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Growing up with HIV – The experiences of young people living with HIV since birth in the UK

Judith Dorrell, Sarah Earle, Jeanne Katz and Shirley Reveley

Introduction

As treatment for HIV has improved, children with the infection are living longer and healthier lives, and with mortality rates declining and survival rates improving, this has become a medical success story (Sharland et al. 2002; Gibb et al. 2003; Foster and Lyall 2005). For many people, the introduction of effective treatment has transformed HIV from an acute terminal illness into a chronic condition and, as a result, there are increasing numbers of older children and young people growing up with HIV. One of the greatest achievements has also been the dramatic reduction in children becoming infected at birth (mother to child transmission). However, in the UK there is a small, but significant number of children and young people who live with HIV, most of them having been infected at birth, before such effective treatment became available (Brown et al. 2000; Gibb et al 2003).

These children and young people face a range of complex issues, and although they are not large in number, they are an important and sometimes forgotten part of the AIDS epidemic. HIV services and care historically have tended to focus on adults, with children and young people's issues becoming marginalised. This has been in part due to their small numbers, but also the dominance of adult services and care in this field. The development of

paediatric treatment and medical management of paediatric HIV has tended to lag behind that of adults (McKinney et al. 2004). Despite the improved treatment, young people still live with an uncertain future and there is still no cure for HIV. Many live with medical crises and some will need to come to terms with the idea of dying prematurely. These young people may also experience multiple losses in their families because of HIV; some may have lost their mother, father or both parents; others may have lost siblings or members of their extended family (Brown et al 2000).

Whilst there have been several clinical studies on young people and HIV (Gibb et al. 2003; Walker et al 2004), and some studies which examine service provision in the UK (Lewis 2001; Conway 2006) there is limited research on the social and psychological impact of living with HIV infection for young people (Thorne et al 2002; Green and Smith 2004). This chapter draws on research carried out as part of a doctoral study exploring the lives of young people infected with HIV. The next section offers a brief background to the research, followed by a discussion on research methods. The final section of the chapter explores how young people articulate their fears of dying and their experiences and feelings about living with loss.

Background to the research

In the UK the numbers of children and young people infected with HIV is small, in 2006, there were less than 1200 under nineteen years of age known to be infected living in the UK, 50 per cent of these being over the age of ten (National HIV Study 2006; Conway 2006). Most of these young people have been infected perinatally (at birth or shortly after). As the young people with HIV in the UK come from diverse ethnic backgrounds, they are not a homogenous group (Conway 2006; Lewis 2001; Miah 2004; NAT.2006; Green and

Smith 2004; Highlight. NCB 2006). In a study of the development of transitional care in a large London HIV clinic (Dodge and Melvin 2003), researchers found that 85 per cent of the parents of perinatally infected children originate from countries outside the UK, predominantly from African countries, although most of the children and young people were either born or lived in the UK for many years.

Researching young people living with HIV

This chapter draws on ongoing qualitative research which aims to document the experiences of young people with perinatally acquired HIV so as to further understanding of how HIV affects young people's lives. Ethical approval for the study was granted by the Open University Human and Participants Material Ethics Committee and the Local NHS Ethics Committee and Research Governance Committee of the hospital. An enhanced Criminal Records Bureau check was also required in order to interview the young people.

Participants who fulfilled the selection criteria were recruited to the study. The selection criteria included:

- To be perinatally infected with HIV (having HIV since birth)
- To be between the ages of 13 and 24yrs
- To be aware of HIV status for at least one year and feel sufficiently comfortable to talk about HIV
- To have been in the hospital service for at least 6months.

The research adopted a purposive sampling method and participants were recruited from a specialist adolescent clinic in a large London hospital. The study was piloted with two young people and, at the time of writing, twenty young people have been interviewed.

The study used semi structured in-depth interviews with young people aged between 13 and 24 years. The interviews focused on topics such as how HIV affects daily life; relationships with family and friends; intimate relationships; school/ work; and the future. It was important that the young people felt enabled to talk openly about HIV and had known about their status for some time in order to minimise any potential distress. Also it was important for them to be familiar with the clinic before being approached to participate in the study. The young people were interviewed alone in a private room in the clinic without their parent/carer or guardian present. As talking about HIV is not easy because it involves talking about personal and sensitive issues (Melvin 2007; Miah 2007; Wiener et al. 2006; 2007), and there is always the potential risk of distress, it was important to ensure there was good support and care in place. Following the interviews, the young people were given details of support organisations and there was easy access to a psychologist or clinical nurse specialist to speak to should they be upset.

The interviews lasted between one and three hours; they were audio taped and transcribed verbatim. Many themes emerged from the data, but the concepts of 'living with dying' and 'living with loss' were prominent. It is these themes which are now considered.

Living with dying

The fear of dying looms large in the lives of the young people interviewed for this study. Many talked about 'living in the shadow of HIV'. For example:

HIV is always in my head, it is always there whatever I do, whenever I sleep, when I wake HIV is there, it never goes away that fear of dying.

(Rebecca 18yrs)

Some young people have lived with the expectation of death around them for many years, having been diagnosed at a time when there was limited treatment available for children, as Paul – one of the respondents – commented:

At that time, we were just not expected to live, we were meant to die, I was surprised when I just kept on living. (Paul 24yrs)

Most of young people interviewed live in families where one or more family members have HIV or have died from HIV, and therefore some will have observed the illness trajectory at first hand. Although there is now much more effective treatment available, the progress of HIV remains unpredictable and the fear of illness is reflected in what the young people said, for example:

Living with HIV is sometimes like living with dying, I am always waiting to become ill, waiting to deteriorate, waiting for my time. (Liam 17yr old)

When I fall ill, I get sad cos I think the worst, and I think I am not going to make it this time, I have been ill quite a lot. (Carmel 18yrs)

The fear of death was one of the common reactions reported by the young people when they were told about having HIV. They reported feeling frightened, feeling a fear of dying and fearing they would die soon. Some young people expressed feeling a need to condense their living into fewer years as they were unsure as to how long they have to live. They expressed needing to live for now and not to look too far into the future. Another respondent, Emily, expresses this as follows:

I feel as if I have to do it all quickly because I don't know how long I will stay well, I haven't got time to waste. (Emily 19yrs)

The young people interviewed clearly identified living with the fear of dying as an issue and felt that living with HIV resulted in a heightened sense of their mortality. For these young people, this is further reinforced by their experiences of multiple losses in the family.

Living with loss

Although treatment has changed the course of this disease for many, most of these young people will have experienced the long term illness and loss of a parent, sibling or other family member from HIV. When parents/carers die it can lead to family disruption, separation and relationship breakdown (Lewis 2001; Lyon and D'Angelo 2006; Weiner and Battles 2006; Rotherham-Borus et al. 2005). Such breakdown may result in young people being cared for by foster carers, grandparents or other family members (Conway 2006; Lewis 2001; Miah 2004). When there is a death from HIV, it is often difficult for families (and the young person) to be open about the cause of death due to the fear of discrimination and stigma. When a family member dies from HIV young people spoke

about having to lie about what their parent or sibling had died from, and they found this very distressing, and they found it equally hard to share their grief with anyone, because they could not tell the truth. For example:

I didn't tell people what my brother died of, when they asked I just lied, well it was partly the truth, he did die from a lung infection, but it was caused by HIV. (Paul 24yrs)

I just told them he died of cancer, what else could I say? (Emily 18yrs)

Living with HIV involves keeping many secrets, often these are family secrets which can create barriers in young people's social relationships. Living with an illness that you cannot discuss with people you meet every day presents difficulties for young people and problems from keeping secrets have been reported by other researchers (Lewis 2001; Battles and Weiner 2006; Bond et al. 2000; Brown et al. 2000). HIV remains a stigmatised condition and as a sexually transmitted infection brings a complex mix of issues for a young person to deal with. Young people may perceive that they have to keep the family secret, as in disclosing their own status to people they are also disclosing their mother's infection and this is a difficult issue for them. Talking about HIV in their families may risk raising issues that have not been addressed by parents in relation to how they became infected. The data suggest that a young person's HIV status is not always disclosed even within families that live together, for example Charlotte says:

I don't tell my sister because I wouldn't do that to my mum, it wouldn't be fair to her as she has told no-one, not even my sister knows, only me as I have it too. (Charlotte 18yrs)

Young people express great loyalty to their parents and do not want to be the cause of their distress. They are mindful that disclosing their own status or talking openly about HIV may cause difficulties for their families. Young people seek to protect parents by keeping their status secret and not discussing it, as Luke and Emma comment:

I can't talk about HIV to Mum and Dad as I know it upsets them so I don't feel able to talk to them, I don't think they want to talk about it. I just know I can't tell anyone. I think they want to protect me, but sometimes I think it would help to talk to them about it, it might make it a bit easier. (Luke 16yrs)

We never spoke about it, we all just pretended it wasn't there, but it was.
(Emma 17yrs)

In other studies young people report feeling sad, depressed, lonely and isolated from family and friends (Lewis 2001; Lyon and D'Angelo 2006; Miah 2004). They fear other people finding out and find it difficult not being able to talk about HIV in their families. In some families not everybody is told about HIV, in others all the family may be aware, but it may never be spoken about. Young people, such as Luke and Emma, are aware that talking about HIV for some of parents may be upsetting, so they learn to keep silent (Lewis

2001; Melvin 2003; Bond et al. 2000). Some of the other respondents in this study talked about the need to keep their HIV status a secret from friends:

The bit I hate is lying to my friends, but if I did tell them how could I explain why I didn't trust them enough to tell them before? (Carmel 18yrs)

Young people observe how HIV is viewed differently from other illnesses, such as cancer and they comment on how it feels impossible to be open about living and dying from HIV, because of the fear of the stigma and discrimination. Sarah – another respondent – makes this point:

You know if he had died from cancer I would have got loads of sympathy and people would be kind, but with HIV, you can't even tell people the truth, all the sadness has to stay inside for ever. (Sarah 18yrs)

The loss of a brother or sister is also common for this group and these losses reinforce the reality to the young people that they may be the next one to die. A brother or sister is part of the peer group for young people and a death of someone close in age has profound effects.

When my brother died, it was a case of when was it my turn, you know that was definitely it, I thought well mum's gone, my brother's gone, so next in line is me, so it's me next. (Paul 24yrs)

Outside the small number of people that may know in their family, most young people do not talk about HIV with friends and therefore when a brother or sister dies, most say they have no-one to talk to about their loss. At the same time as experiencing this loss they are reminded of and fear their own death. Evidence suggests that many of these young people have limited and somewhat fragile support networks, and little emotional support (Nostlinger et al.2004, 2006; Rotherham-Borus 2005). This is emphasised by the comment made by Paul below:

I think when my brother died I felt the pain of my mum dying and there was pain in that place, I was 13yrs. When he died, I just felt that I basically took it upon me and all of my brother's goals he had and I put them on my shoulders and I did all of them for him. (Paul 24yrs)

The young people interviewed in this study emphasised that they want their lives to be meaningful and want to leave their mark on their world, like any other young person, but this becomes more important when living with a condition that may limit your lifespan. This is reflected in what they say, for example:

I have to make my life count, or what does it all mean? I will have gone through all this for nothing. (Emma 17yrs)

No one can cure you, the tablets won't make you better so all the time you just live day by day, not planning too much, but whatever you do, make sure you really live, make it worth while. (Ben 17yrs)

Most of the young people interviewed had experienced the loss of a close family member from HIV, and whilst they tried to make sense of these losses, young people are reminded of the stigma of HIV, as they do not feel able to talk openly. They carry the additional burden of secrecy and fear of disclosure of their condition. Whilst they know there is no cure for HIV, they see their lives of value and worth and most try to find a way to focus on living positively.

Conclusion

Living with HIV is difficult for young people but new treatment has made a significant difference by extending their lives. The social stigma of HIV remains and the difficulties of not being able to talk openly to friends and family about HIV means that many of these young people feel isolated and lonely. Unlike adults, these young people have grown up in the presence of HIV which has been an integral part of their narrative and as such the virus is always part of their identity. For example, Paul says:

I have two worlds, my normal one and then my HIV one, I am alone in my HIV world, but that's ok. (Paul 24yrs)

Whilst it is not possible to predict how these young people's health and lives may develop and how HIV will affect their future, many are living fulfilling lives. Some have become parents, most are either working or studying and many see HIV as just one part of their lives, in spite of the fears they have about dying and their experiences of loss. As one young person said:

I am more than just HIV, I am a young person who just happens to have HIV, so what, I am still here and I am going to live the life I want for as long as I can. (Matt 18yrs)

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