

A FRAMEWORK TO ADDRESS THE IMPACT OF HIV RELATED STIGMA:

GUIDANCE FOR CLINICIANS

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EXECUTIVE SUMMARY

What is HIV stigma?

The process of stigma generates disregard and disapproval for a person with a discounted attribute (e.g. HIV) and they become to be considered as unworthy of equal regard or worth resulting in social consequences (discrimination, social isolation). HIV stigma is a multi-faceted experience that has complex and mostly negative effects on the lives of people living with HIV.

How does HIV stigma affect young people?

HIV stigma may complicate the ordinary developmental tasks and challenges of adolescence that includes increased independence, forging an adult identity, forming and sustaining friendships, making educational and occupational choices and entering romantic and sexual relationships. HIV stigma may harm the psychological well-being of young person with HIV by reducing expectations of themselves, trust in others, undermining learning at school/college, undermining competent self-management of HIV or acting as a barrier to accessing health care.

What are signs that a young person may be affected by HIV stigma?

Clinicians may misattribute behaviours that are the effects of coping with the impact of HIV stigma to factors such as:

- personality or behavioural issues
- complex family or relationship issues
- immaturity or poor adjustment to HIV status
- poor understanding of the disease
- unwillingness to engage with healthcare

It is worth considering these issues within a framework of the effects of HIV stigma.

Identifying and discussing the effects of HIV stigma with young people:

Clinicians should be able to identify the nature and functions of stigma and be able to discuss with young people. It is important to note that on-going discussions are vital as a single discussion will not achieve any long-lasting positive effects.

- That the function of stigma is to create shame about having HIV

- That feelings of shame and guilt are common responses to stigma
- The effects of stigma may result in wishing to keep secret their HIV diagnosis, having difficulty taking care of themselves (difficulties with adherence), wishing they didn't have HIV and feeling different to other people

A stepped approach to addressing the effects and impact of HIV stigma in clinical practice:

Clinicians have a unique opportunity to address HIV stigma in practical ways in their clinical work by ensuring that the effects of HIV stigma are addressed early with families and individual children and young people.

Discussions with parents and caregivers:

- Exploring how HIV is discussed (or not) within their own family paying attention to the effects of secrecy about having HIV
- Explaining the nature of stigma, its mechanisms and effects in order to emphasize that the function of stigma is to ensure that people feel ashamed of themselves. E and who they are and how this may affect family functioning
- Explaining the importance of peer support through meeting other people with HIV

Discussions with children:

- Discussions about their understanding of HIV to identify positive and negative attitudes towards HIV in general and their own status in particular
- Facilitating and encouraging attendance at locally available services and national projects

Discussions with young people

- Pay particular attention and discussing any difficulties with sharing HIV status to family, friends and romantic and sexual partners
- Exploration of where the effects of stigma are emerging in the life of the young person. This may include not sharing HIV status with others (particularly family members and sexual partners), poor or non-adherence to medication, poor self-care in other domains (alcohol, tobacco and drug use) and poor engagement with HIV healthcare professionals
- Discuss the emotional, psychological and social effects of feelings of shame and guilt.
- Facilitating and encouraging peer support and attendance at local services where available and national projects run by CHIVA and the development of individual supportive relationships

Working with schools:

Engaging and working with schools is essential to ensuring that the educational environment positively supports the educational, emotional, social and cognitive development of the individual child/young person with HIV by actively implementing policies, measures and interventions to reduce the impact of HIV stigma. 'HIV in Schools' practice guidance for schools is available on CHIVA website.

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Introduction

Young people living with HIV, both in the UK and worldwide, experience the ordinary challenges of adolescence that include becoming increasingly independent with regard to self-management, forging their own identities, forming and sustaining friendships, making educational and occupational choices and beginning to enter romantic and sexual relationships.

However, for many young people living with HIV there are additional challenges and stressors. These include medical concerns (medication adherence, regular check-ups), concerns about discussion of status to others (commonly to romantic and sexual partners), an increased prevalence of depression and exposure to HIV-related stigma.

HIV stigma is a multi-faceted experience that has complex and mostly negative effects on the lives of people living with the disease. The experience of HIV-related stigma may interfere with adjustment to, and coping with, the experience of having HIV.

Generally, being a member of a stigmatized group results in relatively poorer outcomes across a range of health and social factors compared with groups that are not stigmatized.

The experience of stigma and discrimination may harm psychological well-being of young person with HIV by reducing expectations of oneself and others, undermining learning in educational settings, or reducing access to adequate health care.

What is HIV stigma?

Stigma is created when four distinct but related components converge:

1. Differences amongst people are articulated and labelled
2. Dominant cultural beliefs link labelled persons to undesirable characteristics (or negative stereotypes)
3. Labelled persons are placed in distinct categories that facilitate the separation of 'us' from 'them'
4. Labelled persons experience status loss and discrimination that leads to unequal outcomes (e.g. health, economic, social)

The process of stigmatisation is also dependent upon the existence of inequalities in social, economic, and political power that enables these four components of stigma to unfold.

The process of stigma generates disregard for the discounted person and others like him/her, and they become to be considered as unworthy of equal regard or equal worth. This may further result in social sanctions (discrimination) against those who possess that attribute.

Discrimination can create a sense of powerlessness. There is a lack of control over one's life as an important part of one's experience has to be hidden and may be found out, with potentially disastrous consequences.

There may also be possible exclusion from valued social groups and activities (e.g. family events, school, the workplace etc).

Given the experience of devaluation, exclusion, and lack of control caused by discrimination, the impact of stigma and the perception of discrimination have negative effects on well-being for the effected person.

This includes an effect on the psychological status of the discounted person as the experiences threaten their positive self-concept.

What are the mechanisms though which HIV-related stigma operate?

At an individual level, the feeling of being stigmatised becomes internalised. This process occurs when an HIV-positive person starts to believe societally derived negative attitudes associated with HIV and accepts them as applicable to her/his self.

This process of devaluation occurs when people living with HIV believe that they now belong to a group of people whom others view negatively. Once these attitudes have been incorporated into ones' own beliefs, the result is an experience of '**internalized expectations of rejection**'. This internalisation of a sense of rejection because of HIV positive status becomes characterised by feelings of shame, guilt and worthlessness.

The process of internalizing HIV-related stigma affects the person in different ways. This complex process creates a sense of powerlessness over one's life that reduces a sense of being able to set personal goals or aspirations and the belief that one has the personal characteristics to achieve these. The process of internalisation of stigma also reduces expectations of self, others and quality and enjoyment of life.

There may be an anticipation of negative treatment by others. Additionally, as there is an expectation of negative responses the maintenance of positive self-regard becomes difficult. This can become manifest in poor self-care behaviours.

HIV Stigma may build on other experiences of being devalued

This idea refers to HIV being particularly prevalent in certain groups, or associated with particular sexual behaviours (e.g. gay/lesbian/transsexual) or alcohol/drug-using behaviours that are already stigmatised.

In this way, the interaction of personal characteristics that may already have stigma attached to them (e.g. young age, female gender, Black ethnic origin, African ancestry) and HIV disease provides a context in which the contribution and importance of any one factor becomes blurred and stigma is experienced at many levels.

Young people living with HIV and stigma: Long-term effects on mental health and coping

HIV-related stigma negatively mental health, self-acceptance, ability to share HIV status, adherence to ART, and overall adjustment of young people with HIV.

Stigma affects the degree to which people living with HIV choose to share their status, given the potential negative social consequences. The experience also may affect both support-seeking and the likelihood of being offered social support.

Higher rates of stigma-related distress have been associated with depression and anxiety (Andrinopoulos et al, 2011), and decreased self-esteem (Varni et al, 2012; Tanney et al, 2012).

Longitudinal evidence suggests that HIV-related stigma has lasting and damaging effects on the mental health of adolescents (Boyes & Cluver, 2013). These negative effects may further reduce the capacity of young people with HIV to practice safe sex (Cluver et al. 2013) and adhere to treatment (Sayles et al. 2009).

High rates of psychological distress, in turn, has been associated with higher rates of participation in sexual and substance use risk behaviours (Varni et al, 2012) as well as decreased adherence to antiretroviral therapies (Martinez et al, 2012) and reduced attendance at medical appointments (Magnus et al, 2010).

Having HIV can be a barrier to accessing general healthcare, but also specialist HIV healthcare (Aggleton et al, 2005).

HIV-related stigma and its consequences (e.g. discrimination, prejudice, violence, etc.) have been identified as stressors that have negative consequences for young people with HIV (Kotchick et al, 2001). For adolescents and young adults living with HIV, stigma negatively influences their quality of life and adherence to care (Harper et al, 2013).

Young people who acquired HIV perinatally have lived with HIV all their lives. They may not always have known their diagnosis and little is known about the gradual realization of the disease and, as the young person matures, the unfolding and often unwelcome realization of the complexity of both the disease and societal attitudes toward HIV (Campbell et al, 2011). The management of social relationships to avoid stigma and discrimination, by not sharing HIV status, has been suggested as an added source of stigma-induced stress amongst young people (Rao et al, 2007).

HIV Stigma in the UK

The effects of stigma emerge in different ways in the lives of people with HIV in the UK where most of the evidence comes from research with adults.

Experiences of discrimination are common with some studies reporting that up to 50% of participants had experienced stigma as a result of their HIV status (Campbell et al, 2011; Weatherburn et al, 2003). In an ethnically mixed sample of 1385 participants nearly one-third of respondents (29.9%) said they had been discriminated against because of their HIV status with nearly half (49.6%) reporting that this involved their dentist or primary care physician (Elford et al, 2008).

African and African-Caribbean communities in the UK tend to be religious and the role of religious belief and participation can be a double-edged sword with regard to coping with HIV. Religious belief can assist individuals to better cope by providing a sense of community, having a belief in a higher power and belief in redemption.

However, a qualitative study focused on the experiences of HIV-positive adults of Caribbean origin noted high rates of perceived stigma in this population (Ridge et al, 2008). Participants reported high levels of HIV stigmatizing behaviour and attitudes in others and attributed this to a combination of fear of contamination, homophobia and ignorance of HIV that was reinforced by religious beliefs. The authors noted that religion serves a double role in Caribbean culture – both underpinning stigma and assisting in coping with HIV – a phenomenon also noted by other researchers (Chinouya & Keefe, 2005).

Similarly, a qualitative study of gay men and heterosexual African people with HIV in England reported that prevalent social discourses of homophobia, racism and xenophobia underpin individuals' experiences of HIV-related stigma (Dodds, 2006).

With regard to the links between stigma and mental health, nearly 50% of the 1576 participants who responded to the 2015 UK Stigma Index survey reported that they had felt shame, guilt and self-blame with regard to their HIV status in the preceding year in the preceding year. Almost 20% had felt suicidal because of their HIV status (at some point) and suicidal feelings were more common in people who had been more recently diagnosed (Hibbert et al, 2015).

Campbell et al (2016) explored experiences of HIV-related stigma in a group of UK based young people with HIV. In a mixed gender sample (n=21) females reported more enacted stigma experiences than males (77% vs. 25%) e.g. more females than males reported losing friends because of their status. Females also reported more serious experiences of being hassled or threatened because of their status. Males reported feeling less stigmatized than females on measures of perceived stigma except with regard to shame, to which there was an equal percentage of response. Feeling socially rejected was the most common experience in males and females, followed by feeling shame about their HIV status. One-third of both males and females reported feeling shame because of their status.

A stepped approach to addressing the effects and impact of HIV stigma in clinical practice:

Clinicians have a unique opportunity to address HIV stigma in practical ways in their clinical work by ensuring that the effects of HIV stigma are addressed early with families and individual children and young people.

Given the range of negative psychosocial and medical outcomes associated with HIV-related stigma, it is important to develop tailored interventions to equip with the practical skills needed to address and cope with the negative effects of HIV-related stigma.

Interventions should aim to promote effective adjustment to HIV and the development of effective self-care behaviours (e.g. attending medical appointments, effective adherence to medication etc).

Such interventions require a constant focus as there are different challenges to be faced as children/young people progress through childhood and adolescence

Discussions with parents and caregivers:

- Exploring how HIV is discussed (or not) within their own family paying attention to the effects of secrecy about having HIV

- Explaining the nature of stigma, its mechanisms and effects in order to emphasize that the function of stigma is to ensure that people feel ashamed of themselves. E and who they are and how this may affect family functioning
- Explaining the importance of peer support through meeting other people with HIV

Discussions with children:

- Discussions about their understanding of HIV to identify positive and negative attitudes towards HIV in general and their own status in particular
- Facilitating and encouraging attendance at locally available services and national projects run by CHIVA

Discussions with young people

- Pay particular attention and discussing any difficulties with sharing HIV status to family, friends and romantic and sexual partners
- Exploration of where the effects of stigma are emerging in the life of the young person. This may include not sharing HIV status with others (particularly family members and sexual partners), poor or non-adherence to medication, poor self-care in other domains (alcohol, tobacco and drug use) and poor engagement with HIV healthcare professionals
- Discuss the emotional, psychological and social effects of feelings of shame and guilt.
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Interventions to address HIV-related stigma

Peer based interventions

There is now evidence that interventions that are solidly based within a theoretically driven framework can be useful in equipping young people with HIV with the skills necessary to cope more effectively with HIV stigma (Lut, Evangeli, & Ely, 2017; Evangeli, Nesbitt, Hinch, Ely, & Lut, 2019; Conway, 2016).

Peer-based group approaches also facilitate participants to build social support within the groups, and perhaps to create a supportive network of other young people with HIV.

Components of effective group-based interventions seem to share a number of features. Firstly, the provision of information about the nature and function of stigma is important in order to provide an explanation of how these processes work. This enables young people with HIV to consider and understand how the process of stigma works and allows them to place their own experiences within an articulated and explicable framework. Secondly, it is important that there is a discussion about how the experience of stigma emerges in the lives of young people with HIV. As previously discussed, stigma may emerge in many different forms and may not immediately be experienced as the effect of stigma. Lastly, the intervention needs to contain ways of identifying personal emotional and cognitive responses to HIV stigma and ways in which the effects can be recognized and countered.

A cognitive-behavioural approach to managing negative thoughts and emotions can be useful. This is a psychological approach to identifying negative thoughts, feelings and beliefs about the self that underpin behaviours that are consonant with the underlying beliefs.

Thus, if one's beliefs about oneself are negative then one's thoughts and feelings are also negative. Behaviours, especially in domains associated with the negative beliefs (medication, sharing HIV status, healthcare) are also likely to be affected negatively thus reflect the underlying stigmatized beliefs.

A CBT approach starts with the identification of negative beliefs about oneself and then proceeds to an exploration of how personal behaviours reflect these beliefs. This can be a very powerful process for young people with HIV who may have never encountered a systematic exploration of how they may feel about themselves and examine how their previously unspoken feelings are reflected in important self-care behaviours particularly with regard to managing their HIV disease.

The next step is to explore how powerful and usually automatic beliefs can be reduced in their impact and intensity. This might take the form of finding alternatives to the emotional and behavioural responses to the experience of HIV stigma (e.g. not avoiding discussions of HIV, not assuming that others will react negatively to a sharing of HIV status, seeing adherence of medication as an act of self-care).

Maintaining a hopeful and optimistic approach is important while emphasizing that each person approaches these issues from a different perspective and each will have a different solution to the unique set of circumstances and challenges in their own lives. Asking young people with HIV to imagine themselves a year hence, having at that point addressed a personally important stigmatizing experience, and writing a letter that outlines the steps undertaken to achieve this, can be a powerful and motivating strategy.

Finally, the process of exploring these issues in a supportive group context cannot be underestimated. Through the sharing of stories and experiences, young people with HIV can readjust their previously unarticulated expectations of themselves and others and forge new bonds of acceptance of themselves and others.

Working with an individual child/young person

Clinicians have a unique opportunity to address HIV stigma in practical ways in their clinical work. Clinicians often feel powerless to address the effects of stigma because they may not understand the mechanisms by which stigma affects their patients and are not able to articulate ways in which patients can identify and address the impact of stigma in their lives.

Clinicians may also misattribute behaviour and difficulties in coping with HIV to other factors such as personality issues, poor adjustment to HIV status, complex family or relationship issues, immaturity, poor understanding of the disease or unwillingness to engage with healthcare when these issues might be better considered and understood within a framework of HIV stigma.

Within clinical settings HIV stigma may be addressed by:

1. Discussing the young person's experience of HIV paying particular to any difficulties with sharing HIV status to family and friends, difficulties in adjusting to HIV diagnosis and changes to a sense of self-esteem.
2. Explaining the nature of stigma and what are the mechanisms and effects.
3. Discussing the young person's views about HIV would help to identify their own attitudes. Attitudes towards people with HIV may be positive or negative (or a

mixture of both) and may underpin and contribute towards their attitudes about their HIV status.

4. It will be useful to broaden the discussion of stigma to discuss groups of people in society and in history who have also been stigmatized. This will help to identify the wider societal reasons for creating stigma, the mechanisms through which this was achieved and the effects on the groups concerned. It will also emphasize that the experience is common and may help to reduce the sense of being singled out for exceptional treatment, which is a consequence of stigma.
5. Most young people with HIV in the UK acquired it perinatally. HIV is often not easily discussed within families because of the effects of stigma, parental concerns about discussion of status outside the family and fear of discrimination within the wider family, friendships groups and communities of origin. It is important to try to help the young person to understand their own family context of HIV in order to help them make sense of their own story of HIV in their family.
6. Some young people will have acquired HIV through sex or drug use. Those past behaviours (especially those associated that led to acquiring the infection) and desires (especially sexual ones) may now intensify the experience of stigma.
7. Discuss the impact of shame and guilt.
8. All families have rules about expected behaviours, how individual members are expected to behave and what is, and is not, acceptable for discussion with the family context. Secrecy and concerns about the effects of HIV being known by others can disrupt ordinary discussions about within the family. The effects on young people may be that they have not had any control over with whom they would discuss their experiences of their own status and required permission from parents to have such discussions. They may need assistance to understand any tensions within their own family created by the family experience of HIV.
9. Exploration of where the effects of stigma are emerging in one's life: not sharing HIV status with others (particularly family members and sexual partners), poor or non-adherence to medication, poor self-care in other domains (alcohol, tobacco and drug use) and poor engagement with HIV healthcare professionals

Working with schools

Schools are important in the lives of children and young people and can positively affect cognitive, emotional and educational development, self-esteem and the development of crucial social skills. School may also be a difficult place for a child/young person who is carrying a secret and may be worried of the social consequences of the secret being discovered.

Families/caregivers are often concerned about discussing their children's HIV status with schools. However, if a school is unaware of a child's HIV status they may not be able to provide an encouraging and optimistic environment for the individual child and may not actively address any stigmatising attitudes, educational material and behaviours that may occur.

Parent/caregiver consent may be required in order that a clinician may contact a school to facilitate a discussion about stigma. The clinician should aim to raise the school's awareness of the negative effects of stigma for the child/young person and facilitate the school to put measures in place to address HIV stigma. Provide schools the 'HIV and Schools' practice guidance document on the CHIVA website.

Learning points:

As HIV is a stigmatized disease it is probably not possible for any individual not to be affected by stigma in some way

Stigma is associated with guilt and shame, especially when it comes to past and future sexual/romantic relationships

Points for discussion with young people:

What is the function of stigma?

Where does the experience of HIV stigma emerge in your life?

What was the story of HIV in your family?

What were the ways in which your family coped/is coping with HIV?

Do you think these are good ways?

Looking back, do you think that there are other ways that might have been better for you?

How do you think of yourself now as a person living with HIV?

What do you imagine others would think of you if they were aware of your status?

Are you aware of any feelings of shame or guilt related to your status?

Do you try to conceal your status from others?

Are you worried about “being found out”?

What are your ambitions?

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