Understanding disclosure behaviours in HIV-positive young people

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Abstract

Disclosure of sero-status is part of living with HIV and involves a complex decision-making process. Disclosure is not a one-off event and can be viewed as a sequential process and, while affording opportunities for individuals to access appropriate physical and psychological support, it is also an important part of secondary prevention. It is, however, often fraught with emotional challenges, and there is a considerable amount of evidence demonstrating the barriers that individuals face to making a disclosure. Adolescents are one such group that face challenges over disclosing their HIV status. Many adolescents are choosing not to disclose their status, through fear of potentially adverse outcomes, such as rejection and stigma, which could amplify onward transmission rates. In order to better support young people through disclosure journeys, it is essential to understand the reasons and motivations behind why young people choose not to disclose their sero-status in order to develop interventions which may facilitate supporting young people through the disclosure process.

Keywords

Adolescents, children and young people, HIV, disclosure, sero-status

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Introduction

The overall prevalence of HIV in the UK in 2014 was around 1.9 per 1000 of people aged 15 years and over (Yin et al., 2014). In the UK, a total number of 1934 children have been reported to the UK and Ireland Collaborative HIV Paediatric study by June 2015 (CHIPS, 2016). Of these children, 43% were born in the UK or Ireland, with 55% being born abroad. Place of birth is significant as these children may present much later than their UK counterparts (CHIPS, 2016). There are currently active data on 979 children being followed through CHIPS, with 78% of these children being of Black African ethnicity. The majority of HIV infection (93%) in children and young people is acquired through vertical transmission (CHIPS, 2016). Adolescents and young people account for a smaller proportion, with 3% of under 24s and 1% of under 15s living with HIV (National AIDS Trust, 2016).

The epidemiology of HIV has evolved from its first descriptions. Advances in HIV treatment including accessibility to antiretroviral therapies have meant that for many of these children and young people, they are living beyond original expectations and leading much healthier lives

(Wiener and Battles, 2006; Greenhalgh et al., 2013; Fair et al., 2016). Mortality and morbidity rates have improved significantly, and for many the perception of living with HIV has transformed from being viewed as an acute terminal illness to a chronic condition and consequently these young people now confront living with HIV as such and the challenges that go with living with chronic conditions (Sopen et al 2010, Hogwood et al 2012).

Conversely, these young people are now progressing through adolescence, and with this comes an increase in independence and autonomy, which has some contextual relevance. Adolescence is a turbulent period, where peer and romantic relationships become paramount, and with this associated normative challenges such as negotiating and managing relationships, risk-taking behaviour

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and likelihood of sexual activity which could potentially proliferate infection rates. Young people aged 16–24 years represent only 12% of the UK population yet have the highest burden of disease in relation to sexually transmitted infections (Department of Health, 2009, 2013). For young people with HIV, sexual risk behaviours not only compromise their own wellbeing, but can present concerns regarding onward transmission (Seery, 2011). This necessitates an effective strategy for education on sexual health, and supporting young people to develop skills in communication and negotiation, including supporting disclosure.

It is widely accepted that adolescents should know their HIV status and current guidance advises that children and young people should be made aware of their sero-status by the time they reach secondary school, unless in exceptional situations and diagnosis disclosure is often an incremental process (Evangelini and Foster, 2014; Melvin and Donaghy, 2014; World Health Organization, 2011). This is of particular relevance to the majority of young people who acquired HIV through vertical transmission.

However, as young people move through and navigate the complexities of adolescence, the issue of active or self-disclosure also becomes important and is of relevance to all young people regardless of mode of transmission (Michaud et al., 2009). For a small number of young people, acquisition of HIV will have occurred through horizontal transmission and in these circumstances the young person may have more difficulty adapting to their status, as they come later to clinical services. Disclosure of HIV status can be a challenging, emotive process for any individual, regardless of circumstance, and the decision and motivation to disclose one's status is both facilitated and inhibited by several concerns. Disclosure affords an individual opportunities to access additional resources, improve therapeutic adherence and acquire psychological support, and has a role to play in secondary prevention (Evangelini and Wroe, 2016). However, disclosure of status is also associated with ethical and psychological concerns, such as potential violence, fear of rejection and stigma (Fair and Albright, 2012; Fernet et al., 2011; Hogwood et al., 2012). What is known is that a singular disclosure experience, whether negative or positive may shape any subsequent decisions and likelihood to disclose to others. So it is favourable to consider the importance of young people's disclosure experiences and journeys and suitable interventions which support the decision to disclose (Chaudoir and Fisher 2010).

Experience of disclosure

For the majority of children and young people who acquired HIV through vertical transmission their first experiences of disclosure may have been framed around the build-up to 'naming' their diagnosis, and this often has taken place within healthcare settings in collaboration with health professionals, families and other agencies (Melvin and

Donaghy, 2014). An audit in 2007, exploring disclosure practices within clinical services in the UK and Ireland, acknowledged that the median age of naming HIV occurred usually around the age of 12 years (Melvin et al., 2008, cited by Melvin and Donaghy, 2014). Since this audit, clinics have begun to facilitate earlier 'naming' of a diagnosis and more open discussions about HIV which supports evidence that children cope better when told about their diagnosis at a younger age and a general transparency around HIV awareness (Melvin and Donaghy, 2014).

Parental anxieties, presence of a significant learning disability and social isolation were cited as reasons for delayed disclosures in the 2007 audit (Melvin and Donaghy, 2014). Furthermore, health beliefs and attitudes are also much more likely to be culturally specific which has potential impacts on the active role of children in decision-making and inclusion (Seery, 2010). Greenhalgh et al. (2013) intimated a possible association between the ethnic background of parents and the frame of reference used to perceive the condition within families and this is of particular relevance due to the proportion of children affected by HIV in the UK coming from a Black African ethnic background.

As many of these young people acquired HIV through vertical transmission, they are likely to have experienced living with other family members with HIV and may have experienced cultural sensitivities alongside observed consequences on the decision to disclose, which may motivate their own behaviours. Fear of exposing a family member's status may also carry an additional burden of secrecy (Dorrell et al., 2008; Evangelini and Foster, 2014). A study in the Netherlands exploring the sexual behaviour profiles of young people with HIV acknowledged that 40% of their cohort were unaware of how they came to have acquired HIV. It was recognised that many of these young people were from non-western backgrounds and were living with relatives as their biological parents had often died and emphasised the reluctance of some cultures to discuss HIV (Van der Knapp and Jeledoo, 2015). How one experienced a disclosure as a child or young person may have much significance later in life and there is much more limited evidence regarding managing onward disclosures to others, such as to peers or partners (Chaudoir and Fisher, 2010; Evangelini and Foster, 2014). Young people may choose to reflect on their own experience of disclosure when considering onwards disclosures to others and this emphasises the need to ensure positive disclosure journeys and narratives and understand what prevents a young person from disclosing (Fair et al., 2016).

Barriers to disclosure

There is much evidence which acknowledges the barriers to disclosing one's HIV status and these barriers are not necessarily exclusive to any one group (Thoth et al., 2014).

Barriers to disclosures include: fear and rejection, stigma and discrimination, status of partner and fear of criminalisation (Hogwood et al., 2012; Seery, 2011). Stigma and rejection are significant barriers to adolescent disclosure, as young people navigating adolescence are attempting to formulate and establish a sense of identity, belonging and tribalism, especially through peer relationships. A disclosure might increase the likelihood of being alienated by one's peers, therefore may carry greater risks for many young people, which may outweigh any perceived benefits and overall gains. Stigma, by its very definition, accentuates some kind of disapproval and can have negative effects on self-esteem and social support (Evangeli and Wroe, 2016; Stutterheim et al., 2011). Despite shifts in public attitudes, many people with HIV face stigmatising attitudes on a daily basis (All Party Parliamentary Group, 2015). In a study by Hogwood et al. (2011), young people living with HIV identified that stigma and fear of rejection were major inhibitors to disclosure of status. Much of this related to myths and assumptions about HIV, and a lack of knowledge, especially within their peer group and culture which is also supported by further evidence (Dempsey et al., 2012; Edwards et al., 2013; Wiener and Battles, 2006). There is evidence that where young people source information about sexual health has an impact on outcomes and behaviours (Macdowell et al., 2015). Peer relationships are often a primary source of information relating to sex and sexuality but can be viewed as both a risky and protective force and impact on behaviours (Ricardo et al., 2006). Many social norms, pressures and hierarchies may largely develop from peer relationships. The perceived sexual attitudes and values of peers may reinforce both positive and negative behaviours. For example, a French study demonstrated that perceived liberal attitudes of peer groups was a risk factor in sexual behaviour, with perceived conservative peer attitudes reflecting more protective behaviours; perceived permissiveness was associated with a higher risk of being sexually active, and reflected young people feeling under pressure to engage in intercourse. Whereas beliefs that reflected the idea that intercourse should occur when young people are in love were less likely to result in riskier behaviour (Potard et al., 2008). The study also found positive correlations to contraceptive behaviours when the perception is that the peer group are also using contraception. It is also acknowledged that school-based sex and relationship education has some way to go to meet and support the needs of young people (Office for Standards in Education, Children's Services and Skills, 2013). The use of peers in delivering sex and relationship education has proven a popular method with young people and been utilised in some areas, but is acknowledged that this method may have limited impacts in relation to some outcomes, and their use be recommended as a much broader strategy with sex and relationships education (Stephenson et al., 2008).

There is also the issue of 'normality' which is significant to young people with HIV. Many adolescents do not want to be defined by the fact they are HIV-positive, and as adolescents have many other priorities and desire a recognition that they are young people first and foremost (Hamblin, 2011; Hogwood et al., 2012). By disclosing one's status, young people may expect others to treat them differently so choosing not to disclose may offer young people an opportunity to reject being different and perhaps some control, choosing when it is relevant to disclose (Hogwood et al., 2012; Wiener and Battles, 2006). The development of peer support is one area which goes some way to substantiate normality in young people's lives and various peer support programmes and workshops have been developed, which include face-to-face and secure online support (Campbell et al., 2009; Hamblin, 2011).

Onward disclosures to current or future partners

The decision to disclose is an important one, and this is particularly relevant for young people within the context of romantic or intimate relationships and sexual behaviour, particularly in terms of secondary prevention. There is evidence that rather than disclosing their status, young people may be adopting behaviours in order to potentially minimise risk, due to the perception of risk associated with onward future disclosure to a partner or potential partner (Evangeli and Wroe, 2016; Michaud et al., 2009). Evidence has indicated that young people with HIV will assume protective behaviours as a strategy to avoid disclosure or infection, such as condom use, and non-engagement of high-risk activities, which in some way is reassuring (Fernet et al., 2011; Marston and King, 2006). However, there is also evidence that young people with HIV are choosing to have children or at least express a desire to, which would assume a level of risk taking behaviour (Kenny et al., 2012). In order to meet this need, would necessitate a positive choice not to engage in adopting contraceptive behaviours. So the generic discourse around adolescent sexual behaviours and experiences occupies some relevance here.

Discourse around young people's sexual health and behaviours explores the many confounding factors that impact on their lives, and the theoretical frameworks devised to understand health-related behaviours, such as the Theory of Reasoned Action and Health Belief models (Ingham, 2006). However, it is important that one does not assume that health behaviour is always rational and based solely on the concepts of health maintenance and preservation. There are many other rationalities which influence the health behaviours of young people, such as parents, peers, and political and social constructs (Ingham, 2006; Seery, 2011; Stenner et al., 2006). For example, if sex is unplanned, young people are far more likely to engage in unprotected intercourse, and young people's embarrassment at

obtaining condoms can preclude many young people from their use (Widham et al., 2014). What is interesting is that while there are many similarities in young people's sexual experiences, the sexual experiences of young people with HIV are also marred by anxiety over onwards transmission, loss of freedom and spontaneity, and a diminished sense of sexual attractiveness (Fernet et al., 2011). The sexual health needs of a young person with HIV are in some ways no different to their non-HIV counterparts, and all young people regardless of status require appropriate advice and support (HIV in Young People Network (HYPNET) et al., 2011).

Disclosure can differ between casual and longer-term relationships and is more likely in longer-term relationships (Fernet et al., 2011; Van der Knaap and Jedaloo, 2015; Wiener and Battles, 2006). Adolescent intimate relationships tend to be more fleeting and sporadic, making disclosure in these circumstances more challenging. UK guidance emphasises the need for all HIV-positive adolescents to disclose their status, even when engaging in protected intercourse, and discusses how to manage the disclosure when it does not proceed well, but this could prove insolent where young people are engaging in relationships with someone living in the same area or at the same school (HYPNET et al., 2011). Fair and Albright (2012) found two distinct categories concerning disclosure to romantic partners, which related to physical protection of self and others, but also acknowledged the emotional protection through non-disclosure. The second category concerned acceptance. The eventuality of finding an accepting partner, which is rather reassuring and not only reflects the desire of young people not to be defined by their status, but also self-acceptance. Therefore, equipping young people with coping strategies and communication skills may enable resilience building and emotional readiness for disclosure.

Conclusion

Disclosure of HIV status is beneficial in terms of social and psychological support, treatment adherence and prevention of onward transmission (Evangeli and Foster, 2014; Evangeli and Wroe, 2016) but is also influenced by the concern over the potential consequences (Edwards et al., 2013; Hogwood et al., 2012; Michaud et al., 2009). These journeys contain many antecedents and challenges and a better understanding of motivations around non-disclosure may support the development of strategies which enable positive disclosure journeys. Improved communication and discussion within families and healthcare settings around HIV are one such way which may enable this process. Healthcare professionals should model disclosure by openly naming HIV in consultations and discuss the advantages and potential disadvantages of disclosure, including safety planning for when disclosures do not go well (Fair and Albright, 2014; HYPNET et al., 2011).

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