

Adolescents with HIV: Issues for practice

Young people diagnosed with HIV face unique social, psychological and ethical issues. Paula Seery presents an overview of this sensitive and evolving area of care

Globally it is estimated that 1,600 children are infected with human immunodeficiency virus (HIV) each day (WHO 1997). A not insignificant number of these children are likely to migrate to this country, so the numbers of children with HIV in the UK will continue to rise. Vertical transmission from mother to child is the major route by which children acquire HIV infection (European Collaborative Study 1992) and so the majority of adolescents with HIV are living in families where other members are also infected or have died.

The dramatic improvement in the effectiveness of medical treatments available in the UK has meant that children with HIV are now living longer and more are reaching adolescence. Too old to be children, yet too young to be adults, adolescents' needs are often underestimated or simply overlooked. It is therefore crucial to identify the issues facing adolescents to ensure that appropriate services are developed to meet the specific needs of this group. This is particularly important regarding the transition of adolescents with HIV to adult services.

This article considers the experiences of adolescents living with HIV, summarising the main issues that they face, and exploring the difficulties encountered in talking to young people about their diagnosis, along with the ethical dilemmas this raises.

Social issues

The clinical and social issues involved in caring for young people with HIV are highly interrelated. As many families have migrated to this country and are living as asylum seekers or refugees, the social contexts for many adolescents will involve multiple separations, immigration difficulties and poverty, as well as possible discrimination associated with their minority status (Funck-Brentano *et al* 1997).

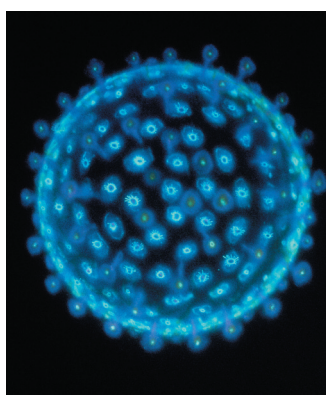


IMAGE BANK

These young people are also very likely to have experienced illness and bereavement of other family members as a result of HIV infection. Some of them will have been the main carers for parents or relatives during periods of sickness and disability. Furthermore, there is a lack of similar experiences within their peer group. This reduces the social support and normative informing available to young people who have to deal with

death and grief issues early in their lives (Sherr 1997).

Some adolescents might have taken on a parenting role for younger siblings because of poor parental health and the absence of other resources or support. The many disruptions and altered responsibilities that young people experience within their family relationships can act as a further barrier to forming intimate friendships or relationships. In turn, this may intensify their feelings of isolation and low self-esteem.

Psychological issues

Young people may find it difficult to ask questions or express their concerns, fears or needs. At times of stress behavioural challenges may be one way in which the adolescent can 'act out' her or his anxieties (Sherr 1997). The different ways in which young people react to stress are complex. Individual coping strategies are dependent on environmental factors that in turn are determined by young people's social and cultural backgrounds. Behavioural problems can become apparent through a deterioration of achievement at school or the development of extreme risk-taking behaviour (Rotheram-Borus *et al* 1998).

Research illustrates how adaptation and coping styles are likely to have implications for individuals' quality of life and adherence to protective health behaviours (Brown *et al* 2000). Many young people are living with a chronic illness which may have necessitated complex medical treatment and interventions, and many will not have a

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full understanding of their diagnosis (Thorne *et al* 1998). Coping with their illness, while being excluded from the 'truth' and surrounded by 'secrecy', inhibits young people's ability to gain control and develop independence. Information to help adolescents understand the need for adherence to treatment regimes will have more meaning if it follows discussion of their diagnosis and support in coming to terms with their altered lives.

To tell or not to tell?

One of the main problems experienced by professionals working in this field is the issue of what young people understand about their illness. Although it is widely accepted that all children require some explanation (at a developmentally-appropriate level) about why they need regular blood tests or medications (European Forum on HIV/AIDS Children and Families 2000), families find it difficult to name the disease. For many families, deciding whether to tell the child can be extremely stressful and emotionally exhausting. Indeed, parents who cannot bring themselves to talk to their children about the illness are more likely to experience depressive symptoms (American Academy of Paediatrics 1999, Weiner 1998).

Many families express a desire to protect their children from the secrecy, shame and emotional burden associated with the diagnosis of HIV. Parents often worry that by discussing these issues they might force disclosure of their own (parental) diagnosis, thereby raising questions of blame and reproach. Cultural factors can also affect the timing or manner in which family affairs are shared with children (Melvin 2000).

Parents might also worry that their child will not be discreet about illness outside the family, thereby increasing their feelings of vulnerability. However, research has demonstrated that naming the disease can often ease young people's anxieties, with some demonstrating better coping skills and higher self-esteem (American Academy of Pediatrics 1999). It could therefore be argued that if the child is more informed and involved in matters relating

to his own health, he or she will have more control over his or her life.

Talking to young people is part of a process in which knowledge and understanding is gained over time and through experience (Melvin 2000). It is thought to be in the young person's best interest for these discussions to take place when the family is ready and able to provide ongoing support (Weiner 1998). Research with young people has suggested that they feel it is their right to be told. They feel anger and betrayal about being lied to or excluded from the truth (European Forum on HIV/AIDS Children and Families 2000).

Children's rights

A young person's right to information concerning his or her health becomes especially pertinent when he or she is taking potentially toxic drugs on the advice of health professionals, and with the support of parents. Many younger children view medicine as something that is 'good' for them. But, how might they feel if they discover that the 'good' medicines could also make them very sick? This puts health professionals in an extremely difficult position, because by colluding with this 'dishonesty' and secrecy professionals risk damaging the trust built up between themselves and young people. This could have a profound effect on young people's attitudes to any future treatment or interventions.

The Royal College of Psychiatrists (1999) provides guidelines on treatment decisions in young people, drawing on ethical and legal frameworks such as the Gillick case. Parental right to determine whether their child (below the age of 16) will have medical treatment terminates if, and when, the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed. This includes the treatment's purpose, nature, likely effects and risks, chances of success and any alternatives. The UN Convention on The Rights of the Child (1989) states that children have the right to be involved in all decisions concerning their lives and future well-being, and for their views and opinions to be heard.

Conclusion

Helping children and young people to understand their diagnosis could be viewed as a rights issue. Nevertheless, when considering the holistic needs of adolescents it is important that these are looked at in the context of the family's cultural values. Paediatric nurses have a duty to advocate for the rights of children, but also to address this difficult issue with sensitivity and care. It is clear that a balance is required between the parents' or carers' needs with the child's needs and right to be included and involved **PN**

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