MANCH**E**ST**E**R
1824

Young People's Experiences of Living with Medical Technology

Susan Kirk

As a result of medical advances there are more children and young people with complex and continuing health care needs who need the support of medical technology. This study focussed on the experiences of 28 young people who were living with a range of different technologies and examined what this meant for their day-to-day lives and their future aspirations. In addition the study explored how young people experienced different transitions and used support networks.

Key Findings

- Medical technology was seen as both an enabling and disabling presence in young people's lives. Although the devices structured their lives, most young people enjoyed the same activities and had the same aspirations as their non-disabled peers.

- Young people valued schools in which they were supported following absences and where they were able to incorporate therapy regimens into school routines without making them feel different. They were unhappy when they were prevented from going on school trips because of their condition and medical technology needs.

- Parents were the key providers of emotional and practical support for young people and were the link with services. Friends were an important part of young people's lives both socially and in terms of providing emotional and practical support.

- Young people felt that information was important in understanding their condition and its treatment. However, they did not always receive information they could understand or which included negative aspects of treatments. Parents played an important role in interpreting information given by professionals. In general young people did not feel involved in consultations with professionals.

- Support worker provision could be fragmented and lack continuity unless families were using direct payments to provide more personalised support.

- Young people with complex healthcare needs experience multiple, concurrent transitions. However, young people and parents reported little preparation and planning for these transitions and for some young people there was no equivalent adult service.

Background

Medical advances have led to the emergence of a group of children and young people who need the ongoing support of medical technology for their survival and wellbeing. Over the last decade in the United Kingdom these children have been increasingly cared for at home rather than spending all or large parts of their lives in hospital. The young people in this group differ in terms of how often they need to use technology; whether they have cognitive and/or sensory impairments; whether their need for technology is temporary or lifelong and the underlying reason for needing technology (e.g. accident, prematurity, congenital impairment, long-term health condition). Some young people need high levels of support that require intervention from a number of agencies and the provision of complex home support packages. A number of studies have examined how parents experience caring for a technology-assisted child and their views on the support they receive from services. However, the experiences and perspectives of young people themselves have been overlooked. This study addresses this gap in knowledge.

Findings

The 28 young people in the sample were aged between 8 and 19 years old. The medical technologies on which the study focused are presented in Table 1. Thirteen young people used more than one of these devices. In addition to these technologies, the young people had other medical devices in their lives, such as suction machines, nebulisers, 'coughing machines' as well as equipment such as wheelchairs, hoists and standing frames. The medical technology was only one element of managing and living with a long-term condition or with disability. However, its presence created additional challenges and needs.

How young people view medical technology

The young people had a good understanding of why they needed the support of technology as a result of their parent's explanations. They felt that information was important in understanding their condition and its treatment. They saw the medical technology as having both positive and negative influences on their lives. Some young people recognised that the medical technology had saved their lives. It was seen as improving their health: some now experienced fewer infections, and/or had gained weight and had fewer hospital admissions. Gastrostomies were felt to have relieved the stress of oral feeding for both young people and parents, improving both relationships and social opportunities. Some young people described how changing to newer technologies had enabled them to engage in social activities that would have been impossible with older forms of devices.

Young people also described the negative aspects of needing medical technology. Their sleep (and sometimes their siblings') could be disrupted by machine alarms, the background noise of equipment, discomfort from face- masks and leaking feeds. A significant amount of time could be taken up by therapy routines, particularly at the beginning and the end of the day. Consequently therapy regimens structured the young people's daily lives. Although they and their families made adaptations to them in order to engage in social activities, the technology could be a barrier to taking part in social activities and going out with friends. Parent proxies described difficulties in finding a private place to tube feed their children outside the home. Going on holiday was difficult because of the amount of equipment (and in some cases home care teams) needed to accompany families. Some young people described physical discomfort caused by devices and their dislike of the sensation of it in their body. For a small number of young people the need for particular devices indicated that their health was deteriorating.

The technologies that the young people needed varied in terms of how visible they were to other people. Some were immediately apparent while others only became visible in certain situations (e.g. changing for PE, having a feed at school). Young people differed in whether they preferred to keep the technology a secret or be open about it. Parents appeared to be influential in how they made these decisions. Both young people and parents had developed their own ways of dealing with the visibility of the technology and people's reactions to it.

Ordinary Lives

For many young people the technology was a background issue for them. They had become used to the sensation of the devices and therapies over time and in some ways saw the technology as part of them and their lives. Young people had the same aspirations and enjoyed the same social activities and pastimes as their non-disabled peers. They described enjoying a wide-range of activities such as socialising with their friends and family, sports, computers and gaming. In the future they wanted to continue their education, have 'good' jobs and live happy, fulfilling lives independently from their families. Parent proxies similarly spoke about the enjoyment their children obtained from social activities and their desire for them to have 'ordinary' lives within their local communities. The use of direct payments to employ personal assistants was described as enabling young disabled people to have an independent social life. 'Nights off'

therapies helped young people take part in social activities such as staying overnight at friends' houses. Both young people and parents displayed a determination to not let the condition or technology prevent them from living a full life.

School, College and Work

School was an important part of young people's lives. They described how they liked the opportunities it provided for socialising with friends and particular subjects they enjoyed. They valued teachers and other staff who were supportive and who understood and made allowances for their needs - without being overprotective and making them feel different. It was important that there were facilities at school, college and work where young people could look after their healthcare needs (for example, storage space for equipment, feeds and medications; space to give feeds/infusions with privacy).

School absences due to hospital appointments and illness could disrupt friendships and affect educational achievement. Some young people felt that they had not been given additional support to make up for lost time. In addition young people with high support needs could miss school if their support worker was on sick leave. Their need for technology could lead to their exclusion from school activities. Some young people said that they had not been allowed to go on school trips due to the medical technology. A number of parents with children in special schools reported that children who were tube fed could be excluded from mealtimes and fed separately. For some young people moving from primary school to secondary school was a difficult adjustment to make.

Support Networks

Social support networks were very important to young people. Parents were seen as important sources of emotional and practical support and in encouraging independence. They negotiated the service system on their child's behalf – interpreting information and negotiating service provision. Friends were a significant part of young people's lives. As well as being people they socialised with, friends were seen as providing both practical and emotional support to them both at school and if they were living independently. Young people kept in touch with friends not only by face-to-face contact but via the Internet. However, for many of the young people in special education their friendships appeared to centre on the school day and they had fewer opportunities to socialise with peers outside school. When living independently friends were seen as an important source of practical support.

Just over half of the young people (n=15) had support workers helping them at school and/or at home. There was a range in the amount and type of support they provided and some young people had support workers who only helped them. However, other young people were supported by teams of workers who supported a number of families in a locality, or they had different support workers provided by different organisations. This made continuity difficult and young people spoke of never knowing who was coming to help them. Some families were using direct payments as a means of obtaining more personalised support. Parents saw this an important way for young people to engage in social activities and have an independent social life. Being supported by young support workers enabled them 'to do young people's stuff'. However,

support workers could mean that young people were almost continually in the presence of adults. Some felt a loss of personal and family privacy as support workers could be present not only in the daytime but whilst they slept and accompanied them on family holidays.

Young people spoke little about professional support unless they had transferred to adult services. This may have been because parents were the main points of contact for professionals. However, they reported valuing continuity of relationships with professionals and highlighted the importance of personal qualities such as their friendliness, thoughtfulness and gentleness. Parents valued professionals who recognised their child's individuality. Apart from those transferred to adult health services, in general young people did not feel involved in consultations with professionals. Some were unhappy about this situation but some younger children preferred their parents to talk to professionals. Some parents spoke about trying to facilitate their child's participation in conversations with professionals.

Transitions

Young people with complex healthcare needs experience multiple concurrent transitions as they move from children's to adult health services; from children's to adult social care services, and from school to further/higher education or work. In addition they experience 'status' transitions as they move to adulthood and independence. Young people and parents reported that information and planning for service transitions and transfers was lacking. Parents reported a lack of information on future options for their children, with many feeling that they were being directed towards residential care. For some young people there was no equivalent adult service in the hospital and/or community setting. Young people who had moved into adult services commented on the different culture in adult health services and how they had had to adjust to different ways in which services worked as well as the loss of familiar and trusted professionals. Another transition that young people were experiencing was the gradual transfer of control and responsibility for managing their long-term condition to them from their parents. This appeared to be an individualised process of taking on different aspects of self-care depending on the young person's readiness to accept responsibility. One young person had an independent advocate to help them with making decisions.

Implications for policy and practice

• It is important that young people receive flexible, personalised support that responds to their needs and promotes their social inclusion in school, work and social activities. Continuity of support is particularly important for young people with communication impairments as it takes time to become familiar with their communication styles and repertoires.

• Transition support needs to be coordinated and take a holistic view of transition. Young people and their families need information and preparation for transition. Planning needs to be integrated and person-centred to ensure that young people's and families wishes are at the centre of the process.

• Medical devices/technologies need to be developed and provided that minimise sleep disruption and maximise social inclusion and the integration of technology into everyday life.

• Assessment should place increased emphasis on young people's needs for emotional support, information needs and participation/decision-making preferences. Some young people may value guidance with how to disclose their condition and need for medical technology to their peer group.

Methods

The study was conducted between 2004 and 2006 and was funded by the Department of Health. The aims were

• To explore young people's experiences of needing the support of medical technology and what this means for their day-to-day lives and their future aspirations.
• To explore how young people experience different life and service transitions.
• To examine the support networks that young people use.

The focus of the study was on young people aged between 8 and 20 years old who lived at home and needed the support of medical technology continually or repeatedly. The technologies included in the study are presented in Table 1. Twenty-eight young people were recruited via Community Children's Nursing Teams in the North West of England. Data for the study were collected through face-to-face interviews with the young people themselves. Parents were the key informants where young people did not use verbal communication or alternative communication systems (n=9).

Table 1: Medical Technologies Used by Young People in the Sample (n=28)

Medical Technology	Number
Gastrostomy	19
Intravenous drug therapies	7
Mechanical Ventilation	6
Tracheostomy	4
Oxygen therapy	4
Parenteral Nutrition	1
Peritoneal Dialysis	1

Table 2: Education and Employment Locations (n=28)

Education/Employment	Number
Mainstream primary school	6
Special education primary school	2
Mainstream secondary school	5
Special education secondary school/college	9
Further/higher education	2
Work	1
Unemployed	2
Other	1

Further Information