

Growing Up, Gaining Independence Principles for Transition of HIV Care

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Issues in adolescence

What the young person needs to know

Conclusions

The majority of HIV infected children who attend our clinic are vertically infected and are considered as children living with a chronic condition.

This protocol describes the family clinic's plans to prepare for and manage the process of transition from paediatric to adult care in this population. This process of preparation begins in middle childhood and progresses through adolescence at a speed appropriate for each child and their family.

We have described below the important phases of this process which the child and family will need to work through for transition to adult care to successfully occur.

Issues in adolescence

There are a number of issues, which make transition to adult care particularly difficult for this population.

Many of the children currently in early adolescence were diagnosed to have HIV before effective treatment was available and initially were not expected to survive beyond early childhood. This has resulted in a tendency for families, and services, to shelter or overprotect these children. In turn this adds extra strain on the processes of independence, autonomy and self esteem which are developing during adolescence.

Most of the children attending this clinic have parents who are from African countries where the expectations for young persons may be very different from what they observe in their peers in the UK. These differences may be further heightened by gender expectations and religious beliefs. Conflicts within the family relationships are generally more frequent during adolescence and may be exacerbated by these issues and those relating to HIV.

A diagnosis of HIV is still a stigmatising diagnosis for many families and parents may find it extremely hard to share this with their child. Without this knowledge it is not possible for the child to progress completely through the transition process.

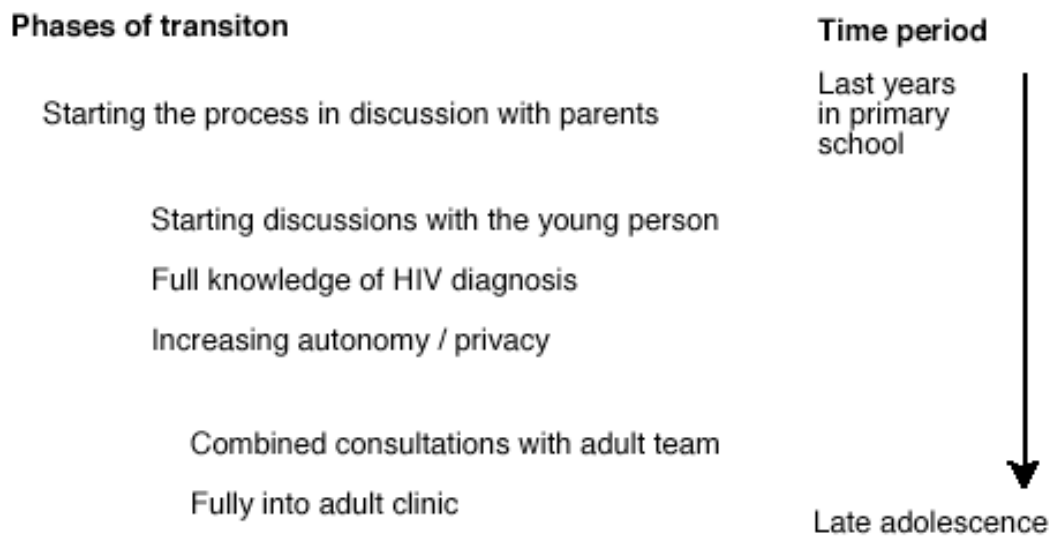
What the young person needs to know

The Family Clinic staff will have helped support parents in providing explanations and information for their child about what is happening from a young age.

The very young child will want explanations about what happens at the hospital especially why they have blood taken or have to take medicines. Later it is possible to talk about goodies and baddies in the blood and sometimes about viruses or bugs. Providing truthful explanations, appropriate to the age and maturity of the child but which do not name the diagnosis is possible when the child is young. These can help build an understanding of health and illness. However by early adolescence it becomes increasingly important that a full and open discussion which includes the diagnosis can take place. This enables the young person to feel involved and participate in decisions and feel more in control of treatments and care. It can also help allay any confusion about what is happening to them and provides an opening for the young person to talk about any fears or concerns that they may have about themselves and the future. Self-esteem and independence

are developing during adolescence and knowledge enables these processes to continue and expand. Those young people who have been fully informed about their diagnosis mention the importance of hearing this information from their parent or at least with the parent's involvement and agreement. Planning and supporting the family and youngster during the sharing and afterwards helps the adjustment to the news and reduces long term anxiety. Situations where the young person found out or was told inappropriately have always been more upsetting. Whilst recognising that by the ages of 12-13yrs most young people with HIV should have had a full and open discussion about their diagnosis there will always be circumstances which mean that exceptions will occur. The stigma which still surrounds this diagnosis and the family impact, where other family members are HIV positive or may have died from the condition, increases anxiety about sharing the knowledge with children often for fear of who else will get to know. Particular situations in which the sharing of the diagnosis is more difficult include those where the family live in very isolated circumstances, where the parent or carer has strong beliefs that it is wrong for the child to know and would not support them knowing and where the child has a learning or cognitive difficulty. In all these cases it may be that progress through the transitional care will be delayed or take longer. However it is likely that transition to adult services would be delayed in all of these kinds of situations anyway.

Although we have suggested an overall time frame for this whole process, it has to be stressed that families and youngsters will progress through different parts at different rates.



Starting the process in discussion with families

It is important to start a discussion with the parents as the child progresses through primary school so that they are prepared for what to expect of this process. Giving parents ideas on how to continue telling their children more about HIV (see above) is part of this and takes time. Explaining to the parents about puberty and the changing needs and expectations of the young person as well as how we will progress with their care over the next few years gives the family a time frame to work with. Explaining that as the young person enters early puberty it is usual within the clinic to begin to give them some personal time within the clinic. This is important to give them opportunities to discuss issues such as physical and sexual development, which are not necessarily related to HIV. It also allows for opportunities for them to mention any worries or concerns of their own. This will start in quite an informal way, e.g. when they go to be weighed and measured in private with our specialist health visitor / nurse. Parents will be reassured that young people may always have a same sex chaperone.

Increasing Knowledge and Autonomy for the young person

The changes in the clinic noted above also need to be explained to the young person. Greater emphasis will be given to providing opportunities for the young person to take more of a lead in consultations with the doctor as they approach adolescence. In time they will be offered the choice of part of the health consultation to be by themselves.

Once the young person knows their diagnosis of HIV then discussions around HIV issues can also begin, some of these will be with parents in the consultation and as time goes by without parents too. Issues of privacy and confidentiality will need to be given particular consideration during this time.

If this process is working well then both parents and the young person should feel that they can discuss freely all aspects of their care.

Medical / Social Review of the HIV history

The young person may wish to have an up to date summary of their HIV disease history as they may not remember early childhood illness, nor have understanding of their significance. This may be especially important for young people who have lost parents and cannot easily refer back to them for past events. Flow charts of the treatment history, CD4 progression and viral loads etc may also be offered. These will also be very useful to the adult doctor during the transition process (see summary sheets below).

Communication with other professionals

Most children are unaware that with their parents' consent communication about them goes to other professionals e.g. the GP. As the young person is gaining autonomy they should be asked permission for information to be shared with other professionals.

Combined consultations moving to consultations only with the adult team

When it appears appropriate for the individual and after discussions, and with agreement from the young person, the parents and the team, joint consultations with the paediatrician and the adult HIV doctor will begin. In this clinic where most of the young people have attended for many years the adult doctor will already be a well know face. Parents may or may not be part of this. Over a period of time the adult doctor will take over the consultations, this may be as short/ long a time as is considered necessary. Although the young person's doctor may no longer be the paediatrician, other team members e.g. the psychologist or clinical nurse specialist may still be actively involved.

An Information pack and web site are currently under construction.

These will aim to give good information and resources about general heath issues, sexual heath, and HIV related issues.

Conclusions

Transition of care from a paediatric to adult setting is not specific to HIV, but occurs in a number of paediatric specialities (e.g. cystic fibrosis, congenital heart disease, diabetes etc). Indeed the over all principles of helping young people to gain knowledge and independence and maintain good self esteem can be applied to all adolescents with or without chronic diseases. However, there are important differences for young people with HIV which may make this process more difficult.

Other family members are also likely to be infected and one or other parent may even have died. HIV is a sexually transmissible infection, which is a complex burden for a young person developing their sexual identity to carry. HIV remains a stigmatised condition so it is very hard to share this diagnosis with peers (unless they are also infected). For these reasons it is especially important that young people are: 1) well educated about their condition and its treatment; 2) confident in their ability to talk about HIV with those who they want to know about their

condition; 3) have a support system, so they know where to get help and advice when they need it.

Medical and Social Review

A template for medical and social review is attached. This can be seen as an educational process for the young person who may be unaware of illnesses / treatments in early life. Review of the social situation is also important, as there may be areas to consider which the young person has not been able to discuss previously (e.g. family bereavements).

Supporting Change: Successful transition for young people who have grown up with HIV infection

Guidance on transition and long term follow up services for adolescents with HIV infection acquired in infancy

<http://www.chiva.org.uk/publications/transition>

National Transitional Care Guidance

- Royal College of Paediatrics and Child Health (2003) The Intercollegiate Working Party on Adolescent Health. Bridging the gaps: health care for adolescents.
<http://www.rcpch.ac.uk/Education/Adolescent-Health-Project>
- National service framework for Children Young People and Maternity services (2004)
<http://www.dh.gov.uk>
- Adolescent Transition Care. Guidance for nursing staff. Royal College of Nursing (2004)
www.rcn.org.uk
- National service framework for long term conditions (2005)
www.dh.gov.uk

- You're Welcome quality criteria: Making health services young people friendly (2007)
www.dh.gov.uk
- A Transition guide for all services. Key information about the transition process for disabled young people (2007)
- Transition Information Network.
<http://www.transitioninfonetwork.org.uk>
- Transition moving on well (2008).
www.dh.gov.uk