devices on a daily basis. The devices were associated with artificial feeding, assisted ventilation, dialysis and other forms of technologically-based care.

The rhythms and routines of caring for a technology-dependent child were found to be variable across the sample and subject to change over time. Most of the children used their devices at regular times on a daily basis and also on a more irregular basis, as and when required; one child was constantly dependent on her ventilator for 24 hours a day. 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.

The technical care provided by parents involved a range of time-consuming activities, such as: assisting the child when he/she was using a device; monitoring the child by close visual observation and/or use of secondary devices; managing the equipment (for example, cleaning

and preparing it for use, ordering supplies and managing stocks); maintaining the interface between the device and the body (for example, care of entry and exit sites); accessing technical support from service providers; and providing technical support to others through training formal or informal carers or preparing equipment for use by other carers.

Sixteen families received support from service providers in the form of respite care away from the home (N=12) and/or paid care in the home (N=4 at night; N=7 during the day), but 20 received neither. Twelve children had support at nursery/school from carers who had been trained to use their devices. This support generally enabled the children to attend nursery/school, but 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 co-ordinating some technical care around school timetables.

While the patterns of usage and provision of technical care varied from family to family and over time, they were structured around different *natural*, *technological* and *social temporalities*. Thus, the timescales of some of the biological functions of the children's bodies were performed at different rates and times to those performed naturally. For example, peritoneal dialysis was performed for 10 hours a night, and tube-feeding was performed continuously overnight and/or at intervals during the day. In addition, the design of the devices varied in the extent to which they restricted children's and carers' movements in time and space when the former were using these machines, or where both the device and a technical carer had to be readily accessible in case they were needed.

At the same time, the regimes were to varying degrees orchestrated around the social schedules of the family and other institutional timetables. Thus, peritoneal dialysis was generally programmed to start at a time which allowed the requisite number of cycles to be completed in time for the child 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, respite care and babysitters were mainly employed on those nights when the children were not using their device. Families found it difficult to access technically competent carers on the nights when the devices were being used. As previously noted, many of the children also used devices on a more irregular and unpredictable basis which could not be scheduled and hence some families

found it difficult to commit themselves to regular activities such as paid work and to plan ahead for holidays.

In general, the children's use of medical devices was recognised to have benefited the child's health and quality of life and made lives easier for their parents. However, the parents, children and siblings highlighted various difficulties relating to the rhythms and routines of technical care. In common with previous work, the study found families experienced problems with the availability and scheduling of services and, in particular, a lack of appropriate respite care both away from the home and inside the home, especially in the evenings and overnight. Where out-of-home respite for the whole family was provided this service was greatly valued and families would have liked more of it. The study provided further evidence of the difficulties parents face in combining caring and working, as well as their experiences of sleep disruption. In addition, it has provided a relatively rare insight into the children's and siblings' own views on how the time-demands of technical care affect them and, for example, limit their participation at school and in social activities.

Overall, the study has added to understanding of the time of the technology-dependent body and associated patterns of technical care, showing how these place considerable time-demands on families and do not always fit with the institutional timetables of community care, work and school. More support in the form of carers able to provide technical care and increased availability of respite care, and better coordinated and more flexible institutional timetables, would help to reduce the time-demands of technical care on families and promote their social inclusion. Design improvements to devices could also help to limit disruption to sleep and other activities.

MAIN REPORT

Background

This study focuses on so called 'technology-dependent' children. The term refers to a vaguely defined group of children who use a medical technology (usually embodied in a medical device) that compensates for the partial failure or loss of a vital body function, and who require a technically skilled carer to prevent death or further disability (US Congress OTA 1987). Examples of such technologies include assisted ventilation, artificial nutrition, intravenous drug therapies, oxygen therapy and dialysis. Some children use a number of medical devices to support/replace the loss of more than one body function. Various secondary devices may also be used to monitor their condition.

Advances in medical technologies have enabled more children in the UK and other developed countries to survive and increasingly to be cared for at home with their families. 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). Recent research has begun to explore the experiences of this group (for example, see Horne, 1999; Kirk and Glendinning, 1998; Manns, 2000; Mohammed and McDowell, 1998; Noyes, 1999a, b; Noyes *et al.*, 1999; Townsley and Robinson, 2000; 1999a, b; Watson *et al.*, 2002), adding to previous work which has been carried out in North America (for example, Aday and Wegener, 1988; Doyle *et al.*, 1992; Petr *et al.*, 1995; Spalding and McKeever, 1998; Wilson *et al.*, 1998; see also reviews of the literature by Kirk 1998 and Murphy 2001). This literature has highlighted the complex and demanding nature of the care provided at home. While space does not allow a full review of the literature here, it has identified various problems with the availability, coordination and reliability of service provision (for example, Kirk and Glendinning, 1999; Watson *et al.*, 2002). It has also described the social, emotional and financial effects on the parents and, to a lesser extent, the children and their siblings (for example, Kirk, 1998; Noyes, 1999a, b; Noyes *et al.*, 1999; Wilson *et al.*, 1998). Negative effects include: exclusion from work, social isolation, loss of privacy in the home and sleep disruption. The present study adds to this work by delineating the rhythms and routines of care for technology-dependent children living at home in England and by examining how parents, children and siblings perceive these to affect their lives.

Policy and practice context

In the Health Act of 1999 the government acknowledged that there were major problems with the organisation and delivery of services, and that working arrangements across departments and agencies were inefficient. The Quality Protects programme, introduced in 1998, is the main initiative in a drive to improve children's social services. Objectives concerning services for disabled children are contained within this programme and aim to ensure that their needs are adequately assessed and met, enabling them to live with their families or in other appropriate settings in the community.

Since the present study commenced, health reforms have been implemented, such as the establishment of Primary Care Trusts (PCTs) that have started to work with social services, with the option under the Health Act 1999 of pooling budgets and jointly commissioning reconfigured services. A Children's National Service Framework (NSF) is currently being developed. This will set national standards for children's health and social care services and suggest interventions and service models that can be implemented to achieve these standards. These developments meant that the present study was undertaken at a time of great change and the findings have been able to feed into the development of the NSF.

A temporal perspective on innovative health technologies

The theoretical context for the study was developed from previous work exploring the ways in which social life is structured around multiple temporalities (Adam 1998, 1995, 1994/1990, 1992; Giddens, 1984; Gurvitch, 1964, Hagerstrand, 1978a, b; Horning, *et al.*, 1999; Nowotny, 1994; Young, 1988; Young and Schuller, 1988). In this literature, various concepts of time and rhythms of natural and social life have been distinguished, such as 'clock time', 'linear and cyclical time', 'public and private time' and 'circadian rhythms', and we draw on and add to this conceptual framework in this study. The present study was also informed by other more empirical research on the social organisation of time in hospitals and other care settings (Brown and Brooks, 2002; Goffman, 1968; Lee and Piachaud, 1992; Roth, 1963; Zerubavel, 1990, 1981, 1979), and studies which have explored patients' and family's experiences of illness and care from a temporal perspective (for example, Daly, 1996; Todd and Shearn, 1996; McKie *et al.*, 2002).

Drawing on the multi-dimensional view of time developed in the aforementioned literature, we examine the *temporal organisation* of care for technology-dependent children living at home and the *time consequences* for the children and their families. What are the rhythms and routines of caring for a technology-dependent child? How are these regimes structured? To what extent do they fit with the ‘timescapes’ (Adam, 1998) of school, work and everyday life in general? What are the benefits and drawbacks of existing regimes? And what are the implications for policy and practice concerning this group?

Objectives

The overall aim of the study was to examine the temporal organisation and time consequences of the care regimes for technology-dependent children and their families. It had three main objectives:

- to describe the daily, weekly and monthly patterns of technologically-based home care provided by the children’s families and other formal care providers;
- to examine the impact of these care regimes on the children and families’ everyday lives, including the extent to which these regimes affect other areas of the families’ lives (including school, work and leisure time);
- to identify the implications for policy and practice relating to health and social care provision and the interface of such provision with education, employment and leisure opportunities for this group.

Methods

The study was designed to examine the experiences of 36 families of technology-dependent children using qualitative methods. A sample of families with children who met the following criteria and who lived in three areas of the north of England was recruited via hospitals, a hospice, the Family Fund Trust and a previous study:

- aged up to 18;
- lived at home;
- relied on one or more medical devices on a daily basis;
- used any of the following devices or similar: ventilators, feeding pumps, dialysis machines, oxygen therapy, tracheostomies and suction machines.

A purposive sampling strategy was used in order to minimally include the following in the final sample and among those interviewed:

- six single-parent families;
- six families from minority ethnic backgrounds;
- interviews with 12 technology-dependent children;
- interviews with 12 siblings.

Various qualitative methods were used to obtain the perspectives of the children, their siblings, and their parents, including: face-to-face semi-structured interviews, time-line drawings and written/photographic diaries kept over a week. All the interviews with family members took place in the family home. 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). In these cases, notes were taken. Interviews were transcribed in full (where recorded). Transcripts and notes of interviews were anonymised and entered on to computer for analysis using Atlas.Ti. 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. The analysis was carried out using the 'framework approach' (Ritchie and Spencer 1995).

Ethical considerations

Ethical approval for the study was obtained from four NHS LRECs. Consent was obtained from all participants who took part in the study. In the case of children under 16, consent was obtained from both the child and a parent.

Results

This report of the findings is structured around the stated aims and objectives of the study. Given the limitations on space, we focus on the main themes arising from the analysis and will be expanding on these in related publications (in preparation). In the section on the time consequences of care we concentrate on the interviewee's views on their own experiences, rather than those of other family members which will be covered in other reports.

The sample

Thirty-six families took part in the study, including eight families from ethnic minorities and seven single-parent families. Seventy-five members of these families were interviewed, including 46 parents, 13 technology-dependent children, 15 siblings, and one grandparent. The gender and age profile of the interviewees is shown in Figure 1 (see appendix).

The gender balance of the parents who were interviewed reflects the fact that the children's mothers tended to be the main carers. The proportion of technology-dependent children who were interviewed (N=13/38) partly reflected the age of the children: the average age of all the children was 7.8 and hence many were too young to take part, although some young children were very mature for their age and wanted to be included. Some children were also unable to take part because of their medical condition, although efforts were made to involve those who wanted to and could do so with assistance. Fifteen siblings were interviewed, although a number of those still living at home chose not to be involved in the study. Some of the siblings were too young to take part; others may have not regarded themselves as being involved in the 'care' of the technology-dependent child, although in the study information sheets we tried to appeal to all siblings regardless of whether or not they were 'carers'.

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 Figure 2).

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 population 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 in the sample 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 £10k, while four families had incomes of over £30k. All the families received Disability Living Allowance and several received additional benefits including Invalid Care Allowance, Income Support and Housing Benefit. Twenty of the families owned their own homes; the remainder lived in rented accommodation.

The children had various and, in several cases, multiple disabilities relating to their medical conditions. Their primary and secondary medical diagnoses are summarised in Figure 3. 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 types of devices used and the number each child used (see Figures 4 and 5). Many of the children (N=32) in the sample were also on complex medication regimens, including three whose parents gave intravenous drugs (IVs) at home. Thirty children attended a special or mainstream school or nursery while three were home educated; five did not go to school or nursery.

Overall, the sample targets were met and an appropriately diverse sample of families and interviewees - in terms of demographic, social, medical and technological characteristics - was obtained, although the views of fathers were relatively under-represented.

The temporal organisation of technical care

The rhythms and routines of caring for a technology-dependent child were found to be variable across the sample and subject to change over time. Here we describe the patterns of usage of devices, and provision of informal and formal technical care.

a) Patterns of usage of devices

All of the children used (or 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. One child used a ventilator *constantly*, for 24 hours a day. 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 ten 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 (for example, suctioning machines) to a few times a year in the event of a medical crisis (for example, oxygen therapy).

The patterns of usage shifted over time with changes in the children's 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 hospitalized within the last 12 months because of illness or for procedures to be undertaken.

b) Patterns of informal 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. In this study we focused mainly on the technical care that was provided as part of the overall care regime.

The provision of technical care involved a range of activities, namely:

- assisting the child when he/she was using a device;
- monitoring the child by close visual observation and/or use of secondary devices;
- managing the equipment (for example, cleaning and preparing it for use, ordering supplies and managing stocks);
- maintaining the interface between the device and the body (for example, 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);
- 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.

c) Patterns of formal technical care

Formal technical care was provided in a variety of settings, including schools/nurseries, the family home, and respite care in hospices and family placement schemes.

Twelve children received technical care at school/nursery from individual members of staff (such as 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/ 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 co-ordinating some technical care around school timetables (for example, the timing of a feed at lunchtime).

At home, formal technical care was provided for eight families by 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 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. Only seven families had packages of care where hours of paid care were allocated during the day. This ranged from one hour a week to eight 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 on an evening, either because the service was not available, or because it had to be booked well in advance - which parents were reluctant to do as 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. The remaining formal technical care comprised of occasional home visits, particularly when the children were first discharged or when training in the use of (new) devices was required, or when specialist technical tasks (such as IVs) were being carried out.

Twelve families had received respite care away from the home over the last year for between one weekend a year and two weeks a year plus one weekend a month; four children stayed with relatives occasionally through the year. The remaining 20 families received no respite care away from the home. During respite 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 respite through a family placement scheme, where these carers had been trained to provide the technical care required while the parents had a break.

Parents from two families reported problems in accessing staff familiar with and competent in the use of the children's devices in general practices and local hospitals. Some parents also

reported difficulties contacting hospital staff by phone out of hours for help with problems with equipment at night (dialysis and tube-feeding were often conducted overnight). One parent had used a 24-hour help line run by a manufacturer of dialysis machines and found this helpful.

Twenty-seven families also 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 organized, 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 (for example, when a child is at home unwell and looked after by a single-parent).

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 in the use of the devices, and concerns about the quality of the care provided, usually based on problems previously experienced.

While the above patterns of usage and provision of technical care varied from family to family and over time, they appeared to be structured around different *natural, technological and social temporalities*. In technology-dependent children, some of the functions of their bodies were performed artificially, with the aid of their medical devices, while others were carried out naturally. The timescales of these artificial processes varied in the extent to which they 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 this study tended to work at different timescales 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.

The varying degrees of contrast between the natural and artificial rhythms of the technology-dependent body are illustrated by the technologies of dialysis, tube-feeding and ventilation. The children using dialysis machines (N=8) all received 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 three days a week over three hours, and/or continuous ambulatory peritoneal dialysis (CAPD) where fluid constantly dwelled in the body and was exchanged in three to four bag changes during the day taking around 30 minutes. Of the children who received artificial nutrition (N=22), some were totally dependent on this while others also fed normally. Some children were fed by tube at intervals of up to every two hours a day and/or continuously overnight for 10-12 hours a night for between five and seven 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 had assistance at night while sleeping or when unwell.

These artificial processes were often programmed to reflect the needs and characteristics of the children (for example, 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 orchestrated around the social schedules of the family and other institutional timetables. Thus, peritoneal dialysis was generally programmed to start at a time which allowed the requisite number of cycles to be completed in time for the child 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, respite care and babysitters were mainly employed on those nights when the children were not using their device 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.

In the next section, we consider the ways in which the temporal organisation of care around these natural, technological and social temporal imperatives impacted on the families.

The time-consequences of technical care

In general, the children's use of medical devices was recognised to have benefited the child's health and quality of life and made lives easier for their parents. However, as one parent said, it was not an 'easy' life. In this section we examine the self-perceptions of the children, siblings and parents who were interviewed on how the rhythms and routines of care affected their own lives.

a) For technology-dependent children

In the interviews with the technology-dependent children, their perspectives on using medical devices and receiving technical care were explored with the aid of a time-line drawing of self-defined 'good' and 'bad' days. 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 device 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, operations or tests. The children talked about what the care routines involved and how they affected their everyday lives. Here we focus on three issues: risk and responsibility, school, and social life.

Eleven of 13 children interviewed were aware to some extent that their daily lives involved a degree of 'risk' that was over and above that experienced by non technology-dependent children. This meant that they required (although did not always want) much closer supervision from their families or carers who spent a lot of time with them. Children also described the steps parents took to minimize the risk of, for example, a life threatening infection. Four older children had become responsible for managing aspects of their own care. For example, one 12 year old had been taught and assessed as competent to unplug herself from her feeding pump, take her own medications, operate her nebuliser and care for her gastrostomy stoma. This afforded greater freedom to control and mediate her own regime of care around activities that she enjoyed.

All but one child 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 device(s) and health needs. The day started earlier (for

some around 5.00am) and children described the ‘race’ to get everything done (as did several parents). Two children said that the school bus picked them up too 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 where possible therapies were coordinated around key lessons; and having difficulties fitting their homework around medical routines (N=2). Almost all children said they got very tired on school days, which for some was exacerbated 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.

b) For parents

As the main provider of technical care, parents, and particularly mothers, were affected in various ways by the patterns of usage and provision of care outlined above. Here we focus on three main areas of impact: work/finance, sleep and social life/relationships.

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 their child’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 disabled and technology-dependent child.

A large proportion of the families (N=22/36) reported regular sleep disruption (getting up in the night at least two 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. For families who had respite care away from the home, a major benefit was getting a good nights sleep.

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. Some parents and children also got up early (from 5.00am), especially on school days, in order to perform aspects of technical care before the child went to school.

The time-demands of being a technical carer, and lack of formal or other informal technical carers who were available to provide routine or respite 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 families were particularly socially isolated, having little social life and no employment.

c) For siblings

Living in a family with a sibling dependent on technology conferred a different type of childhood for brothers and sisters whereby the focus and routines were fixed around the child using the technology. Descriptions of good days and bad days mirrored those of the technology-dependent children. Three areas of impact are focused on here: roles and responsibility, school, and sibling health.

Within the home, siblings described the divisions of labour that dictated their individual roles and responsibilities. Roles and responsibilities varied between families, changed in nature over time, and increased with age. For example, most children started off with considerable domestic responsibilities (cleaning, washing and cooking) and some progressed to taking on aspects of technical and nursing care, as well as monitoring, supervising or parenting 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 etc. One sibling was able to care fully for her sister (which conferred a very high level of responsibility) so that her parent(s) could have short breaks. Almost all the 15 siblings were acutely aware of the risks of something untoward happening with their technology-dependent sibling and their responsibilities concerning keeping their sibling safe and well. They also felt that their considerable responsibilities in the home limited time for social activities outside the home.

Around half of the siblings said that their attendance at school/college was often affected by the care regimes. For example, one six year old was frequently late for school in the mornings as 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 they witnessed arguments between their parents which they disliked. The atmosphere could be exacerbated by 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 due to lack of resources (but not clients).

Policy implications

Although the children's use of medical devices either improved or maintained their health and quality of life in many ways, there were also negative effects on their and their families' participation in school, employment, social and family life. Lack of sleep, due to the need to care for the child and attend to devices during the night, was a common and serious problem for parents. Many of these effects were due, not just to the use of the device, but to the lack of well-coordinated and skilled support from services. While the population of children who have complex medical needs is growing and many of these children are now cared for at home (Glenndinning, *et al.*, 2001; Kirk, 1998), there are few non-parent carers available who are trained and insured to provide this care (Jackson and Robinson 2003) and thus parents, and in some cases siblings, bear the brunt of care.

Demand for respite services for disabled children is greater than supply and many areas have long waiting lists; provision for children with complex needs is particularly lacking (Robinson, *et al.*, 2001). Many families in this study (N=20) had no overnight or daytime respite support, either from in-home or out-of-home services. As a result, parents' social lives and employment opportunities were limited, fatigue due to frequent sleep disruption was common, and some relied heavily on siblings for domestic tasks and/or care of the child.

A number of families in the sample used a children's hospice for respite care away from the home. 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. The hospice service was highly valued by parents, children and siblings, but is not available to all children. A particular benefit for parents was that it enabled them to have a good night's sleep and there is clearly a need for greater provision.

Children's hospices are voluntary bodies, depending upon fundraising, and are unevenly scattered throughout the country. They are often heavily subscribed and have to limit eligibility criteria and the amount of service they are able to provide for any one family (Jackson and Robinson, 2003). Greater government recognition and funding of the service they provide is needed, along with an increase in the both in- and out-of-home respite services

provided by the statutory sector. Currently, most respite services have to be pre-booked. Parents found this difficult because of the unpredictability of the child's condition. Greater flexibility and more responsive provision is needed (Olsen and Maslin-Prothero, 2001). Such increases in provision require investment in training to ensure that staff and respite carers are competent in providing technical care.

Lack of co-ordination of services and multiple appointments with professionals and hospitals also consumed time. 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 (Sloper, *et al.* 2003; Townsley and Robinson, 2000).

Better organisation and support services for technical care could also allow more time for children to take part in 'fun' and social activities. This requires recognition that children's participation in education, play and social activities is a priority for their development and well-being, and greater attention being given to fitting technical care and medical appointments into these time cycles.

Attention should also be given to the needs of siblings. Some families relied heavily on help from siblings and 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 (Department of Health, *et al.*, 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 which is much over and above the norm (Roberts and 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. When parents' and professionals' main focus is on the needs of a severely disabled or seriously ill child, siblings' needs are often neglected (Sloper, 2000). More consideration should be given to provision of resources for siblings, such as breaks from care and social opportunities.

Finally, two main concerns were raised in relation to operation of the technical devices. First, the need for easily accessible support when problems arose with equipment. Clear plans of access to such support with defined response times are required. These should be negotiated before the child goes home from hospital, copied to parents and updated regularly. Secondly, the contribution of factors inherent to the devices, particularly avoidable alarms going off during the night, to sleep disruption and ensuing daytime tiredness for children and parents. The transfer of technology from hospital to home has gathered pace over the last 25-30 years and designs have changed; indeed, some of the families had used different devices and commented on the design changes. However, it may be that further refinement of technologies and their supporting services could alleviate some of the problems with tube connections and kinking.

Contribution to knowledge

In conclusion, the findings of the study have added to the small but growing literature on the experiences of technology-dependent children and their families in the UK. Like other studies, it has shown that there are problems with the availability and scheduling of services and, in particular, a lack of appropriate respite care both away from the home and inside the home especially in the evenings and overnight. Where out-of-home respite for the whole family was provided this service was greatly valued and families would have liked more of it. The study also provided further evidence of the difficulties parents face in combining caring and working, as well as their experiences of sleep disruption. In addition, it has provided a relatively rare insight into the children's and siblings' own views on how the time-demands of technical care affect them and, for example, limit their participation at school and in social activities.

Overall, the study has added to understanding of the time of the technology-dependent body and associated patterns of technical care, showing how these place considerable time-demands on families and do not always fit with the institutional timetables of community care, work and school. More support in the form of carers able to provide technical care and increased availability of respite care, and better coordinated and more flexible institutional timetables, would help to reduce the time-demands of technical care on families and promote their social inclusion. Design improvements to devices could also help to limit disruption to sleep and other activities.

Activities

Noyes J, Heaton J, Sloper P, Shah R (2002) 'Methods for involving technology-dependent children and their families in the study of technology and time'. Poster presentation, Sleep Disorders in Infancy and Childhood annual conference, Rancho Mirage, USA (17-19 January).

Noyes J, Heaton J, Sloper P, Shah R (2001) 'Methods for involving technology-dependent children and their families in the study of technology and time'. Oral presentation, Society for Social Studies of Science conference: Fashioning the Future: Science, Technology and Visions of Progress, Cambridge, USA (1-4 November).

Noyes J, Heaton J, Sloper P, Shah R (2001) 'Methods for involving technology-dependent children and their families in the study of technology and time'. Poster presentation, BSA Medical Sociology Group conference, York, UK (21-23 September).

Outputs

We are working on a number of publications exploring particular aspects of the study. These include papers for policy makers, practitioners and academics on:

- the sleep disruption experienced by families;
- the nature of 'technical care' and the experiences of those who provide and receive it;
- the concepts of natural, social and technological time and how these are exemplified by the experiences of technology-dependent children and their families;
- families perceptions of risks associated with caring for technology-dependent children.

We also hope to publish a paper exploring the methodological aspects of the study.

Other dissemination includes a presentation at an IHT programme initiated joint workshop on 'Ageing, Health Technologies and the Built Environment' in Sheffield and an IHT event at the ESRC Social Science week in York. Other abstracts are being prepared for the forthcoming BSA Medical Sociology conference.

A summary of the results of the study will also be disseminated through an issue of SPRU's *Research Works*. This will be sent to various organisations and individuals, including: the

families and staff who helped with the study; members of the project's advisory group; NHS acute Trusts and Primary Care Trusts; the Department of Health; and relevant voluntary organisations, such as the Association for Children with Life-threatening or Terminal conditions (ACT) and the Association of Children's Hospices.

Impacts

The staff who helped us to recruit families are very interested in the study and its implications for their practice. We will be feeding back the results through reports and in person. Tricia Sloper (one of the research team) is a member of, and Francine Bates (one of our Advisory Group) is Chair of, the Children's National Service Framework External Working Group on Disabled Children. This will ensure that the results of this work are fed into the development of the NSF. Another of the researchers (Jane Noyes) is also a member of a UK paediatric long-term ventilation working party and is contributing to a national campaign concerning ventilator-dependent children coordinated by the charity Barnado's. Other members of our Advisory Group (who include representatives from health, social, voluntary and commercial services; the Medical Devices Agency; parent representatives; and academics) will also be able to act on the findings, inform relevant pressure groups of the findings, or follow issues up through further research. Interest in the work has also been shown by Dr Patricia McKeever in Canada which may lead to further collaboration in this area.

Future research priorities

This study has highlighted a need for further research on the following:

- fathers' perspectives on the issues explored;
- the design of medical devices and, in particular, the temporal properties of the devices (for example, how the programming and operation of devices fits with everyday life; the portability and use of machines away from the home; how the noise of machine and frequency of alarms due to children lying on tubes and faults can be reduced to minimise sleep disruption for families);
- the effects on siblings (for example, educational achievement of siblings compared to children from families without a child with complex needs; mental health needs of siblings).

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Appendix

Figure 1: Gender and age characteristics of interviewees/total sample population

	<i>Female</i>	<i>Male</i>	<i>Average (age/range)</i>
Parents			
Interviewees N=46	34	12	37.3 years (22-52)
Sample N=65	35	30	37.3 years (22-52)
TD children			
Interviewees N=13	5	8	10.1 years (4-19)
Sample N=38	22	16	11 months – 19 years
Siblings*			
Interviewees N=15	7	8	14.3 years (7-22)
Sample N=54	15	39	(2-27)
Grandparents			
Interviewees N=1	1	0	
Total			
Interviewees N=75			
Sample N=158			

*includes only siblings living at home.

Figure 2: Number of children per family*

<i>Total number of children per family (living at home)</i>	<i>Number of families (N=36)</i>
One child (i.e. the technology-dependent child)	9
Two children	15
Three children	6
Four children	2
Five+ children	4

* one family had three technology-dependent children

Figure 3: Primary and secondary diagnoses*#

	<i>Primary</i>	<i>Secondary</i>	<i>Total</i>
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

* with thanks to Dr Preece for help with this classification

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

Figure 4: Medical devices used by the children in the sample (N=38)

<i>Device</i>	<i>Used by N children</i>
Feeding pump/bolus	21
Suction machine	9
Nebuliser	8
Dialysis machine	8
Ventilator	6
Tracheostomy	5
IVs	4
Volumatic spacer	4
Oxygen machine	4
NG tube	3
BP machine	3
SATS monitor	2
Humidification unit	2
Inhaler	2
Others (including: colostomy; cough machine; PEP mask; portacath)	1

Figure 5: Number of devices used per child (N=36)

<i>Number of devices</i>	<i>Number of children</i>
1	11
2	9
3	5
4	6
5+	5