



Technology and Time: Home Care Regimes and Technology-dependent Children

KEY FINDINGS

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COUNCIL

In the UK, 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. This study focussed on the experiences of 36 families of technology-dependent children who used one or more medical devices (such as feeding pumps and dialysis machines) on a daily basis. We examined what the carer routines relating to the devices involved (technical care) and how they impacted on the children, their parents and siblings. The key findings were:

RESEARCH FINDINGS

- Routines relating to the devices varied from family to family depending on what types of devices were used, the children's age and medical diagnoses, and fluctuations in their health status.
- Family routines were variously structured around the children's use of the devices, monitoring of the children's condition, the time taken for the devices to perform their function, and school or work schedules.
- Technical care was mainly provided by the children's parents, particularly mothers, with varying levels of involvement from other family members and service providers.
- Some children relied on technical care from trained staff to enable them to attend nursery or school.
- One-third of the families had help from services in the home and a third received respite care away from the home where the child or the whole family were looked after; however, over half the sample received neither of these services.
- 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 the children's medical condition was generally more stable. However, families highlighted problems with: availability of appropriate respite care both away from the home and inside the home; difficulties combining caring and working; sleep disruption; social isolation; and children's and siblings' relatively limited or disrupted participation at school and in social activities.

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Who are 'technology-dependent' children?

'Technology-dependent' children is the term used to describe those children and young people who use one or more medical devices to compensate for the partial failure or loss of a vital body function, and who also require a technically skilled carer to look after them. Such devices include dialysis machines, ventilators and feeding pumps.

In 2001, it was estimated that there could be up to 6000 technology-dependent children living in the community in the UK. The present study adds to previous research on this group by examining what the care routines involve and how the parents, children and siblings were affected by them.

Care routines

A range of devices was used by the 38 technology-dependent children in the sample (see Table 1). Over two-thirds used more than one device (see Table 2). A few children used their devices 24 hours a day, while most used them at regular intervals during the day and night, and as and when required. Patterns of usage changed over time as the children became more or less dependent on the devices, and as they physically grew. Use of devices tended to increase when the children were ill.

Table 1
Medical devices used by the children in the sample

Device	Used by N children
Feeding pump/bolus	21
Suction machine	9
Nebuliser	8
Dialysis machine	8
Ventilator	6
Tracheostomy	5
Intravenous (IV) therapies	4
Volumatic spacer	4
Oxygen machine	4
Others (including naso-gastric tube, humidification unit, inhaler, colostomy; cough machine; portacath)	13

Table 2
Number of devices used per child

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

Family routines were variously structured around the children's use of the devices, the time taken for the devices to perform their function, and monitoring of the children's condition. For example, the eight children on dialysis all received peritoneal dialysis at home for 9-10 hours a night for 6-7 nights a week. By contrast, the 22 children who received artificial nutrition were fed at intervals of up to two hours every day and/or continuously overnight.

The provision of technical care involved following medical protocols and operating programmes for devices that were set up according to the children's medical diagnoses, needs and characteristics (including their body size and tolerance to the rates at which fluids and foods could be pumped through the body). At the same time, these processes were to varying degrees adapted to fit around the social schedules of the family, including school and work, and also the schedules of services families received. Hence children were unplugged from feeding pumps in time to get up for school and this schedule could be adjusted at weekends and non-school days. Some children were also given medical permission to suspend being tube-fed while they were away on holiday.

Technical care

Technical care was mainly provided by the children's parents, particularly mothers, with varying levels of involvement from other family members, including siblings, and service providers. Parents and siblings provided other types of personal and practical care for the children; siblings also helped those performing technical care by doing household chores. Some of the young people interviewed took responsibility for their medical device.

Parents provided technical care in the home and in other places where the children spent time, such as when visiting friends and relatives, and when on day trips and holidays. They also often continued to provide technical care while their children were in hospital.

Technical care at school

Thirty children attended a special or mainstream school or nursery, three were home educated and five did not go to school or nursery. Twelve children relied on technical support from trained carers while they were there. This support enabled them to attend, but they sometimes missed school when their carers were not available, adding to the time they missed through being off ill or attending medical appointments.

Respite care in the home

One-third of families had help from services in the home. Seven families received help during the day from services. This ranged from between one hour a week to eight hours a day. The evenings were the most difficult time to obtain this help and it did not always include looking after siblings.

Four families had a trained carer during the night (for two nights a week in two cases, and seven nights a week in the others). However, this service was not always dependable or sufficient.

Respite care away from the home

Twenty families received no respite care away from the home. A third received respite care where either the child or the whole family were looked after. These breaks ranged from a minimum of one weekend a year through to a maximum of two weeks a year plus one weekend a month. The family model of respite care provided by a hospice for eight families in the sample was very highly valued. Family placement schemes, where just the child stayed, were used by three families and

were also valued by them; however, this model of respite was not for all families in the sample, some of whom did not want to be parted from their children.

Effects on families

The children's use of medical devices was recognised to have benefited the children's health and quality of life, and made lives easier for their parents. However, families highlighted problems, detailed in Box 1, which affected the children's and families' well-being.

Box 1: Problems experienced by children and families

- Lack of availability of appropriate respite care both away from the home and inside the home, especially in the evening and overnight.
- Difficulties combining caring and working.
- Sleep disruption.
- Social isolation, particularly for single parents and mothers from minority ethnic groups.
- Children's and siblings' relatively limited or disrupted participation at school and in social activities.

Implications

As one of the parents who took part in the study said, her child's use of a medical device had made their lives 'easier', but it was not an 'easy' life for them. The priority for health and social care policymakers and providers is to ease the time-demands of caring for a technology-dependent child by providing more technically-trained carers and suitable respite care for families. Better co-ordinated and more flexible organisational timetables would also help to promote parents', children's and siblings' social inclusion in work, school and other social activities.

The key recommendations of the study are that:

- Support is needed for parents and particularly single mothers and mothers from minority ethnic groups, who were found to be particularly socially isolated and coping with little, if any, support from service providers or extended family networks.

More trained carers are needed to provide technical care in schools, at home and to accompany some families when they go away on holiday.

- There is a serious shortage of suitable respite care for these families both within and away from the home. Respite provision for the whole family away from the home was very highly valued by those children, siblings and parents who received it. It is also more likely to appeal to parents who need respite but do not wish to be parted from their children. There is a need to expand this model of respite care to promote access for more families on a more frequent basis.
- Hospital appointments, work schedules and school timetables could be arranged and co-ordinated to better reflect the children's care routines and minimise disruption to parents, children and siblings where possible.
- Siblings were found to be both involved in and affected by the care of technology-dependent children. Assessment of children and families needs should encompass the circumstances of and impact on siblings and consider what support is needed for them.
- There may be scope for improving the design of medical devices to minimise sleep disruption caused by alarms triggered by machine faults, including

tubes from feeding and dialysis machines becoming disconnected and blocked when laid on.

- Future research might usefully consider issues such as: the involvement in and effects of caring for a technology-dependent child on fathers, including single-parents; an international comparison of the organisation and delivery of services for this group; and the costs to families of caring for a technology-dependent child at home.

About the Project

The project was funded as part of the ESRC Innovative Health Technologies research programme and carried out between January 2001 and December 2002.

Families were recruited via hospitals, a hospice, the Family Fund and a previous study. A purposive sampling strategy was used in order to ensure single parents and ethnic minorities were included in the sample, and that a number of children and siblings were among those interviewed. The final sample of 36 families included 38 technology-dependent children who used one or more devices on a daily basis (or had done so recently). A total of 75 family members were interviewed, including 46 parents, 13 technology-dependent children, 15 siblings and one grandparent. Data for the study were collected through face-to-face semi-structured interviews; a structured questionnaire, covering socio-demographic characteristics of the family, types of technologies used and services used, completed at the interview; time-line drawings and self-completed diaries. Additional contextual information was collected from interviews with 13 professionals involved in the provision of services for this group.

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