# HIV COMMUNICATION WITHIN THE FAMILES OF ADOLESCENTS WITH PERINATALLY ACQUIRED HIV

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# Abstract

Due to developments in anti-retroviral treatment, young people with perinatally infected HIV are now surviving into late adolescence and adulthood. In addition to normative challenges presented throughout adolescence, HIV-positive adolescents must adjust to living with their diagnosis. There has been a considerable amount of research investigating how and when young people should learn of their diagnosis, and who should communicate this. Familial experiences of paediatric disclosure have been explored, however, limited studies have investigated familial HIV communication after this process.

This Grounded Theory study aimed to explore the experience of HIV communication within the families of adolescents with perinatally acquired HIV following paediatric disclosure. It aimed to identify factors that facilitate or act as a barrier to HIV communication; how family members feel about HIV communication - or lack thereof – and its impact on wellbeing; and whether family members would like support in having discussions about HIV with each other. A final aim was to develop a model of familial HIV communication between adolescents and their biological mothers. Five adolescents with perinatally acquired HIV and their biological mothers were interviewed about their experiences.

Data analysis led to a theoretical model of familial HIV communication following paediatric disclosure. The model comprised eight theoretical codes: (1) triggers to HIV communication; (2) barriers to HIV communication; (3) HIV topics that are up for discussion; (4) factors that influence HIV communication; (5) the experience of HIV communication; (6) the impact of HIV communication; (7) the role of others; (8) and the absence of sex communication.

The findings highlight a number of suggestions for supporting families, and particularly mothers, with HIV communication. These are presented alongside possibilities for future research.

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# Introduction

## Overview

This study investigates how adolescents and their biological mothers with perinatally acquired Human Immunodeficiency Virus (PaHIV) communicate about HIV. Information about HIV and perinatal transmission will be discussed. Aspects of adolescence and adolescent life within the context of the family will be presented, followed by an overview of the literature describing the impact of HIV for this population. Current literature on communication within families affected by HIV will be presented, followed by findings related to family communication about other illnesses. Finally, the rationale for the present study is provided alongside the research aims.

## Human Immunodeficiency Virus

An estimated 35 million people worldwide were living with HIV in 2013 (UNAIDS, 2014a). The largest proportion of people living with HIV is in sub-Saharan Africa, estimated at 24.7 million people (UNAIDS, 2014b). According to the UK HIV Report an estimated 107,800 people were living with HIV in the UK at the end of 2013 (Public Health England, 2014). The UK HIV population is largely made up of men who have sex with men (MSM), who account for 40% of this population, and black-African heterosexual men and women, who account for 36% of this population (Public Health England, 2014).

The introduction of effective HIV treatment called antiretroviral therapy (ART) in the mid-1990s has led to a dramatic improvement in morbidity and mortality rates (Gortmaker et al, 2001). For those with access to treatment, HIV can now be viewed as a chronic health condition, as opposed to a terminal illness, and many can expect a near-normal lifespan if diagnosed promptly. Being treated successfully with ART so that an individual's viral load (the level of HIV in the blood) is undetectable means that the risk of passing on HIV to someone else through sexual contact is almost entirely eliminated (Attia et al, 2009). ART prevents HIV from destroying CD4 cells that are vital in protecting and fighting against infection. An individual's CD4 count and viral load will indicate how well the treatment is preventing HIV from advancing and damaging the immune system. In 2013 an estimated 66% of people living with HIV in the UK were treated with ART and 61% (of the total HIV population) had an undetectable viral load (Public Health England, 2014).

## Perinatal HIV transmission

HIV can be transmitted through the transfer of blood, semen, pre-ejaculate, vaginal fluid and breast milk. Perinatal transmission refers to HIV being passed from mother to child and can occur during pregnancy, labour or breastfeeding. In 1999 the Department of Health (DoH) issued a Health Service Circular advising the universal offer and recommendation of antenatal HIV screening alongside existing antenatal testing. Antenatal testing can reduce the rate of perinatal transmission from 25-30% to less than 1% if the mother is made aware of her status and treated during pregnancy. Increased use of testing and

treatment during pregnancy has resulted in a significant reduction in the incidence of perinatal transmission. Fewer than 2% of all the babies born to HIV positive women in the UK between 2006 and 2012 were diagnosed with HIV (Public Health England, 2014).

As per the guidelines from the British HIV Association (BHIVA; 2012), HIV positive women in the UK should have commenced ART by week 24 of their pregnancy and continue to take it during labour. Women are often encouraged to have a caesarean section and to feed their baby formula milk to further reduce the risk of transmission. Further tests are carried out when the baby is six and twelve weeks old. A final test is carried out at 18 months and a negative result at this point will confirm the baby is not infected.

Despite the success of prevention of mother to child transmission strategies, there remains a cohort of children and adolescents living with HIV in the UK (born either before opt-out testing was introduced or in countries with less access to testing or treatment). The introduction of ART has meant that the number of children surviving HIV is higher than ever (Patel et al, 2008). As such, global health services are required to provide care for a previously non-existent cohort. As HIV moves from a cause of death to that of a chronic health condition, new challenges arise for these young people. These include the need to take life-long medication, sexual and reproductive health needs, decisions about onward disclosure (telling other people their status), managing friendships, familial and romantic relationships, mental health needs and future career options (Mofenson

and Cotton, 2013). These challenges are examined in further detail below but first, aspects of normative adolescence are discussed.

## Adolescence

Adolescence is a transitional stage associated with the teenage years and is often viewed as the transformation from childhood to adulthood. It is a time for biological, physical and psychological change. The terms 'adolescence,' and 'adolescents' described hereon in are within the context of western culture (although considerable variation exists here too) unless stated otherwise.

### Brain changes

A number of changes take place in the brain during adolescence, particularly in areas of the cortex that process emotional and cognitive information (Casey, Getz and Galvan, 2008). Some of the greatest changes occur in the pre-frontal cortex, responsible for decision-making and higher-order cognitive functioning (Casey, Getz and Galvan, 2008). Increased dopamine levels (responsible for pleasure) are thought to explain risk-taking behaviours and vulnerability to boredom during adolescence (Spear, 2000). Changes in serotonin levels (associated with emotion and mood regulation) can result in greater emotional lability and responsiveness to stress (Spear, 2000).

### Peer relationships

Adolescence is often a period in which friendships become more important, particularly from mid- to late-adolescence (Way and Greene, 2006). Adolescent

friendships provide the opportunity to develop individual identity and social skills, although pressure to conform and fit in with a peer group has been reported (Brechwald and Prinstein, 2011).

**Romantic relationships**

Romantic and sexual relationships are often first experienced during adolescence. These tend to increase in prevalence over time and it has been suggested that 53% of teenagers will have had a romantic relationship lasting one month or more by the age of 15 (Carver, Joyner and Udry, 2003). Positive romantic experiences have been associated with greater self-esteem, self-confidence and social skills (Zimmer-Gembeck, Siebenbruner and Collins, 2004).

**Adolescence and the family**

During adolescence the family system often changes to prepare the adolescent for the adult world (Garcia Preto, 2005). This may involve the young person having more responsibility, independence and autonomy. Cultural and socioeconomic factors are likely to have a significant influence on the way a family approaches adolescence.

Adolescence also marks a time where the young person may hold more influence over family decisions as their opinions are taken into consideration (Beatty and Talpade, 1994). It can be a period of turbulence for the family, as attempts at negotiations are made over a myriad of topics such as privacy, curfews, friendships, relationships or clothing (Steinberg, 2001). Young people may also

be guided by friendships in ways that do not match up with parental expectations, leading to friction or upset (Steinberg, 2001).

## Family communication

Family communication refers to verbal and non-verbal interactions between family members (Epstein, Ryan, Bishop, Miller, and Keitner, 2003). Its importance for individual wellbeing and family functioning has been widely investigated. Communication enables family members to express their needs, wishes and concerns to one another. Ineffective family communication (e.g. communication that is unclear, lacking openness, involving high levels of criticism or entirely absent) may lead to conflict, difficulties in problem solving and weaken emotional relationships.

Olsen's Circumplex Model of Marital and Family Systems (Olsen, 1993) identifies three necessary dimensions for optimal family functioning: flexibility, cohesion and communication. Communication is viewed as a 'facilitating dimension' in that it allows families to move along the dimensions of flexibility and cohesion. Olsen described examples of positive communication such as attentive listening, staying on topic, self-disclosure and empathy as ways of enabling families to maintain optimal functioning. Flexibility and cohesiveness is expected to change as the system changes over time (e.g. in response to family illness) and it is suggested that communication will determine how families cope with and navigate through these changes.

Throughout adolescence, the frequency and content of interactions between parent and child often changes, for example, adolescents may spend less time with their parents (Larson, Richards, Moneta, Holmbeck and Duckett, 1996). Parents and their children may have differing opinions about the quality of their relationship or hold different beliefs about the level of autonomy the child should be given. As a result, communication and relationship difficulties may arise (Collins and Luebker, 1994). Parents, particularly mothers, tend to view family relationships more positively than adolescents do (Laursen and Collins, 2009). Adolescents in the US have been found to share more emotional and personal information with mothers than with fathers (Smetana, Campione-Barr and Metzger, 2006).

An American study examining parent-adolescent communication asked fifty parent–adolescent triads (adolescent, mother and father) to complete questionnaires, hold a discussion, and report on thoughts during the discussion using video-assisted recall methods (Sillars, Koerner and Fitzpatrick, 2005). They found that frequent and open parent-adolescent communication was associated with greater parental understanding of the child's self-concept, high parent–child relationship satisfaction, and a strong child self-concept.

Fitzpatrick and Ritchie (1994) identified three types of family communication environment: family expressiveness, structural traditionalism and conflict avoidance. Expressive families are 'conversation friendly' with children who are openly expressive of their thoughts and feelings. Structural traditionalism

represents families who are orientated towards conformity. Here, parents assert more control over their children as well as having more traditional views on family life. Conflict avoidance families represent those who avoid and suppress communicating about unpleasant topics that may lead to conflict or distress. Research has indicated that families who talk more (i.e. expressiveness) are more satisfied with family life. Greater communication has been found to positively correlate with stronger family cohesion whilst structural traditionalism and conflict avoidant families have reported less cohesion (Schrodt, 2005; Burns and Pearson, 2011).

Parenting style also dictates how family members communicate with one another. In a US study, authoritative parenting styles (characterised by emotional responsiveness, clear and consistent boundary setting) were correlated with adolescent maturity, school performance and low levels of psychological and behavioural difficulties across Americans of differing ethnicities (Steinberg, Mounts, Lamborn and Dornbusch, 1991). Authoritarian (characterised by high expectation, obedience and punishment) and neglectful parenting styles (low parental responsiveness, little communication and emotional detachment) were related to lower levels of adolescent maturity, poorer school performance and higher levels of psychological and behavioural difficulties.

## Culture and parent-child relationships

Different cultures adopt different family ideals about parent-child relationships. Whilst cross-cultural differences can be observed, large differences within cultures also exist as families themselves vary greatly in their own ideals and values. Immigrant families may display further variations as individual beliefs and behaviours may reflect those of the parent's birthplace or those of the host culture. If the two cultures are markedly different in their expectations of family members, it is possible that conflict may arise, particularly when the child may have spent all or the majority of their life in the host country (Farver, Narang, and Bhadha, 2002). As will be described in the next section, this demographic is commonly observed in the families of adolescents with PaHIV living in the UK.

## Adolescence and HIV

### Adolescents living with HIV in the UK

The Collaborative HIV Paediatric Study (CHIPS) was set up to follow and record data about children and adolescents living in the UK and Ireland with HIV. In March 2014, 1037 children were enrolled in CHIPS; 79% were black-African, 10% were of mixed ethnicity, 5% white and the remainder from other ethnic minority backgrounds. Of the 1037 young people, 999 had been perinatally infected with the majority (83%) of maternal diagnoses being made after the child's birth. Half of the cohort lived in London, 39% across the rest of England and the remainder in Scotland, Ireland and Wales. 86% of the young people were aged between ten and 19 years of age and represent nearly all of the older children and adolescents living with HIV in the UK.

## HIV-related stressors for adolescents

Adolescents living with PaHIV face a number of challenges, some of which relate specifically to having acquired HIV from their mother. The process of full paediatric disclosure (where HIV is first named) will be discussed first. Medical stressors, the family system, onward disclosure and stigma will then be presented as other examples of HIV-related stressors. The outcomes associated with these stressors will then be discussed.

### *Full paediatric HIV disclosure*

Much of the research investigating communication about HIV within the families of perinatally infected youth has focussed on paediatric disclosure. Paediatric disclosure can be understood in several ways; as a one-time 'event' where HIV is specifically named (Ledlie, 1999; Thorne, Newell and Peckham, 2000; Flanagan-Klygis et al, 2001) or as a 'process' whereby healthcare providers and caregivers provide the child with information about their diagnosis over time (World Health Organisation; WHO, 2011). Disclosure can also relate to the child being told his or her parent's HIV status. Here, 'full disclosure' refers to the time at which the child is first told that they are HIV-positive.

Children with PaHIV will be aware from a young age that they have an illness (alerted by daily medication and numerous visits to the doctors), but they are unlikely to be told their diagnosis until later on in childhood. As children enter into adolescence, the risk of onward transmission of HIV through sexual activity increases - one of the reasons HIV disclosure becomes increasingly necessary.

Disclosure is complex and the decision of when and how to do so involves perceptions of a number of factors including the child's developmental age, whether they are able to cope with and understand the nature of the illness, familial relationships, stigma and social support (WHO, 2011).

Rates of full disclosure have varied across studies. A literature review of global paediatric HIV disclosure reported that between 1.2% and 75% of HIV-positive young people were informed of their diagnosis (Pinzón-Iregui, Beck-Sagué and Malow. 2013). The most commonly cited barriers to full disclosure (concerns about emotional trauma to the child and the child disclosing their status to others) and perceived benefits (greater medication adherence) were consistent across countries. Mothers often describe strong feelings of guilt for their child's ill health and as such, a reluctance to disclose (DeMatteo et al, 2002; Hirschfeld, 2002). Factors prompting disclosure have included the child's age and right to know, their cognitive development, a need to maintain family trust, problems with treatment adherence and the need to protect others from infection (Vaz, Eng, Maman, Barbarin, Tshikandu and Behets, 2011).

In 2011 the WHO created guidelines for healthcare providers detailing how to support parents and caregivers with HIV disclosure to children of up to twelve years old. The guidelines recommend that children of school age (six to twelve years old) be told their diagnosis at a time to suit their cognitive and emotional development. They state that younger children should be provided with

information about their health incrementally and in line with development, as preparation for full disclosure.

Several studies have indicated that HIV disclosure to young people does not lead to mental health problems, as is often feared by parents. For example, ethnic minority children in the USA who knew their HIV status were less likely to be depressed than those who did not (Krauss, Letteney, De Baets, Baggaley and Okero, 2013). Understandably, at the time of disclosure young people have reported feeling sadness, worry and anger but also a relief that they know the cause of their illness and that they will be able to take care of themselves (Blasini et al, 2004; Vaz, Eng, Maman, Tshikandu and Behets, 2010).

Other studies have highlighted the potential consequences of not telling young people their HIV status, including mistrust, impeded psychosocial development, poor understanding of HIV and difficulty coping (Abadía -Barrero and LaRusso, 2006; Vaz et al, 2010). Research investigating paediatric HIV disclosure in São Paulo demonstrated an association between a lack of adult-child HIV communication and increased levels of distress, self-stigma and a lack of adherence to medication in children under 16 (Abadía-Barrero and LaRusso, 2006). Following interviews with children, the authors also concluded that unsupportive environments and the stigma or secrecy associated with their diagnosis meant that many young people suppressed asking questions about their illness.

A team in Puerto Rico designed a protocol to support healthcare providers and families with paediatric disclosure (Blasini et al, 2004). The model incorporated training for health professionals; parental preparation of paediatric disclosure; assessments for children to identify the appropriate time point to disclose; and support groups post disclosure. Post-disclosure follow up involved monthly sessions with individuals and family members and were used to assess the impact of disclosure, answer questions, and encourage support amongst families. Of those who were treated using the protocol, 70% of the young people felt 'back to normal' 6 months post disclosure and 85% of the young people (and 97% of their caregivers) believed disclosure to be a positive event for themselves and their families. Whilst the findings highlight the benefits of informing young people of their diagnosis and providing support for the whole family, both during and after the disclosure process, it was unclear as to which aspects of the intervention were particularly helpful. The absence of a control group was a further limitation.

***Medical stressors***

Despite effective treatment, HIV remains an extremely complex and chronic health condition requiring regular monitoring from healthcare professionals. In the UK, for adults and children over the age of five, ART is initiated when the CD4 cell count drops under 350 cells/$mm^3$ (BHIVA, 2014) and most adolescents with PaHIV will meet, or have met, this criterion. ART medication may result in side effects and some children have demonstrated developmental delay and cognitive deficits (Laughton, Cornell, Boivin and Van Rie, 2013).

Children may become ill due to difficulties with medication adherence, resistance, dosage or the complexities of drug combinations (Sohn and Hazra, 2013). Medication adherence is a particular concern and adolescents have shown difficulty with this. Self-report adherence figures for adolescents with PaHIV range from 40% to 84% in resource-rich countries (Buchanan et al, 2012; Agwu and Fairlie, 2013) but for ART to remain effective dosage adherence must remain consistent at 95% or more (Paterson et al, 2000). Continued non-adherence to treatment can result in HIV attacking CD4 cells to a count below 200cells/$mm^3$ (CD4 counts in HIV-negative individuals will range between 400 and 1600cells/$mm^3$) and at this point HIV will have progressed to AIDS (Migueles and Connors, 2010). If untreated, this will prove fatal as a result of contracting other infections (Morgan et al, 2002; Lawn, 2004).

Non-adherence in children has been associated with a number of factors including poor relationships and a lack of communication with parents, greater caregiver stress, lower caregiver quality of life and youth-reported lack of control in their lives (Mellins, Brackis-Cott, Dolezal and Abrams, 2004; Buchanan et al, 2012). These factors cite the need for family – as well as individually - focussed support for those struggling with medication adherence.

### *Perinatal HIV in the context of the family*

A defining feature of adolescents with PaHIV is that they will have, (or will have had) at least one HIV-positive parent. Perinatal transmission therefore adds a further layer of complexity and potential stressors for these families. Mothers

have spoken about the guilt they feel about their child's status and this has been identified as a barrier to disclosing to the child, for fear of creating difficulties in the mother-child relationship (Hirschfield, 2002). Disclosure of the child's status can also lead to questions as to how the child came to have HIV and therefore disclosure of the parent's own status, which some may be reluctant to talk about (Kennedy, Medley, Sweat, and O'Reilly, 2010).

Children with PaHIV may observe their parents becoming very unwell, requiring hospital admissions or witness their death. These distressing experiences may be exacerbated if the child is aware that they too have HIV, becoming fearful for their own health. Young people may also be limited in the amount of support they have access to in these difficult circumstances due to HIV-related stigma (this will be covered in more detail shortly). Children may also need to provide parents or other siblings with care and, as such, be forced to take time out from school or miss out on other social activities (Richter and Mofenson, 2014).

Social and economic factors are also likely to affect the families of adolescents with PaHIV. As has been described, a high proportion of adolescents living with HIV in the UK are of black-African ethnicity. Migrant African families living with HIV in the UK and Western Europe have been found to experience extensive difficulties with immigration, poverty, housing, racism and unemployment (Prost, Elford, Imrie, Petticrew and Hart, 2008). Those who have moved to the UK will also have had to adjust to living in a new country with cultural and social

differences. These challenges are significant and are a likely contributor to further stress.

***Onward disclosure, friendships and romantic relationships***

As adolescents get older, they may want to have more say as to whom they disclose their status to (i.e. onward disclosure). Parents are often fearful of their children disclosing to others, not only for fear of discrimination but also of losing control over who knows their own status. This can act a barrier to full paediatric disclosure (Pinzón-Iregui, Beck-Sagué and Malow, 2013). Reported rates of onward disclosure have ranged from approximately one-third of sexually active adolescents with PaHIV in America to 48% of adolescents in Thailand (Lee and Oberdorfer, 2009; Tassiopoulos et al, 2013). Reasons cited as barriers to onward disclosure by young people include a fear of discrimination, a fear that the recipient will tell others, a lack of disclosure self-efficacy, and awareness of the parent's wishes to keep it a secret (Hogwood, Campbell and Butler, 2013).

As has been described, adolescence is often a time at which young people begin to seek out romantic relationships. Young people with HIV have described struggling with their status in the context of romantic relationships and rejection from partners post-disclosure is not uncommon (Fair and Albright, 2012). Interviews with young people with PaHIV reported a need to protect themselves both physically (from sexually transmitted infections and pregnancy) and emotionally (from rejection), although participants also spoke of remaining

hopeful that one day they would find a supportive partner (Fair and Albright, 2012).

Despite these difficulties, some evidence has suggested that children who tell their friends about their HIV status have better health outcomes (e.g. an increase in CD4 count) without any detrimental effect on the child's behaviour or self-concept (Sherman, Bonanno, Wiener and Battles, 2000).

***Stigma***

Stigma can be associated with almost all of the stressors outlined above, for without it, many aspects of HIV would be far more manageable. Despite the understanding that HIV can be viewed as a chronic health condition, its negative history and association with death, promiscuous behaviour and illegal drug use maintain the stigma surrounding it (Tomaszewski, 2012). Stigma and discrimination may deter people from accessing social support, resulting in poorer health outcomes and further social exclusion (Ogden and Nyblade, 2005; Flowers et al, 2006; Simbayi et al, 2007).

Different types of stigma have been described; anticipated stigma relates to an individual's fear of societal responses or discrimination due to their status whilst enacted stigma refers to the actual experience of being discriminated against (Earnshaw and Chaudoir, 2009). Both anticipated and enacted stigma have been described by young people living with HIV (Ayres et al, 2006). People with HIV

can also experience internalised stigma whereby an individual adopts discriminatory beliefs about themselves (Earnshaw and Chaudoir, 2009).

Internalised and anticipated stigma may influence behaviour to avoid enacted stigma, for example, adolescents in America have reported non-adherence to medication to ensure friends and family remain unaware of their status (Rao, Kekwaletswe, Hosek, Martinez and Rodriguez, 2007). Unfortunately, people living with HIV in London have also reported stigma from healthcare professionals. 30% of a large cohort (n=1,385) stated that they had been actively discriminated against, with half of these involving a healthcare worker including dentists and primary care physicians (Elford, Ibrahim, Bukutu and Anderson, 2008).

**Psychological impact of HIV stressors**

According to Lazarus and Folkman's theory of cognitive appraisal (1984), stress is a two-way process, that is, the production of a stressor and the response of an individual. The theory proposes two forms of simultaneously occurring processes; firstly, primary appraisal where an individual identifies the stressor and what it means for them. This appraisal involves identifying whether the stressor is a threat, challenge or something that has already caused harm (e.g. being diagnosed with an illness). The secondary appraisal refers to whether an individual believes that they can cope with the stressor. Higher levels of stress are thought to occur when an individual identifies a threat or something that has caused harm and feels unable to cope or respond effectively.

The impact of HIV-related stressors has been associated with a range of outcomes for both the individual with HIV and those around them. As has been described, HIV can lead to significant physical health problems. Some adolescents may have lost one or more family members, or be young carers for parents or siblings. Due to the stigma that surrounds the illness, being HIV-positive may impede the quality of relationships with those who are both aware and unaware of the young person's HIV status. The need for secrecy also limits the availability of support. The social and economic difficulties some families experience may add further stress to that caused by an already complex health problem. In addition to this, adolescence comes with its own challenges that can be difficult to navigate. The psychological impact of these factors combined is potentially quite significant.

Families affected by HIV may also experience social and economic problems that then lead to psychological difficulties. A US study compared a sample of HIV-positive children with a demographically matched HIV-negative sample and found that psychological and emotional difficulties were more common in those without HIV (Bachanas et al, 2001). One reason for this may be that the children with HIV had more support than those without. The interaction between social, health, economic and psychological factors for families affected by HIV is very difficult to dissect, highlighting the range of difficulties they encounter and the level of support they may require from public services.

A recent review investigating the mental health of young people with HIV (with the majority of studies carried out in the USA or Europe) indicated that whilst many adolescents with PaHIV experience adequate mental health, a significant number experience emotional and behavioural problems that exceed the levels expected in the general population and other high risk groups (Mellins and Malee, 2013). The authors note that the complexity of HIV and the stressors attached is such that it is unclear whether being HIV-positive is the cause of psychological disturbance. They reported that in some studies, adolescents uninfected but affected by HIV (e.g. living in a house with someone who is HIV-positive) had similar or even higher prevalence rates of emotional and behavioural difficulties. They were, however, able to pick out factors that were associated with greater psychological difficulties including the health status of the young person, parental physical and mental health, stressful life events, the child's cognitive function and neighbourhood disorder.

An absence of psychological difficulties has been reported in other studies with HIV-positive adolescents. A small UK study (n=30) found no evidence of clinically significant psychological difficulties in a group of perinatally infected adolescents aged eleven to 17 (Sopeña, Evangeli, Dodge and Melvin, 2010). Adolescents also reported feeling satisfied about the level of communication about their status, despite having few confidants.

**Social support for adolescents with HIV**

As has been described, young people are often limited in who they may approach for support due to the secrecy around their illness. Whilst healthcare providers play a significant role in offering support to the young person, there is a need for support outside of this setting (possibly to act as a buffer between stressors and the potentially negative psychological effects). This is perhaps largely down to the family whilst friends remain unaware of a young person's status. Support from family members may present itself in a number of ways. Wills (1991) identifies different aspects of social support, each offering a different function. These are, emotional support (e.g. offering empathy, love, care), instrumental support (e.g. attending medical appointments with the young person) and informational support (e.g. providing the young person with information about HIV).

A number of authors have suggested that familial communication about HIV and HIV-related topics is a helpful method of social support for HIV-positive youth (Battles and Wiener, 2002; Ayres et al, 2006). A US study investigating social support for HIV-infected adolescents (both perinatally and behaviourally infected) found that 71% of young people had someone to remind them or go with them to clinic appointments (Abramowitz et al, 2009). Lower levels of general perceived support were associated with higher levels of depression. Satisfaction with family support was the best predictor of general perceived social support indicating its importance for the young people.

## Communication in the families of adolescents with PaHIV

As has been described, family communication is an important aspect of family functioning and is likely to be an important component of support for young people with HIV. Communication about HIV or HIV-related topics is one way in which parents or family members may support a young person with PaHIV, and yet little is known about how, or whether, families engage in such discussions.

In this section, general communication in families affected by HIV will be discussed before looking specifically at communication about HIV and HIV-related topics. Here, a model of family communication within the context of other systems will be presented to highlight what may facilitate or, indeed, inhibit HIV communication. Finally, family HIV communication post-full disclosure to adolescents will be explored.

### Communication in families affected by HIV

Communication more broadly (as opposed to communication about HIV) has been explored within the families of children with PaHIV. Research investigating social support and the relationship with child behaviour in the families of children with PaHIV indicate that the greater the child's perceived social support, the lower the parent-reported problem behaviour (Battles and Wiener, 2002). This finding was supported by Elkington et al (2011), who investigated psychological functioning in children perinatally infected, affected (i.e. caregivers were HIV-positive but they were not) or unaffected (neither caregiver nor child infected) by HIV. Irrespective of the young person or caregiver's HIV status,

youth mental health was consistently associated with caregiver mental health and family processes. Family processes was measured using a single assessment of family functioning (Parent Child Relationship Inventory; Gerad, 1994) and investigated the quality of parent-child communication, parent involvement and child autonomy. The communication scale consisted of nine items that assessed a parent's perception of how effectively he or she communicates with a child, for example, asking about parental empathy and the ability to talk to the child across a range of situations. Parental involvement asked questions about how much time the parent spent with their child and how much interest they showed. Autonomy asked questions about whether the parent encouraged their child to be independent. For all young people, irrespective of HIV status, lower levels of psychological difficulties were associated with higher levels of parent-child communication and caregiver involvement.

Family communication has also been associated with child health behaviours. Mellins, Brackis-Cott, Dolezal and Abrams (2004) compared the families of children who were non-adherent to HIV medication with those who were adherent. Non-adherence was associated with families with poor parent-child communication (measured using the Parent Child Relationship Inventory, as described above; Gerard, 1994).

**Family communication in the context of wider systems**

Steele, Nelson and Cole (2007) present a model, based on Bronfenbrenner's ecological systems theory, to highlight the various systems that surround a child with HIV (see Figure 1).

The microsystems include the people who have a direct influence on the child. This may be the child's parent, teachers, peers and the healthcare team. Next are the mesosystems, demonstrating how pairs of systems within the microsystem interact e.g. the child/parent interaction and the child/healthcare team interaction. The degree or quality of the communication between microsystems is likely to impact the child's physical, psychological and social functioning.

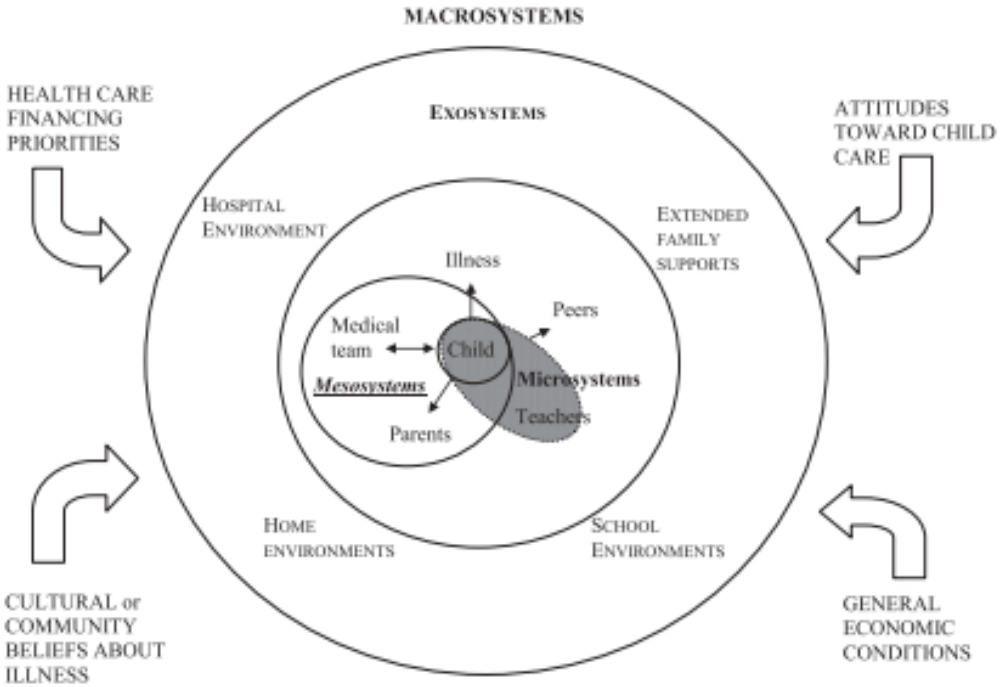



*Figure 1: Socio-ecological systems related to children's HIV (from Steele, Nelson and Cole, 2007)*

Further out are the exosystems; these may not directly include the child but they will have an impact on their health and wellbeing, often by providing a source of support for others within the microsystem, for example, a parent support group. Surrounding all systems is the macrosystem, which incorporates the cultural values and norms that influence the child's care and development. In the case of HIV, an example may be a family's cultural attitudes or beliefs about HIV and the subsequent influence this has over parent-child communication. In the families of children with PaHIV, a mother's own experience of living with HIV is also likely to have a significant impact on the way in which she feels able to support or communicate with her child about the illness, for example if she has experienced high levels of stigma she may be more likely to instruct her child to keep his or her status a secret.

**Family communication about a mother's HIV-positive status**

Similarly to their fears about paediatric disclosure, mothers with HIV have also reported feeling concerned about disclosing and discussing their own status with their HIV-positive and HIV-negative children (Corona et al, 2009). Findings as to the impact of parental disclosure are mixed. Some studies have indicated that parental disclosure can lead to difficulties within family relationships (Lee and Rotheram-Borus, 2002) and lowered self-esteem and mood in children (Nöstlinger, Bartoli, Gordillo, Roberfroid and Colebunders, 2006). Other findings indicate positive outcomes with disclosure resulting in improved family relationships, decreased childhood depression and that any initial negative impact of the disclosure dissipates over time (Murphy, Steers and Dello Stritto,

2001; Lee and Rotheram-Borus, 2002). The quality of the parent-child relationship has been highlighted as an important buffer against child behavioural difficulties in children who are aware of their mother's status (Jones, Foster, Zalot, Chester and King, 2007). Outcomes are also thought to be more positive if mothers personally disclose their own status to their children (Murphy, Steers and Dello Stritto, 2001).

One study looking at family communication about HIV in the context of the mother's positive status (child HIV status was not collected) reported that children (both under 18 and adult children) felt uncomfortable talking about HIV with parents for fear of upsetting them or reminding them of their HIV status (Corona et al, 2009). Parents and children who described having conversations about HIV reported having closer relationships and a more open general communication style, however, it was unclear as to the direction of causality in these associations. Children also reported finding it easier to talk about and ask questions when parents were open with their own experiences.

Bauman, Silver, Draimin and Hudis (2007) comment that a mother's ability to provide their child with support may be compromised if she herself is unwell, either emotionally or physically. In the families of children with PaHIV, the mother must not only cope with her child's HIV diagnosis but that of her own. HIV-positive mothers have been shown to experience high levels of psychological distress when looking after HIV-positive children (Chalfin, Grus and Tomaszeski,

2002). This may result in their finding it harder to facilitate effective communication about HIV with their children.

In summary, much of the research about familial communication about HIV has focussed around paediatric and parental disclosure. Those that have addressed family communication about HIV have tended to focus on talking about the mother's (or father's) HIV status. Little is known about how families communicate about the child's HIV status or factors related to their status, such as sex, medication use or onward disclosure. If families find it difficult to talk about HIV in relation to the mother's status, it may be that they also struggle to talk about the child's HIV status following paediatric disclosure.

**Family HIV communication post-disclosure**

Following paediatric disclosure, it is likely that a child will have questions for parents and require support in coming to terms with the diagnosis. One role of healthcare providers is to ensure that they work together with families leading up to an occasion whereby HIV can be named to the child. In the UK, healthcare providers continue to see families post-disclosure to provide support with medication, physical and emotional wellbeing and to offer opportunities for questions to be asked (British HIV Association; 2013). If families are struggling to have these conversations, it is important that healthcare providers are aware of this so that they are able to offer support.

Few studies have explored communication about HIV post-disclosure in the families of children with PaHIV. Dorrell, Earle, Katz and Reveley (2008) very briefly touched on the subject whilst interviewing 20 young people with PaHIV, aged between 13 and 24 in the UK. The research aimed to explore the effects of HIV on daily life, relationships and school or work. One participant described feeling unable to talk about HIV with their siblings because this would result in disclosing their mother's HIV status as well as their own. One also described feeling that talking about HIV with their parents would upset them and therefore chose not to raise the topic at all. Likewise, discussing HIV with people outside of the family was felt to be inappropriate because this would reveal the mother's HIV status and would potentially create upset within the family. Young people also found it difficult to talk about their HIV status with friends due to the stigma associated with it, resulting in some feeling isolated and lonely.

Whilst this study provided useful insight into familial HIV communication, it was not a focal point of the research and only three quotes were provided to describe familial HIV communication. The age range of recruited participants was also large, from 13 to 24 year olds. This may have resulted in some young people living away from their parents, therefore directly impacting familial HIV communication. Family deaths were also described and it was unclear as to whether all participants lived with their biological mothers.

More recently in Kinshasa, Democratic Republic of the Congo (DRC), eight children with PaHIV aged between eight and 17 years old, and their caregivers,

were interviewed about family communication before, during and after HIV disclosure to the child (Vaz et al, 2010). The caregiver's interview explored preparation prior to disclosure, anticipated responses, the disclosure event itself, and what had occurred following the disclosure. The young person's interview explored the child's understanding of their health before the moment of disclosure, the disclosure event and their reaction to it, and any event of communication post-disclosure. They were also asked about their feelings on disclosure and their understanding of HIV before and after disclosure. Young people reported being given HIV-related advice from caregivers post-disclosure but that they did not have discussions about their health or their HIV status. Communication was described as one-way rather than two-way conversations, with caregivers providing advice or instruction about medication adherence, giving appointment reminders, telling young people to protect others from infection and offering spiritual guidance. The caregivers also reported this pattern of communication and some spoke of feeling uncomfortable in talking about HIV, feeling only able to give advice. Caregivers were not aware that children had concerns or questions despite nearly all young people reporting that they wanted to know more about their HIV status. Young people reported questions being ignored or deflected and frequent episodes of being told 'not to worry.' Most reported having conversations with healthcare providers post disclosure but that these were always clinically focused, related to medication adherence and how to stop infecting others.

These findings provide a useful insight into familial communication about HIV in DRC, however, it remains unclear as to how families living in the UK talk about HIV post-paediatric disclosure. A further critique is that the findings do not give any indication as to what prompted, or got in the way of HIV communication, or why family members felt uncomfortable when talking about HIV. The cognitive and affective aspects of HIV communication decision-making were not explored in depth. A further critique is that not all the mothers interviewed were HIV-positive as some of the adolescents were behaviourally infected. As has been described, it is suggested that the nature of perinatal transmission is such that the mother's positive status will impact how family members talk about HIV.

A recent study in Sweden explored the experience of growing up with HIV in a group of young people (aged between 15 and 21 years old) with perinatal and early-acquired HIV (Rydström, Ygge, Tingberg, Naver and Eriksson, 2013). Participants described feeling particularly frustrated at having to keep secrets from those close to them. They also reported a lack of HIV discussion within the family and some stated that family members expressed negative beliefs about HIV. Participants also spoke of placing a heavy reliance on healthcare providers for support and that staff sometimes 'replaced' family members as they could communicate about HIV and topics that were unrelated to their status.

This study provided further insight into familial HIV communication, however, five of the ten participants did not live with a biological parent, something that will have directly impacted familial HIV communication. A further limitation is

that the sole recruitment of young people, as opposed to a range of family members, resulted in hearing about HIV communication from only one perspective.

A French-Canadian qualitative study explored familial interactions about HIV with 29 young people aged ten to 18 years of age (Proulx-Boucher et al, 2011). All but two participants were perinatally infected and just over half lived with at least one biological parent. When exploring communication about HIV following disclosure to the young person, the majority of young people reported very rare or non-existent conversations with their families about HIV. For participants who were able to discuss HIV, conversations were focussed on clinic appointments and medical information only (e.g. viral load or CD4 count). These conversations often took place in medical settings and were facilitated by medical staff.

The authors suggested that the emotional nature of perinatal transmission meant that both children and parents found HIV too difficult to discuss. The young people described not wanting to bring up the topic of HIV to prevent mothers feeling guilty. Young people also spoke of avoiding conversations about HIV to prevent other family members (e.g. siblings) from becoming distressed or upset. Young people living with host families spoke of feeling more able to talk about HIV in that environment and that the person in charge of the host family would bring it up. This supported the authors' views that the emotional connection between biological mother and child inhibited HIV discussion.

Twelve of the participants' biological mothers had died and seven participants lived with host families. Not all the experiences described therefore related to familial HIV communication between the child and their biological mother. This study also only recruited young people and as such, experiences of family communication were only heard from one perspective.

Whilst these studies have provided valuable insight into conversations about HIV post-disclosure, they have not commented on the psychological impact of being able, or not able, to talk about HIV with their families. Young people reported avoiding discussions about HIV for fear of causing familial upset but it was not always clear as to whether they would like to be able to discuss HIV. The two studies that focussed more on HIV communication (Vaz et al, 2010 and Proulx-Boucher et al, 2011) occurred in contexts that were different to that of the UK, where the availability of treatment and support is potentially different. The latter only gathered information from young people and a proportion of the participants were not describing HIV communication with their biological mothers. It was also unclear as to what motivated family members to talk about HIV, and whether there were specific barriers to communication. Although several studies described individuals finding HIV communication difficult, it was not clear why they felt this way. As has been discussed, the impact of culture, social and economic factors are likely to play a significant role in how families communicate about HIV. We do not yet have an understanding about HIV communication post-disclosure in families living in the UK, from both an adolescent and mother's perspective.

## Family communication about other illnesses

In light of the limited information about family communication about HIV, family communication about other illnesses will be, briefly, discussed.

Sickle cell disease (SCD) shares some similarities with HIV in that it tends to affect people from particular parts of the world, specifically those of African, Mediterranean and Middle Eastern heritage. It requires ongoing medication and can also be a stigmatised illness, although perhaps not to the same degree as HIV (Jenerette and Brewer, 2010). There are, however, clear differences between the two; those who have a diagnosis of SCD are more likely to experience episodes of being acutely unwell. As such, families must fluctuate between acute stress periods and periods of remission. Frequent adaptation and reorganization of family roles is therefore required.

Research has indicated that family communication can have a positive impact on family functioning in families affected by SCD (Herzer et al, 2010). Family communication in the form of parental reminders has been shown to increase adolescent attendance at medical appointments (Crosby et al, 2009). Further research indicated that adolescents feel it is important to talk about SCD, particularly so that they may learn how to look after themselves (Graff et al, 2012).

Research investigating communication style in the families of individuals with psychosis have shown that the way in which family members communicate can

have a significant, direct influence as to whether the individual will relapse. Specifically, relapse is more likely to occur for individuals whose families employ high levels of expressed emotion, that is, critical and hostile attitudes towards the individual who has been unwell (Butzlaff and Hooley, 1998).

## The present study

Adolescents with HIV face a number of challenges in addition to those faced by teenagers without significant health problems. These include, difficulties with their health; adjustment to their diagnosis following disclosure; managing HIV in the context of the family where at least one other family member is HIV-positive; being marginalised or having restricted opportunities due to cultural, social and economic factors; managing onward disclosure, friendships and romantic relationships; and living with the stigma that surrounds their illness. These stressors have been shown to place some HIV-positive adolescents at risk of psychological distress. Whilst healthcare providers must play a significant role in supporting young people, families - specifically parents - also have a part to play. Communication (particularly communication about HIV) is likely to be a fundamental part of the ways in which family members support one another.

Whilst a significant amount of research has addressed when and how young people should be told their HIV status and the impact of these discussions, little is known about how families communicate about HIV in the period after disclosure. The few studies that have addressed this have indicated that HIV communication is rare and often avoided by young people for fear of upsetting other family

members. The present study aims to explore how adolescents and their biological mothers communicate about HIV. It is hoped that the study will identify what determines communication patterns and what the outcomes of communication, or a lack of communication, are. Biological mothers are being recruited because it is believed that a mother's own experience of HIV and the nature of transmission will impact the way in which the mother-child dyad talks about HIV.

Knowing more about these conversations could be very useful, particularly if families are finding it difficult to talk about HIV and wish to communicate more effectively. Health services could be alerted to this and interventions designed, to better support familial discussions about HIV. An intervention supporting HIV positive mothers in disclosing their own status to their child has been shown to be effective (Murphy, Armistead, Marelich, Payne and Herbeck, 2011). Hearing from other families about what helps to facilitate conversations about HIV and the positive impact this has on family members may be useful to inform those who are struggling to talk about the condition.

In the current study, biological mothers and their adolescent children will be invited to take part in semi-structured interviews to discuss HIV communication following full disclosure to the child. The interviews will explore who brings up the topic of HIV, the content of HIV conversations and the perceived impact on family members. Factors that facilitate, or act as a barrier, to HIV communication will also be explored. Participants who report an absence of communication will

be asked about the perceived impact of this and whether they have conversations about HIV outside of the family context. The findings will then be used to develop a model of mother-child HIV communication in HIV-positive dyads.

**The research question**

The main research question is as follows:

*How do adolescents with perinatally acquired HIV and their biological mothers experience familial HIV communication following full paediatric HIV disclosure?*

The study will seek to: -

- Explore which factors facilitate or act as a barrier to HIV discussion
- Explore how family members feel about existing HIV discussion and its impact on wellbeing
- Ascertain whether family members feel that they need support in having conversations about HIV
- Develop a theory and diagrammatic model of mother-child HIV communication

# Method

## Research design

The study adopted a qualitative cross sectional design. A constructivist grounded theory approach was used (Charmaz, 2014).

### Inclusion criteria

Young people were eligible to participate if they:

- had contracted HIV perinatally
- were between the ages of 13 to 17 at the time of the interview
- had been told their HIV status more than twelve months prior to the interview date (as recorded by the clinic). This was to allow for adequate time to process and adjust to their diagnosis and to allow for some post-naming communication to have occurred.

Young people and their biological mothers were eligible to participate if they:

- lived in the same house as one another (as living apart would likely influence the frequency of communication)
- were fluent enough in speaking English to enable interviews to take place without the use of an interpreter
- were without significant cognitive deficits so that they were able to fully consent to the interview and take part without support from others

- were presenting without any current, significant risk issues, such as self-harm, suicidal ideation or significant impairment in functioning as a result of a psychiatric diagnosis (as recorded by the clinic)

The age criteria for adolescents was chosen with the understanding that many young people at the service are fully disclosed to around the ages of eleven and twelve, as recommended by the World Health Organisation (WHO, 2011). Those aged 18 and over are transitioned to a different clinic and as such, 17 was chosen as the upper age limit. It was also felt that participants of this age would be facing similar challenges (both related and unrelated to their HIV diagnosis) and due to the small sample size, having a relatively homogenous sample was thought to be beneficial. Biological mothers (rather than non-biological mothers) were recruited as it was felt that their positive HIV status (and therefore experience of living with HIV) and the nature of perinatal transmission was likely to impact the way parents and children spoke about HIV.

## Choice of methodology

### Qualitative analysis: Grounded Theory

A qualitative approach was deemed to be appropriate so that a theory could be derived from the participants' subjective realities and constructed meanings. Grounded Theory is a method of qualitative analysis initially developed by Glaser and Strauss (1967), although its approaches have evolved over the years. Grounded Theory was novel in its attempts to demonstrate a systematic qualitative analysis that could generate a theory (Charmaz, 2014). The method

of analysis results in the development of a theoretical model that reflects the collected data.

**Rationale for a Grounded Theory approach**

A number of qualitative methods were considered in the early stages of design, however, Grounded Theory was deemed to be the most appropriate approach to meet the research aims of this study. Grounded Theory enables the development of a theory, which reflects and explains experiences derived from the data. The aim of the current study was to develop a theory of family communication about HIV amongst adolescents and their mothers. A Grounded Theory approach has also been shown to be well suited to the involvement of two related groups of participants, including those with children and their caregivers (Hendriksen, Williams, Sporn, Greer, DeGrange, and Koopman, 2014). Grounded Theory has also been identified as a useful approach for studies involving social processes and those that require close examination of the subjective experience of its participants (Tweed and Charmaz, 2012). It has also been employed as a useful methodology in mental health research, particularly within the populations of those who are perceived to be marginalised (Charmaz and Rosenfeld, 2006; Boyd and Gumley, 2007).

Although Grounded Theory was felt to be the most appropriate methodological approach, other qualitative approaches were considered and are briefly discussed below.

### *Interpretative Phenomenological Analysis (IPA)*

This is a widely used methodology where data is interpreted to hypothesise the meaning a participant ascribes to a particular experience (Smith and Osborn, 2007). IPA involves high levels of interpretation by the researcher in comparison to other qualitative approaches and as such, its methods have been criticised (Pringle and Drummond, 2011). The increased reliance on a researcher's interpretations does not always allow for the development of a theory grounded in actual experience, as is the aim of the current study.

### *Discourse Analysis (DA)*

This approach was also considered as a potential qualitative method for this study. DA focuses on the way language is used to create the reality of participants' worlds (Giles, 2002). This approach assumes that multiple realities exist and that these are influenced by prior experience, knowledge and assumptions i.e. discourses. A social constructionist positioning to knowledge underpins DA and whilst this is consistent with the current study's approach, it was felt that the emphasis on broader societal narratives in DA would not allow for sufficient exploration of individual experience and meaning.

## Divergent methods in Grounded Theory

Grounded Theory set out by Glaser and Strauss (1967) was an important step in advancing the credibility of qualitative research. The authors challenged the assumption that qualitative research could not generate theory and the beliefs that qualitative methods were unsystematic (Charmaz, 2014). Following the

success of their early work, Glaser and Strauss have taken Grounded Theory methodology in opposing directions. Despite this divergence, both have remained faithful to the belief that the researcher holds a neutral position in their analysis, ensuring that the emergent theory remains grounded within the data. This is something that has been challenged by recent theorists, who state that researchers are unable to remain entirely neutral in the research process (Clarke, 2005; Charmaz, 2014). Charmaz (2014) in particular has argued that it is not possible to ignore the pre-existing experiences, assumptions and beliefs a researcher brings to the research. A constructivist approach proposes that many factors will influence a piece of research including the age, gender, profession, culture and individual experiences of both researcher and participant. These factors will influence each stage of the research process including how a participant may choose to tell their story, what they are willing to share and the way a researcher responds to and makes sense of the data (Charmaz, 2014).

**Rationale for using Charmaz's constructivist Grounded Theory**

This constructivist approach was deemed appropriate for this study for several reasons. Firstly, the researcher felt that their position and involvement in the construction and interpretation of the project must be accounted for. Charmaz's approach also allowed for more methodological flexibility, for example, she acknowledges that a literature review may need to be conducted before data collection for the purpose of ethical approval, something the original method advised against (Charmaz, 2014).

**Sensitivity to the data**

The current research project was confined within the requirements of a DClinPsy thesis and as such, the author was required to submit a research proposal and literature review prior to any data collection. This process offered opportunities for exposure to existing theories or concepts within the field (Glaser and Strauss, 1967). In more recent years it has been acknowledged that a researcher by profession is likely to have some existing knowledge in their chosen field so that it becomes difficult to 'ignore' or disregard any prior understanding (Heath and Cowley, 2004). It has also been suggested that experience and understanding may in fact enhance sensitivity to the data, as researchers may be more in tune with participants, thus allowing for greater insight into their narrative (Corbin and Strauss, 2008). Researchers with experience must, however, remain cautious that existing beliefs do not prevent them from seeing things that do not fit with their current understanding (Corbin and Strauss, 2008).

In the current study, the researcher was a female trainee clinical psychologist with an interest in working with adolescents and their families. Being a white-British, middle class professional without a diagnosis of HIV, it was felt that the researcher would be different to the majority, if not all, of the participants taking part, given the demographic characteristics of the population. As this may have influenced the researcher's assumptions about participants, or the interpretation of their experiences, it was important that these factors were acknowledged and reflected upon throughout the research process.

The researcher had some previous knowledge of HIV having attended sexual health lectures and whose mother had worked as a nurse in sexual health. The latter is likely to have been a significant factor in the researcher's open and accepting attitude towards people with HIV and other sexually transmitted infections. The researcher also had some experience of working with an HIV-positive adult on an acute mental health inpatient unit. This resulted in some understanding of the challenges posed to individuals living with HIV including discrimination and living with a chronic health condition.

The researcher kept a diary so that thoughts, reflections and responses could be recorded throughout the project. These were also discussed with the academic supervisor throughout. This process of reflexivity and tracking one's personal contribution to a piece of research is thought to be a key component in high quality qualitative research (Mays and Pope, 2000). The diary also offered a space to record other notes including general events that occurred throughout the research process, such as meetings with supervisors and the clinic team (Hutchinson, Johnston and Breckon, 2010).

Peer supervision with two other trainees who were employing a Grounded Theory approach was also extremely useful in allowing for more discussion about methodology and analysis, particularly as one of the trainees was also carrying out research about perinatal HIV. Peer group supervision entailed looking at and commenting on one another's codes, categories and model. The academic supervisor commented on one set of initial coding for both a mother

and adolescent. Both the academic and clinical supervisor also commented on a draft table of focussed codes and categories and on a draft model.

**Owning your perspective**

Unlike quantitative research, qualitative studies seek to understand individuals' experiences from their own perspectives and so it was important for the author to reflect on their position throughout (Charmaz, 2014). The researcher was aware that her life experiences would have been influential during data collection and analysis. The researcher will also have influenced the interview experience for the participant; the way in which they presented themselves and what they chose to share, or not share. These experiences will have influenced the way in which data was interpreted and therefore the final theory must be viewed as a 'co-construction' of data between the researcher and the participants (Charmaz, 2014). Opportunities for reflection on these matters were offered throughout supervision and through the use of the research diary.

**Criticisms of Grounded Theory**

As has been described, the epistemological position of a constructivist approach to grounded theory suggests that a researcher constructs and presents ideas about their social world, rather than representing a true reality (Hammersley & Atkinson, 2007). The usefulness of the findings generated from such studies has been questioned, with the concern that a piece of research may not contribute to knowledge in a meaningful way (Murphy, Dingwall, Greatbatch, Parker and Watson, 1998). Whilst Charmaz points to the importance of a researcher's

awareness and ability to reflect on their assumptions and contribution during the research process, it is unclear as to whether more is required than a recognition of being an 'active researcher.' It has been suggested that one way to develop and enhance a social constructionist approach would be for researchers to pay closer attention to the use of language in the construction of categories, as observed in discourse analysis and thus further grounding theory in the data and the participant's experience (Willig, 2008).

Critics have also cited practical difficulties when conducting grounded theory research, including the employment of theoretical sampling (described in further detail below) and in needing to reach theoretical saturation (or the point at which no new information is obtained from further data; Oppong, 2013). Oppong states that these require more resources - most notably time - and that some researchers may be time or resource limited, particularly those conducting research as part of a doctorate.

## Procedure

### Ethical approval

This study was granted ethical approval from an NHS Research Ethics Committee in May 2014 (Appendix 1). Approval was granted from Royal Holloway University of London Ethics Committee in June 2014 (Appendix 2). Research and Development (R&D) approval was gained from the clinic hospital site in June 2014 (see Appendix 3).

Consideration was given to possible ethical implications of the research, particularly as this project involved young people and those with HIV. Full details of how ethical considerations were addressed in this study are included within the Participant Information Sheet (Appendix 4). The main ethical considerations were as follows:

- **Voluntary basis of participation:** Participation in this study was voluntary, with no impact on treatment from the service.
- **Confidentiality:** anonymity of participants' identities was maintained at all times, although participants were informed about the limits of confidentiality (e.g. should a participant identify a risk to themselves or others)
- **Informed consent:** Information was provided to enable informed consent to be obtained. For adolescents under 16, child assent and parental consent was obtained.
- **Right to withdraw:** Participants were given the right to withdraw from the study up to a specific date and were given clear information as to how they could get in touch with the researcher to do so.
- **Safeguarding children:** Procedures were put in place to ensure child safety and protection at all times, with preparation made for contact with the relevant authorities if necessary. Participants were made aware of this process on the information sheet. Safeguarding issues did not arise during the course of the study.

- **Risk:** All participants were informed of the researcher's duty of care and the need to pass on information should there be concerns about risk for themselves or others.
- **Emotional distress:** Participants were told that they could take breaks or stop the interview at any time if they wanted to. They were also informed of the support available to them on completion of the interview.

**Service setting**

Participants were recruited from an HIV family service in an inner city London hospital between August 2014 and February 2015. The service provides multi-disciplinary health care for young people with HIV and their families from across the UK. Children are supported from birth to 18 years of age, at which point they are transferred to an adult service. The clinic offers a comprehensive and confidential service including HIV testing, treatment monitoring and clinical psychology for both young people and their families. At the time of recruitment, the clinic had 130 children and young people on their caseload. Approximately 87% of children had two black-African parents; 8% had mixed parentage (usually one black-African or Asian mother and Caucasian father); 4% had two Caucasian parents; and 1% had two Asian or South-East Asian parents. This is a good reflection of the ethnicities of the national population of children with HIV, of whom 79% are black-African, 10% are of mixed ethnicity, 5% are Caucasian and the remainder from other ethnic minority backgrounds (CHIPS, 2014).

**Participant identification, engagement and recruitment**

The team's Consultant Clinical Psychologist, Clinical Psychologist and Clinical Nurse Specialist were responsible for the identification of potential participants and their recruitment.

**Five-step recruitment process**

***Step 1: Engagement with clinic staff***

The researcher attended several meetings at the hospital with key members of staff (described above) to discuss the project. Participant information sheets were provided (see Appendix 4).

***Step 2: Participant identification***

Clinic staff identified families who met the inclusion criteria using the medical records database.

***Step 3: Information giving***

Clinicians introduced the study to eligible participants in one of two ways:
i) Eligible adolescents were telephoned by clinic staff to discuss the project;
ii) Clinic staff spoke to eligible adolescents about the project at their clinic appointments and provided information sheets.

If interested, clinic staff sought verbal consent to pass on contact details to the researcher so that they may be contacted directly to discuss the project further. Clinicians approached a total of eight adolescents and five expressed an interest

in speaking to the researcher. The three who declined did not provide a reason. The researcher contacted interested adolescents by telephone to discuss the project and sent information sheets via email (had they not already been given one). Participants were able to ask questions over the phone and were given the option to meet the researcher face to face to discuss the project further. On one occasion the researcher was at the clinic when a clinician approached the adolescent and so they met in person immediately to discuss the research. All five adolescents agreed to take part. They then approached their mothers to check that they were happy for the researcher to contact them about the project. The researcher then either contacted mothers by telephone, or met with them at the clinic, to discuss the research. All five mothers also agreed to take part.

***Step 4: Informed consent***

The researcher arranged a convenient time and location for the interviews to take place. Mother and adolescent interviews did not always take place on the same day and participants were given the choice as to whether they would be interviewed at home or at the clinic. Informed consent was taken in writing at the start of the interview (Appendix 5). For adolescents under 16, parental consent was obtained following adolescent assent, both prior to the interview with the young person. Copies of the signed consent forms (for both family members) were added to the adolescent's patient file.

***Step 5: Debrief and further support:***

Following the interview, participants were given £10 in cash for their time. Participants were also reminded of the available support they could access should they require it.

**Interview schedule**

Semi-structured interviews were selected as the method of data collection. Two draft interview schedules – one each for adolescents and mothers - were developed at the outset of the project in collaboration with the academic and field supervisors (Appendix 6). The questions were developed to allow for an in-depth exploration of familial communication and provide insight into the research questions.

Feedback was sought from a mother of a child with PaHIV from another service and a group of young people with PaHIV. They were asked to comment on the interview schedule in relation to whether questions made sense and felt relevant to the subject matter, whether any clarification was required or if questions should be removed or added. The mother who reviewed the interview schedule discussed her feedback with a member of staff with whom she was familiar before it was sent via email to the researcher. The group of young people gave feedback during a meeting at an annual weekly residential camp held for young people with HIV. The young people had the opportunity to talk about the schedule directly with the researcher in addition to providing anonymous written feedback. Upon collating both sets of feedback, a number of small

changes were then made to the schedule to incorporate some of their ideas (see Appendix 7 – changes/additions are in bold text). The changes consisted of the clarification or rewording of some questions and the addition of questions about culture, religion and support from services.

Interview questions were generally open-ended to allow participants' experiences to emerge (Charmaz, 2014). The interview guide was structured so that mothers and young people were asked to talk about communication more generally (e.g. what sort of thing do you and your mum talk about at home?) before going on to talk about HIV communication. A number of HIV-related topics were provided as prompts including medication, sex, relationships and onward disclosure. Questions about HIV communication were asked chronologically such that participants were asked about HIV communication in the time immediately after full paediatric disclosure, over time and more recently. Participants were also asked about HIV communication with people outside their immediate family, for example extended family and friends, to identify whether this was related to mother-child communication. The involvement of services in HIV communication was also explored, for example, whether healthcare professionals had provided support with familial HIV communication.

**Data collection**

The researcher carried out all ten interviews. The first six were conducted in participants' homes and the final four took place at the clinic. The author

ensured that there was a comfortable and private space for interviews to take place, particularly in participants' homes when other members of the family were there. All interviews were audio recorded, and observations about the setting and the interview itself were recorded in the research diary at the end of each interview (Mills, Bonner and Francis, 2006). Mothers' interviews lasted between 43 and 72 minutes, with a mean interview length of 54 minutes. Adolescents' interviews lasted between 28 and 59 minutes, with a mean interview length of 44 minutes.

The academic supervisor commented on the researcher's interview technique (on the basis of a role-play) before the participant interviews took place. The interview schedule was used as a guide; general topics were covered across all interviews whilst specific questions were based on individual participant responses. Prompt questions were asked throughout to encourage participants to expand answers and to encourage further discussion of key topics. Throughout each interview, the researcher provided participants with summaries of their narrative to ensure that they had been understood and interpreted correctly (Forrester, 2010). At the end of the interview all participants were asked how they had found talking to the researcher. A number of participants commented that they had enjoyed the experience and that it had been interesting to think about conversations they were or were not having with their mother or child. Although some of the topics were of a very sensitive nature, none of the participants became distressed during the interviews.

### Adapting the interview guide

The interview transcriptions and initial codes were completed soon after each interview. The researcher then reviewed the interview schedules and any emerging gaps, ambiguities and key areas of interest were identified from this initial analysis. These were then added to the interview guide to be explored further with subsequent participants. A list of additional questions can be seen in Appendix 8.

### Theoretical sampling

The researcher met with the recruitment team to discuss some of the emerging ideas and queries that had been identified following the first four interviews. The first four participants were of black-African ethnicity, lived in London and the adolescents attended a support group. The research team discussed the possibility of recruiting participants from other ethnic backgrounds and those who lived outside London and did not attend groups. Due to time constraints and the small population size, only the latter two participant characteristics were met. Time constraints also meant that opportunities to discuss further recruitment strategies were not possible.

## Participant characteristics – situating the sample

Table 1 below outlines relevant demographic characteristics of participants, to situate the sample and help provide a context for the research. Participants were asked to complete a demographic questionnaire before each interview (see Appendix 9). Participants' CD4 counts and viral loads were also collected from

medical records (with consent) via the Clinical Nurse Specialist, although not included here as they were not felt to be relevant - all participants were taking medication and in good health.

All participants were black-African and aside from two of the adolescents, all were born abroad. Four of the five mothers were single parents. All ten participants were diagnosed with HIV in the UK and all adolescents were disclosed to at the clinic between the ages of ten and twelve.

*Table 1: Participant demographic information*

| Ppt no. | Age (yrs) | Sex | Country of birth | Year of move to UK | Age at move to the UK | Marital Status | Religion | Age at diagnosis/ disclosure) | Family members (age/status) *denotes living at home |
|---|---|---|---|---|---|---|---|---|---|
| **AD1** | 16 | F | Uganda | 2001 | 4 | Single | Christian | 10 (Disclosure) | BM1*<br>AD1*<br>Daughter (24 HIV-neg) |
| **BM1** | 49 | F | Uganda | 2001 | 36 | Single | Christian | 36 (Diagnosis) | |
| **AD2** | 16 | M | Ethiopia | 2001 | 4 | Single | Christian - Catholic | 12 (Disclosure) | BM2*<br>AD2*<br>Son (5 HIV-neg)*<br>Daughter (8 mths HIV-neg)* |
| **BM2** | 39 | F | Ethiopia | 2001 | 26 | Current Partner | Christian | 26 (Diagnosis) | |
| **AD3** | 16 | F | Zimbabwe | 2003 | 5 | Single | Christian | 12 (Disclosure) | BM3*<br>AD3*<br>Biological Father (HIV-pos)* |
| **BM3** | 41 | F | Zimbabwe | 2003 | 30 | Married | Christian | 30 (Diagnosis) | |
| **AD4** | 15 | F | UK | N/A | N/A | Single | Muslim | 11 or 12 (Disclosure) | BM4*<br>AD4*<br>Son (14 HIV-neg)*<br>Daughter (5 HIV-neg) |
| **BM4** | 40 | F | Somalia | 1998 | 24 | Single | Muslim | 32 (Diagnosis) | |
| **AD5** | 14 | M | UK | N/A | N/A | Single | N/A | 10 or 11 (Disclosure) | BM5*<br>AD5*<br>Daughter (13 HIV-pos)*<br>Son (20+ HIV-neg)*<br>Daughter (20+ HIV-neg)* |
| **BM5** | 49 | F | Zimbabwe | 1996 | 31 | Single | Christian - Catholic | >31 (Diagnosis) | |

## Analysis process

### Transcription

All ten interviews were transcribed verbatim within a week of taking place.

### Coding

Coding is a key characteristic of Grounded Theory and is the process of defining what the data are about. It is the link between data collection and the development of an emergent theory. Charmaz (2014) describes a minimum of two phases of coding: initial coding and focussed coding and the author followed the method of analysis outlined below.

#### *Phase 1: Initial coding*

It was important for initial codes to stay as close to the data as possible as they were provisional whilst the researcher remained open to other analytic possibilities. Initial codes were also reworded to improve their fit with the data. Charmaz (2014) identifies four questions that initial coding should seek to answer: -

1. What is this data a study of?
2. What do the data suggest or leave unsaid?
3. From whose point of view?
4. What theoretical category does this piece of data indicate?

Initial coding also highlighted areas where data was lacking and the identification of these gaps was part of the analytical process. One advantage in

using a Grounded Theory approach was that gaps and queries identified in the early stages of data collection were later explored through subsequent data collection (Charmaz, 2014).

Line-by-line coding was conducted on each of the transcripts resulting in the identification of a label or short summary for every single line, whether a full sentence or not. This label or short summary helped to categorise and reflect the content in each line of data. The use of gerunds (nouns made from verbs i.e. verbs ending in '-ing') was employed to ensure that codes were grounded in the data rather than the individual, for example, "feeling confused" as opposed to, "she did not understand what her sister meant," (Charmaz, 2014).

Another key characteristic of initial coding is the constant comparative method (Glaser and Strauss, 1967). This is used to establish analytic differences and similarities. It is also used to demonstrate the point at which theoretical saturation (put simply, data satisfaction) has been reached, whereby no further categories or theoretical insights emerge. It is at this point when data collection may be terminated (Glaser and Strauss, 1967). At first, data was compared with other sections of data from the same interview to identify whether there were any similarities or differences in how one participant spoke about their experiences. Later, data between participants was compared to explore similarities and differences between their interpretations and descriptions of experiences.

### *Phase 2: Focussed coding*

Focussed coding involved developing the initial codes so that they described or captured larger sections of the data (Charmaz, 2014). Focussed codes were therefore more abstract and conceptual and involved the employment of the most significant and/or frequently adopted codes during the initial coding stage. Focussed coding required decisions to be made as to which of the initial codes made the most sense to categorise and at times involved recoding initial codes (Charmaz, 2014). As Charmaz (2014) encourages, it was important to remain open and to take a critical stance of the initial codes and the development of these into focussed codes. The researcher therefore made efforts to be careful not to over-interpret or force data into preconceived categories.

## Writing memos

Memo-writing is another key characteristic of Grounded Theory methodology (Charmaz, 2014) and were written throughout both coding phases to explore reflections, ideas and concepts arising from the data (Appendix 10). Memos provided the opportunity to capture any comparisons and connections made throughout analysis, in addition to any questions for subsequent interviews. They allowed for the comparison of data and were vital in linking each stage of coding towards the final development of conceptual categories. Memos were stored in a Word document so that they could be added to over the course of analysis.

### Theoretical coding and diagramming

Theoretical coding enabled the focussed codes to be connected and developed into categories before being integrated into a model (Charmaz, 2014). Memos were vital to this process, establishing theoretical links between codes and developing these to form an analytical framework. The emergent theory was made up of the identified categories, each made up of a selection of focussed codes. Initial codes and some raw data (in the form of quotations) were also used to provide further explanation of these. A diagram was also used to further demonstrate the emergent theory and the way in which categories and codes were related to one another (see Figure 2, Chapter 3).

### Grounding in examples

Quotations from raw data were also included in the memos to illustrate any developing codes. Extracts from two interview transcripts (one adolescent, one mother) have been included (Appendix 11) to demonstrate the interview process and the process of developing raw data into initial and focussed codes.

# Results

The analysis is presented below alongside quotations to illustrate each theme. All identifying details have been removed to maintain participants' anonymity. To prevent mothers and adolescents from being able to identify one another, participants have been assigned a random letter throughout this section. Letters do not correspond to one another or to the numbers in Table 2. To further protect the anonymity of participants, analysis is presented in the form of individual responses, as opposed to dyad responses or comparisons between mother and child.

Eight theoretical codes were identified and are presented in Table 2 below. These theoretical codes comprise 29 focussed codes, each made up of the initial codes that were developed during the first stage of coding. A summary table presented in Appendix 12 illustrates the presence of focussed codes across participants. A diagrammatic model is presented at the end of this chapter, showing the relationship between the theoretical codes.

Mothers and adolescents tended to provide similar narratives in their descriptions of HIV communication with one another. Generally, they reported talking and not talking about the same HIV-related topics with similar triggers and barriers identified. Some mothers and children differed in their beliefs about the amount of desired HIV communication. When one half of the dyad wanted to talk more about HIV, this had not been communicated to the other person due to

a number of barriers (described below). Some topics were only described by one half of the dyad; for example, only mothers described reassuring their children about living with HIV and only adolescents described wanting to avoid sex communication, believing it to be awkward.

*Table 2: Theoretical codes, sub-codes and properties*

| THEORETICAL CODES | FOCUSSED CODES | INITIAL CODES |
|---|---|---|
| **1. Triggers to HIV communication post full disclosure** | **1.1 Adolescent having specific questions about HIV** | Adolescent initiating conversations about transmission<br>Asking questions about HIV<br>Needing something answered |
| | **1.2 HIV being mentioned in the media** | Being prompted to talk when HIV mentioned in the media<br>Advising daughter to listen to radio show |
| | **1.3 Choosing a suitable time for conversations to happen** | Daughter's age breaking down remaining boundaries<br>Recalling a change in HIV conversations when older<br>Having discussions once adolescent had learnt about HIV |
| | **1.4 Adolescent feeling distressed** | Attributing increase in discussions to child's difficulties<br>Adolescent showing his distress<br>Being upset and wanting to talk more about HIV |
| **2. Barriers to HIV communication** | **2.1 Lacking self-efficacy in communication skills (with strong cultural influence for mothers)** | Lacking skills to have a conversation with daughter<br>Not knowing the words to use<br>Attributing communication difficulties to culture |
| | **2.2 Lacking the time, availability or privacy to have conversations** | Having limited time for HIV discussion<br>Being too busy for communication<br>Needing there to be no one else around to talk about it |
| | **2.3 Adolescent's lack of willingness to discuss HIV** | Adolescent resisting talking about HIV<br>Recalling lack of willingness to talk about it<br>Adolescent not wanting to talk about appointments |
| | **2.4 Anticipating (and wanting to avoid) adolescent distress** | Attributing lack of discussion to son's avoidance of distress<br>Not wanting to upset adolescent<br>Trying to close down HIV conversations |

| | | |
|---|---|---|
| **3. HIV topics that are up for discussion** | **3.1 Mother providing medication reminders or encouragement** | Talking about medication every day<br>Explaining the risks of non-adherence<br>Mum encouraging medication adherence |
| | **3.2 Mother discouraging onward disclosure (and offering advice on how to maintain secrecy)** | Being advised by parents not to disclose<br>Parents discouraging disclosure to partners<br>Having to destroy letters from the hospital<br>Suggesting a partner with HIV would be better |
| | **3.3 HIV transmission (perinatal infection and guilt)** | Describing maternal HIV transmission<br>Discussing regrets over transmission |
| | **3.4 Mother providing reassurance to adolescent** | Reassuring daughter she can live a normal life<br>Comparing HIV in the UK to others around the world<br>Reassuring son that HIV is not a barrier to a happy life |
| **4. Experience of HIV communication** | **4.1 Experiencing conversations as difficult/stressful/awkward** | Feeling anxious when adolescent initiates conversation<br>Finding it difficult to talk about HIV<br>Feeling forced into discussion |
| | **4.2 Conversations being kept to a minimum / lacking depth** | Talking about HIV infrequently<br>Believing that conversations lack depth<br>Talking to mum once or twice after diagnosis<br>Having quick conversations with mum about HIV |
| | **4.3 Level of satisfaction with amount of HIV communication** | Wanting more HIV discussion with adolescent<br>Being satisfied with amount of HIV talk<br>Recalling past wish of wanting more discussion with mum |
| | **4.4 Adolescent feeling frustrated over different beliefs to mother** | Describing differences in hers and mum's beliefs about HIV<br>Wanting mum to understand his point of view<br>Feeling that parents' advice is not relevant |
| | **4.5 Adolescent perceiving mum as being supportive** | Perceiving mum as wanting to help<br>Perceiving mum's wanting to talk as an example of her care<br>Perceiving mum's advice as a sign of her protecting him |

| | | |
|---|---|---|
| **5. Factors that influence ongoing HIV communication** | **5. 1 Having less need to talk about HIV over time** | HIV's importance shrinking over time<br>Not needing to talk about onward disclosure with mum<br>Forgetting about status<br>Believing there is little left to talk about |
| | **5.2 Mother perceiving the adolescent to be receiving enough information or support elsewhere** | Knowing that adolescent has opportunity to ask questions at support groups<br>Having trust in clinicians to give daughter information<br>Citing nurse as having role as HIV educator |
| | **5.3 Adolescent finding it easier to talk elsewhere (at clinic/support group/siblings)** | Talking about HIV at group is easier<br>Finding it easier to talk to sister<br>Preferring to talk about HIV at the clinic |
| | **5.4 Mother's experience of stigma – (anticipating, observed, enacted) and wish to protect child** | Trying to protect daughter from stigma<br>Being unable to be open because of experiences<br>Viewing health professionals as fuelling the stigma<br>Hearing people with HIV being called an animal<br>Seeing nurses afraid to take her blood |
| **6. The impact of HIV communication** | **6.1 Positive impact of HIV communication** | Viewing HIV communication as a factor in increased closeness in relationship<br>Adolescent feeling better for talking about it<br>Feeling supported<br>Learning more led to medication adherence |
| | **6.2 Negative impact of HIV communication** | Feeling worried after HIV discussion with son<br>Noticing son's low mood after HIV discussion<br>Talking about relationships leads to feeling sad |

| | | |
|---|---|---|
| **7. The Role of Others** | **7.1 Recognising the important role of support groups and clinic staff in providing HIV information and support** | Feeling able to talk about anything at the group<br>Support group covering a wide range of topics<br>Feeling lucky to have the space to talk freely<br>Being helped by clinic staff to understand HIV |
| | **7.2 Receiving social support** | Friends seeking advice and support from one another<br>Being closer to friends at support group<br>Making friends at camp and support group<br>Perceiving family to be supportive to mum |
| | **7.3 Role of services - identifying a need for support with family communication about HIV** | Believing that support group could have run family sessions<br>Recalling never having being asked about their relationship<br>Wishing for someone to help connect them 'create a bridge' |
| **8. Sex communication is off limits** | **8.1 Mothers' cultural experiences and beliefs about the parental role** | Citing cultural influence over talking about sex with children<br>Citing parental role as reason she is unable to talk to children about sex<br>Talking about sex with mum doesn't feel right |
| | **8.2 Adolescent anticipating (and wanting to avoid) awkwardness with mother** | Talking about sex with mum would be awkward<br>Feeling embarrassed<br>Predicting conversation would be awkward |
| | **8.3 The role of others in sex communication** | Believing that child has suitable support about sex<br>Identifying support group as place where child can talk about sex<br>Finding it easy to talk about sex with close friend<br>Finding it easier to talk to clinic staff |

## 1. Triggers to HIV communication post-full disclosure

All five young people were fully disclosed to (i.e. when HIV was named) at the clinic between the ages of ten and twelve. In the time since disclosure, all participants reported having conversations about HIV at home and described several triggers that led to discussion.

### 1.1 Adolescent having specific questions about HIV

Nine of the ten participants described occasions where the young person approached their mother with specific questions about HIV. These questions covered a range of topics, although tended to be requests for factual information such as wanting to know about HIV transmission or other virus specific information. One adolescent also described wanting to hear more about their mother's own experiences.

*"The one time was maybe when I asked how did I get it and then she said it was from mother to daughter,"* (AD-F)

*"It was then like starting to enquire a bit more and starting to talk about it to mum and dad saying like, 'well how did you find it when you found out and how did you react and what sorts of things did you do?'"* (AD-D)

Rarely did mothers and adolescents describe occasions where the mother would approach their child wanting to discuss HIV and, as will be described later, a number of barriers prevented mothers feeling able and willing to do so.

### 1.2 HIV being mentioned in the media

Another catalyst to HIV communication was its mention in the media, usually on the television or radio. Mothers tended to be more likely to recommend their child watched or listened to it, thus indirectly raising the topic.

*"There was a programme I watched the other day and I saved it and said to <child>[1] you need to watch this programme,"* (BM-I)

*"Sometimes, there was something on the radio, they were talking about it, there was <support camp> on Radio 4...and I asked her to listen to it,"* (BM-E)

Some mothers described wanting their child to listen or watch a programme to learn more about HIV. Others had less choice over the timings of conversations, as programmes had come on whilst watching the television together, prompting a discussion there and then.

### 1.3 Choosing a suitable time for conversations to happen

Certain conversations about HIV, particularly those concerning relationships, tended to happen once the adolescent had reached an age where the mother thought it appropriate to raise the issue.

[1] Words placed within an arrow bracket (i.e. <child>) are used to ensure anonymity. Words placed within square brackets (i.e. *[HIV]*) have been added by the researcher so that the extract can be easily understood. A string of dots (….) denotes that a section of the extract has been removed to promote the clarity of the quote.

*"I think we've gotten with the age that she is, I'm beginning not to have any boundaries,"* (BM-E)

This was stated in a way that indicated the mother was pleased to be able to talk more openly with her child. In fact, BM-E was the only mother who felt able to speak freely about HIV with her child, particularly once she had gotten older. Some adolescents also noticed a shift in discussion, which tended to focus more on medical aspects of HIV when first disclosed to, before branching out into other topics.

*"When I got to like, 15, that was when they started to become more about future relationships,"* (AD-J)

This approach to HIV communication reflected the perceived need to initiate conversations about sex and onward transmission as the adolescent became older (although many struggled to do this, as will be discussed in a later section). Several mothers indicated that they had waited until their child was older before talking about relationships, although it was unclear as to why they had chosen a particular age or time to raise the issue. These decisions tended to be culturally informed, with one mother stating that she was planning to talk to her child about relationships at a younger age than if they had lived in her country of origin.

*"In this country I would [talk about relationships earlier with child] because of the society we are living in, but just comparing to people in the same position as me back home they wouldn't, but in this country I think I have to,"* (BM-I)

One mother also described waiting until her child had received enough information about HIV so that they could discuss it together.

*"Then I had to talk about [HIV] me and her openly, more, 'cos she's aware of this, there's more information, she's at this stage of knowledge about HIV,"* (BM-G)

**1.4 Adolescent feeling distressed**

Mothers and young people also described occasions where the adolescent's distress had initiated HIV communication. Young people described being upset and frustrated with HIV interfering with friendships, relationships and job prospects.

*" [We last spoke about HIV] two weeks ago because he wanted to talk to me about how it's affecting his life and his confidence, he says it gets him down because of it. And he was emotional about it,"* (BM-C)

The availability of social support was somewhat reduced for adolescents and their families due to feeling unable to share their status with others. For one adolescent, the devastating impact HIV had on her desired career choice left her with little option but to talk to her parents. This marked a significant shift in the

amount of HIV communication at home, creating the opportunity for more frequent discussions.

*"I'd done all my applications to go to a special sixth form for it and everything and then because of my status they said I couldn't join so…I was fuming…I couldn't really not talk about it with my parents so like, I had to then talk about it with them and it sort of started becoming to a point where we could talk about it more often,"* (AD-D)

## 2. Barriers to HIV communication post full disclosure

Mothers and adolescents described several barriers to HIV communication. These were made up of motivational barriers (i.e. citing reasons not to talk about HIV) and volitional barriers (i.e. factors that got in the way of talking despite wanting to).

### 2.1 Lacking self-efficacy in communication skills (with a strong cultural influence for mothers)

Mothers and adolescents reported feeling that they lacked the skills needed to initiate or participate in a conversation about HIV. For some this was related to particular topics (e.g. adolescent romantic relationships) but for others it interfered with a range of subjects, thus limiting nearly all HIV communication.

*"It's one of them ones like, I dunno how to phrase the words to her and all of that so... I dunno what to exactly say..so then I'll just leave it,"* (AD-F)

This was stated with some sadness and the same adolescent described wanting to have more discussion about HIV with her mother. Several mothers described a strong link between their upbringing and culture and how this influenced their perceived ability to communicate with their child. Some spoke of perceiving differences in the way parents of British origin communicate with their children, viewing them as being more open to discuss sensitive matters, something they felt unable to do.

*"I find myself at a loss of words and really unable to communicate my deepest thoughts. I feel that I'm not completing what I'm meant to do as a parent, to be more open and talk freely, because of my culture it's, it's something in my mind that's keeping me back from discussing more issues… I never grew up discussing anything with my parents so it's really difficult for me. I didn't have that experience to discuss with my child, especially, more issues like this which are very sensitive,"* (BM-C)

All the mothers were diagnosed with HIV as an adult and as such, did not have the experience of talking to their own parents about HIV as a teenager. The only mother who spoke of having an open communication style with her parents, also described having the most open communication style with her HIV-positive daughter, both on topics related and unrelated to HIV.

### 2.2 Lacking the time, availability or privacy to have conversations

Seven participants described lacking the time to talk about HIV at home due to having other commitments, for example work or school assignments. Adolescents in particular spoke of having to focus their attention on schoolwork as they entered into exam years.

*"When I was younger it was, like, there was more communication but, like, since then it's, like, distance because she's doing her work and then… I'm now growing up to do, like, my work so I'm finished my GCSEs, doing A levels and thinking about uni,"* (AD-F)

Participants also spoke of lacking space and privacy to talk at home, either because other family members were unaware of their status or preferring to keep conversations private.

*"I think he would er, I think he would talk to me but we don't have that much space even to talk about [HIV] because small children are around and it's only sometimes when we find ourselves by ourselves that we talk about it,"* (BM-C)

As families struggle to find space to talk at home, their only option might have been to talk about HIV at the clinic (or at support groups, if available).

### 2.3 Adolescent's lack of willingness to talk about HIV

Mothers and adolescents described occasions where the young person did not want to (or appeared as if they did not want to) talk about HIV and, as a result, conversations were never initiated or were cut short.

*"If mum or dad attempted to talk about it I'd shut it down like, I'd say 'I don't want to talk about it, let's move on from the topic.' I really didn't want to talk about it and was really closed off with it… I was at the point where like sometimes I could say that I was in denial about it,"* (AD-D)

As was shown in section 2.1, both mothers' and adolescents' beliefs about their inability to talk about HIV led to avoid doing so. This lack of confidence in their communication skills may have led to a lack of willingness to talk about it. Three mothers also described perceiving that their child did not want to talk about HIV (despite this not always being the case). This perhaps resulted in adolescents feeling uncomfortable to raise the subject or believing that HIV should not be discussed at home. One young person described feeling able to talk about HIV only once their mother had brought it up, perhaps viewing this as permission to discuss it with her.

*"Yeah, at the time I was able, yeah. Once she'd brought it up I was able to,"* (AD-B)

### 2.4 Anticipating (and wanting to avoid) adolescent distress

Both mothers and adolescents described avoiding HIV communication so as to prevent the adolescent becoming distressed. Mothers described occasions where HIV communication had led to their child becoming upset and so chose not to raise the topic again. One mother also spoke of avoiding communication because she wanted her child to feel normal.

*"I think he likes to be more open about [HIV] but when he discusses about it he gets emotional and he finds it more er, a bit more down than before so he doesn't raise it that much and I don't want to raise it on him if he doesn't want to discuss, I don't want to force it on him,"* (BM-C)

*"I don't want to frustrate her all the time, I want her to feel that she is a normal child,"* (BM-A)

When asked how they felt about their child's distress, several mothers spoke of the guilt and regret they feel over the transmission, despite not being aware of their own status at the time and therefore unable to prevent it.

*"It was very difficult for me, because it would have been prevented if I had known that beforehand… I didn't know. It hurts, it hurts all the time because it's a burden you carry all your lifetime,"* (BM-C)

Adolescents also described avoiding HIV communication so as to avoid becoming upset or angry.

*"I was so shut off about it and it was one of those things where if I did talk about it I'd end up in a really bad mood so I just used to avoid it completely,"* (AD-D)

## 3. HIV topics that are up for discussion

In spite of the barriers described above, participants described a set of topics that were more easily and frequently discussed.

### 3.1 Mother providing medication reminders or encouragement

All participants described frequent occasions where mothers would remind the adolescent to take their medication, either in response to reluctance from the adolescent or a wish for their child's viral load to become undetectable. Mothers also spoke to the adolescent about the lack of medication in some parts of Africa and how lucky they were to have it so readily available.

*"Back home people don't get their medicine and saying that people back home can't find, they can't have the drugs, they want the drugs but they can't have them…so I will be telling them, you are lucky you've got the medicines, you need to take them,"* (BM-I)

*"Mum will try and motivate me to like, say like, 'oh get undetectable' and like, 'you can take one pill once per day and it'll be fine,'"* (AD-D)

Reminders tended to happen daily, with some adolescents describing this as being helpful. A shift in medication responsibility and reduction in these reminders was described as adolescents became older and were spending more time away from home.

*"They used to do it daily but now they're like, your meds, you take the responsibility,"* (AD-D)

### 3.2 Mother discouraging onward disclosure (and offering advice on how to maintain secrecy)

Seven participants described occasions where adolescents were instructed by mothers not to share their status with anyone outside of those who already knew (mainly family members and clinic staff). Mothers tended to warn adolescents about the reaction they would receive, predicting negative responses and rejection from friends.

*"When she came to know about it I just said, started directing her please avoid, please avoid, please avoid, please avoid [telling anyone],"* (BM-G)

*"They're completely and utterly against it. Like, they don't want me to disclose because they don't think that like, my friends will stay…that if things go badly that at the end of the day, you just lost a friend and like, the implications that it can have on your life like, you don't know who that person is going to tell,"* (AD-D)

This was stated in a somewhat defiant way, as the adolescent did not agree with her parents. As will be discussed later, a number of adolescents struggled with feeling as though they had to hide their status from friends. To avoid being asked questions by others (e.g. when on school trips or having guests to stay) mothers also offered adolescents advice as to how to keep their status a secret.

*" I would try to think of ways, how could she [take her medication], how could she, for example I say, 'OK, instead of maybe getting it from your suitcase you could put it into your toilet bag so when you're going to the bathroom you just say you're going to brush your teeth before you go to bed so that you can have it,'"* (BM-G)

Discouraging onward disclosure extended to adolescent romantic relationships, with some mothers advising their children to seek out a partner with a positive status, something the adolescents did not readily agree with.

*"Yeah, that type of [romantic] relationships, I mean, but in her mind, me and her we have two different mind-sets; her mind-set is find someone alike, and my mind-set is find someone that will like me for who I am,"* (AD-B)

As will be discussed in section 5.4, some adolescents find these conversations frustrating as they disagree with their mothers' perspectives about onward disclosure, often as a result of hearing different experiences at support groups.

### 3.3 HIV transmission

Several participants recalled having conversations about HIV transmission. As well as describing how HIV had been transmitted, mothers also spoke of expressing their regret to children, explaining that they could not have prevented transmission from occurring.

*"So I have explained myself to her that if I had known that this is the status that I had then I would never have breastfed or if I was supposed to be breast feeding I would have taken antiretrovirals,"* (BM-E)

### 3.4 Mother providing reassurance to the adolescent

This is a topic only mothers' described as an example of HIV communication. Several recalled providing their child with reassurance about living with HIV, particularly in the context of 'living a normal life.'

*"I always encourage her like, I will say, 'OK you see me, you are able to work, you are able to live a normal life,' you know those kinds, I try to be like a role model into her life and ah, she's able to see other friends as I said…we're living a normal life,"* (BM-G)

Mothers also made comparisons with HIV in other parts of the world, to try and highlight the lesser impact of HIV in the UK.

*"People in <country of origin> or in Africa are not very quick to treat it and it can kill a person within weeks, so you shouldn't worry about that,'"* (BM-E)

## 4. Experience of HIV communication

Mothers and adolescents were able to describe what it was like talking about HIV and how these conversations were experienced.

### 4.1 Experiencing conversations as difficult, stressful or awkward

Seven participants described finding it hard to talk about HIV and that conversations could be stressful or awkward. Some of these experiences related to having beliefs about lacking the required skills to talk about HIV.

*"So when I'm talking to her about it, it's hard for me to put it into, I try like, correctly phrase it so that it gets to her and so she understands it but, she can't see what I'm thinking so it's kind of difficult for me,"* (AD-B)

Some adolescents also spoke of feeling forced into having conversations before they were ready to do so, or at times they did not want to talk about it.

*"Yep. The thing is like, when I was 14, I didn't want to talk about it but I sort of had to, it was one of those things where I felt it was forced,"* (AD-D)

This was stated in the context of the young person feeling that her mother and clinicians were attempting to talk about HIV before she was ready. Despite

struggling with this, she later described feeling positive that her mother had persisted, as talking about HIV had had a positive impact on her coping with HIV and on their relationship (see section 6.1).

### 4.2 Conversations being kept to a minimum or lacking in depth

HIV communication was described by seven participants as occurring infrequently, with conversations tending to be short and lacking in detail.

*"It's not really spoken about and then when it is spoken about it's like.. just get it over and done with and said than going into depth,"* (AD-F)

*"Yeah I talked to her, I think I talked to her once or twice after about it and then…I don't think we ever talked about it again after that…it's mostly a quick 5, 6 minute max chat yeah,"* (AD-J)

As will be described in the next section, some participants were satisfied with having minimal discussion, whilst others wanted more.

### 4.3 Level of satisfaction with amount of HIV communication

Several participants spoke of feeling satisfied with the amount of family HIV communication, despite it being quite limited or brief in nature.

*"Yeah it's fine...we talk about it when we need to talk about it and not when we don't need to,"* (AD-D)

Some mothers, however, spoke of wanting to talk more with their children about HIV, or of only feeling satisfied once the amount of communication had increased. Mothers tended to be motivated by wanting to help their child.

*"Not enough that's what I think. I want to talk more about it. If there is anything I could put a light on, if there is anything that worries him, I want to discuss it more,"* (BM-C)

*"This year she has, she has opened up quite a lot [about HIV] and I am glad, I think we have turned a page or turned a corner around that. So, I would say, yeah the relationship now is where it should be,"* (BM-E)

One adolescent recalled a period in which they would have liked to have more conversations with their mother, but that eventually her questions had been answered at a support group.

*"I used to want to have more discussions but then now most of the questions that I wanted have, um have been answered already,"* (AD-F)

### 4.4 Adolescent feeling frustrated over differing beliefs to mother

Several adolescents described having different beliefs to their parents about HIV and of feeling frustrated by conversations. Much disagreement centred around the topic of onward disclosure and romantic relationships, as was briefly described in section 3.2 of this chapter. Whilst mothers would encourage

children to avoid disclosing to friends or to have relationships with people who were also HIV positive, adolescents spoke of wanting to be more open about their status and of wanting to find a partner who accepted them for who they were. These feelings of frustration appeared to contribute to adolescents' lack of willingness to discuss HIV with their mothers, thus perpetuating this barrier to HIV communication (as described in section 2.3).

*"She would say stuff like, 'find someone alike, find someone like this, find someone like that,' and I'll be thinking but, is it for you to be happy or is it for me to be happy… So, we can't come to a compromise so it kind of side tracks me and it kind of, for the rest of the afternoon or day or whatever, it'll be on my mind, so I don't really like talking about it with her, I just try to, you know put it aside and you know, just continue,"* (AD-B)

The three adolescents who spoke of having different beliefs about disclosure and relationships were those who attended support groups and therefore exposed to hearing about a broader range of experiences of people living with HIV. One adolescent described feeling that their parents were out of touch with current views on onward disclosure and living with HIV.

*"I think that some of it's such a long time ago that like, I feel like, some of the things which they say it's not really relevant 'cos like, we live in a different day and age and they grew up in a different age,"* (AD-D)

### 4.5 Adolescent perceiving mum as being supportive

Despite adolescents and parents disagreeing about some topics, several described feeling that their mother's intentions behind their advice stemmed from a place of support.

*"Because I've asked…she might as well say the answer than leaving the question on my mind because she would know that it would still be on my head and yeah.. it's better just said.. then and to just get it out,"* (AD-F)

None of the adolescents described feeling unsupported by mothers, although some spoke of finding it easier to talk about HIV elsewhere, as will be discussed in the next section.

## 5. Factors that influence ongoing HIV communication

A number of factors were found to influence both the choice of topics discussed and the experience of having these conversations.

### 5.1 Having less need to talk about HIV over time

Several adolescents and mothers spoke of having less need to discuss HIV over time, so that it became a less important or necessary topic of conversation. Both referred to the adolescent being given the right amount of factual information so that conversations were no longer necessary.

*"Maybe because, I've got to the point where, most of the stuff I know so yeah… there ain't really much to explain about it,"* (AD-H)

Other young people spoke of adjusting to the diagnosis and feeling that its significance reduced over time, resulting in less need to talk about it.

*"Yeah, yeah. It's like a washing machine, when you put the wrong clothes into a washing machine, over time it's shrunk and shrunk... It's not something that I would keep in the front of mind, like every day, every minute kind of thing,"* (AD-B)

This may explain why young people and their mothers described feeling satisfied with the amount of HIV discussion at home, despite it being limited, because they feel they have been provided with, or imparted, enough information. It suggests that some adolescents want to be given factual information about HIV following full disclosure, so that they have an understanding of the virus and its consequences, but that there comes a time they no longer wish to discuss it. Mothers may feel that once children have enough factual information about HIV, that there is little else to talk about.

*"I don't really see it as something that we really have to talk much about because she has, she's grown into a…she's got quite the right amount she's got amount of, of knowledge about it and…I don't see really any much to talk about it,"* (BM-G)

### 5.2 Mother perceiving the adolescent to be receiving enough information/support elsewhere

Several mothers spoke of their feeling that their child was getting enough support and information about HIV elsewhere, usually at the clinic or at support groups.

*"No, she didn't have that much question because she got a nurse that's teaching her everything, that's <nurse> here [at the clinic], so they are really good so I'm really happy about that and doctor as well,"* (BM-A)

This could be one explanation as to why families have described minimal HIV communication at home, as mothers feel the role of sharing information and supporting their child is being taken care of elsewhere. Some mothers also perceived their child as preferring to talk about HIV elsewhere because of the relationship between teenagers and their parents, and of young people wanting to keep things private.

*"Maybe if he talks more with his physician, consultant, or some of the people from his err <support group> I hope. Because it's not always the same talking to your parents and talking to someone else about it. Because with your parent you're scared that they might say something negative about whatever you're trying to do…but with other people you can talk freely and yeah,"* (BM-C)

### 5.3 Adolescent finding it easier to talk about HIV elsewhere

Adolescents also described finding it easier or preferring to talk about HIV with clinic staff and at the support groups. They spoke of being able to support their friends and of being supported in return.

*"It's easier because some of them [friends at support group] have grown up from the first day I went there and I'm still talking with them and all of that and then sometimes if they have a problem they tell me and if I have a problem I tell them,"* (AD-F)

*"I'd rather talk about it in the hospital than anywhere else. I don't know, it's just, at home it's, I don't know it's at home and I don't really want to be talking about it,"* (AD-H)

One adolescent also described feeling content in not talking to her mother about HIV because she knew clinicians or friends at her support group could answer her questions.

*"It doesn't bother me because I know that when I go there that it will be answered 'cos I can ask one of the members of staff and that or one of my friends [at the support group] if, if just on the day I just ask one of my friends,"* (AD-F)

### 5.4 Mother's experience of stigma and the wish to protect her child

Mothers' experiences of stigma were clearly influential in their choosing to advise their children not to tell anyone about their HIV status. Three mothers spoke of witnessing or experiencing stigma from others and described anticipating stigma from others - something they wanted to protect their child from.

*"At one point I was admitted to one hospital and I could tell, the reaction I got from the nurses who were treating me was completely very horrible and very negative yep… Very very very very difficult. I wouldn't like her to go through that but it was peoples' comments and people what they say it just feels so bad, it just feels so bad and so sad,"* (BM-G)

*"Yes, I don't want him to be bullied or to be harassed or to be…told something negative or er, children to you know, to shun from him, to shun from him,"* (BM-C)

Adolescents, however, did not describe any incidents of seeing or hearing negative things themselves, although many referred to understanding their mother's opinion and of being aware that stigma exists. The generational experience not only influenced the advice offered by parents, but also the way it was received and experienced by young people. Despite feeling worried about receiving a negative response and being told not to disclose, two young people felt able to do so after hearing different, less negative experiences at support

groups. Both adolescents described telling HIV-negative friends about their status and viewing these episodes as positive events.

*"I mean he – surprising to me – just really didn't really, he just asked maybe one or two questions, he wasn't really shocked, he wasn't really surprised, he didn't react badly so..that's what really strengthened us as well, like trust between us two… I felt relieved. Cos, it's a relief to tell someone close to you. And, if that's the way they react then... it makes you positive, you're like, ok, so not everyone is pessimistic,"* (AD-B)

None of the mothers had disclosed to their own friends about their status, because of the experiences they had had or witnessed, and their fears over rejection. Hearing other people with HIV talk about their own, positive, experiences of onward disclosure may have given them the courage to do the same.

## 6. The impact of HIV communication

Mothers and adolescents spoke of the impact HIV communication had on their wellbeing and on their relationships with one another, both positive and negative.

### 6.1 Positive impact of HIV communication

The dyad who reported speaking more regularly about HIV at home described several positive outcomes of HIV communication. Both the adolescent and

mother spoke of how talking about HIV had strengthened their relationship and that talking about it had become easier over time. The adolescent also spoke of feeling as though she had more support available in knowing that she could talk about HIV at home.

*"At the end of the day I feel like I've got more support if I need it so, I know that mum's always there to talk about it and like, it's just one of those things which is like, more of a common topic now rather than something which is special topic to talk about,"* (AD-D)

### 6.2 Negative impact of HIV communication

Several participants described negative outcomes following HIV communication including greater worry or distress in mothers and adolescents.

*"I worry more, I worry more [after talking about it], what's his future going to be, how is he going to cope and down from that and start feeling bad about himself, yeah,"* (BM-C)

*"[Talking about] it gets me, sad and depressed a bit,"* (AD-B)

Choosing to 'opt out' of talking about HIV at home may feel easier in the short term, although one young person spoke of how talking minimally about HIV contributed to a breakdown in other aspects of communication, resulting in a more distant relationship over time.

*"Because of the lack of [HIV] communication it's like, I can't really relate anything with her…Because it's like, the lack of communication has been happening for a while so it's like, it's like, we just distant so there's nothing much to say except "hi, how was your day" and yeah. And if there is… anything's happened like school trips I'll just be like, 'mum I've got a school trip, this is what's happening this day' and that's it,"* (AD-F)

This was spoken in a way that indicated the young person was upset about the lack of communication and how it had negatively impacted their relationship. As one family found, persisting with discussions resulted in finding it easier to talk about over time and a positive effect on the mother-child relationship.

*"Yeah, [talking about HIV] has, it has, to a much more closer relationship, open and no barriers to a lot of things,"* (BM-E)

## 7. The role of others

### 7.1 Recognising the important role of support groups and clinic staff in providing HIV information and support

As has been described in sections 5.2 and 5.3, some adolescents and mothers preferred the young person to talk about HIV at the clinic and support groups. Every participant described the benefits of being able to talk with experienced professionals in a non-judgemental environment.

*" I don't have any complaints at all. You know the difference we feel like we can talk in this environment, they don't er, I haven't seen any judgement, they don't judge us, it's different, you are treated as if you are any other person in a normal way, it's not like, I've never seen anything negative from the staff you know, the nurses, receptionist, I haven't seen anything you know,"* (BM-A)

*"It's good. It's a haven. Very good. You know, finding a place where you can easily, openly talk without getting judged, that's….you know, you'll be very lucky, cos there's not a lot of them. It was only when I was, 12, 13 when I found out about <support group> and not even to the extent that I know now, and I'm very glad that I did cos it's a very good place, yeah,"* (AD-B)

Unlike the experience of talking about HIV at home, adolescents described being able to speak freely, particularly at support groups, about a range of topics associated with HIV.

*"We talk about friends, relationships, events that are gonna happen, school life, education, like everything… Every week it's different. You can't really gauge it, one week it could be about sex education, one week it could be about you know, facts on HIV or it could be about identity, it really ranges,"* (AD-B)

### 7.2 Receiving social support

Mothers and adolescents described the increased level of support the young person had received from attending support groups and in having the opportunity to talk to and make friends with other young people with HIV.

*"She has also got friends who are in the same situation and up until last year when she went to camp it made her feel so much better because you know she is not living alone, she is not the only one,"* (BM-E)

*" I went to <camp> this year and I loved it, 'cos the thing is, I made so many friends and I keep in contact with pretty much all of them and like we talk like, some of them I talk to on a daily basis and it's like, well OK, if I can talk about it here at <camp> what's stopping me from going to <support group> and I was like, OK, let me take a go at it and see how things go and like, I just started going and obviously I started making friends and like, it became more of a, I like going,"* (AD-D)

As with the role of professionals, having access to a network of peers may influence parent and child beliefs as to how important or necessary it is to discuss HIV at home. Young people spoke of finding it helpful to have time away from home and of having the option of speaking to people their own age who were outside the family.

*"I guess it's like an opportunity to like..be away from family life and just be with people round your age who are like you and you can relate to which is a good environment,"* (AD-F)

### 7.3 Identifying a need for more support with family communication about HIV

Having the opportunity to talk about HIV with experienced professionals and peers is clearly important for adolescents – something that is also recognised by mothers. None of the participants reported that healthcare professionals had offered or provided support with family communication about HIV. Two participants described wanting support from services with HIV communication at home, either presently or in the past.

*"Yeah it would have been, it would have been helpful to have someone in the middle to create a bridge between us,"* (AD-F)

*"Yeah, if there was someone to support me to do those conversations it would have flowed more, yeah,"* (BM-C)

The two participants who spoke about wanting support had quite a lot of contact with a variety of services, and still they felt it was important to be able to discuss HIV within the family. This suggests that whilst services offering a space for HIV communication are extremely important, familial discussion also has a role to play.

## 8. Sex communication is off limits

One topic of HIV-related conversation that was described as absent from familial communication was sex. Nine participants described sex as being something they were unable to discuss with their mother or child.

*" I can't talk about sex with her, no. Uhhh that kind of conversation to be honest with you I wouldn't talk to her about,"* (BM-G)

*"I mean, but, with other things, nah. Relationships as far as we've got..and I don't wanna, I wouldn't even think to push it,"* (AD-B)

The factors that influenced the avoidance of sex talk between mother and child will now be discussed in turn.

### 8.1 Mothers' cultural experiences and beliefs about the parental role

Several mothers spoke of the impact culture had on their decision to avoid sex communication with their children. They referred to their country of origin and of their understanding that sex was not something parents should discuss with their children, as they had not done with their own parents. Some perceived practices to be different in the UK, but that their own experience had led them to make the decision not to discuss it. One mother felt that communication about sex with children was the role of extended family members, such as aunties, and not hers.

*"It's just maybe that kind of relationship of girlfriend and boyfriend because we don't really talk about it much. It's like a cultural thing you wouldn't, from back home you wouldn't talk to your parents about, the culture is used to like if you get a girlfriend or boyfriend you talk to the aunties those kind of things,"* (BM-G)

Some mothers spoke of mentioning contraception to their children, usually in the form of advising the adolescent to be careful or to use a condom, but that this was as far as conversations would go. None of the participants described having conversations about deciding when they might be ready to have sex, physical acts of sex, sexuality or sex in the context of having HIV.

### 8.2 Adolescent anticipating - and wanting to avoid – awkwardness with mother

Adolescents also described avoiding conversations about sex with their mothers, feeling that doing so would be very awkward.

*"It's just really awkward. Even talking about relationships is pushing it…if we went to that, it would, that's it, it wouldn't really work, really,"* (AD-B)

*"Like, with her cos like, she's my mum, it's like I'm sort of scared like how's this going to go or something…Like, be really awkward, just not be able to talk to her about it,"* (AD-H)

Like mothers, adolescents appeared to have ideas about the role of parents in sex communication, believing that they were not the right person to talk about sex with. Wanting to avoid sex communication also acted as a barrier to HIV communication. One adolescent spoke of not wanting to talk about HIV in case it led on to the topic of sex, something they would find too awkward or embarrassing.

*"The reason I don't want to talk about HIV with my mum is in case it leads on to talking about sex,"* (AD-H)

### 8.3 The role of others in sex communication

In the same way that mothers and adolescents came to rely on external systems to talk about HIV, participants spoke about their ability to talk about sex with clinicians, friends and at support groups.

*"She feels free… 'cos I tend to get feedback from them, 'she's open, she's spontaneous' she participates very well in them and talks in groups with others. I think she gets the kind of support that she needs,"* (BM-G)

Young people also spoke of finding it easier to talk to clinicians about sex, particularly in the context of HIV, as they were able to offer advice from a medical perspective and were less judgemental.

*"So like we'll have conversations about [sex] like, in regards to my health and like what implications sometimes it can have and sometimes like what paths are better to go down um and it's just a lot easier to talk to [clinicians] about it because like, I can get more informed knowledge so it's just easier for me to understand,"* (AD-D)

## A model of HIV communication between mother and adolescent

One aim of this study was to develop a model of HIV communication between mother and adolescent. Figure 2 below outlines how the main themes (i.e. the theoretical codes) interact in relation to HIV communication between mother and adolescent, following full HIV disclosure to the young person. The focussed codes occurring most frequently across individuals - those that have been discussed in this chapter - sit under each of the eight theoretical codes and are included within the model.

The model begins with identifying common triggers and barriers to HIV communication (boxes 1 and 2). The barriers to HIV communication resulted in no communication occurring or a reduction in the likelihood of further HIV communication. The triggers to HIV communication led to a group of topics that were discussed (box 3) and the experience of HIV communication was described (box 4). A number of moderating factors influenced both the content of what was discussed and how conversations were experienced (box 5). The outcomes identified following HIV communication are also included (boxes 6.1 and 6.2).

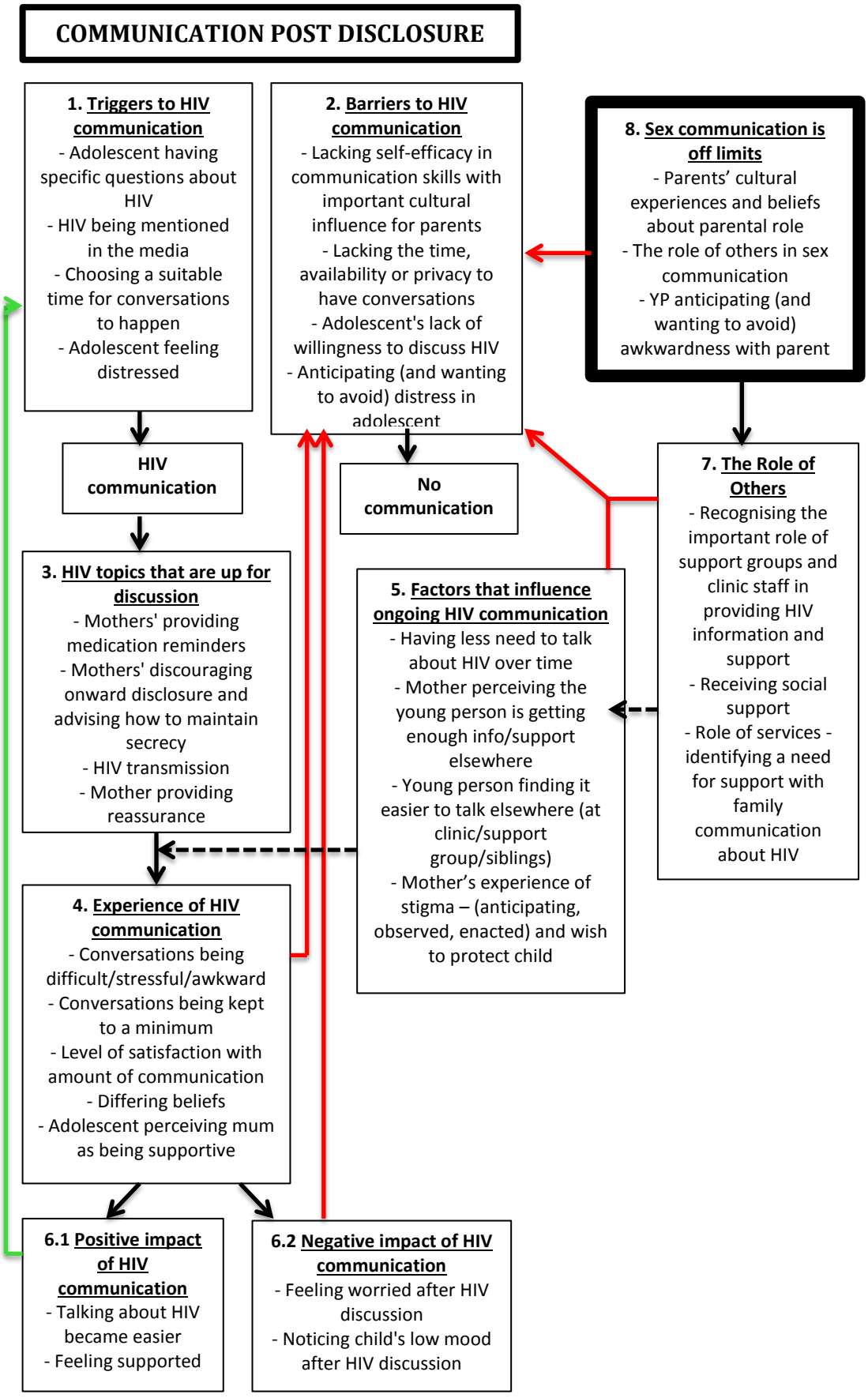
The black arrows show the direction of the communication in chronological order; for example, a trigger to HIV communication then led to HIV being discussed. Dashed black arrows indicate the presence of a moderator, that is, factors that changed the nature or strength of the relationships between different variables. As an example, a young person may have found it easier to talk to their doctor about HIV. Here, the role of others (box 7) and the young person's beliefs about whom they prefer to talk to (box 5), resulted in minimal discussion with their mother. Having the opportunity to talk to their doctor also led to feeling satisfied about having limited familial communication.

Red arrows indicate feedback loops into the barriers to HIV communication. These occur where experiences of HIV communication, either within the family or elsewhere, led to a lack of further HIV communication between parent and child at a later date. An example could be an adolescent finding it distressing to talk about HIV with their mother and, in wanting to avoid further distress in the future, choosing not to discuss HIV with their mother at a later date. The green arrow indicates the event whereby the positive impact of talking about HIV with their mother led to further discussion at a later date. An example may be an adolescent perceiving their mother as being supportive and so when feeling distressed, choosing to seek support from her again.

Sex communication is included in a separate, blocked off box to indicate its absence in the mother-adolescent dyad. The red arrow towards the barriers to HIV communication is included to indicate how a reluctance to talk about sex

interfered with HIV communication. The black arrow leading to box 7, 'the role of others,' demonstrates the adolescent and maternal view that it is preferable for sex communication to occur elsewhere.

*Figure 2 – A model of mother-adolescent HIV communication post-disclosure*



# Discussion

This study explored communication about HIV between adolescents with perinatally acquired HIV and their biological mothers, following full disclosure to the adolescent. Five mothers and five adolescents were interviewed with the aim to answer the following question:

*How do adolescents with perinatally acquired HIV and their biological mothers experience familial HIV communication following full paediatric HIV disclosure?*

Specifically, the study sought to: -

- Explore which factors facilitate or act as a barrier to HIV discussion
- Explore how family members feel about existing HIV discussion and its impact on wellbeing
- Ascertain whether family members feel that they need support in having conversations about HIV
- Develop a theory and diagrammatic model of mother-child HIV communication

## Overview of findings

The findings suggest that a number of systemic, cultural and individual psychological factors influence HIV communication between adolescents and their mothers following full paediatric disclosure. Eight theoretical codes were identified and mapped onto a model of family communication, highlighting the relationships between each theme. The eight themes relate to:

1) Triggers to HIV communication
2) Barriers to HIV communication
3) HIV topics that were up for discussion
4) Experience of HIV communication
5) Factors that influence HIV communication
6) The impact of HIV communication
7) The role of others in HIV communication
8) The absence of sex communication

These will now be examined in the context of the three research aims outlined above. Relevant literature will also be presented, incorporating existing research and psychological theory. The strengths and limitations of this study will then be discussed, followed by the researcher's personal reflections. Finally, suggestions for future research and the clinical implications of the study will be proposed.

## Question 1 – Which factors facilitate or act as a barrier to HIV discussion?

### Barriers to HIV discussion

#### *Lacking self- efficacy*

Several participants felt that they lacked the skills needed to talk about HIV effectively. Both mothers and young people spoke of not knowing how to bring up the topic of HIV and described not knowing which words to use. This finding supports previous research carried out in South Africa, reporting that parents

felt lacking in skills needed to tell their children that they were HIV-positive (Kouyoumdijan, Meyers and Mtshizana, 2005). The current findings demonstrate that caregivers' difficulties in talking about HIV continue past status disclosure. Whilst all mothers were present when HIV was named to their child, the significant role healthcare professionals play in paediatric disclosure perhaps contributes to mothers' feeling less able to talk about HIV away from the support of clinicians.

In support of previous findings, communication difficulties appeared to arise in the context of emotional, rather than factual, topics (Proulx-Boucher et al, 2011). Conversations that may have led to adolescent distress in particular tended to be avoided. The WHO (2011) guidelines and much of the research on paediatric disclosure (e.g. Lesch, et al, 2007) have focussed on the presentation of factual information to children. Limited guidance on communication post-disclosure is available for both clinicians and caregivers. It is perhaps unsurprising, therefore, that emotional issues relating to HIV are more difficult to discuss.

An individual's self-efficacy is the belief that one has the means and abilities to produce desired effects by one's actions (Bandura, 1977a). Self-efficacy theory states that when an individual lacks the belief that they have the ability to carry out a desired action, they will have little incentive to persevere in the face of difficulties (Bandura, 1977a). Previous research in a non-HIV positive population has explored the link between adolescent self-efficacy and family communication. A large, longitudinal study in Italy explored adolescents'

perceived self-efficacy to talk about problems with their parents even when things are tense; express positive feelings; manage negative emotional reactions toward their parents; and get their parents to understand their point of view (Caprara, Pastorelli, Regalia, Scabini and Bandura, 2005). The authors then explored the relationship between self-efficacy and familial relationship satisfaction. The findings indicated that adolescents with greater communication self-efficacy experienced family communication more positively and that self-efficacy was associated with satisfaction with family life, both at the time of data collection and at a two-year follow up.

A large study with African-American females found that less frequent parent-adolescent communication about sex was associated with adolescents feeling less able to talk about and negotiate safe sex with partners (DiClemente et al, 2001). It may be that families who adopt an open communication style and who talk about a range of topics provide the child with opportunities to strengthen communication skills and self-efficacy. A child's communication self-efficacy may then encourage more open discussions with family members and a circular pattern ensues. This is consistent with Bandura's social learning theory (1977b), which states that individuals learn from one another via observations of another's behaviour through imitation and modelling. In the current study, both mothers and adolescents reported feeling unequipped to talk about HIV. These feelings may have led to an avoidance of communication on both sides, limiting opportunities to model HIV communication and to improve or become more

comfortable in doing so. Minimal discussions may have therefore strengthened individual beliefs about being unskilled at talking about HIV.

### *Cultural influence for mothers*

In the current study, mothers cited their culture as a barrier to HIV communication. All five mothers were brought up in countries across sub-Saharan Africa. They described feeling both unable and unwilling to talk about certain HIV-related topics (e.g. sex or relationships) with their child, either as a result of their experience with their own parents, or due to wider cultural beliefs as to what is or is not appropriate to talk about with children. This supports previous findings in South Africa and DRC, which reported that parents with HIV felt uncomfortable and emotionally unprepared to discuss HIV with their children both during and post-paediatric disclosure (Kouyoumdijan, Meyers and Mtshizana, 2005; Vaz et al, 2010).

This finding also supports the systems model presented by Steele, Nelson and Cole (see Figure 1, chapter 1), which suggests that cultural attitudes about parent-child communication will influence what is spoken about within the context of illness communication. In the current study, several mothers described an absence of open communication with their own parents and found themselves struggling to talk about more sensitive topics with their child as a result of this.

***The absence of sex communication***

Culture was certainly a factor for mothers when describing barriers to sex communication. The taboo of talking about sex within families across Africa - for parents in particular - has been well documented in the normative population (Amuyunzu-Nyamongo, Biddlecom, Ouedraogo & Woog, 2005; Paruk, Petersen, Bhana, Bell, & McKay, 2005; Mbugua, 2007). Parents in sub-Saharan Africa have described feeling that discussion about sex with children is shameful, immoral or inappropriate (Bastien, Kajula & Muhwezi, 2011). The current findings were, however, at odds with a US study, who found that 95% of HIV-positive mothers (n=57) had spoken to their adolescent children about a range of sex-related topics from the age of twelve (Murphy, Roberts and Herbeck, 2011). This difference may be due to cultural variations, as mothers in the US sample were either Latina or African-American and not born in Africa, as in the current study.

Parental communication self-efficacy has also been described as an important determinant of familial sex communication. A study with African-American mothers and their adolescent children found that mothers with greater sex communication self-efficacy were more likely to discuss sex with their children (DiIorio et al, 2000). Several mothers in the current study spoke of a lack of sex communication with their own parents, contributing to their feeling unable to talk about sex with their own children. This perhaps reflects the wider social norms about familial sex communication described above, although this relationship has also been demonstrated in a US study. Fisher (1991) explored familial sex communication in a non-clinical sample. She found that mothers

who did not talk about sex with their own parents were less likely to have discussed it with their children. The same study showed that the general communication style of the family was related to sex communication, in that families who described their communication style as being open were more likely to have conversations about sex. This highlights the fact that the same relationships (i.e. an absence of sex talk with parents and a lack of sex talk with own children) are present whether one has an STI or not. That is, even when there is an important reason to talk about sex (e.g. stopping others from getting HIV) the same barriers arise. In the same vein, all five mothers in the current study were diagnosed with HIV well after their teenage years and so did not have the experience of talking to their parents about HIV as a teenager. This may have also contributed to their feeling unsure about how to talk about HIV with their own children.

The role of extended family members in discussions about sex across sub-Saharan Africa, particularly that of aunties, has also been described (Bastien, Kajula & Muhwezi, 2011). This is something that several mothers referred to in the current study, feeling that a parent should not be the person to talk about sex with their child. A number of families did not live near extended family members and so perhaps the clinicians and support group workers took on the role of the external family in the UK (this is discussed further in the next section).

Whilst the mothers in the current study felt that culture was a significant barrier for sex communication, familial difficulty or reluctance to talk about sex is also

something that occurs across Western cultures (Schalet, 2004; Jerman & Constantine, 2010; Abrejo, 2011). Parental discomfort in talking about sex with children has been described in Australian and UK families (Kirkman, Rosenthal and Feldman, 2005; Turnbull, van Wersch, & van Schaik, 2008). Parental beliefs that adolescents will receive information about sex elsewhere (e.g. in school) has also been identified as a barrier to sex communication in Western families (Regnerus, 2007).

Adolescents in the current study wanted to avoid sex communication with their parents due to feeling awkward or embarrassed. This is in contrast to findings in a non-clinical sample in the UK, that suggested young people do want to learn about sex from their parents (Turnbull, van Wersch, & van Schaik, 2008). It may be that adding HIV into the equation made things feel more difficult for individuals in the current study, although adolescent embarrassment about familial sex communication in non-clinical samples has been described elsewhere (Schalet, 2004; Buchananarvay, & Keats, 2005). Italian adolescents were found to prefer talking about sex with a same-sex sibling as opposed to a same-sex parent (Guerrero and Afifi, 1995). Other findings have shown that adolescents talk more about sex with friends than with fathers, although communication with mothers was equal to that with friends (DiIorio, Kelley, & Hockenberry-Eaton, 1999). It could be hypothesised that individuals feel more comfortable sharing information with those who are of a similar age and who might be going through similar experiences. HIV support groups provide a

perfect opportunity for this and several adolescent participants described valuing the opportunity to talk to other HIV-positive people of the same age.

### *Wanting to avoid adolescent distress*

The current study showed that some mothers did not want to bring up HIV for fear that the adolescent might become distressed. Adolescents also avoided the topic fearing that doing so might be upsetting for them. A similar theme has been identified in previous research, where children (whose status was not collected) have reported feeling reluctant to bring up HIV for fear of upsetting their HIV-positive parents (Corona et al, 2009).

A wealth of research has highlighted the use of avoidance as a way of responding to or preventing anxiety (e.g. Barlow, 2002; Maner & Schmidt, 2006). According to the communication privacy management (CPM) theory (Petronio, 1991; 2000; 2002), individuals in all relationships have boundaries separating the topics they will discuss and those they will avoid. Decisions over what to discuss are governed by beliefs and rules, described as 'privacy regulation rules', which dictate what information can be shared. The CPM theory states that people generate these rules based on different criteria, including cultural values about privacy and individual motivations for regulating privacy. It is suggested that individuals will avoid topics that might involve personal risk, for example distress or embarrassment, despite perhaps valuing open communication in relationships. The CPM theory also states that individuals may choose to avoid

topics to reduce damage within a relationship, for example, upsetting the other person.

These ideas have been supported in research where individuals have described avoiding topics for self-protection against embarrassment, upset and vulnerability, or to protect and prevent deterioration in a relationship (Afifi and Guerrero, 2000). The findings in the current study also support this theory, where young people explicitly stated that they avoided HIV communication to avoid becoming upset. In addition to wanting to protect their child from distress, it may be that mothers also wanted to avoid conversations to protect the relationship. In accordance with Fitzpatrick and Ritchie's classification of family communication (1994; see Chapter 1), it may be that some of the families interviewed would fall into the conflict avoidance category (wanting to avoid communicating about unpleasant topics that may lead to conflict or distress), although not enough information was collected about general communication style to be sure of this.

Mothers described feelings of guilt and regret over their child's HIV status. Previous findings have identified maternal guilt as a barrier to paediatric disclosure (Hirschfield, 2002). In addition to wanting to protect their child from distress, mothers may also have wanted to avoid HIV communication to minimise their own feelings of guilt and distress. In contrast with previous findings, none of the adolescents described feeling unable to discuss HIV with their mother for

fear of upsetting her or making her feel guilty (Dorrell et al, 2008; Proulx-Boucher et al, 2011).

One mother spoke of wanting to avoid HIV communication so that her child could feel normal. This supports findings in a French Canadian study where an absence of HIV communication was used by young people as a way of coping with HIV, to feel normal and avoid seeing themselves as stigmatised (Proulx-Boucher et al, 2011).

### *Adolescents' lack of willingness to discuss HIV*

Adolescents' unwillingness to talk about HIV was identified as another barrier to HIV communication. Mothers described avoiding the subject, perceiving that their child did not want to talk about it. One young person spoke of feeling able to talk about HIV only once his mother had introduced the topic. It may be that adolescents take the lead from parents as to which topics should and should not be discussed. If a mother does not initiate conversation, the adolescent may feel unable to bring it up. Equally, this pattern of behaviour may lead mothers to assume their child does not want to talk about HIV (as was described in the current study) and so a cycle ensues.

### *Lacking the time, availability and privacy to have conversations*

Several mothers reported not having the time, availability or space to talk to their child about HIV. All but one family were single parent families, and several mothers had three or more children. The fact that some children were HIV-

positive and some were not may also have added to the difficulty of finding a private space to have conversations with one another.

## Triggers to and topics of HIV communication

### *Adolescent showing distress*

Clinical information about adolescent psychological state was not collected, however, four of the five adolescent participants described struggling with their status, of feeling worried about the future or experiencing low mood as a result of being HIV-positive. This is in keeping with previous findings that have shown young people living with HIV can experience mental health difficulties, including anxiety and depression (Mellins and Malee, 2013). Both adolescents and mothers described incidents where the young person's distress had led to communication about HIV.

Mothers described occasions of reassuring their child, telling them that they could live a normal life, work and have children, at times in response to these expressions of distress. Adolescents did not refer to these discussions with parents, although all reported that they felt able to cope with their status most of the time, perhaps partly as a result of parental reassurance.

Research findings with HIV-positive youth in Africa have suggested that sometimes parental reassurance and being told not to worry can be frustrating, as children described wanting both practical support and more detailed discussion (Vaz et al, 2010). This suggests that adolescents require more than

one type of social support, having identified a mix of instrumental and emotional needs (Wills, 1991). Despite being told they could live a normal life, adolescents' descriptions of their experiences would indicate that, at times, they do not feel like normal teenagers. Many felt unable to talk openly about their status with friends and faced challenges with prospective romantic relationships. Mothers may have felt positive about the prospect of a normal life for their child, having made comparisons with historical accounts of HIV, those in their country of origin and relating to their own experiences. This may not have had as much meaning to the adolescents who have spent the majority (if not all) their lives in the UK with access to effective treatment. For them, living with HIV may not equate to a normal life when compared to that of their peers. Friendships have been found to become increasingly important during adolescence (e.g. Brown, 2004), and whilst it might be reassuring to hear about the positive health aspects, the impact that HIV has on relationships and friendships may be of more concern throughout the teenage years.

***Adolescent having specific questions***

Adolescents described occasions of having specific questions about HIV. At times this would result in HIV communication with mothers, although young people also described turning to the internet for answers. Some questions were related to topics that only mothers could answer, for example, how their mother had come to have HIV. Past research has shown that some HIV-positive parents are reluctant to talk about details of HIV transmission with their children (Kennedy et al, 2010). This is not true of the current findings, where several families spoke

about the route of transmission, often as a result of adolescent questioning. It may be that mothers could not avoid the topic when directly asked by their child, or felt that doing so would be unfair. When talking about HIV transmission mothers shared their feelings of guilt and regret with their children. It may be that sharing these feelings was a way of attempting to alleviate them. Some authors have suggested that feelings of guilt in interpersonal relationships are likely to lead to reparative behaviour, for example, apologising or disclosing wrongdoing (Tangney, 1995; Siflver, 2007).

Adolescents also reported having specific questions about onward disclosure and both mothers and adolescents described having conversations about this topic. Mothers were extremely reluctant for their children to share their status with others. They spoke of wanting to protect the adolescent from discrimination (discussed in further detail below) and of wanting to maintain control over who is aware of their own status. This is consistent with previous findings, with parents often reporting concern or reluctance about their child's onward disclosure (Michaud et al, 2009; Pinzón-Iregui, Beck-Sagué and Malow. 2013).

Young people have described barriers to onward disclosure, including being fearful of a negative response from others and their parent's wish to keep it a secret (Hogwood, Campbell and Butler, 2013) - similar concerns to those provided by the adolescents in the current study. Despite this, two young people chose to disclose to their HIV-negative friends (despite knowing that their mother would not approve), partly as a result of feeling frustrated with having to

keep it a secret. This frustration has been described by young people in a Swedish study, who described disliking having to keep their status a secret from those close to them (Rydström et al, 2013). This is also in keeping with findings in Switzerland, where older adolescents were more likely to decide whether to disclose independently of their parents' wishes (Michaud et al, 2009). The experience of onward disclosure for the adolescents in the current study was described very positively, leaving these young people optimistic about future disclosure events. Interestingly, the two adolescents who chose to disclose to friends reported the most HIV communication with their mother. They also attended support groups and were perhaps more confident in talking about HIV than the other adolescent participants.

***HIV being mentioned in the media***

Another trigger to familial communication was HIV being mentioned in the media. Here, mothers would recommend that their child watch or listen to a programme. It could be that rather than having to discuss HIV directly (due to the barriers outlined above), mothers felt that it would be easier for both parties if the young person could learn about HIV through an external channel. Given that some young people turned to the internet to learn about HIV, this may also be their preferred method of learning about HIV. Mothers may also have wanted to use external tools as a way of facilitating conversations that were difficult. Some authors have suggested that entertainment education (e.g. via the internet or through media channels) can be an effective tool to communicate health

information and inform health behaviour change (Michael & Cheuvront, 1998; Farr, Witte, Jarato, & Menard, 2005).

### *Waiting for a suitable time to have conversations*

Another trigger to HIV communication was related to the timings of conversations. Mothers spoke of waiting for the child to be a particular age before talking about certain topics, for example, romantic relationships. Decisions about the 'right' time related to mothers' beliefs about what topics are appropriate to discuss with adolescents of a certain age. Many of these beliefs were described in the context of the mother's own experiences growing up in their country of origin, although similar findings have been described elsewhere. Research in Australia demonstrated that parents wait to talk about sex and relationships until they feel the child is the right age or maturity (Kirkman, Rosenthal and Feldman, 2005).

One mother also described waiting for the young person to have a good understanding of the medical aspects of HIV before discussing it with her child, perhaps suggesting that she did not feel she was the right person to provide medical information, preferring clinicians to do so.

### *Conversations about medication adherence*

Medication adherence was the most commonly reported topic of conversation in the current study. These conversations are important, as findings have suggested a negative relationship between medication adherence in children and

familial communication (Mellins et al, 2004). Some of these discussions were described in the context of the adolescent's reluctance to take medication, something that has been previously identified in adolescents with HIV (Buchanan et al, 2012; Agwu and Fairlie, 2013). Conversations about medication also came about whilst giving regular, sometimes daily, reminders. This is in keeping with previous research with adolescents in DRC, where parental reminders about medication and clinic appointments occurred regularly (Vaz et al, 2010).

## Question 2 – How do family members feel about existing HIV discussion and what is the impact of communication on wellbeing?

### Experience of HIV communication

#### *Conversations kept to a minimum/lacking depth*

Conversations about HIV were described as being rare or, on the occasions that they did occur, being kept short and lacking depth. This supports previous findings about an absence of, or minimal HIV communication in the families of perinatally infected adolescents (Dorrell et al, 2008; Vaz et al, 2010; Proulx-Boucher et al, 2011; Rydström et al 2013).

As has been described above, conversations tended to consist of parents instructing the adolescent not to disclose to others, offering reminders about medication, providing information about transmission and of offering reassurance. Rarely did participants describe having in-depth conversations,

where ideas or feelings about HIV could be shared. This supports Vaz et al's (2010) study in DRC, where young people described parents offering them advice, but that communication tended to be one-way instruction rather than two-way discussion (Vaz et al, 2010). Similar findings have also been described in studies about sex communication in sub-Saharan Africa, with parents offering instruction rather than engaging in a two-way dialogue (Bastien, Kajula & Muhwezi, 2011). It may be that parents felt they lacked the skills to have a more in depth discussion with their child, or worried that in-depth or longer discussions would lead to distress.

As Olsen's Circumplex Model of Marital and Family Systems describes (1993; see Chapter 1), several elements of positive communication are required for optimal family functioning: attentive listening, staying on topic, self-disclosure and empathy. The descriptions provided by participants would suggest that mothers particularly struggled to stay on topic and have more lengthy discussions with their children. It could be hypothesised that this also reduced the opportunity for them to listen carefully to their child's experiences, concerns and feelings. Mothers rarely described sharing their own experience of living with HIV except when reassuring their child that they could live a normal life, as they had.

### *Finding conversations stressful, difficult or awkward*

Many participants described experiencing HIV communication as being stressful or difficult. These experiences perhaps contributed to an avoidance of conversations and strengthened the barrier to future communication (as

described above). Stress and discomfort may also have resulted in conversations being shut down before individuals had the chance to negotiate HIV communication in a way that suited both parties.

Becoming more skilled and feeling comfortable talking about HIV was described by only one mother-adolescent dyad, who found that discussions felt easier and more natural as time went on. This was the only mother who also reported having an open communication style with her own parents. Drawing on studies with individuals who are anxious about social situations, research suggests that people become habituated to social stressors with repeated exposure (Mauss, Wilhem and Gross, 2003). Although participants described feelings other than anxiety about HIV communication (e.g. sadness and guilt), it may be that conversations would become less difficult with exposure.

***Differing beliefs***

Some adolescents reported feeling frustrated at their mothers' beliefs about relationships and onward disclosure. Young people described wanting to share their status with friends whilst mothers instructed that they did not. Some of these frustrations developed as a result of attending support groups and of hearing different experiences to those that their mothers described. Some adolescents described this conflict as interfering with HIV communication and of avoiding conversations in an attempt to avoid disagreement. This adds support to the CPM theory described above, whereby individuals will avoid topics of discussion that may lead to conflict in an attempt to protect the relationship

(Petronio, 1991). Despite holding different beliefs, adolescents generally felt that their mothers were being supportive and understood the reasons (e.g. fear of discrimination) behind their views.

### *Level of satisfaction with the amount of discussion*

Most participants were satisfied with the amount of HIV communication, supporting findings from a UK study, where young people with PaHIV described feeling satisfied about the level of communication about their status, despite having few confidants (Sopeña, Evangeli, Dodge and Melvin, 2010). Adolescent satisfaction may arise from the belief that their need for HIV communication is being met. Satisfaction with a limited amount of discussion may also result from wanting to avoid the stress or awkwardness that comes with talking about HIV. The amount of external support from clinicians and support groups may also have contributed to satisfaction with minimal familial discussion.

## Factors that influence the content and experience of conversations

### *Mothers' experiences of stigma*

Several mothers described personal experiences of discrimination; describing occasions they had heard or seen negative responses to themselves and others, both in the UK and in their country of origin. This is something that has been reported by other black-Africans living with HIV in the UK (Flowers et al, 2006). Several mothers also described receiving negative treatment from healthcare professionals, supporting previous findings in London where 30% of a large

cohort in London reported experiences of being discriminated against by healthcare workers, including nurses and dentists (Elford et al, 2008).

Steele, Nelson and Cole's systems model (2007; see Figure 1, Chapter 1) suggests that mothers' experiences of living with HIV will influence how and what they talk about with their children. The current findings indicate that mothers' experiences of stigma have, understandably, influenced the advice offered to adolescents regarding onward disclosure. Mothers tended only to speak to family members about their status and did not attend support groups. This perhaps limited the opportunity to hear positive stories about onward disclosure, as their children had done.

***Conversations occurring elsewhere***

Several mothers spoke of feeling satisfied with the amount of HIV communication at home because their child was talking in other settings; usually at the clinic and support groups. If mothers perceive the support their child receives as being good enough, this may have relieved them of pressure to initiate conversations at home, something they have described as being difficult. As HIV is a medical condition, they may also have felt that it should be treated as such (i.e. by clinicians) and so chose not to discuss it.

Maternal beliefs about the benefits of conversations occurring elsewhere may be reinforced by the young person, as many adolescents described finding it easier to talk about HIV elsewhere. If conversations at home are awkward or stressful,

it is perhaps unsurprising that young people find it easier to talk with health professionals who are experienced in talking about HIV (although the majority will not have experience of living with HIV). Equally, if young people become accustomed to discussing HIV outside the home, they may simply wait until they are in these environments, rather than initiating conversations at home. Indeed, one young person spoke of waiting to talk to staff at the support group rather than going to her mother. Experiencing conversations as being easy or stress free in other settings may further highlight the awkwardness of conversations at home, reinforcing beliefs that it is a topic best discussed with healthcare professionals.

## The impact of HIV communication

### *Feeling worried and upset after conversations*

Some adolescents described feeling worried or sad in the hours or days after conversations about HIV took place. This is likely to have impacted on future willingness to talk about HIV and may have formed additional barriers to familial discussion. Some mothers also spoke of feeling worried or concerned for their child, and of feeling helpless in being able to support them. Reflecting on a difficult conversation may result in parents wishing they had said the right thing and one mother explicitly described feeling that she was not supporting her child effectively.

***HIV communication and its impact on the parent-child relationship***

The mother-adolescent dyad who spoke more regularly about HIV described developing a closer relationship over time, in part due to their openness with one another. Research involving the families of HIV-positive mothers also found that those who were able to talk about HIV reported having closer relationships and a more open general communication style (Corona et al, 2009). It was not clear whether families who were closer and more open found discussing HIV easier, or whether talking about HIV had led to families feeling closer and more open with one another. It is suggested that this is a circular relationship, with each component contributing and strengthening the other.

Whilst some participants described having a close relationship in spite of having limited discussion about HIV, it is important to consider how an absence of HIV communication may affect some families, particularly where the adolescent would like to talk more about it. Studies in non-clinical populations have shown that avoidance of communication is related to less satisfaction with relationships between children and their parents and step-parents (Golish, 2000; Caughlin & Golish, 2002). This finding supports the CPM theory (described above), which states that the avoidance of topics can lead to relationship dissatisfaction. Over time, if individuals who believe in the benefits of open communication continue to avoid topics, they may begin to view the relationship negatively (or less positively). Adolescents clearly described how much they valued talking about HIV with clinicians and at support groups. At times this was in contrast with their experience of talking to mothers, where communication was more

restricted. Dissatisfaction may therefore arise when differing beliefs about the importance of communication occur. Equally, where parents and children hold the same beliefs about openness and HIV communication between parent and child, the relationship may be less likely to be affected.

Imber-Black (2014) described how family members might fear talking about certain topics or maintain secrets in the face of family illness, to protect themselves against emotional distress. As subject matters are identified as 'off-limits' (i.e. by never talking about them), the range of other topics become restricted as family members become fearful of conversations leading on to discussion of those that are forbidden. Imber-Black stressed that not allowing topics to be discussed may lead to difficulties with problem solving, a vital skill in the face of child illness. This in turn may inhibit other conversations and the development of relationships. This theory echoes the experience described by one of the adolescents in the current study, who explained how a lack of HIV communication led to a reduction in other topics of conversation with her mother, creating distance in their relationship.

***The role of others – clinicians, support groups and peers***

As has been described, adolescents and mothers spoke with high regard about healthcare professionals and support group staff. A positive experience of HIV communication elsewhere may have highlighted the awkwardness or any stressful conversations with mothers. Over time, it may be that a mother's role in HIV communication is superseded by that of clinic and support group staff,

resulting in fewer attempts at discussing HIV at home. Certainly, the experience of hearing experiences that were more congruent with the adolescent's own beliefs (e.g. regarding onward disclosure) appeared to increase their reluctance to talk about HIV at home, thus strengthening the barriers to familial HIV communication.

Past research has shown similar findings with young people with HIV. A Swedish study found that young people with HIV relied heavily on healthcare professionals and that some were described as 'replacing family' (Rydström et al, 2013). They also found that young people began to talk to clinicians about topics that were both related and unrelated to HIV over time. It may be that feeling confident in talking about HIV - a sensitive and challenging topic - allows young people to feel more able to talk about a wide range of topics.

The adolescents who attended support groups also described the benefits of being able to talk to peers about HIV. They spoke of the difference in being able to spend time and develop friendships with people their own age and who are in a similar situation. The benefits of attending support groups for people with HIV have previously been explored; evaluation of an adult support group in America highlighted how important HIV communication was for individuals (Cawyer and Smith-Dupre', 1995). Following discussions with group participants, the authors suggested that talking about HIV acts as a healing agent and as an outlet for expressing emotions.

Parent and child perspectives of support groups have also been explored in Zimbabwe (Mupambireyi, Bernays, Bwakura-Dangarembizi, & Cowan, 2014). Their study found that both parents and young people viewed support groups as a safe, social space for learning about HIV and for acquiring confidence. Research has also highlighted other positive outcomes for adolescents who attend support groups, including a reduction in worry about HIV and greater medication adherence (Funck-Brentano et al, 2005).

Evidently, support groups and supportive clinicians are a vital resource of information and support, as well as providing the opportunity to meet other young people with HIV. Adolescents should be given sufficient information about groups (where available) so that they may make an informed choice as to whether they would like to attend. Positive relationships with clinicians can only benefit the young person adjusting to and learning about their diagnosis, however, it may be that the benefits of these resources reduce the motivation or perceived need for familial communication. Previous findings suggest that a wide range of support from a range of people including parental, peer *and* clinicians, results in lower levels of psychological difficulties for adolescents with HIV (Mellins and Malee, 2013).

## Question 3 – Do family members feel that they need support with HIV communication?

Two participants described wanting services to provide support with HIV communication. Although a greater number of participants described feeling

satisfied with the amount of discussion, it may be that individuals wanted to avoid family communication due to finding conversations difficult or distressing. It may also be that families did not want support because they did not feel it to be an important subject matter.

If family members were offered support they would still have the option of choosing not to talk about it, however, it may allow them to feel more skilled should they choose to do so. A communication intervention supporting mothers disclose their HIV status to their child resulted in positive outcomes for both mother and child (Murphy, Armistead, Marelich, Payne & Herbeck, 2011). The Teaching, Raising, And Communication with Kids (TRACK) program was an intervention designed to assist mothers in disclosing their status to their HIV-negative children. Mothers attended three sessions and received a follow-up phone call. Sessions two and three focussed on improving mother-child communication and included a self-evaluation of the mother's communication skills and weaknesses; offering advice from other mothers on disclosure; quotes from children on their reactions to disclosure; disclosure role-plays; and information about issues to address after disclosure. A follow up session was arranged for the mothers who went on to disclose to their child. The majority of mothers reported they were able to keep an appropriate emotional tone during the disclosure process and felt ready to answer questions that the child might ask. All mothers (i.e. those who did and did not go on to disclose) reported improved emotional functioning after the intervention and child mental health scores showed significant positive change.

This research demonstrates the effectiveness of communication interventions and shows that positive outcomes can be gained for all family members, not just those taking part in the intervention. In the current study, mothers particularly spoke of feeling that they lacked the skills to communicate about HIV. Providing them with confidence may create a more open and comfortable space for all family members. Offering practical support using role-play and providing positive accounts of communication in other families may be a useful starting point for post-disclosure interventions – of which there are currently none.

## Summary

Having access to support from a range of systems, including clinicians, support groups, friends and family is thought to place the child in the best possible position for coping and living with HIV (Mellins and Malee, 2013). Family support has been shown to be the best predictor of overall perceived support for adolescents with both perinatally and behaviourally acquired HIV, indicating its importance (Abramowitz et al, 2009). It is suggested that mothers may be able to provide support where others cannot, for example, in talking about their own experiences of living with HIV or being able to offer their child advice about disclosing to a particular friend or family member. Young people may also prefer to receive emotional containment from their mothers as opposed to clinicians. In addition to this, relying solely on healthcare professionals may result in the young person receiving irregular support as appointments can occur just three times per year.

If families were to receive support with HIV communication, some may continue to choose not to discuss it, perhaps preferring to talk during clinic appointments or elsewhere. It is suggested that what is important, is that all family members understand why HIV communication could be helpful and that they feel they have the skills to do so if they wish. As was described in Chapter 1, Olsen's Circumplex Model (1993) suggests that family communication allows families to remain cohesive and flexible in times of difficulty or change. Familial HIV communication may help to support young people adjust to, learn about and live with what is a complex and chronic health condition.

## Strengths and Limitations

### Strengths

A key strength of the current study was the inclusion of both adolescents and their mothers, whose experiences of familial HIV communication post-paediatric disclosure had only been explored in DRC previously. The current study also placed far greater emphasis on exploring motivations and barriers to communication, the psychological impact of communication and what factors influence discussions about HIV than previous studies.

The current sample was similar to that of the broader clinic population and the national population of HIV-positive adolescents living in the UK (CHIPS, 2014). Adolescents were both male and female and all participants were of black-African heritage (87% of the clinic population and 79% of the national paediatric population are of black-African parentage). The geographical location of

participants also reflected that of both the clinic and wider adolescent population, with approximately half living in or around London. These factors strengthen the generalisability of the current findings to the broader pediatric HIV population.

To assess the quality of a grounded theory approach, Charmaz (2014) recommends using Glaser's four components (fit, work, relevance and modifiability; Glaser, 1978) alongside four further factors: credibility, originality, resonance and usefulness. Briefly, ''fit'' relates to how closely the concepts and theory describe the data they represent. A theory ''works'' if it is able to provide insight and explanation in the context to which it seeks to refer. The ''relevance'' of a theory refers to whether the theory focusses on a core concern or process and is not only of academic interest. Modifiability refers to the theory's ability to be open to further development to accommodate new insights. Credibility refers to whether the researcher has achieved familiarity with a topic, that there are strong links between the gathered data and analysis and whether a reader would be able to provide an independent assessment of the findings and agree with them. Originality refers to whether the findings offer new insight and how these contribute to existing social and theoretical understanding. Resonance refers to whether the categories accurately portray the studied experience and whether it makes sense to participants. Finally, usefulness refers to whether the theory can be of use to people in their everyday lives, how it contributes to knowledge and whether it can offer any improvement to peoples' lives. The current research will be evaluated in the context of these eight concepts below.

The study was novel in its detailed and single focus of exploration about familial HIV communication following paediatric disclosure, thus meeting criteria for relevance described above. Whilst previous studies have explored what families talk about and how they feel about HIV communication, the current study also identified the triggers, barriers and factors that may influence HIV communication. These novel contributions contribute to the originality of the research.

Another strength of the study was the use of a range of external bodies to maintain quality of the research (Madill, Jordan & Shirley, 2000). A group of young people with HIV and a mother of a perinatally infected adolescent reviewed the interview schedule. This allowed for both face-to-face and written feedback. The reviews ensured that the questions were clear, relevant and that they made sense. It also provided an opportunity to discuss additional topics to be considered for the interviews. It is suggested that the involvement of service users provides evidence for resonance, as the questions being asked were relevant and meaningful to individuals who matched the recruitment criteria.

The constant comparative method was used throughout analysis, allowing for rigorous comparison both within and between participants (Charmaz, 2014). The use of memos, which were updated throughout data collection, were also used to capture the researcher's ideas and played a significant role in the development of focussed and theoretical codes. These processes ensured that the analysis remained rooted in the data (Charmaz, 2014). It is suggested that

these methods provide evidence for fit, work, modifiability and credibility as described above. The use of a journal allowed the researcher to make note of reflections throughout the entire research process. This was useful in capturing the researcher's personal views, assumptions and experiences, and how these interacted with the data - an important component of a constructivist approach in grounded theory (Charmaz, 2014).

Supervision was used throughout all stages of coding, the development of categories and the model, to provide verification. A peer support group was also used to check focussed codes and categories, and to ensure that these did not overlap. Discussions with the group and supervisor also allowed for the fine-tuning of code and category titles, ensuring that these fit the breadth of data they covered. A telephone consultation was carried out with a psychologist from the service who looked over the table of themes and a draft model, again to provide feedback as to whether the model and categories captured the lower level codes. The psychologist also provided feedback regarding the researcher's suggestions for the clinical applications (see below). The involvement of these individuals provides further evidence of fit, work and credibility. It is argued that the involvement of someone working within the service also provides evidence of resonance, as it allowed the researcher to create links between the findings and the institutions and professionals involved in participants' lives (Charmaz, 2014).

The usefulness of the research will be discussed in the clinical implications section below.

## Limitations

Given that the research was about HIV communication, those who were recruited were perhaps more likely to be open to talking about HIV. Three young people declined to take part and may have had very different experiences to those interviewed. As such, the findings may not be generalisable to the wider adolescent perinatally infected population at the clinic.

Participants were recruited via clinicians with whom they had long and established relationships. This may have allowed them to feel comfortable talking about HIV with the researcher, as they associated the researcher with staff whom they were used to talking about HIV with. On the contrary, it may be that participants chose to withhold some information for fear that the researcher would pass it on to clinicians, despite confidentiality being explained.

In adopting a constructivist grounded theory approach it is recommended that conducting a literature review is delayed until after the data are collected so as not to influence the researcher's views (Charmaz, 2014), however, due to ethical and course requirements, this was not possible. In an attempt to counter this, the reflective diary was used to capture any assumptions before interviews took place. These entries were then revisited throughout analysis to ensure that any assumptions did not encroach on the analysis, although Charmaz states that some prior knowledge can be useful as an informant, as long as it does not direct the analysis (Charmaz, 2014).

Clinicians were informed of the recruitment criteria throughout the recruitment process, however, some young people were not approached to take part. This was based on the judgement of clinicians, with some patients already being involved in other studies or experiencing other difficulties. It may be that people with very different experiences to those interviewed were missed. This raises questions as whether the findings 'work' (as described above), in that the theory derived may not reflect that of the context it seeks to refer.

Grounded theory suggests theoretical sampling is adopted in the latter stages of recruitment, once the development of categories has begun (Charmaz, 2014). This then allows for tentative themes and categories to be explored, as participants are chosen to collect data that will help to confirm or refute the developing categories. Whilst analysis and recruitment occurred concurrently, leading to the development of new questions (which were then explored with later participants), theoretical sampling was not always possible due to timing constraints. As a result of this, saturation was not reached for all categories. This again impacts on how well the research works and may therefore influence how closely the findings match the experience of individuals who were not recruited (i.e. resonance).

Although feedback from clinicians, supervisors and a peer group was obtained throughout analysis, feedback about the final results and model from participants was not sought. This was an oversight, as the ethics approval did not include permission to approach participants for feedback. This would have been

a valuable contribution to determine whether the findings were representative of their experience and would have added to the resonance of the findings.

## Personal reflections

Throughout the research process, I spent time reflecting on my own family and our communication style. I recognised some similarities between the participants' experiences and my own, particularly the avoidance of sex communication with my own parents as a teenager. I spoke about this with my mother, father and sister and whilst my parents could not remember much about it, my sister and I clearly recalled a lack of discussion about sex and relationships. This led me to think about how I might communicate (both about sex and more generally) with my own children in the future, should I have any. I have also noticed that I have become more willing to discuss sensitive matters with friends and family, I think partly a result of carrying out this research.

Despite noticing some similarities, there were obvious differences between the participants and myself given that I am a white, middle-class professional and HIV-negative. Having spent time in the clinic, I noticed that the majority of clinicians fit these characteristics (something I have noticed throughout my clinical work too). Culture is certainly something that came up repeatedly, with mothers particularly, although at times it was unclear as to whether this was in the context of individual family culture, their country of origin or something else. It is something I wish I had explored more with mothers, to further understand the meaning of the word for them and what it encompassed. My absence of

further questioning perhaps suggested to them that I understood exactly what they meant, when at times I did not.

In contrast to my original assumptions, I felt that the six participants who were interviewed in their own home were more open than those interviewed at the clinic. This may be because the clinic setting felt more formal and perhaps participants viewed it as more my territory than theirs. I wondered whether the balance of power evened out, as I became a guest in their home. Saying this, I felt that I was able to build up a good rapport with all ten participants and several commented that they had enjoyed speaking with me.

After each interview, I was aware of feeling hugely privileged that participants had spoken about such deeply personal and occasionally upsetting events. Several participants asked why I was doing the research and I was always pleased to answer as it gave me the opportunity to say that the findings may be used to support families with HIV communication in the future. Although participants may have felt pleased that they were contributing to this, I was aware that they were perhaps not benefiting directly from taking part. I often wondered whether mothers and adolescents had had conversations after the interviews had taken place and whether taking part had in any way changed or sparked new conversations about HIV, or the way in which they spoke together about the condition.

During the interviews, and in speaking with mothers particularly, I was aware of feeling extremely angry about the level of ignorance and prejudice that remains in today's society. Some of the mothers' experiences of stigma were horrifying, particularly those involving health professionals. I felt frustrated about the clear lack of training provided to professionals and was saddened to discover that many people have reported similar experiences. More encouragingly, I was pleased to hear that some of the young people had felt able to talk about their status with friends and that these had been positive experiences. In talking to the adolescents, I felt a little more hopeful about the possibility that one day HIV would - quite rightly - no longer be viewed in a negative light.

## Suggestions for future research

One potential avenue for future research would be to carry out a longitudinal study, revisiting participants to determine whether familial communication had changed over time. It may be particularly useful to understand how family communication changes once the young person has left home, given that perhaps few people will be aware of their status outside the family.

Some studies have shown that the amount of family communication, or avoidance of communication, can be dependent on the relationship type, specifically that daughters and sons tend to be more open with their mothers and that they are less likely to be open with their fathers (Younis and Smoller, 1985). A further piece of research could be to explore HIV communication with fathers and other family members, for example, siblings. Several participants lived with

siblings, some who were HIV-positive and some not. Given that research suggests young people prefer to talk to siblings or people their own age about certain topics (e.g. sex) it may be useful to hear experiences of sibling communication about HIV.

The current findings indicate that some family members find talking about HIV difficult, feel lacking in skills and some identified a need for support. One area for future research could be to design and evaluate an HIV communication intervention (as described below). A number of outcomes could be investigated when evaluating the research, including communication self-efficacy, experience of HIV communication, psychological wellbeing for mother and child/adolescent, medication adherence, and relationship satisfaction.

## Clinical implications

The findings indicate a number of areas where healthcare services could provide support with familial HIV communication. As previous findings have indicated, a range of sources of support results in lower levels of psychological difficulties for adolescents with HIV (Mellins and Malee, 2013). It is suggested that communication about HIV is one way in which adolescents can be supported and that families would benefit from feeling confident in discussing the topic, should they wish to.

With older children, the relationship history between parent and child is longstanding and as such, communication patterns may be well established. It is

suggested that conversations with mothers about HIV communication with their children are initiated early on, perhaps before paediatric disclosure, so that from this point the parent feels confident in discussing HIV with their child. If mothers (and fathers) can be provided with an understanding as to why talking to their child about HIV may be helpful before the child is disclosed to (and provided with the skills to do so), family communication may be less difficult from the outset. The current study identified that the questions young people have following disclosure tend to focus on factual information, usually related to medical aspects and virus transmission. If mothers can become confident in talking about factual information outside of the clinic (resulting in HIV communication becoming a 'normal' topic to have at home) they may find it easier to discuss more challenging or emotive topics (e.g. relationships) as the adolescent becomes older.

Support with communication could be provided in a range of formats, to address a range of needs. Some may prefer to be offered leaflets, self-help booklets or online tutorials about HIV communication. These could be topic and person specific (e.g. 'talking about sex with your mum' for adolescents). Others may wish to have (or require) more comprehensive support in the form of face-to face sessions. These could be provided in a group format or individually with clinicians. Both formats could incorporate motivational interviewing techniques (Miller and Rollnick, 2012). These could be used to explore ambivalence about HIV communication and to strengthen intrinsic motivation to act. Cognitive behavioural techniques could also be employed to test out beliefs (e.g. where

individuals predict very negative outcomes as a result of familial communication) and to explore the relationship between anxiety and avoidance. Skills based sessions involving role-play may be one way of strengthening mothers' skills to speak about HIV and sex with their children. Ensuring that parents have accurate, factual information about HIV so that the messages provided match those that are offered in the clinic may also be helpful. For some, support with general communication may be required in addition to that of HIV communication. Offering psychoeducation about why family communication is important and how it can be beneficial may be necessary.

Group sessions may be helpful so that mothers can share experiences, thus normalising the difficulties people have with HIV communication. Groups also offer a space for social support, something that mothers in the current study appeared to be lacking. Psychologists, who are existing members of the multi-disciplinary team at the clinic, could run individual and group sessions. Psychologists may also be able to provide training to other staff members (e.g. nurses) so that they are also able to support family members.

Interventions supporting parents with communication about sex and relationships have been shown to be effective both in the UK and Africa (Phetla et al, 2008; Kesterson and Coleman, 2010). A group intervention in South Africa (designed to reduce HIV transmission and partner violence) included an intervention for sex communication and resulted in positive outcomes (Phetla et al, 2008). Mothers attended group sessions where they were offered education

and engaged in discussion about topics including sex, communication, gender inequality and empowering change. The women who took part reported more frequent discussion about sex with their children, felt that they had developed a skill set to discus sex effectively and that they were more comfortable doing so. As described earlier, individual sessions with mothers have also been shown to help women talk to their children about their own HIV status (Murphy et al, 2011).

Providing support to young people, both individually and in the context of family work, may also be helpful. Several participants described clinic appointments revolving mainly around the medical aspects of the adolescent's HIV, focussing on CD4 counts and the young person's health. To establish how families are talking about HIV over the course of adolescence, it is suggested that clinicians open up this dialogue during appointments. This will give services the opportunity to determine whether families are having conversations outside of appointments and whether they would like support (or whether clinicians feel they need some support) with HIV communication. It may be helpful to ask mothers and young people about family communication separately in the first instance, giving individuals the opportunity to speak without feeling uncomfortable in the presence of one another. It may also be important to raise the topic a number of times, as there may be periods where conversations become more important, for example, when the young person becomes interested in having a relationship. Should a need for support be identified, sessions could be run with individual family members, or together, depending on

the needs and circumstances. Introducing opportunities to discuss HIV together at clinic appointments (with support from clinicians) may increase individual self-efficacy about HIV communication and result in the mother-child dyad finding it easier to talk about when outside of clinical appointments.

Currently, no guidelines about HIV communication post-paediatric disclosure exist. This is something that could be offered to families as a self-help or educational tool. It may also be useful to inform healthcare staff about the range of support family members might need and how best to provide this. Ensuring that all clinicians are able to do this would also place less reliance on specialist clinicians, for example psychologists, who may not be present in all HIV services.

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# Appendix 1 – NHS Ethics Approval Letters

NHS
Health Research Authority
NRES Committee London - Dulwich
Health Research Authority
Skipton House
80 London Road
London
SE1 6LH

Telephone: 020 797 22551

16 May 2014

Miss Caroline Gibbs
Trainee Clinical Psychologist
Royal Holloway University
Doctorate in Clinical Psychology
Royal Holloway University of London
Egham TW20 0EX

Dear Miss Gibbs

| | |
|---|---|
| **Study title:** | **Communication about HIV within the families of adolescents with perinatally acquired HIV (PAH)** |
| **REC reference:** | **14/LO/0730** |
| **IRAS project ID:** | **143358** |

The Research Ethics Committee reviewed the above application at the meeting held on 14 May 2014. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Stephanie Hill, NRESCommittee.London-Dulwich@nhs.net.

**Ethical opinion**

A. The Committee informed you that this was an interesting study and had clearly been thought through.
B. Members noted that information will be kept for 3 months and anonymised statements may appear in published research publications. The Committee agreed that you need to specify in all relevant documents the date to which participants have to withdraw their information and to emphasise to the adolescents that quotes will be used in anonymised form.
C. The Committee noted that you were aware that the interview questions may raise difficult issues for which help will be sought from the appropriate clinician. Members did query whether, as the adolescents will be children in law, the relevant child protection policies will be followed. You explained that by law you are not obligated to tell anyone

of any information disclosed during the interview, unless there was any risk of harm to the child or others. Ms Gibbs assured members that routine practice is to strongly advise the participants to speak to a member of the clinical team and if you are concerned you can speak to a clinician anonymously. Only if the clinician requests the name will you disclose this. You assured members that the Child Protected Policy will be complied with at all time.

D. The Committee queried why there is no GP letter and if the GP will know of the participants HIV status. You explained that there is a possibility that confidentiality might be breached by sending a letter as anyone may open the letter and the information is sensitive. She added that not all GPs will know of the participants HIV status. The Committee noted this.
E. The following discussion took place regarding the participant information sheet (PIS):

i. Add that National Research Ethics Service Committee London-Dulwich reviewed the application.
ii. On page 2 of the adolescent information sheet clearly state that the interview will not be in the presence of the biological mother.
iii. The Committee noted that there was a 24 hour helpline however it is automated. Members agreed that they would prefer contact numbers for individuals. You noted that you will have a study specific work phone that you will have on her. The Committee agreed that this needs to be added with the times she will be available for contact. The Committee expressed a preference for there to be someone available by phone for 24hours after the interviews. You agreed to look into this and assured the Committee that there will be someone available in the clinic.
iv. Clearly state that the research is for a doctorate in clinical psychology.
v. Change the word 'obtain' consent to 'seek' as this is less pressurising. You assured the Committee there will be no perceived pressure and potential participants will be sent study information prior to their appointment if they meet the inclusion criterion.
vi. At point 5 clearly state that you will not be looking at the biological mothers medical records.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

**Ethical review of research sites**

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

**Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

***Changes to Study Documents***

1. In the participant information sheet (PIS) and consent form add a date which the participants have until to withdraw their information from the study and clearly state that anonymised quotes may be published.
   i. In section 11 of both PIS, after 'Any data you do not want included will be destroyed' please add the sentence. 'However, as the data will eventually be analysed and written up, the deadline for withdrawal is [….enter date….].
   ii. In the Consent forms please add the sentence (as new point 3) 'I understand that I can withdraw from the study at any time up until [….enter date….]

2. Regarding the PIS:

   i. Add to both in Section 2; 'This study has been approved by the National Research Ethics Service Committee London-Dulwich.
   ii. Please add to Section 5, after '…family members about HIV. This interview will be with you alone – your mother will meet with Caroline separately for her interview.'
   iii. Add Miss Gibb's study mobile and state the times which they can call between (after the mobile number at the end of the PIS. Add contact numbers for participants to cover 24 hours after the interview.
   iv. Please add to Section 2, after '….Trainee Psychologist at Royal Holloway University of London. The research is being carried out of a Doctorate in Clinical Psychology'
   v. Change the word 'obtain' consent to 'seek'

**You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.**

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**Approved documents**

The documents reviewed and approved at the meeting were:

| *Document* | *Version* | *Date* |
|---|---|---|
| Evidence of insurance or indemnity | Royal Holloway University of London Indemnity Letter | 02 September 2013 |
| Interview Schedules/Topic Guides | Draft Interview Schedule - Mothers v:1 | 07 April 2014 |
| Interview Schedules/Topic Guides | Draft Interview Schedule - Young People v:1 | 07 April 2014 |
| Investigator CV | Caroline Gibbs | 04 March 2014 |
| Letter from Sponsor | | |
| Other: Supervisor CV - Dr Michael Evangeli | | 17 February 2014 |
| Other: Royal Holloway University of London Research Sub-committee Approval Form | | 07 February 2014 |
| Other: Research Passport | 1 | 08 April 2014 |
| Other: Reserach Sub-Committee Provisional Approval Letter | 1 | 16 January 2014 |
| Other: Caroline Gibbs response to Holloway Reserach Sub-Committee Provisional Approval | 1 | 06 February 2014 |
| Participant Consent Form: Young person | 1 | 07 April 2014 |
| Participant Consent Form: Young person assent | 1 | 07 April 2014 |
| Participant Consent Form: Biological Mother | 1 | 07 April 2014 |
| Participant Information Sheet: Young Person | 1 | 07 April 2014 |
| Participant Information Sheet: Biological Mother | 1 | 07 April 2014 |

| | | |
|---|---|---|
| Participant Information Sheet: Parent | 1 | 07 April 2014 |
| Protocol | 1 | 04 December 2013 |
| REC application | | 14 April 2014 |

**Membership of the Committee**

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

There were no declarations of interest.

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**After ethical review**

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

| | |
|---|---|
| **14/LO/0730** | **Please quote this number on all correspondence** |

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

**Dr Michael Philpot**
**Chair**

Email: NRESCommittee.London-Dulwich@nhs.net

*Enclosures:* *List of names and professions of members who were present at the meeting and those who submitted written comments*
*"After ethical review – guidance for researchers" [SL-AR2]*

NHS
Health Research Authority
NRES Committee London - Dulwich
Health Research Authority
Skipton House
80 London Road
London
SE1 6LH

Telephone: 020 7972 2582

24 June 2014

Miss Caroline Gibbs
Trainee Clinical Psychologist
Royal Holloway University
Doctorate in Clinical Psychology
Royal Holloway University of London
Egham TW20 0EX

Dear Miss Gibbs

**Study title:** **Communication about HIV within the families of adolescents with perinatally acquired HIV (PAH)**
**REC reference:** **14/LO/0730**
**IRAS project ID:** **143358**

Thank you for your email of 06 June 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 21 May 2014

**Documents received**

The documents received were as follows:

| *Document* | *Version* | *Date* |
|---|---|---|
| Other [Clarification Email] | | 06 June 2014 |
| Participant consent form [Biological Mother] | 1.3 | 06 June 2014 |
| Participant consent form [Parent] | 1.3 | 06 June 2014 |
| Participant consent form [Young Person] | 1.3 | 06 June 2014 |
| Participant consent form [Assent Form] | 1.3 | 06 June 2014 |
| Participant information sheet (PIS) [Biological Mother] | 1.3 | 06 June 2014 |
| Participant information sheet (PIS) [Parent] | 1.3 | 06 June 2014 |
| Participant information sheet (PIS) [Young Person] | 1.3 | 06 June 2014 |

**Approved documents**

The final list of approved documentation for the study is therefore as follows:

| *Document* | *Version* | *Date* |
|---|---|---|
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) | Royal Holloway University of London Indemnity Letter | 02 September 2013 |
| Interview schedules or topic guides for participants | Draft Interview Schedule - Young People v:1 | 07 April 2014 |
| Interview schedules or topic guides for participants | Draft Interview Schedule - Mothers v:1 | 07 April 2014 |
| Letter from sponsor | | |
| Other [Research Passport] | 1 | 08 April 2014 |
| Other [Reserach Sub-Committee Provisional Approval Letter] | 1 | 16 January 2014 |
| Other [Supervisor CV - Dr Michael Evangeli] | | 17 February 2014 |
| Other [Caroline Gibbs response to Holloway Reserach Sub-Committee Provisional Approval] | 1 | 06 February 2014 |
| Other [Clarification Email] | | 06 June 2014 |
| Other [Royal Holloway University of London Research Sub-committee Approval Form] | | 07 February 2014 |
| Participant consent form [Biological Mother] | 1.3 | 06 June 2014 |
| Participant consent form [Parent] | 1.3 | 06 June 2014 |
| Participant consent form [Young Person] | 1.3 | 06 June 2014 |
| Participant consent form [Assent Form] | 1.3 | 06 June 2014 |
| Participant information sheet (PIS) [Young Person] | 1.3 | 06 June 2014 |
| Participant information sheet (PIS) [Parent] | 1.3 | 06 June 2014 |
| Participant information sheet (PIS) [Biological Mother] | 1.3 | 06 June 2014 |
| REC Application Form | | 14 April 2014 |
| Research protocol or project proposal | 1 | 04 December 2013 |
| Summary CV for Chief Investigator (CI) | Caroline Gibbs | 04 March 2014 |

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

**14/LO/0730** **Please quote this number on all correspondence**

Yours sincerely

**Stephanie Hill**
**REC Manager**

E-mail: nrescommittee.london-dulwich@nhs.net

# Appendix 2 - Royal Holloway University of London Ethics Approval

## Ref: 2014/056 Ethics Form Approved

Psychology-Webmaster@rhul.ac.uk

Fri 04/07/2014 16:02

To: nxjt010@rhul.ac.uk <nxjt010@rhul.ac.uk>; Evangeli, Michael <Michael.Evangeli@rhul.ac.uk>;

Cc: PSY-EthicsAdmin@rhul.ac.uk <PSY-EthicsAdmin@rhul.ac.uk>; Leman, Patrick <Patrick.Leman@rhul.ac.uk>; Lock, Annette <Annette.Lock@rhul.ac.uk>; umjt001@rhul.ac.uk <umjt001@rhul.ac.uk>;

| | |
|---|---|
| Application Details: | View the form click here Revise the form click here |
| Applicant Name: | **Caroline Gibbs** |
| Application title: | **Communication about HIV within the families of adolescents with perinatally acquired HIV** |

# Appendix 3 – Local R&D Approval

Consultant Clinical Psychologist

[redacted]

Dear Dr Melvin

**RE: JRCO Study Approval**

**Project Title: Communication about HIV within the families of adolescents with perinatally acquired HIV**

**Joint Research Compliance Office Reference number: 14SM2085**

**Ethics reference number: 14/LO/0730** **Principal Investigator: Dr D Melvin**

I confirm that this project has now been approved by the Joint Research Compliance Office. The project may now start at [redacted] sites. Please note that the start date of the project is the date of this letter and the duration is the same as that provided in your application form.

The list of documents reviewed and approved by the Joint Research Compliance Office under requirements of the Research Governance Framework are as follows:

| Document | Version | Date |
|---|---|---|
| Evidence of sponsor insurance | Royal Holloway | 02 September 2013 |
| Participant Consent Form (Biological Mother) | 1.3 | 06 June 2014 |
| Participant Consent Form (Parent) | 1.3 | 06 June 2014 |
| Participant Consent Form (Young Person) | 1.3 | 06 June 2014 |
| Participant Consent Form (Assent Form) | 1.3 | 06 June 2014 |
| Participant Information Sheet (Young Person) | 1.3 | 06 June 2014 |
| Participant Information Sheet (Parent) | 1.3 | 06 June 2014 |
| Participant Information Sheet (Biological Mother) | 1.3 | 06 June 2014 |
| Divisional approval | | 11 June 2014 |
| REC Application Form | | 14 April 2014 |
| SSI form | | 20 May 2014 |
| Research Protocol | 1 | 04 December 2013 |

Before you commence your research, please note that you must be aware of your obligations to comply with the minimum requirements for compliance with the Research Governance indicators 17 (Data Protection); 25 (Health and Safety) and 22 (Financial Probity). Details of the requirements to be met can be found in the Research Governance Framework available on www.dh.gov.uk.

Under the Research Governance regulations, Serious Adverse Event Reports, Adverse Reactions and amendments to the protocol or other supporting documents must be forwarded to the Joint Research Compliance Office and Ethics Committee.

In accordance with the Research Governance Framework, research projects carried out in the Trust will be randomly chosen by the Joint Research Compliance Office for auditing. Please see the attached checklist for documentation that will be required during the audit.

I wish you well in your research.

Yours sincerely

Christine Buicke

Christine Buicke
Research Governance Manager

# Appendix 4 – Participant Information Sheets

**Biological Mother Information Sheet**
*Version 1.3 (06.06.14)*

**Research Project: Communication about HIV within the families of adolescents with perinatally acquired HIV**

We would like to invite you to take part in a research study. Before you decide, you must understand why the research is being done and what you will be asked to do. Please take time to read the information below carefully and discuss it with your child, the clinical team at the Family Clinic or the researcher if you wish.

**1. What is the study for?**
We want to find out how adolescents and their families talk about HIV and we are particularly interested to hear about young people and their biological (birth) mothers' experiences. To do this we would like to meet separately, with young people and their mothers (two meetings, one with the young person and one with their mother) to talk about how they experience family conversations about HIV.

**2. Who is organizing and conducting the research?**
The study is being carried out by Caroline Gibbs who is a Trainee Clinical Psychologist at Royal Holloway University of London. The research is being carried out of a Doctorate in Clinical Psychology. Dr Diane Melvin, Consultant Clinical Psychologist and Dr Caroline Foster, Consultant Paediatrician at the Family Clinic are overseeing the research. It will also be supervised by Dr Michael Evangeli who is a Senior Lecturer at Royal Holloway University of London. This study has been approved by the National Research Ethics Service Committee London-Dulwich. It has also been approved by xxxx Trust Research and Development and Royal Holloway, University of London Departmental Ethics Committee.

**3. Why am I being invited to take part in this study?**
We are asking the biological mothers of young people aged between 13 and 17 who were born HIV-positive and who are being treated at the Family Clinic at xxx Hospital.

**4. Do I have to take part?**
No - the study is voluntary and you do not have to take part. It is up to you to decide whether or not you take part. You can change your mind at any point without giving a reason. Whatever you decide to do, it will not affect the treatment you or your child receives at the Family Clinic.

**5. What will I be asked to do if I decide to take part?**
For you to take part in this study, your child must also agree to take part. If you both decide you would like to take part in the research, you will be asked to meet with Caroline Gibbs, Trainee Clinical Psychologist (the researcher for this project). If possible, you will be asked to meet with Caroline at the Family Clinic at Xxx's Hospital. If it is not possible to be seen in the clinic (or you would prefer not to), Caroline will meet with you at your home. Caroline will be able to answer any questions you might have before deciding whether or not you would like to take part. You can also contact Caroline via telephone or email at any time (see the bottom of this information sheet for contact details).

You will be asked to sign a consent form before taking part in the study. You will keep a copy of this consent form. The researcher will also keep a copy. The original consent document will be kept in the medical records at the Family Clinic. Once you have signed the consent form, you will meet with Caroline for approximately 1 hour to answer some questions about your experience of talking about HIV in the family. Your child will meet with Caroline separately for their interview.

If you choose to take part in this research project, you will also be asked to provide some basic demographic information e.g. age, place of birth. The researcher will also ask some information about your health e.g. when you were diagnosed, CD4 count.

**6. Expenses and payments**
You will be paid £10 for taking part in the study.
If you travel to the clinic only to take part in the research (i.e. not for any other appointment at the Family Clinic) your travel expenses will be also reimbursed.

**7. What are the possible benefits of taking part in the study?**
You would be helping us to learn more about how young people with HIV and their families talk about HIV. This may help to develop new approaches for supporting young people and families to talk about HIV

**8. What are the possible disadvantages of taking part?**
Few disadvantages are anticipated, however, sometimes people feel nervous about taking part in research particularly when discussing personal subjects. Caroline, will be there to provide you with support and is able to discuss any concerns you might have. You will not have to say anything you do not want to. If you become upset at any time you will have the opportunity to take breaks or to stop talking altogether. If you feel you need to speak to someone after taking part, suggestions will be made to help you with this. . If during your interview you raise a particular concern or worry, we can give you some advice on how or where to get help.

**9. Will my taking part in this study be kept confidential?**
Yes - everything discussed with the researcher and any personal details will be kept anonymous and strictly confidential. Any information about you will have your name removed so that you cannot be identified. Any information you share with the researcher will not be discussed with your child or with staff at the clinic

This interview will be digitally recorded so that it may be transcribed (written out on a computer) and analysed at a later date. Once it has been analysed the recording will be deleted. Copies of the transcription will not include your name or any identifiable information and will be assigned with a number. The transcription will be kept as a word document and will be password protected on a computer (which will also be locked with a password). Only the researcher, Caroline, will have access to this document. At the end of the research the written interviews will be kept in a locked filing cabinet in Dr Evangeli's office at Royal Holloway University of London. These will all be anonymised and Caroline's supervisor will not be given the name of the person being interviewed when looking at the written document. The document will be destroyed after five years.

The only occasion where Caroline, the researcher, would need to break confidentiality or tell anyone about something discussed is if we feel there is any risk of harm to you or to

anyone else. Caroline is legally required to share this information as she has a duty of care to both you and the public. In this situation Caroline will need to discuss this matter with a member of the clinical team at the Family Clinic. Before we begin the interview, Caroline will tell you who the staff member is. Caroline will always talk about this with you before speaking to the any member of staff at the Family Clinic.

**10. What will happen to the results of the study?**

The information you give us will be included in a report which will focus on findings from the whole set of interviews in the project. Any information you provide is strictly confidential and will be completely unrecognisable as being yours. In any paperwork you will not be identified by name, but by a number. Anonymised (without names) quotes from your interview may be used in the final report to help explain the findings. We hope the results will be published in a scientific journal so we can share our knowledge about the ways in which families communicate about HIV and you will not be able to be identified in these. You will be asked if you would like to receive a summary of the main findings of the research project.

**11. What will happen if I change my mind and don't want to carry on with the study?**

Even after you have decided to take part, you can change your mind and withdraw from the study. You do not need to give a reason. You will have a copy of the researcher's contact details so you are able to get in touch with her after your meeting with her. You can let her know if you have changed your mind or wish to have parts of the interview taken out. Again, you do not need to give a reason for this. Any data you do not want included will be destroyed, however, as the data will eventually be analysed and written up, the deadline for withdrawal is 15.02.2015. Choosing to withdraw from the study at any time will not affect the care you receive at the Family Clinic.

If you would like any further information you can ask the researcher or staff at the Family Clinic. You can find contact telephone numbers and email addresses at the bottom of this information sheet. Thank you for taking the time to read through this information sheet.

**Thank you for considering taking part in this study**

**Parent Information Sheet**
**For parents of young people under the age of 16**
*Version 1.3 (06.06.14)*

**Research Project: Communication about HIV within the families of adolescents with perinatally acquired HIV**

We would like to invite your child to take part in a research study. Before you decide if you are happy for them to do so, you need to understand why the research is being done and what they will be asked to do. Please take time to read the information below carefully and discuss it with your child or the team at the Family Clinic if you wish.

Throughout this information sheet we will be referring to the "biological mother of the child." We are aware that you, the reader, may be the biological mother of the child and so these parts may sound strange when reading them.

**1. What is the study for?**
We want to find out how adolescents and their families talk about HIV and we are particularly interested to hear about young people and their biological (birth) mothers' experiences. To do this we would like to meet separately, with young people and their mothers (two meetings, one with the young person and one with their mother) to talk about how they experience family conversations about HIV.

**2. Who is organizing and conducting the research?**
The study is being carried out by Caroline Gibbs who is a Trainee Clinical Psychologist at Royal Holloway University of London. The research is being carried out of a Doctorate in Clinical Psychology. Dr Diane Melvin, Consultant Clinical Psychologist and Dr Caroline Foster, Consultant Paediatrician at the Family Clinic are overseeing the research. It will also be supervised by Dr Michael Evangeli who is a Senior Lecturer at Royal Holloway University of London. This study has been approved by the National Research Ethics Service Committee London-Dulwich. It has also been approved by xxxx Trust Research and Development and Royal Holloway, University of London Departmental Ethics Committee.

**3. Why is your child being invited to take part in this study?**
We are asking young people aged between 13 and 17 who have a diagnosis of perinatal HIV and who are being treated at the Family Clinic at Xxx's Hospital.

**4. Do they have to take part?**
No - the study is voluntary and your child does not have to take part. It is up to you both to decide whether or not they take part. You and your child can change your mind at any point without giving a reason. Whatever you decide to do, it will not affect the treatment you or your son/daughter receives at the Family Clinic.

**5. What does participation in this study involve?**
We will only ask your child to take part in the research if their birth mother also agrees to take part (there is separate information sheet for mothers in relation to this). If your child and their biological mother would like to take part in the research, they will both be asked to meet with Caroline Gibbs, Trainee Clinical Psychologist and the researcher

for this project. If possible, they will be asked to meet with Caroline at the Family Clinic at Xxx's Hospital. If it is not possible to be seen in the clinic (or you would prefer not to), Caroline will meet with you at your home.. Caroline will be able to answer any questions you might have before deciding whether or not you would like your child to take part. You can also contact Caroline at any time via telephone or email (see the bottom of this information sheet for contact details).

Your child will be asked to sign an assent form and you will be asked to sign a consent form so that they may take part in the study. You and your child will keep a copy of these respective forms. The researcher will also take copies. The original documents will be kept in your medical records at the Family Clinic.

Your child will then meet with Caroline for approximately 1 hour to answer some questions about their experience of talking to family members about HIV. Your child's biological mother will be asked to meet with Caroline separately for her interview.

If you agree to your child taking part in the research we may also ask you (or your son/daughter) to provide some basic demographic information e.g. age, place of birth. The researcher would also like to access your child's medical records for information about their health e.g. when they were diagnosed, CD4 count.

**6. Expenses and payments**
Your child will be paid £10 for taking part in the study.
If your child travels to the clinic **only** to take part in the research (i.e. not for any other appointment at the Family Clinic) their travel expenses will be also reimbursed.

**7. What are the possible benefits of taking part in the study?**
Your child would be helping us to learn more about how young people with HIV and their families talk about HIV. This may help services like the Family Clinic to provide support to families in having conversations about HIV.

**8. What are the possible disadvantages of taking part?**
Few disadvantages are anticipated, however, sometimes people feel nervous about taking part in research particularly when discussing personal subjects. Caroline, will be there to provide your child with support and is able to discuss any concerns they might have. They will not have to say anything they do not want to. If your child becomes upset at any time they will have the opportunity to take breaks or to stop talking altogether. If it felt they might benefit from speaking with a member of clinical staff at the end of the discussion, this will be offered and arranged. If during your interview they raise a particular concern or worry, we can give them some advice on how or where to get help.

**9. Will their taking part in this study be kept confidential?**
Yes - everything discussed with the researcher and any personal details will be kept anonymous and strictly confidential. Any information about your child will have their name removed so that they cannot be recognised. The information your child shares with the researcher will not be discussed with you or with staff at the clinic.

The interview with your child will be digitally recorded so that it may be transcribed (written out on a computer) and analysed at a later date. Once it has been transcribed the recording will be deleted Copies of the transcription will not include your child's name or any identifiable information and will be assigned with a number. The

transcription will be kept as a word document and will be password protected on a computer (which will also be locked with a password). Only the researcher, Caroline, will have access to this document. At the end of the research the written interviews will be kept in a locked filing cabinet in Dr Evangeli's office at Royal Holloway University of London. These will all be anonymised and Caroline's supervisor will not be given the name of the person being interviewed when looking at the written document. The document will be destroyed after five years.

The only occasion where Caroline, the researcher, would need to break confidentiality or tell anyone about something is if we feel there is any risk of harm to your child or to anyone else. Caroine is legally required to share this information because she has a duty of care to both your child and the public. In this situation Caroline will need to discuss this matter with a member of the clinical team at the Family Clinic. Caroline will give the name of this staff member before beginning the interview with your child. Caroline will always talk about this with your child before speaking to any member of staff at the Family Clinic.

**10. What will happen to the results of the study?**
The information your child gives us will be written up as a project. Any information your child provides is strictly confidential and will be completely unrecognisable as being theirs. In any paperwork they will not be identified by name, but by a number. Anonymised (without names) quotes from their interview may be used in the final report to help explain the findings. We hope the results will be published in a scientific journal so we can share our knowledge about the ways in which families communicate about HIV and your child will not be able to be identified in these. You and your child will be asked if you would like to receive a summary of the main findings of the research project.

**11. What will happen if one of us changes our mind and do not want to take part in the study?**
Even after you have decided to take part, you or your child can change your mind and withdraw from the study. You do not need to give a reason. You will have a copy of the researcher's contact details so you are able to get in touch with her. You can let her know if you have changed your mind or if your child wishes to have parts of the interview taken out. Again, you do not need to give a reason for this. Any data your child does not want included will be destroyed, however, as the data will eventually be analysed and written up, the deadline for withdrawal is 15.02.2015. Choosing to withdraw from the study at any time will not affect the care your family receives at the Family Clinic.

If you require any further information you can ask the researcher or staff at the Family Clinic. You can find contact telephone numbers and email addresses at the bottom of this information sheet. Thank you for taking the time to read through this information sheet.

**Thank you for considering taking part in this study**

**Young Person Information Sheet**
*Version 1.3 (06.06.14)*

**Research Project: Communication about HIV within the families of adolescents with perinatally acquired HIV**

We would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what you will be asked to do. Please take time to read the information below carefully and discuss it with a parent, staff at the Family Clinic or the researcher if you wish.

**1. What is the study for?**
We want to find out how adolescents and their families talk together about HIV and we are particularly interested to hear about the experiences of young people and their biological (birth) mothers.

**2. Who is organizing and conducting the research?**
The study is being carried out by Caroline Gibbs who is a Trainee Clinical Psychologist at Royal Holloway University of London. The research is being carried out of a Doctorate in Clinical Psychology. Dr Diane Melvin, Consultant Clinical Psychologist and Dr Caroline Foster, Consultant Paediatrician at the Family Clinic are overseeing the research. It will also be supervised by Dr Michael Evangeli who is a Senior Lecturer at Royal Holloway University of London. This study has been approved by the National Research Ethics Service Committee London-Dulwich. It has also been approved by xxxx Trust Research and Development and Royal Holloway, University of London Departmental Ethics Committee.

**3. Why am I being invited to take part in this study?**
We are asking young people aged between 13 and 17 who were born HIV-positive and who are being treated at the Family Clinic at Xxx's Hospital.

**4. Do I have to take part?**
The study is voluntary and you do not have to take part. It is up to you to decide whether or not you take part. You can change your mind at any point without giving a reason. Whatever you decide to do, it will not affect the treatment you receive at the Family Clinic.

**5. What will I be asked to do if I decide to take part?**
For you to take part in this study, you and your mother must both agree to take part. If you both agree you will be asked to meet separately with Caroline (the researcher for this project). If possible, you will be asked to meet Caroline at the Family Clinic at Xxx's Hospital. If it is not possible to be seen at the clinic (or you would prefer not to), Caroline will meet with you at your home. Caroline will be able to answer any questions you might have before deciding whether or not you would like to take part. You can also contact Caroline via telephone or email at any time (see the bottom of this information sheet for contact details).

You will be asked to sign a consent form before taking part in the study. This form is used to check that you understand the study and that you agree to take part. You will keep a copy of this form. The researcher will also keep a copy. The original document

will be kept in your medical record at the Family Clinic. If you are under 16, one parent must also agree to you taking part in the study and sign a consent form for you.

You will meet with Caroline for about 1 hour to answer some questions about your experience of talking to family members about HIV. This interview will be with you alone – your mother will meet with Caroline separately for her interview.

If you choose to take part in this research project, you will also be asked to provide some basic demographic information e.g. age, place of birth. The researcher would also like to access your medical records for information about your health e.g. when you were diagnosed, CD4 count.

**6. Expenses and payments**
You will be paid £10 for taking part in the study.
If you travel to the clinic only to take part in the research (i.e. not for any other appointment at the Family Clinic) your travel expenses will be also reimbursed.

**7. What are the possible benefits of taking part in the study?**
You would be helping us to learn more about how young people with HIV and their families talk about HIV. This may help to develop new approaches for supporting young people and families to talk about HIV

**8. What are the possible disadvantages of taking part?**
Few disadvantages are anticipated, however, sometimes people feel nervous about taking part in research particularly when discussing personal subjects. The researcher, Caroline, is able to discuss any concerns you might have about this. You will not have to say anything you do not want to. If you become upset at any time you will have the opportunity to take breaks or to stop talking altogether. If you feel you need to speak to someone after taking part, suggestions will be made to help you with this. If during your interview you raise a particular concern or worry, we can give you some advice on how or where to get help.

**9. Will my taking part in this study be kept confidential?**
Yes - everything discussed with the researcher and any personal details will be kept anonymous and strictly confidential. Any information about you will have your name removed so that you cannot be recognised. Any information you share with the researcher will not be discussed with your parents or with staff at the clinic.

The conversation with the researcher will be digitally recorded so that it may be written out at a later date. Once it has been written out the recording will be deleted. Copies of your written conversation will not include your name and will be assigned with a number. The written document will be password protected on a computer (which will also be locked with a password). Only the researcher, Caroline, will have access to this document. At the end of the research the written interviews will be kept in a locked filing cabinet in Dr Evangeli's office at Royal Holloway University of London. These will all be anonymised and Caroline's supervisor will not be given the name of the person being interviewed when looking at the written document. The document will be destroyed after five years. The same data will also be kept securely at the Family Clinic and destroyed after a maximum of 10 years. This data will also be anonymised.

The only occasion where Caroline, the researcher, would need to tell anyone about something discussed is if she feels there is any risk of harm to you or to anyone else. She

is legally required to share this information. In this situation Caroline will need to discuss this matter with a member of your clinical team at the Family Clinic. Before we begin the interview, Caroline will tell you who the staff member is. Caroline will always talk about this with you before speaking to the any member of staff at the Family Clinic.

**10. What will happen to the results of the study?**

The information you give us will be written up as a project using findings from all participants. To maintain confidentiality, any individual information you provide will be completely unrecognisable as being yours. In any paperwork you will be identified a number not your name. Any quotes from your interview will be anonymised ( without name) if it is used in the final report to help explain the findings. We hope the results will be published in a scientific journal so we can share our knowledge about the ways in which families talk together about HIV and you will not be able to be identified in these. You can receive a summary of the main findings of the research project if you would like.

**11. What will happen if I change my mind and don't want to carry on with the study?**

Even after you have decided to take part, you can change your mind and withdraw from the study. You do not need to give a reason. You will have a copy of the researcher's contact details so you are able to get in touch with her after your meeting and let her know if you have changed your mind or wish to have parts of the interview taken out. Again, you do not need to give a reason for this. Any data you do not want included will be destroyed, however, as the data will eventually be analysed and written up, the deadline for withdrawal is 15.02.2015. Choosing to withdraw from the study at any time will not affect the care you receive at the Family Clinic.

If you would like to know more about the project you can ask the researcher, Caroline Gibbs, or staff at the Family Clinic. You can find contact telephone numbers and email addresses at the bottom of this information sheet. Thank you for taking the time to read through this information sheet.

**Thank you for considering taking part in this study**

# Appendix 5 - Consent Forms

## Consent Form for Biological Mother

Version 1.3 06.06.14

**Research Project: Communication about HIV within the families of adolescents with perinatally acquired HIV**

The section below is to confirm that you would like to take part in the research and that you know what you have to do. **Please tick the boxes if you agree with each statement.**

1. I confirm that I have read and understood the information sheet (version 1.3, dated 06.06.14) and been given the opportunity to ask questions ☐

2. I understand that the participation of myself is voluntary and that I am free to withdraw at any time without giving any reason, and that it will not affect my family's care or treatment at the Family Clinic ☐

3. I understand that I can withdraw from the study at any time up until 15.02.15 ☐

4. I consent to an audio recording if the interview being made and understand what will happen with the recording afterwards ☐

5. I understand that the researcher, Caroline Gibbs, may publish direct quotations said by me during the interview but that these will be anonymised and that all names, places and anything that could identify me will be removed ☐

6. I understand that the researcher, Caroline Gibbs, will be accessing my medical records to collect some information about my health ☐

7. I agree to take part in the above study ☐

| Name of Participant | Signature | Date |
|---|---|---|
| _____ | _____ | _____ |
| Name of Researcher | Signature | Date |
| _____ | _____ | _____ |

When completed: 1 copy for participant, 1 for researcher, 1 copy (original) for medical notes

I want to / do not want to be sent a summary of the main findings of this study (please circle)

**Consent Form For Parent/Guardian**
Version 1.3 06.06.14

**Research Project: Communication about HIV within the families of adolescents with perinatally acquired HIV**

The section below is to confirm that you would like to take part in the research and that you know what you have to do. **Please tick the boxes if you agree with each statement.**

1. I confirm that I have read and understood the information sheet (version 1.3, dated 06.06.14) and been given the opportunity to ask questions ☐

2. I understand that the participation of my child is voluntary and that he or she is free to withdraw at any time without giving any reason, and that it will not affect his or her care or treatment at the Family Clinic ☐

3. I understand that I can withdraw from the study at any time up until 15.02.15 ☐

4. I consent to an audio recording if the interview being made and understand what will happen with the recording afterwards ☐

5. I understand that the researcher, Caroline Gibbs, may publish direct quotations said by my son/daughter during the interview but that these will be anonymised and that all names, places and anything that could identify my son/daughter will be removed ☐

6. I understand that the researcher, Caroline Gibbs, will be accessing my child's medical records to collect some information about their health ☐

7. I agree for _____ (name of son/daughter) to take part in the above study ☐

| Name of Parent | Signature | Date |
|---|---|---|
| _____ | _____ | _____ |

| Name of Researcher | Signature | Date |
|---|---|---|
| _____ | _____ | _____ |

When completed: 1 copy for parent, 1 for researcher, 1 copy (original) for medical notes

I want to / do not want to be sent a summary of the main findings of this study (please circle)

**Assent Form For Young Person**
Version 1.3 06.06.14

**Research Project: Communication about HIV within the families of adolescents with perinatally acquired HIV**

**Section 1 – To be signed by the young person**
The section below is to confirm that you would like to take part in the research and that you know what you have to do. **Please tick the boxes if you agree with each point.**

1. I confirm that I have read and understood the information sheet (version 1.3, dated 06.06.14) and been given the opportunity to ask questions ☐

2. I understand that I do not have to take part in this study and that I can stop at any time, without having to give a reason, and it will not affect my care or treatment at the Family Clinic ☐

3. I understand that I can withdraw from the study at any time up until 15.02.15 ☐

4. I consent to an audio recording of the interview being made and understand what will happen with the recording afterwards ☐

5. I understand that the researcher, Caroline Gibbs, may publish direct quotations said by me during the interview but that these will be anonymised and that all names, places and anything that could identify me will be removed ☐

6. I understand that the researcher, Caroline Gibbs, will be accessing my medical records to collect some information about my health ☐

7. I want to take part in the above study ☐

Name of young person_____ Date_____

I want to / do not want to be sent a letter with the results of this study (please circle)

**Section 2 – To be signed by the Parent**

I …… confirm that this project has been explained to the above child and I am satisfied that they have a full and complete understanding of the procedures involved, what the information will be used for, and what the benefits and risks of taking part in the project may be.

| Name of Parent | Signature | Date |
|---|---|---|
| _____ | _____ | _____ |
| Name of Researcher | Signature | Date |
| _____ | _____ | _____ |

**Consent Form For Young Person**
Version 1.3 06.06.14

**Research Project: Communication about HIV within the families of adolescents with perinatally acquired HIV**

The section below is to confirm that you would like to take part in the research and that you know what you have to do. **Please tick the boxes if you agree with each statement.**

1. I confirm that I have read and understood the information sheet (version 1.3, dated 06.06.14) and been given the opportunity to ask questions ☐

2. I understand that the participation of myself is voluntary and that I am free to withdraw at any time without giving any reason, and that it will not affect my care or treatment at the Family Clinic ☐

3. I understand that I can withdraw from the study at any time up until 15.02.15 ☐

4. I consent to an audio recording if the interview being made and understand what will happen with the recording afterwards ☐

5. I understand that the researcher, Caroline Gibbs, may publish direct quotations said by me during the interview but that these will be anonymised and that all names, places and anything that could identify me will be removed ☐

6. I understand that the researcher, Caroline Gibbs, will be accessing my medical records to collect some information about my health ☐

7. I agree to take part in the above study ☐

| Name of Young Person | Signature | Date |
|---|---|---|
| _____ | _____ | _____ |
| Name of Researcher | Signature | Date |
| _____ | _____ | _____ |

When completed: 1 copy for participant, 1 for researcher, 1 copy (original) for medical notes

I want to / do not want to be sent a summary of the main findings of this study (please circle)

# Appendix 6 - Draft Interview Schedules

**Adolescents**

1. Introductions

- Introduce myself using my name, where I am training, the purpose of my undertaking this research, my interest in HIV and relationships within the family
- Give details of: purpose of the interview / timings / sorts of questions / breaks. Talk about confidentiality / limits to confidentiality e.g. risk to self/others. [Remind clients that this information is included in the information sheet for them to refer back to if they wish] Consent form/any questions/any concerns? Collect demographic information

2. Communication behaviours within the family

Who lives in your house?
Who else do you consider to be part of your family who doesn't live in your house?
How would you describe how your family communicate with each other?
What sort of things do you talk about at home?
Do you talk about more personal things with your family such as relationships, sex, health, friendships? Is there anything you wouldn't talk about with people at home? Elaborate…
If not, is there anybody else you talk about this sort of thing with? Why that person/why not?

3. Introducing the topic of HIV

I'd like to talk about HIV with you now. I was wondering if you could tell me about when you were first told you were HIV positive, so when HIV was named - when was this? Can you remember how you felt when you were first told your diagnosis was HIV?

Do you remember how you spoke about HIV with mum at home, in the first few months after you were told your HIV diagnosis? Was there anyone else you spoke about HIV with at home? Elaborate…

4. HIV discussions within the family

How is your HIV spoken about now within your family at home?
Has the amount you talk about HIV changed over time? Elaborate… (If yes) Do you have any idea as to why this might be?

Can you tell me about the last time you spoke about HIV at home?

a) if they do talk about HIV at home
How much have you and mum spoken about HIV and [medication, medical appointments, relationships, friendships, disclosure – either now or in the future, your mum's diagnosis, HIV specific information, sex, general health, any other concerns about the future?]
Do you talk about any of these things with other members of your family? Are these conversations different to those you have with your mum? Elaborate…

Who tends to bring up the subject of HIV in conversation first?
How do you feel when mum (/other) brings up the subject of HIV? How do you think mum (/other) feels when you bring up the subject of HIV?

Are there people in the family who you talk to about HIV more than others? (If yes) Why do you think you speak to them the most?

Is there anyone else outside of your immediate family (parent/caregiver & siblings) who you talk to about HIV? (If yes) Why do you think this may be?

Do you think that being able to talk about HIV [with your mum] has affected the way you feel about having HIV? Elabroate…

How do you feel about the amount of HIV discussion you have with your mum at the moment? [prompt - happy, not so happy?] And with other members of your family?

Can you think of anyone who might be able to support you in talking about HIV with your family? Is this something you would find helpful?

b) If they don't talk about HIV at home
(Following Can you tell me about the last time you and mum spoke about HIV at home?)
Who brought up the conversation? Does anyone in your family try to bring up topics related to HIV (e.g. medication, medical appointments, relationships, friendships, disclosure – either now or in the future, your mum's diagnosis, HIV specific information, sex, general health, any other concerns about the future?]

How do you / mum / other members of your family respond when the subject is brought up?
How do you feel / what's your reaction to [the person] who brought it up?
(If YP brings it up] How does your mum respond when you bring up a topic related to HIV? How do you think she feels? What about other people in the family?

Is there anyone else outside of your immediate family (parent/caregiver & siblings) who you talk to about HIV? (If yes) Why do you think this may be?

How do you feel about the amount of HIV discussion there is in your family at the moment? [Prompt satisfied/would like more]

Do you think that not talking about HIV with your mum has affected the way you feel about having HIV – are you able to say why?

Can you think of anyone who might be able to support you in talking about HIV with your family? Is this something you would find helpful?

5. Ending and debriefing

- Is there anything else you would like to talk about?
- How did you find talking about this with me today?
- Do you have any questions for me?
- Explain what will happen following the interview, [offer follow up support info], explain how the findings will be disseminated, and ensure participants have my contact details.

**Biological mothers**

1. Introductions

- Introduce myself using my name, where I am training, the purpose of my undertaking this research and my interest in HIV and relationships within the family

- Give details of: purpose of the interview / timings / sorts of questions / breaks. Talk about confidentiality / limits to confidentiality e.g. risk to self/others. [Remind clients that this information is included in the information sheet for them to refer back to if they wish] Consent form/any questions/any concerns? Collect demographic information

2. Communication behaviours within the family

Who lives in your house?

Who else do you consider to be part of your family who doesn't live in your house?

How would you describe how your family communicate with each other?

What sort of things do you talk about at home?

Do you talk about more personal things with [your family] such as relationships, sex, health, friendships? Is there anything you wouldn't talk about with [people at home/daughter]? Elaborate…

3. Introducing the topic of HIV

I'd like to talk about HIV with you now. I was wondering if you could tell me about when x was first told that they had HIV, so when it was named as HIV - when was this? Can you remember how they reacted at the time? How do you think x (child) felt? How did you feel at this time?

(If a number of years ago) Can you tell me about how often you spoke/ (If more recent) Can you tell me about how often you and x (child) spoke about HIV in the first few months following the disclosure of x's diagnosis?

Has the amount you and x speak about HIV changed as time has gone on? For instance, before or after disclosure to x? (If it has changed) Are you able to say why you think this might be?

Can you tell me about the last time you spoke about HIV at home?

a) if they do talk about HIV at home - How much have you spoken about HIV and [1. Medication 2. hospital appointments 3. relationships/friendships 4. your child's future romantic relationships 5. Disclosure – either now or in the future 6. Any other concerns about their future]

Who tends to bring up the subject of HIV in conversation first? (If other people bring up HIV) How do you feel when child brings up the subject? How do you think x (child) feels when you bring up the subject of HIV? What do they do/how do they respond?

[If participant has identified a partner in demographics] Do you and your partner discuss HIV together - either your own HIV or your child's HIV? Do you discuss either your own or your child's HIV with anyone else? Elaborate…

- Are there people in the family who talk about HIV more than others? [Again, this could be broken down into particular subject matters e.g. sex, relationships, disclosure, medication, symptoms, clinic attendance] (If yes) Can you tell me about that?

Is there anyone else outside of your immediate family (parent/caregiver & siblings) who x (child) talks about HIV with? (If yes) Why do you think this may be?

- In what way/is the way in which you speak about your child's HIV diagnosis as a family the same or different as to how you discuss your own diagnosis with your family?

How do you feel about the amount of HIV discussion there is in your family at the moment? [satisfied, would like more?] Would you like to talk more or less about your own or (x's) HIV diagnosis with x (child). Elaborate…

If not covered: - How, if at all, do you think being able to talk about HIV has effected x's (child) wellbeing or the way he/she feels? How, if at all, do you think being able to talk about HIV has affected the way you feel? How, if at all, do you think being able to talk about HIV has affected how x (child) manages his/her diagnosis?

Can you think of anyone who might be able to support you in talking about HIV with your family? Is this something you would find helpful?

b) if they don't talk about HIV at home
(Following Can you tell me about the last time you spoke about HIV at home?)
Who brought up the conversation? Does anyone in your family try to bring up topics related to HIV (e.g. medication, hospital appointments, relationships/friendships, future relationships, telling other people you have HIV, any other concerns about the future].
How do you / x [child] / other members of your family respond when the subject is brought up?
Is it usually [that person] who tries to bring up HIV? Can you remember the last time HIV the word was used in conversation at home with x [child]

(If not already discussed) Are you able to tell me about what gets in the way of, or what stops you, from talking about HIV with x (child)?

Is there anyone else outside of your immediate family (parent/caregiver & siblings) who x (child) talks about HIV with? (If yes) Why do you think this may be?

How do you feel about the amount of HIV discussion there is in your family at the moment? [satisfied, would like more?]

Do you think that not really talking about HIV with x (child) has affected the way he/she feels and manages their HIV? [Prompt about medication, the future, relationships] And what about your own wellbeing or the way you feel? Elaborate…

- Is the way in which you speak about your own HIV diagnosis different, either with x or other members of your family? (If yes) In what ways?

Can you think of anyone who might be able to support you in talking about HIV with your family? Is this something you would find helpful?

5. Ending and debriefing

- Is there anything else you would like to talk about? How did you find talking about this with me today? Any questions? Explain what will happen following the interview, [offer follow up support info], explain how the findings will be disseminated, and ensure participants have my contact details.

# Appendix 7 - Interview Schedules Version 2 (post-feedback)

**Adolescents**

1. Introductions

- Introduce myself using my name, where I am training, the purpose of my undertaking this research, my interest in HIV and relationships within the family
- Give details of: purpose of the interview / timings / sorts of questions / breaks. Talk about confidentiality / limits to confidentiality e.g. risk to self/others. [Remind clients that this information is included in the information sheet for them to refer back to if they wish] Consent form/any questions/any concerns? Collect demographic information

2. Communication behaviours within the family

Who lives in your house?
Who else do you consider to be part of your family who doesn't live in your house?
How would you describe how your family communicate with each other?
What sort of things do you talk about at home?
Do you talk about more personal things with your family such as relationships, sex, health, friendships? Is there anything you wouldn't talk about with people at home? Elaborate…
If not, is there anybody else you talk about this sort of thing with? Why that person/why not?

3. Introducing the topic of HIV

I'd like to talk about HIV with you now. I was wondering if you could tell me about when you were first told you were HIV positive, so when HIV was named - when was this? Can you remember how you felt when you were first told your diagnosis was HIV?

Do you remember how you spoke about HIV with mum at home, in the first few months after you were told your HIV diagnosis? Was there anyone else you spoke about HIV with at home? Elaborate…

4. HIV discussions within the family

How is your HIV spoken about now within your family at home?
Has the amount you talk about HIV changed over time? Elaborate… (If yes) Do you have any idea as to why this might be?

Can you tell me about the last time you spoke about HIV at home? **(Clarification - This may or may not be when HIV the word was actually used – it could be anything at all that is related to HIV, so medication, medical appointments, relationships, friendships, disclosure – either now or in the future, your mum's diagnosis, HIV specific information, sex, general health)**

a) if they do talk about HIV at home
How much have you and mum spoken about HIV and [medication, medical appointments, relationships, friendships, disclosure – either now or in the future, any other concerns about the future, **your mum's diagnosis, HIV specific information, sex, general health]**
Do you talk about any of these things with other members of your family? Are these conversations different to those you have with your mum? Elaborate…

Who tends to bring up the subject of HIV in conversation first?
How do you feel when mum (/other) brings up the subject of HIV? How do you think mum (/other) feels when you bring up the subject of HIV?

Are there people in the family who you talk to about HIV more than others? (If yes) Why do you think you speak to them the most?

Is there anyone else outside of your immediate family (parent/caregiver & siblings) who you talk to about HIV? (If yes) Why do you think this may be?

Do you think that being able to talk about HIV [with your mum] has affected the way you feel about having HIV? Elaborate…

How do you feel about the amount of HIV discussion you have with your mum at the moment? [prompt - happy, not so happy?] And with other members of your family?
**Would you like to talk more/less about it – could you say why?**

**What do you think has affected how you talk about HIV in your family?**
**Would you say that your culture / religion has impacted how you or your family talk about HIV?**

**Is there anyone who has helped or supported you to have conversations about HIV with x (child)?**
If not - can you think of anyone who might be able to support you in having conversations about HIV with x [child]? Is this something you would find helpful?

b) If they don't talk about HIV at home
(Following Can you tell me about the last time you and mum spoke about HIV at home?)
Who brought up the conversation? Does anyone in your family try to bring up topics related to HIV (e.g. medication, medical appointments, relationships, friendships, disclosure – either now or in the future, your mum's diagnosis, HIV specific information, sex, general health, any other concerns about the future?]
How do you / mum / other members of your family respond when the subject is brought up?
How do you feel / what's your reaction to [the person] who brought it up?
(If YP brings it up] How does your mum respond when you bring up a topic related to HIV? How do you think she feels? What about other people in the family?

Is there anyone else outside of your immediate family (parent/caregiver & siblings) who you talk to about HIV? (If yes) Why do you think this may be?

How do you feel about the amount of HIV discussion there is in your family at the moment? [Prompt satisfied/would like more]

**What do you think has affected how you talk about HIV in your family?**
**Would you say that your culture / religion has impacted how you or your family talk about HIV? In what way?**

Do you think that not talking about HIV with your mum has affected the way you feel about having HIV – are you able to say why?

**Is there anyone who has helped or supported you to have conversations about HIV with x (child)? How did they do this?**
If not - can you think of anyone who might be able to support you in having conversations about HIV with x [child]? Is this something you would find helpful?
Elaborate…

5. Ending and debriefing

- Is there anything else you would like to talk about?
- How did you find talking about this with me today?
- Do you have any questions for me?
- Explain what will happen following the interview, [offer follow up support info], explain how the findings will be disseminated, and ensure participants have my contact details.

**Biological Mothers**

1. Introductions

- Introduce myself using my name, where I am training, the purpose of my undertaking this research and my interest in HIV and relationships within the family

- Give details of: purpose of the interview / timings / sorts of questions / breaks. Talk about confidentiality / limits to confidentiality e.g. risk to self/others. [Remind clients that this information is included in the information sheet for them to refer back to if they wish] Consent form/any questions/any concerns? Collect demographic information

2. Communication behaviours within the family

Who lives in your house?
Who else do you consider to be part of your family who doesn't live in your house?
How would you describe how your family communicate with each other?
What sort of things do you talk about at home?
Do you talk about more personal things with [your family] such as relationships, sex, health, friendships? Is there anything you wouldn't talk about with [people at home/daughter]? Elaborate…

3. Introducing the topic of HIV

I'd like to talk about HIV with you now. I was wondering if you could tell me about when x was first told that they had HIV, so when it was named as HIV - when was this? Can you remember how they reacted at the time? How do you think x (child) felt? How did you feel at this time?

(If a number of years ago) Can you tell me about how often you spoke/ (If more recent) Can you tell me about how often you and x (child) spoke about HIV in the first few months following the disclosure of x's diagnosis? **(Clarification - When I ask about HIV here, this could be anything at all that is related to HIV, so medication, medical appointments, relationships, friendships, disclosure – either now or in the future,, your own diagnosis, HIV specific information, sex, general health)**

Has the amount you and x speak about HIV changed as time has gone on? For instance, before or after disclosure to x? (If it has changed) Are you able to say why you think this might be?

Can you tell me about the last time you spoke about HIV at home? **(Clarification - This may or may not have been using the word 'HIV' specifically. Could be anything related to HIV)**

a) if they do talk about HIV at home
How much have you spoken about HIV and [1. Medication 2. hospital appointments 3. relationships/friendships 4. your child's future romantic relationships 5. Disclosure – either now or in the future 6. Any other concerns about their future **7. HIV general discussion, about the illness 8. Mother's HIV diagnosis 9. Sex 10. General health]**

Who tends to bring up the subject of HIV in conversation first? (If other people bring up HIV) How do you feel when child brings up the subject? How do you think x (child) feels when you bring up the subject of HIV? What do they do/how do they respond?

[If participant has identified a partner in demographics] Do you and your partner discuss HIV together - either your own HIV or your child's HIV? Do you discuss either your own or your child's HIV with anyone else? Elaborate…

- Are there people in the family who talk about HIV more than others? [Again, this could be broken down into particular subject matters e.g. sex, relationships, disclosure, medication, symptoms, clinic attendance] (If yes) Can you tell me about that?

Is there anyone else outside of your immediate family (parent/caregiver & siblings) who x (child) talks about HIV with? (If yes) Why do you think this may be?

**Reworded: Can I ask how your own HIV status is discussed at home? And how about with your own family, parents, siblings etc?**
**How does this compare with how your child's status is discussed with you?**

How do you feel about the amount of HIV discussion there is in your family at the moment? [satisfied, would like more?] Would you like to talk more or less about your own or (x's) HIV diagnosis with x (child). Elaborate…

If not covered: - How, if at all, do you think being able to talk about HIV has effected x's (child) wellbeing or the way he/she feels? How, if at all, do you think being able to talk about HIV has affected the way you feel? How, if at all, do you think being able to talk about HIV has affected how x (child) manages his/her diagnosis?

**What do you think has affected how you talk to your child about HIV? Or within your own family? Would you say that your culture / religion has impacted how you talk about HIV? Elaborate…**

**Is there anyone who has helped or supported you to have conversations about HIV with x (child)?**
If not - can you think of anyone who might be able to support you in having conversations about HIV with x [child]? Is this something you would find helpful?

b) if they don't talk about HIV at home
(Following Can you tell me about the last time you spoke about HIV at home?)
Who brought up the conversation? Does anyone in your family try to bring up topics related to HIV (e.g. medication, hospital appointments, relationships/friendships, future relationships, telling other people you have HIV, any other concerns about the future].
How do you / x [child] / other members of your family respond when the subject is brought up?
Is it usually [that person] who tries to bring up HIV? Can you remember the last time HIV the word was used in conversation at home with x [child]

(If not already discussed) Are you able to tell me about what gets in the way of, or what stops you, from talking about HIV with x (child)?

Is there anyone else outside of your immediate family (parent/caregiver & siblings) who x (child) talks about HIV with? (If yes) Why do you think this may be?

How do you feel about the amount of HIV discussion there is in your family at the moment? [satisfied, would like more?]

Do you think that not really talking about HIV with x (child) has affected the way he/she feels and manages their HIV? [Prompt about medication, the future, relationships] And what about your own wellbeing or the way you feel? Elaborate…

**Reworded: Can I ask how your own HIV status is discussed at home? And how about with your own family, parents, siblings etc?**
How does this compare with how your child's status is discussed with you?

**What do you think has affected how you talk to your child about HIV? Or within your own family?**
**Would you say that your culture / religion has impacted how you talk about HIV?**

**Is there anyone who has helped or supported you to have conversations about HIV with x (child)? Elaborate…**
If not - can you think of anyone who might be able to support you in having conversations about HIV with x [child]? Is this something you would find helpful?

5. Ending and debriefing

- Is there anything else you would like to talk about? How did you find talking about this with me today? Any questions? Explain what will happen following the interview, [offer follow up support info], explain how the findings will be disseminated, and ensure participants have my contact details.

# Appendix 8 – Additional/amended interview questions

General communication – What is x like? How would you describe relationship with x? What sort of things do you do together? Are there other people you might talk about x, y, z with?

Disclosure – Following question about feelings at disclosure - How do you feel about your diagnosis today? Have your feelings about HIV changed over time?

HIV communication – Have there been times you've wanted to talk about HIV /something related to HIV but haven't? What got in the way? Any particular worries about that? Any questions/conversations you would like to have but have not?

Is there anything that helps you and x to talk about HIV? (prompts – people being there/not being there, times of day/mood). When do you talk about HIV? Who is there?

Anyone else you talk about HIV with? What's different about talking with them?

Any topics you avoid for fear they may lead to discussions about HIV? Explore…

Mothers – how is HIV spoken about within your own family? How is it spoken about in country of origin? Influenced familial discussion?

YP – Do you talk about mum's status? What sort of things? What is it like? Would you like her to share her experiences with you?

Explore different relationships between mother and HIV+ children and HIV- children

How would you like to talk about HIV with x?

# Appendix 9 – Demographic Questionnaires

**Demographics – Mothers**

**1/ Age: _____**

**2 /Ethnicity (please circle):**

a. White British b. White Irish c. White Other

d. Asian or Asian British - Indian e. Asian or Asian British – Pakistani

f. Asian or Asian British – Bangladeshi g. Asian or Asian British – Chinese

h. Asian or Asian British – Other i. Black or Black British – Caribbean

j. Black or Black British – African k. Black or Black British – Other

l. Mixed White-Caribbean m. Mixed White-African

n. Mixed White-Asian o. Other Mixed

p. British Arab q. Other _____

**3/ Marital status (please circle):**

a. Single b. Cohabitating c. Current partner d. Married

e. Divorced f. Widowed g. Other _____

**4/ Country born in: _____**

**5/ If not born in the UK, year of move to the UK: _____**

**6/ Religion: _____**

**Health information**

**7/ Age of diagnosis: _____**

**8/ Country diagnosed with HIV in: _____**

**9/ CD4 count at last check: _____**

**10/ Viral load: _____**

**Demographics - Adolescents**

**1/ Age: _____**

**2 /Ethnicity (please circle):**

a. White British b. White Irish c. White Other

d. Asian or Asian British - Indian e. Asian or Asian British – Pakistani

f. Asian or Asian British – Bangladeshi g. Asian or Asian British – Chinese

h. Asian or Asian British – Other i. Black or Black British – Caribbean

j. Black or Black British – African k. Black or Black British – Other

l. Mixed White-Caribbean m. Mixed White-African

n. Mixed White-Asian o. Other Mixed

p. British Arab q. Other _____

**3/ Country born in: _____**

**4/ If not born in the UK, year of move to the UK: _____**

**5/ Religion: _____**

**Health information**

**6/ CD4 count at last check: _____**

**7/ Viral load: _____**

# Appendix 10 – Example Memos

**Memo 5 – Role of support groups**

Interviews 1 – 4: All have referred to the support groups. I wonder whether the groups have taken the mother's 'communication role' or need for mothers to communicate away somewhat. Perhaps this is a gradual process that happens over time, as young people get used to talking away from home, mothers feel less need to raise the issue? YP2 spoke about finding it difficult to talk to mum or that he becomes upset. Seems to find talking with staff/peers at group much easier? BM2 also spoke of finding it difficult to talk about HIV. Perhaps conversations are difficult at home and easy at support groups? BM1 described feeling that her daughter is better of speaking with people at the support group as she is able to be more open there. Definite influence of culture, the role of the extended family being taken by the support group? BM1 spoke of aunties role – support group are UK aunties? What about adolescents who don't go to support groups/live near them? Do they talk more with parents? Would YP2 have told friends if he had not attended support group and heard positive disclosure experiences? Seemed to get different advice to mum's?

Codes

Feeling lucky to have the space to talk freely
Support group covering a wide range of topics
Support group offering a space for questions
Feeling able to talk about anything at the group

Quotes

*"They just advise you, like…to make your own decision, judge it in your way so everybody has got different situations and circumstances so…it's not really 'you should, you shouldn't' it's more of, 'if you do, it's this this this, if you'don't, it's this this.' So, you can decide"*

*"It's good. It's a haven. Very good. You know, finding a place where you can easily, openly talk without getting judged, that's….you know, you'll be very lucky, cos there's not a lot of them. It was only when I was, 12, 13 when I found out about <support group> and not even to the extent that I know now, and I'm very glad that I did cos it's a very good place, yeah"*

Interviews 5 – 6: Again the young person experienced a massive shift after attending support group. Not only did it allow her to feel more positive about diagnosis, but it also led to her disclosing to non-HIV+ friends (three friends!). YP2 who also attended the group also disclosed to a friend. Both mothers wanted the young person to withhold onward disclosure. The decision to do so must have come with some influence from the group. And these were positive experiences. And disclosing to people is perhaps the only way to begin changing attitudes towards HIV? The attendance and perhaps experience of being able to talk openly about HIV also impacted communication at home with mum. Mum spoke of importance of daughter being able to meet other young people her age and how this had been a big deal for daughter, knowing that she was not the only one. I'm aware that my interviews are mainly happening in and around London. I wonder whether the young people who don't live in London and don't have access to groups (or don't want to go) feel differently about their diagnosis or onward disclosure or whether it affects communication at home? Interesting BM3 still felt talking about HIV at home was extremely important, she did not want the role to be taken away from her as BM1 described. Her own familial communication was more open… link with memo about culture/maternal upbringing?? Both YP and BM spoke about role of friendships at group – something YP1 also referred to. So widening social support, meeting people own age with HIV is significant. Also something mothers don't have??

Codes
Daughter turning to friends for support
Disclosing status to friend as a consequence of camp attendance
Hearing perspectives from adults at camp

Quotes
*"Yeah she does because she has got these people, these friends that she has from <support group>. It's kind of a very strong and supportive network that is good for her because sometimes if she is feeling low she, I would hear that she has spoken to <friend> and she has spoken to <friend> and she has spoken to <friend> and when they speak they talk about why she is feeling low and...she would say, 'oh I was feeling sad on that day and I spoke to <friend> and everything was fine'"*

*"I wouldn't have told her. Cos the thing is, cos I was told from a young age, 'don't tell anyone, it's a bad thing, it'll end badly, don't do it' so like, I was against it so, but then when*

*I went there, I had the experiences with all the other kids,like how they felt about it and I was like, 'ok that's fine', I wasn't so scared to talk about it"*

Interviews 7 – 10: Interestingly the 2 young people do not attend support groups, one because they live far away but she also did not want to go to the camp. The other is considering going. YP4 also speaks the least about HIV at home, although perhaps as a result of mum being so reluctant to do so. Rather than looking to the support groups to offer information about HIV, they looked to the clinic staff. Looking back over the first three interviews, all families did this to an extent too, particularly for medical information. So the role of others in HIV communication seems to play a significant role in all families. Both the latter participants (YP and BMs) spoke of preferring to talk about HIV at the clinic and not at home. I wonder if the fact they have not attended support groups means they are less used to talking about HIV and as such find it more difficult at home? Although YP1 also spoke less about it at home (again on basis of mum's reluctance). YP4 described coping very well with her diagnosis and not needing much support, forgetting about it. I wonder whether group attendance would change her feelings, not to become concerned but to become more engaged with it…would this be a positive thing? Perhaps the group is not for all people…although it seems as though it had such an important, positive impact on the first three adolescents. So support groups and clinic staff seem to play significant role in supporting young person with HIV. Parents all advocate the involvement of these services – perhaps because they find talking about HIV difficult? Few BMs want to/intend to talk about sex with their child – culture again playing a massive role. I wonder if combination of lacking self-efficacy and of believing the role is with professionals contributes to limited conversations with added factor of knowing that the young person is being well supported elsewhere? So the role of others – key theme?

Codes
Being helped by clinic staff to understand HIV
Appreciating the treatment at clinic
Experiencing the clinic as being very supportive

Category - Role of others? Influence of others?

**Memo 9 – Mother-adolescent sex communication**

Interviews 1 – 4: None of the young people or mothers have spoken about sex. YP2 very vocal in his wish to avoid having this topic of conversation with his mother. Again – role of support groups was mentioned, being able to talk openly about sex there. YP1 also spoke about sex elsewhere – either with sister or support group. Both mothers spoke extensively about their culture in COI and how they did not feel able to talk to their child about sex. BM2 spoke a little about wanting to be more open with child but that she felt restricted because nothing was spoken about at home and that she did not know how to do it. So influence of parenting/broader culture growing up evident. BM1 was far more sure of her role and believing that sex talk was not something a mother would do with her child. She again spoke of extended family members – aunties. So similar feelings about sex talk and HIV talk. Considering the age of the participants and the inextricable link between HIV and sex, I wonder whether it is of greater importance that these families are able to talk about sex together or whether there is less need given the support and information they can receive at the clinic and groups. Presumably research will suggest that most young people want to avoid sex talk with their parents? Or perhaps it's parents who want to avoid. What are the benefits of family communication about sex? **[check research]**. Where do young people get information from? School/friends? Is that satisfactory? Are young people with HIV in fact likely to get a much better sex education because clinicians will go into it in depth with them? YP2 spoke of the openness at the group and how helpful it is, describing it as a haven.

Questions to consider for interviews

Q. Is awkwardness something all young people feel in relation to talking about sex with mothers/parents? What is their explanation/understanding of this?

Q. Do they all receive information about sex at the clinic/support groups? What is their experience of this?

Q. How do parents feel about sex communication with child?

Codes

Reiterating the supportive role HIV group and sister have in context of sex talk

Identifying support group as place where daughter can talk about sex

Attributing difficulty of discussing sex with daughter to lack of conversation growing up in culture where this isn't done

Quotes

*"Uh, it's just something which I really have grown, you know when you grow into a culture where you can't talk such a thing I remember growing up with those kind of conversations it was in schools and in your aunties would come and talk to you about that kind of thing"*

*"cos as a parent I never grew up we couldn't talk about such a thing with your parents so I don't even know how to start that kind of conversation yeah..that's the honest truth about it so with her getting more information from support groups and from her sister"*

*"I as a parent to be honest, I can't talk to my… kids about sex"*

Interviews 5 – 6: Another YP who was extremely reluctant to talk about sex with mum. Described changing the subject as quickly as possible. Themes of awkwardness/embarrassment. Preferring to speak with nurses, support group or friends. Mum spoke of having some conversations about sex, these seemed more focussed about waiting so that disclosure was not necessary. Sounded minimal on the basis of what adolescent said. YP3 spoke of finding it easy to talk about sex with nurse in particular. Not feeling judged. Would be embarrassed and very reluctant to have a discussion about sexual experience to date with mum. No talk at all about sex with dad – absolute no go topic. If any more male participants interviewed with fathers, it would be interesting to see whether they have had conversations with dads. Would that be preferable to mums? BM3 spoke of more open communication with own parents and that has influenced/helped her to be open with daughter. So culture impacted but in a different way.

Codes
Finding it easier to talk to clinic staff about sex
Reiterating ease of talking to staff about sex
Feeling embarrassed about sex communication
Talking about sex with mum would be awkward

Quotes
*"I've got like, I usually talk about it with like people at <support group> because I usually go there and then also when I'm up at clinic so it's easier for me to like talk to them because even though they're not family like I know I won't be judged as much so it's just like easier*

*and also I've got a nurse in <local hospital> who does my bloods and it's usually easier to talk to her if I have any concerns"*

Interviews 7 – 10: Again strong theme of embarrassment/awkwardness from young people. Neither YP4 or YP5 wanted to talk with mother about sex. YP5 (male) did not have much contact with father but spoke of potentially talking with older brother. Described feeling awkward talking about sex with anyone. **Wants to avoid HIV communication with mum so that a conversation about sex doesn't come up.** So sex and HIV communication barriers to one another? Or sex communication barrier to HIV communication? YP4 also wanted to avoid sex communication. Similarly to YP3 she did not want to talk to mum about sexual experience. BM4 described culture and upbringing as impacting her beliefs about sex communication, feels that it is not her role as a mother to do that. She spoke of telling all her children to use condoms but that's it and sounds as though this is in a humorous way as opposed to a serious conversation. Again YP4 spoke of talking to healthcare professionals at the clinic about relationships – described finding this a bit awkward sometimes depending on who it was with. Does talk to friends about sex but not in the context of HIV as they are unaware of her status. YP5 spoke of not really having anyone to talk about sex with. Is aware that clinicians will raise it with him, feels that this will be uncomfortable although less so than with mum. BM5 spoke of difference in age with regards to when you might choose to talk about sex with child compared to in COI. Feels would need to do it earlier here, says that she would talk about it with son at a later date although also felt the job would be better off being done by his dad. So role of others theme continues. [Check research for anything about sex communication between parent/child and gender.]

Codes
Viewing certain conversations as off limits between parent and child
Talking about sex with mum doesn't feel right

Quotes
*"Just, just the whole sex thing like, I don't know, it just don't feel right...I don't know…just that, she's my mum, talking about that stuff just doesn't feel right to me, like, you know"*

*"Because I never talk to them such things, the way I've brought them up so there's a gap between mum and daughter so there are certain things that we cannot talk of"*

*"The reason I don't want to talk about HIV with my mum is in case it leads on to talking about sex,"*

Theme: Lack of sex communication? Influenced by BM culture; YP avoidance/ embarrassment/ awkward; role of others
Could avoidance of sex communication be considered a barrier to HIV communication? Choosing not to talk about it interferes with talking about HIV in context of sex surely?

**Memo 11 – Stigma – mothers' experiences**

Interviews 1 – 4: Both mothers spoke a lot about their wanting to protect child from stigma, based on their own experiences. BM1's experience of enacted stigma particularly distressing for her, when she was in hospital, nurses avoiding her and not wanting to take her blood. She has also had experience at work, hearing people talk about patients with HIV and the way they talk about HIV itself. General feeling of ignorance in society and that people don't understand, in addition to the very negative and stigmatising attitudes. BM2 spoke less about personal experience but also described hearing people talking about HIV and being inaccurate or misinformed. Described this as awkward, feeling unable to correct them in case they guess or assume she has HIV. Seemed less adamant about son's disclosing to others after he told a friend, could see that this has been positive though wants him to remain very cautious. Both mother spoke of not wanting anyone to hurt or respond negatively to their child. Both young people (particularly YP2) spoke of attending group and hearing different experiences and advice of people disclosing or being more open with their status. Neither of the mothers had disclosed to HIV- friends due to their experiences and were sure they would not do so at any point. Interesting difference of opinion across the generations. Is this related to the parent's understanding of the cultural attitude towards HIV in COI? Is it different to the UK? They seem to perceive it negatively here and in COI? But young people were not exposed to the high(er) levels of stigma in the 80s and 90s and have not experienced it directly, so perhaps feels more able or motivated to be open?

Codes
Witnessing peoples' negative response to hearing someone has HIV
Hearing negativity about HIV at university
Trying to protect daughter from stigma

Quotes

*"Well…my experience has been like, at work places I've realised how staff react when they bring in a patient who is HIV positive, even at school at the university when we were studying, we were all studying but you could hear what comments people make about people who are HIV positive and just…it's quite..it's very very very negative yeah"*

Questions to consider for interviews:
Mothers - Cultural influence on beliefs about stigma and onward disclosure?
If young person wanting to be open, where does this come from?

Interviews 5 – 6: Mother also spoke of observed, enacted stigma. Insensitive treatment from healthcare professionals, views them as contributing to the maintenance of stigma. Has witnessed family members respond to other family members about their status, negatively. Was more understanding that daughter might want to disclose to HIV-friends at some point but wants her to wait, for protection but also to maintain control over who knows her own status. Views clearly informed by experiences of stigma. Discussions about onward disclosure come up a lot. YP3 aware of mum's views and her experiences of stigma but struggles with secrecy. Has not experienced stigma directly. Again the generational difference seems to play a part, mothers have understandably had far more exposure to stigma about HIV, both personally and in the media. Also cultural attitudes towards HIV in COI. BM3 spoke of how people in COI still view it in a negative light, despite understanding it better. Also spoke of ignorance in the UK and how people understand health aspect better (i.e. life expectancy) but feels that general attitudes have not changed.

Quotes

*"I feel sometimes health professionals make the most stigma out of an illness because I had it at work as well. When people were saying, 'oh when we have a patient, if an inpatient has got HIV we put on more protective clothing than anybody else' and I thought you know, you never get HIV even if you have your gloves put on properly and you haven't any cuts or anything you won't get it, there is no need for extra protection, putting on masks and stuff like that. It's not going to change anything! But it just made me feel like, health professionals are the ones who are…they fuel the stigma"*

Interviews 7 – 10: Stigma and its direct links with advice about onward disclosure. BM4 so concerned about response of others YP4's siblings were unaware of their status and mother felt that they would never share due to her son making comments in the past about people with HIV. When asked, she did not feel giving him education about it would change his view. Spoke of her own opinions about people with HIV before being diagnosed. Belief that people view those with HIV as animals and prostitutes. Feels that any reaction would be negative and that no one else at the clinic would share their diagnosis with people. YP4 did not seem concerned about not telling anyone including siblings. Mum telling daughter that she must not disclose to anyone and that they must keep it a secret. Left me wondering whether mum has recommended she doesn't go to the support groups? And whether daughter feels alone with diagnosis? Though she descried coping and adjusting well. Somewhat detached? BM5 also spoke of experience of stigma and that she feels HIV status should be kept within the family. YP5 also agreed with this, preferring people do not know. He spoke of understanding there was a negative attitude towards people with HIV. Interesting that those who do not attend groups tend to agree with parental attitudes towards stigma and towards onward disclosure whilst those who do go to groups have a different understanding. Will HIV stigma be overcome if people continue to withhold their status from others and therefore accurate information and education about HIV is not passed on? Are support groups key in changing attitudes of young people and therefore changing attitudes of wider population?

Codes

Citing cultural view that people with HIV are prostitutes, hearing people with HIV being called an animal

Seeing nurses afraid to take her blood

Quotes

*"Yeah people talk about it, yeah. Yeah say, yeah she's got this, we call it an animal In UK. Yeah so I've thought hmm, let me just, zip my mouth"*

*"Yeah, they think you are a prostitute, that's how you get the HIV. Yep. Most of the times"*

Category: Influence of stigma / mother's experience of stigma and influence on onward disclosure

# Appendix 11 – Extracts from Interviews – Initial and Focussed Coding

## Biological Mother

| Interview Extract | Initial Codes | Focussed Codes |
|---|---|---|
| I: And how, when she was first told you felt that she was kind of angry and upset about being given the diagnosis. And how do you think she feels about it now? | | |
| 2085. Now I think she has come to terms with it, | Daughter adjusting to diagnosis | Perception of child's HIV experience - adjustment |
| 2086. she understands | Daughter understanding illness | |
| 2087. but sometimes she hates it, she at times hates it and | Daughter hating status | Perception of child's HIV experience - struggling |
| 2088. she has said she doesn't like the idea but that is there, | Daughter struggling | |
| 2089. there is nothing she can do, | Daughter feeling helpless | |
| 2090. she just learns she has to learn to live with it. | Daughter being forced to accept it | |
| 2091. But she has also got friends who are in the same situation and | Finding comfort in knowing other HIV+ adolescents | Role of others - support groups<br>Role of others - social support |
| 2092. up until last year when she went to | Perceiving role of camp fundamental in | |

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| camp it made her feel so much better | adjusting to diagnosis | |
| 2093. because you know she is not living alone, she is not the only one | Daughter no longer feeling alone | |
| I: And she has made good friends from there? | | |
| 2094. Mhmm. Yeah she's made good friends. | Daughter making good friends | |
| I: That's good. And so in the initial stages after she was told about her diagnosis, did you talk about HIV at all then at home, away from the clinic? | | Triggers to HIV communication – YP having questions |
| 2095. Yeah, she would have questions but um… | Daughter having questions about HIV | |
| 2096. once I had answered the question she wouldn't want to know anything | Daughter resisting further discussion | Barriers to HIV communication – YP's willingness |
| I: So it was quick chats? | | |
| 2097. Quick chats and not sit down and talk about it | Having brief discussions about HIV | |
| 2098. but..I think last year, before she went to camp, | Citing a change in communication | Experience of HIV communication – kept to a minimum |
| 2099. I've got my sister-in-laws brother passed away because he was HIV positive. | Family member passed away due to HIV | Triggers to HIV communication - family death – YP distress |
| 2100. We had gone home in 2012 and this guy was playing with <daughter> and they had | Daughter having close relationship with family member | |

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| a very good relationship and she, | | |
| 2101. it was a shock to her that he had died, | Daughter being shocked by death | |
| 2102. ohh it was bad, I didn't know how to console her | Daughter being very distressed | |
| 2103. and she said, 'tell me it's not HIV' and I said, 'I'm sorry I have to tell you it is. | Having to explain the death was HIV related | |
| 2104. Unfortunately people in Africa sometimes they don't understand they need to take medication early enough. | Comparing HIV in Africa | |
| 2105. I can't lie to you I have to be honest with you. | Choosing to be honest with daughter | HIV communication - Providing medication reminders/encouragement |
| 2106. This diagnosis of HIV, if it's not looked after, if you don't take your medication you will die from it, that's the truth, that's the honest truth about it.' | Explaining the risks of non-adherence | |
| 2107. So she, she… she was hurt, and… | Daughter being upset | |
| 2108. kind of wanted to talk a bit more about it and said, | Daughter wanting to talk more about HIV | Triggers to HIV communication – YP distress |
| 2109. 'when did he then started to know that he was HIV positive?' and | Daughter asking questions about HIV | Triggers to HIV communication – YP asking questions |
| 2110. I said 'I don't know, when you saw him, | Being unsure of what happened | |

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| he looked well, but um… what happened between 2012 and 2013 we don't really understand, we don't know, but it was very quick and he passed away.' | | |
| 2111. So I explained to her about the diseases that are in Africa, that are prevalent in Africa, things like the meningitis, there is what they call Cryptococci meningitis, TB meningitis, those 2 are the major illnesses that kill people. And there is <unclear> as well, I have seen people die from it | Teaching daughter about illnesses related to HIV | Providing reassurance - Comparing own HIV to HIV in Africa / historical HIV |
| 2112. but, I have said to her, 'these are only statistics, of people who have started medication and stop, think they are well, they start drinking. | Teaching daughter about consequences of non-adherence | |
| 2113. This illness or taking medication, you can only have a drink once in awhile, don't be an everyday drinker and | Needing to adapt lifestyle | |
| 2114. once you start taking medication you can't drink like, people in the general population, you can't behave like them, | Being different to others | HIV communication – encouraging a |

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| 2115. solely because alcohol sometimes depresses your mood and the moment you start feeling low you don't want to take your medication and then, that's when things spiral down and you don't want to do that | Limiting alcohol intake | healthy lifestyle |
| 2116. so if you have to have a drink, you have a drink once in awhile, Christmas time, birthday and if you know when you're having a drink. I'd prefer maybe you have a glass of wine here with food and not just, drink for the sake of drinking | Offering daughter advice about alcohol | HIV communication – encouraging a healthy lifestyle |
| I: So looking after health and looking after yourself | | |
| 2117. Mmm and we have talked about it so she understands because then we, I said to her, '<family friend> who passed away, it could be because he had Cryptococci meningitis because once people in <COI> or in Africa are not very quick to treat it and it can kill a person within weeks, | Explaining HIV related illnesses can cause death | Providing reassurance - Comparing own HIV to HIV in Africa / historical HIV |
| 2118. so you shouldn't worry about that' and she understood | Reassuring daughter treatment in UK is better | |

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| I: So that was perhaps the first time where she'd heard of someone becoming that unwell to the point where they died from HIV? | | |
| 2119. Yeah, very quickly yeah, very quickly. | Confirming trigger to discussion | |
| I: And was the first really long conversation that you had about health and HIV, was it as a result of that event? | | |
| 2120. Yeah I'd say yeah… I would say that one, | Perceiving death as a catalyst for first conversation about HIV | Trigger to HIV communication – YP distress |
| 2121. we did have a very long discussion but | Having first long discussion about HIV | |
| 2122. after that it also went onto the camp | Citing support camp as another catalyst | |
| 2123. and now becoming on a weekly basis or every 2 weeks | Having weekly / fortnightly discussions | |
| 2124. because she goes to <support group> she, | Citing support group as catalyst for discussion at home | Triggers to HIV communication – critical event - YP going to support groups |
| 2125. they bring up different topics, | Support group raising different topics | |
| 2126. so it's more often now, | Talking more often than before | |
| 2127. since the death and the camp. | Citing the death and camp as point of change | |
| I: And so before that time it was just quick questions that she'd ask and then she'd change the subject? And so it sounds like camp and your family member who | | |

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| passed away, those things really sparked a turn I guess? And now she's going to <support group> the things she talks about there she comes home and will raise it with you, so that kind of is a trigger then to conversation as well? | | |
| 2128. Yeah | Confirming noticeable change in daughter following events | |
| I: And so when you talk about HIV is it normally <daughter> that brings it up or do you kind of all… | | |
| 2129. We both do it. | Both raising topic of HIV | |
| 2130. Sometimes, there was something on the radio, they were talking about it, there was <camp> on radio 4 | Hearing HIV on the radio | |
| I: Oh right! | | Triggers to HIV communication – HIV in the media |
| 2131. Yeah and I asked her to listen to it and she, | Advising daughter to listen to radio show | |
| 2132. we talked about disclosure, | Talking about disclosure | |
| 2133. we always talk about disclosure and | Talking regularly about disclosure | |
| 2134. she says that, 'at some point I want to be able to disclose and | Daughter wanting to disclose in the future | |
| 2135. not live 2 double lives' and I said, | Daughter living a double life | |
| 2136. 'it will be up to you, when you are an | Telling daughter she must wait until she is an | HIV communication – onward |

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|---|---|---|
| adult, | adult | disclosure |
| 2137. you will decide what you want to do and | Telling daughter she will have autonomy in the future | |
| 2138. sometimes you don't have to disclose to people who'll just be..' I think relationships | Discouraging disclosure with everyone | |
| 2139. I have given an example of her relationship with one of her friends who was a friend to her since year 7 but now they are not so close and | Warning daughter that friendships won't last | HIV communication – discouraging onward disclosure |
| 2140. I said, 'imagine if you had disclosed this information to her, | Highlighting risk of disclosing too young | |
| 2141. how do you think she would have taken this information now that you are no longer friends.' | Predicting negative consequences | |
| 2142. And she said, 'oh yeah I do agree with you.' | Daughter agreeing with mum | HIV communication – discouraging onward disclosure |
| 2143. You need to have people who are consistent, people who will not leave your life that | Disclosing only to long term friends | |
| 2144. because these are the problems that you have and therefore you have become | Reminding daughter of HIV transmission | |

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| contagious yeah, | | |
| 2145. so… we both bring it up | Both raising conversations | |
| I: And you said disclosure is a big topic, something you're always returning to, and you spoke about there about your advice to her is to hold off telling anyone would you say? You don't… | | |
| 2146. I always say, you always have people by the nature of going to <support group> | Feeling daughter has enough support at group | |
| 2147. you have already disclosed, by turning up to <support group> you have disclosed so, | Perceiving no need for daughter to tell others | |
| 2148. you have a group, you have a network of people | Reminding daughter of her support network at group | |
| 2149. who never leave your life, who are friends and… | Perceiving friends with HIV as friends for life | HIV communication – discouraging onward disclosure |
| 2150. you find that maybe there is another friend of hers who is not HIV positive, <name> and they appear to be very good friends and at some point I would think she would want to talk to her about it, | Recognising daughter's wish to tell close friends who are not HIV positive | |
| 2151. but I said to her, 'you need to prepare her to understand, because | Telling daughter to prepare friend before disclosure | |

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| 2152. sometimes when, you need to start doing the teaching first before you say this is what has happened | Advising daughter to teach friends about HIV before disclosure | |
| 2153. because sometimes when you say I'm HIV positive, people would be like, 'what?!' but, | Warning daughter about negative response | HIV communication - Onward disclosure – anticipating stigma |
| 2154. look at her perception about HIV and her understanding, if she doesn't understand, | Predicting friends will not have HIV knowledge | |
| 2155. give her some information about it and | Needing to provide information ahead of disclosure | |
| 2156. then when people are a bit aware of the illness then you say, by the way I am HIV positive. | Disclosing only when friends have been educated | |
| 2157. Sometimes when you bring the conversation bit by bit, it's easier for people to understand than | Perceiving disclosure to be easier when done slowly | |
| 2158. just drop a bombshell. | Perceiving disclosure at potentially 'dropping a bombshell' | |
| I: And what's, what would be your fear if she did tell her friends or other people? | | |
| 2159. Um…it's not a fear as such, the issue is um… | Not fearing others' responses | |

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| 2160. with, young people you don't understand whether they are going to continue to be the same friends or not, | Predicting teenage friendships are not long lasting | |
| 2161. at times if she discloses herself she has disclosed for me, | Daughter disclosing mum's status with her own | Onward disclosure – mother's concern about own status being disclosed |
| 2162. she hasn't disclosed just herself, so…it means she has disclosed for dad, who is not ready to disclose, | Husband being private about status | |
| 2163. so the implications are not just her disclosure yeah. That's the only thing. | Perceiving consequences for other family members | |
| 2164. Until, when she is at an age where she can say it herself | Feeling daughter should wait until she is older | |
| 2165. with people who she thinks I am going to be friends for life or partner or things like that, she will then disclose, | Feeling daughter should only tell friends for life and partner | Onward disclosure – mother's concern about own status being disclosed |
| 2166. and I don't have a problem to say, to <daughter's> friends that yeah, this is the situation, don't worry about it and she has been like this for a long time and I can talk to them about it. | Having the opportunity to talk with daughter's friends too | |

**Adolescent**

| Interview Extract | Initial Codes | Focussed Codes |
|---|---|---|
| I: Um, just coming back to relationship with mum, do you talk about things perhaps more personal to you so things about relationships, close friendships or sex? | | |
| 779. Haaaaaa <laughs> nope! Nope! <both laugh> | Laughing at the thought of talking about sex with mum | Absence of sex communication |
| 780. I mean, like, if I'm honest we've talked about relationships | Acknowledging talking about relationships with mum | |
| I: OK, roman- in terms of romantic relationships? | | |
| 781. Yeah, that type of relationships, I mean, but in her mind, me and her we have two different mind-sets; | Identifying a difference of opinion with mum | Experience of HIV communication – differing beliefs |
| 782. her mind-set is find someone alike, | Mum suggesting that he have a relationship with someone HIV positive | |
| 783. and my mind-set is find someone that will like me for who I am | Wanting to have a relationship with someone who likes him regardless of status | HIV communication – encouraging partner with HIV |
| 784. and not just run away 'cos at the end of the day I could find someone who is, in her words 'alike' | Predicting that some people might reject him | |

| | | |
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| I: When you say 'alike' do you mean similar to you… | | |
| 785. Yeah, as in as in, you know, someone who understands about HIV and has positive status… | Mum believing it would be easier for him to be in a relationship with someone who has HIV | |
| 786. but in my mind I'm thinking, woah, what difference does that make | Disagreeing with mother | |
| 787. cos they could also run away and be like, 'bye' you know like, | Believing chance of being rejected is same regardless of HIV status | Experience of HIV communication – differing beliefs |
| 788. it doesn't guarantee anything at all you know. | Choosing a partner with HIV does not equate to a successful relationship | |
| 789. Fair enough you have something in common | Acknowledging mum's reasoning | |
| 790. but it doesn't guarantee anything at all. | Disagreeing with her view | |
| 791. But..and also you're keeping yourself close minded and you're not like, being open minded, you never know. | Wanting to remain open minded about prospective relationships in the future | |
| 792. I mean, but, with other things, nah. Relationships as far as we've got..and I don't wanna, I wouldn't even think to push it… | Not wanting to discuss sex with mum | Absence of sex communication |
| I: <laughs> You're shaking your head! | | |
| 793. Nah, nah, nah, nah! | Vehemently denying wish to discuss sex with | |

| | | |
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| I: OK, so you've talked about future relationships and future partners | mum | |
| 794. Mmmm, yeah you could say that yeah | Acknowledging discussion about relationships with mum | |
| I: And your mum, you think that your mum would prefer it if you had a relationship with someone who was also HIV positive? Is that something that she has explicitly said? | | |
| 795. Yeah, | Mum advising him to have a relationship with someone with HIV | |
| 796. that's what she's hinted as well. | Mum hinting at HIV+ positive | Barriers to HIV communication – lack of privacy |
| 797. But I mean it's not like we talk about it on a regular basis, it's, | Talking about relationships with mum is a rare occurrence | |
| 798. if it comes up randomly within a conversation and it's just the two of us | Needing there to be no one else around to talk about it | |
| 799. cos..as I said, me and my stepdad, I wouldn't talk to him anything about this. | Not being able to discuss relationships with step dad | |
| 800. You know, he's a nice guy, I respect him, he respects me, | Having a respect for stepdad | |
| 801. you know we say 'hi, how are you, how was your day?' blah blah, day to day things but when it comes to other topics…it's…no | Talking with stepdad is limited to day to day topcis | |

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| I: And, are those sorts of things, with your step dad <his mobile phone rings, cancels call> Um, are those sorts of things with your stepdad, have they ever come up, has he ever tried to bring up...sorry, has he ever tried to bring up um…things that aren't day to day topics with you? | | |
| 802. No | Not recalling stepdad ever initiating conversation about relationships | |
| I: And have you ever tried to talk about things with him? | | |
| 803. No | Not wanting to initate conversations with stepdad | |
| I: OK. Um..and with mum, when you have talked about relationships with her, who was it that brought up those conversations? | | Triggers to HIV communication – YP asking questions - wanting mum's perspective |
| 804. I would try to, | Identifying self as person who brings up conversations about relationships | |
| 805. cos there was a time where I wanted to hear what she'd say | Wanting to hear mum's opinions about relationships | |
| 806. but it's hard from me to bring it up aswell, | Finding it difficult to bring up | Barriers to HIV communication - time |
| 807. it's when I get the window of opportunity as I call it, to actually, you know, | Waiting for the right time to talk to mum | |

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| bring one in like to actually talk one about her | | |
| 808. but, like, really I don't really talk about it with her | Not talking about relationships often with mum | |
| I: And what creates or what is a window of opportunity for you? | | Barriers to HIV communication – mother's mood |
| 809. Um, a window of opportunity | Describing window of opportunity | |
| 810. it would be if I see she's in a happy mood etc etc,, | Waiting for mum to be in a good mood | Barriers to HIV communication - privacy |
| 811. like for example if she's, I dunno if it's just me and her or the little ones | Waiting for some time alone with mum | |
| 812. but in the end it just gets me frustrated when I hear what she says | Feeling frustrated by mum's views on relationships | |
| 813. so hence why I don't really, | Being put off talking about relationships because of her views | Impact of HIV communication – YP frustration |
| 814. like in the end I'll be like, 'forget it forget it,' | Wanting to cut short conversations with mum | YP's experience of HIV - struggling |
| 815. she'll be like, 'no, why, no no, why' | Mum wanting to discuss relationships further | |
| 816. I just get really frustrated | Becoming frustrated | |
| 817. and I don't wanna talk about it anymore so I mean, yeah. | Wanting to end the conversation | |
| I: What is it about the conversation that is frustrating | | |

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| to you do you think? | | Experience of HIV communication – YP frustration |
| 818. I mean, cos I know what she's gonna say | Being able to predict what mum will say | |
| 819. and I know her reactions | Predicting her response | Impact of HIV communication – YP frustration |
| 820. and that kind of frustrates me.. | Feeling frustrated at her response | |
| 821. cos I'm not the kind of person who would do something behind her back, who would, I dunno, do some little sly things that she wouldn't know of, | Wanting to be upfront with mum about his frustration | |
| 822. like that so I respect her in that sense | Respecting mum | |
| 823. it frustrates me to hear what she says, so I dunno… | Being frustrated about mum's views on relationships | |
| I: And what kind of things does she say, is it that you don't agree with? | | |
| 824. I mean, as I said to you she would say stuff like, 'find someone alike, find someone like this, find someone like that' | Mum advising on who to have a relationship with | Experience of HIV communication – frustration/anger |
| 825. and I'll be thinking but, is it for you to be happy or is it for me to be happy? | Believing own happiness to be more important than mum's | Experience of HIV communication – differing beliefs |
| 826. Cos, we have two different mind-sets, we can't, s | Having different views to mum | |

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| 827. he can't come to a…what's the word, I always forget it…middle ground? So…it kind of..compromise that's it, I'll never forget that again now! | Struggling to compromise | Experience of HIV communication – differing beliefs |
| 828. So, we can't come to a compromise so it kind of side tracks me and it kind of, for the rest of the afternoon or day or whatever, it'll be on my mind, | Being distracted by conversations with mum for the whole day | Impact of HIV communication – negative effect on day |
| 829. so I don't really like talking about it with her, | Finding it easier not to have conversations | Barrier to HIV communication – avoidance of distress/frustration |
| 830. I just try to, you know put it aside and you know, just continue… | Putting thoughts or questions aside | |
| I: And so, do you talk about those things with other people then? Do you talk about relationships with your friends or… | | |
| 831. Mmm. It won't be a serious conversation if anything. It'll be a little bit jokey. | Having light-hearted conversations about relationships with friends | Sex communication – finding it easier /preferring to talk elsewhere |
| 832. Some serious but mostly joking. So no, not really | Joking with friends | |
| I: And is it something you would like to talk about? | | |

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| 833. I wouldn't mind. But, it's not… | Wanting to talk about relationships with someone | |
| 834. it's not something I find easy to talk about | Finding it difficult to talk about relationships | |
| I: Sure, it's difficult, it's personal and… | | |
| 835. For me it's not even that it's personal | Not being put off by personal nature of conversations | Impact of HIV communication – feeling depressed |
| 836. it's just, it gets me, sad and depressed a bit, but..yeah, | Talking about relationships leads to feeling sad | |
| 837. I mean..err.. I wouldn't mind but yeah | Wanting to talk about relationships despite this | |
| I: And what kind of person do you think, is there someone in mind that you think, 'it would be good to talk about it with that person' or.. is there, either to do with friends, or to do with people at the clinic or other places and you think, 'that might be a good place to talk about things' | | |
| 838. Not off the top of my head, | Having few people to talk about sex and relationships with | |
| 839. I mean, I've tried talking about it some places, like there's <support group> I've tried talking about it with someone there | Attempting to talk about it at HIV support group | Role of others – support group |

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| 840. but, I don't really…find a place and person and yeah.. | Struggling to find a place and person at support group | Experience of HIV communication – differing beliefs |
| 841. I mean.. I don't get that opportunity often so..and, | Not having the opportunity often at support group | |
| 842. in my mind, it's not about talking about it, | Talking about relationships is not the priority | |
| 843. it's about trying to get my mum to get, to understand what I'm thinking and my mind-set, | Wanting mum to understand his view on relationships is more important | Experience of HIV communication – finding it difficult/stressful |
| 844. so when I'm talking to her about it, it's hard for me to put it into, | Finding it difficult to find the words to talk about it with mum | |
| 845. I try like, correctly phrase it so that it gets to her and so she understands it | Trying to phrase things 'correctly' so that mum understands | |
| 846. but, she can't see what I'm thinking | Mum struggling to understand his viewpoint | |
| 847. so it's kind of difficult for me | Finding conversations difficult | |
| I: And where do you think or, are you able to talk about where there differences might lie or where, where your mum's coming from. How do you understand her position? | | Experience of HIV communication – differing beliefs |
| 848. I mean, I understand her position | Acknowledging mum's views about finding an HIV positive partner | |

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| 849. because, at the end of the day she's thinking like, | Describing mum's viewpoint | |
| 850. if you have a partner who is not positive and who does not know about HIV and you tell them about it, they're not going to be..they're not going to stay with you | Mum predicting that an HIV negative partner would end a relationship upon discovering they were HIV positive | Onward disclosure – anticipating stigma |
| 851. and it could end badly. | Predicting a negative ending to the relationship | Experience of HIV communication – finding it difficult/stressful |
| 852. So I respect it and I understand her point of view | Respecting mum's point of view | |
| 853. but..she kind of doesn't see mine, | Wanting mum to understand his point of view | Experience of HIV communication – differing beliefs |
| 854. which is what frustrates me, | Finding lack of understanding frustrating | |
| 855. because I've gotten to, I've taken the time to understand hers | Taking the time to understand mum's position | |
| 856. but she hasn't mine, | Believing mum has not made effort to understand position | |
| 857. she's stuck to hers and I can't budge her, I can't move her, | Being unable to convince mum | Experience of HIV communication – frustration |
| 858. I can't do anything | Feeling helpless | |
| I: And what do you think that's about for her, her wanting you to… | | |

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| 859. I actually don't know, I actually don't know…I tried to suss it out but I can't<br>I: And does she, how does she respond when you talk about your feelings about wanting to meet someone who you like and who likes you? | Being unable to figure out mum's position | |
| 860. 'Oh wait, wait until you've done this, wait til you've got whatever, finish this, do that.' | Mum advising him to wait to start a relationship | |
| 861. I'm like, it could happen any time. | Not agreeing with mum's advice | Experience of HIV communication – frustration |
| 862. So if I'm there, close minded, | Believing mum to be close minded | |
| 863. I could just, someone who I may be with for the rest of my life, | Feeling worried that he may miss out on an important relationship | |
| 864. I could have just missed them. And, I don't…I could have…yeah…<br>I: Ok. Um…and so when I asked if you talk about sex with your mum you said no straight away You've never spoken about it at all? | Missing out | |
| 865. No<br>I: <laughing> Your head is really going! <both laugh> What gets in the way of you talking about that with your mum? | Confirming never having had a conversation about sex with mum | Barriers to sex communication – |

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| 866. It's just really awkward. | Talking about sex with mum would be awkward | anticipating awkwardness |
| 867. Even talking about relationships is pushing it… | Finding relationship discussion difficult | |
| 868. if we went to that, it would, that's it, it wouldn't really work, really | Viewing sex as more difficult to discuss than relationships | |
| I: What makes it awkward do you think? | | Barriers to sex communication – awkwardness |
| 869. I don't know, | Being unsure of why sex is awkward to discuss | |
| 870. I think in every, like in every family to what I hear, in most families, it's not a topic that's easily discussed | Acknowledging the common theme of sex chat with parents being awkward | |
| 871. but I find surprisingly in some families it's an open day every topic | Being surprised that some families discuss sex openly | Barriers to HIV communication – family culture |
| 872. like and, that's not an everyday thing for me and the way I've been raised up, | Not experiencing sex as an open topic growing up | |
| 873. it's, we've been accustomed not to talk about certain things | Being brought up to not speak about certain topics | |
| 874. and you've been like, it's a sixth sense not to talk about it | Having an unspoken rule not to talk about sex | |
| 875. so, I just tend not to even, slightly even | Never attempting to bring up the topic of sex | |

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| bring up the topic so… | with mum | |
| I: And has your mum ever tried to bring it up? | | |
| 876. No. No. Unless she's tried to hint it and I didn't see it. But. No. | Denying mum ever having brought up sex in conversation | |
| I: How do you think she'd respond if you brought it up? | | |
| 877. Haaaa, I don't even wanna know! | Not wanting to predict how mum would respond if sex brought up | |
| I: <laughing> You don't even wanna think about it! | | |
| 878. I don't even wanna know! | Not wanting to guess what it would be like | Timings of conversations - age |
| I: Can you guess?! I'm not gonna make you do it, don't worry! | | |
| 879. She'd probably say stuff like, 'why are you thinking about that?' rather than um…uh…anything. | Predicting mum to be surprised at his thinking about sex | |
| 880. She'd probably stay stuff like, 'focus on your education, focus on this..' etc etc | Predicting mum to advise him to focus on education instead of thinking about sex | |
| I: And have you talked about stuff like that at school? Have you had sex education and stuff like that? | | |
| 881. We've had minor things | Having a small amount of sex education at school | |
| I: It's not great is it? | | |
| 882. It's never great | Finding quality of school sex education to be | Role of others – support groups |

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| I: And what about with, anyone at the clinic? | poor | |
| 883. Well at <support group> we've definitely yeah. | Having sex education at HIV support group | Impact of HIV communication – positive impact for YP |
| 884. It's quite a frequently raised topic | Sex being a regularly discussed topic at group | |
| 885. and I can openly, well not about my experiences cos I have none but I can openly like, discuss my views and my ideas there, | Feeling able to openly discuss views on sex | |
| 886. without restriction | Feeling unrestricted | |
| I: And how is that then? To be able to do that? | | |
| 887. It's good. | Finding it helpful to be able to talk at group | Role of others – support groups |
| 888. It's a haven. | Describing it as a 'haven' | |
| 889. Very good. | Reiterating how helpful it is | |
| 890. You know, finding a place where you can easily, openly talk without getting judged, that's….you know, | Experiencing the environment as non-judgmental | Impact of HIV communication – positive impact for YP |
| 891. you'll be very lucky, | Feeling lucky to have the space to talk freely | |
| 892. cos there's not a lot of them. | Experiencing a lack of places to talk about sex | |
| 893. It was only when I was, 12, 13 when I found out about <support group> | Discovering support group at 12 | |
| 894. and not even to the extent that I know now, | Learning a lot at the support group | |

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| 895. and I'm very glad that I did<br>896. cos it's a very good place, yeah<br>I: So it's provided that space for you to go to topics that it doesn't feel you can go to at home<br>897. Yeah, oh yeah, definitely<br>I: And what other things do you talk about there?<br>898. Every week it's different. Every week it's different.<br>899. You can't really gauge it,<br>900. one week it could be about sex education, one week it could be about you know, facts on HIV or it could be about identity, it really ranges. | Being grateful to have the support group<br>Praising the support group<br>Having a space to talk about topics that are unvisited at home<br>Support group covering a wide range of topics<br>Being unable to predict what the topic will be each session<br>Support group covering sex education, HIV information, identity | Role of others – support group |

## Appendix 12 – Summary of focussed codes across participants

| THEORETICAL CODES | FOCUSSED CODES | BM1 | BM2 | BM3 | BM4 | BM5 | YP1 | YP2 | YP3 | YP4 | YP5 |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 1. Triggers to HIV communication post full disclosure | 1.1 Adolescent having specific questions about HIV | x | x | x | | x | x | x | x | x | x |
| | 1.2 HIV being mentioned in the media | x | | x | | x | | | | x | |
| | 1.3 Choosing a suitable time for conversations to happen | x | | x | x | | x | | x | | |
| | 1.4 Adolescent feeling distressed | | x | x | | | | | x | | |
| 2. Barriers to HIV communication | 2.1 Lacking self-efficacy in communication skills with strong cultural influence for mothers | x | x | | | | x | x | | | |
| | 2.2 Lacking the time, availability or privacy to have conversations | x | x | x | | x | x | x | | x | |
| | 2.3 Adolescent's lack of willingness to discuss HIV | | x | x | | x | | | x | | |
| | 2.4 Anticipating (and wanting to avoid) distress in adolescent | | x | | x | x | | x | x | | |
| 3. HIV topics that are up for discussion | 3.1 Mother providing medication reminders or encouragement | x | x | x | x | x | x | x | x | x | x |
| | 3.2 Mother discouraging onward disclosure and advising as to how to maintain secrecy | x | x | x | x | | x | | x | | x |
| | 3.3 HIV transmission (perinatal infection and guilt) | | x | x | | x | | | | | x |
| | 3.4 Mother providing reassurance to adolescent | x | x | x | | | | | | | |
| 4. Experience of HIV communication | 4.1 Experiencing conversations as difficult/stressful/awkward | x | x | x | x | | | x | | x | x |
| | 4.2 Conversations being kept to a minimum / lacking depth | x | | | x | x | x | x | | x | x |

| THEORETICAL CODES | FOCUSSED CODES | BM1 | BM2 | BM3 | BM4 | BM5 | YP1 | YP2 | YP3 | YP4 | YP5 |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **4. Experience of HIV communication** | **4.3 Level of satisfaction with amount of HIV communication** | | | | x | x | x | x | x | x | |
| | **4.4 Adolescent having different beliefs to mother** | | | | | | x | x | x | | |
| | **4.5 Adolescent perceiving mum as being supportive** | | | | | | x | | x | | x |
| **5. Factors that influence ongoing HIV communication** | **5.1 Having less need to talk about HIV over time** | x | | | | | | x | | | x |
| | **5.2 Mother perceiving the young person is getting enough info/support elsewhere** | x | | | x | | | | | | |
| | **5.3 Adolescent finding it easier to talk elsewhere (at clinic/support group/siblings)** | | | | | | x | | | x | x |
| | **5.4 Mother's experience of stigma – (anticipating, observed, enacted) and wish to protect child** | x | | x | x | x | | | | | |
| **6. The impact of HIV communication** | **6.1 Positive impact of HIV communication** | x | | x | | | | x | x | | x |
| | **6.2 Negative impact of HIV communication** | | x | | | | x | x | | | x |
| **7. The Role of Others** | **7.1 Recognising the role of support groups and clinic staff in providing HIV information and support** | x | x | x | x | x | x | x | x | x | x |
| | **7.2 Receiving social support** | x | | x | | | x | x | x | | |
| | **7.3 Role of services - identifying a need for support with family communication about HIV** | | x | | | | x | | | | |
| **8. Sex communication is off limits** | **8.1 Mothers' cultural experiences and beliefs about the parental role** | x | | | x | x | | | | | |
| | **8.2 Adolescent anticipating (and wanting to avoid) awkwardness with parent** | | | | | | | x | x | | x |
| | **8.3 The role of others in sex communication** | x | x | | | x | x | | x | x | |