Qualitative

Ventilator dependent young people had unnecessarily prolonged time in hospital resulting in educational and social exclusion

Noyes J. *Enabling young 'ventilator-dependent' people to express their views and experiences of their care in hospital.* *J Adv Nurs* 2000 May;31:1206–15.

QUESTION: What are young peoples' views and experiences of their health and social care when they are dependent on a ventilator?

Design

Phenomenology.

Setting

UK.

Participants

18 participants aged 6–18 years (56% boys) who were ventilator dependent. 9 participants had spinal injury, and 9 had a congenital diagnosis.

Methods

Face to face focused interviews were done with the 18 participants where they lived and with the family members of 15 participants. Because some participants had

communication impairments, alternative methods (eg, draw or play), caregiver help, and interpreters were used when needed. Interviews were reflexive and explored participants' health, social, environmental, and educational needs, and their future aspirations. The researcher took or obtained photographs and other materials, and kept a field diary. Interviews were taped, transcribed, and analysed for thematic content. A graphic artist was used to illustrate common experiences in cartoon format; these cartoons were verified for accuracy. A patient centred needs assessment framework was used to develop individual participant profiles.

Main findings

Compared with the UN Convention on the Rights of the Child, findings of this study showed that the rights of young people and their parents were not always respected or upheld. Participants experienced discrimination with healthcare services and incompetent treatment. All participants had faced lengthy hospital stays after the initiation of assisted ventilation and felt that they had remained in hospital longer than they needed or wanted to be there. Lengthy time in hospital contradicted the families' understanding of cost effective care. A predominant complaint was dissatisfaction with how the hospital discharge was handled; most felt that earlier discharge would have avoided many of their negative experiences. Most parents faced frustration over the lack of hospital rehabilitation programmes. All participants missed substantial periods of education and sensed a lack of quality control in the hospital education system. Participants did not always have access to appropriate play activities and felt that they were unable to maintain adequate contact with their belongings, families, culture, first language, nationality, and religion. A communication system based on patient needs was not always available and feelings of having been excluded from important decision making were expressed.

Conclusions

Young people who are ventilator dependent and their families had negative experiences with their hospital care. Young people endured educational and social exclusion because of unnecessarily prolonged hospital stays. Nursing care, rehabilitation and education programmes, and other services did not meet their or their families' needs. In some cases, human rights were not respected or upheld.

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COMMENTARY

The study by Noyes is new in its focus on children and young people who use artificial ventilation in the UK context, and adds to previous work that has explored parental perspectives¹ and young people with complex needs.² The context is the UN Convention on the Rights of the Child and increasing recognition that children and young people should be enabled to become active participants in their health care. Although the interviews are described as reflexive, there is little indication of how relationships between the interviewer and interviewees were considered in the interpretation of the data. It is not clear whether the reports of incompetent care given by almost all families indicate problems with service provision or should be subject to further interpretation, perhaps as an example of the development of expertise among parents involved in their children's care. The cartoon technique used in the study was not evaluated and so its potential value for communication between nurses and young people is not clear. The cartoons were used because many of these young people did not use speech as a method of communication.

The study reports problems associated with dependence on ventilation, most of which arise from prolonged stays in hospital. Participants described poor experiences of what they felt to be unnecessary admission to hospital, some lasting 2–6 years. However, the extent of unnecessary delays in discharge is unknown. A range of problems is reported, including perceived deficiencies in rehabilitation, education, leisure and cultural activities, advocacy, information and decision making, parental involvement, discharge from hospital, and complaint procedures. Nurses might be able to improve provision, but other professionals and policy makers control decisions in some of these areas. It is, however, possible to identify implications for practice at the level of principles: the study by Noyes provides evidence that services can treat young people as passive recipients of care. Potential exists to improve services, and an essential first step is to find out the views of young people, especially those with profound communication impairments.

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- 1 Wilson S, Morse JM, Penrod J. Absolute involvement: the experience of mothers of ventilator-dependent children. *Health & Social Care in the Community* 1998;6:224–33.
- 2 Morris J. *Hurting into a void: transition to adulthood for young disabled people with "complex health and support needs."* Brighton: Pavilion Publishing, 1999.