



# Learning guide

Stigma in women living with HIV

This learning guide has been prepared in conjunction with the Women for Positive Action slide presentation and speaker notes resource concerning challenges associated with stigma and discrimination in women living with HIV.

The guide identifies the key learning objectives for this educational resource and suggests topics for discussion and self-learning. The modules are intended for use by both health professionals and community representatives who want to create or participate in learning opportunities relating to improving the care of women with HIV.

## **Learning objectives**

After completing this module, participants will be able to discuss the following issues and appreciate their implications for both patients and healthcare providers.

### **Women with HIV may experience stigma and discrimination on a number of levels**

- Stigma is defined as “an attribute that is deeply discrediting” and that reduces the bearer “from a whole and usual person to a tainted, discounted one”
- Discrimination is a consequence of stigma and is defined as “when, in the absence of objective justification, a distinction is made against a person that results in that person being treated unfairly on the basis of belonging or being perceived to belong to a particular group”
- There are four main types of stigma, each of which can lead to discrimination
  - internalised stigma (felt or imagined stigma)
  - enacted stigma (feelings or actions towards those with HIV)
  - perceived stigma (how an individual believes society views them)
  - symbolic stigma (refers to blaming and shaming those with HIV)
- Women can experience an overlap in the types of stigma experienced, known as ‘layers’. This can be in relation to particular issues e.g. stigma around being unable to breast feed or stigma due to the route of transmission
- Stigma and discrimination can occur on a number of different levels;
  - micro level (related to individual beliefs and close personal relationships)
  - meso level (referring to stigma from the community)
  - macro level (referring to stigma experiences from health and social service systems)

## **HIV-related stigma and discrimination can impact on health-related outcomes**

- Women living with HIV experience greater stigma than men
- The impact of HIV-related stigma and discrimination on the health and wellbeing of women include
  - negative experiences from health care professionals and medical institutions
  - poor medication adherence
  - reluctance to plan for a family
  - avoidance of HIV testing and risk of late diagnosis
- Personal and psychological effects that can be experienced include loss of hope and feelings of worthlessness, depression and increased internalization of negative views of HIV
- Social and community effects can be experienced and include exclusion from religious/cultural communities, difficulties with education and housing and avoidance of social interaction
- The impact of HIV-related stigma and discrimination on partnerships and family relationships includes reduced chance of marriage, rejection by partner, family and/or friends, reluctance to disclose or delayed disclosure to children and family

## **Disclosure is a significant step and when a woman decides to disclose they must feel supported**

- Disclosure is a step which reoccurs over the course of a lifetime and affects every area of a woman's life. If a woman feels that she may experience stigma or discrimination it may affect her willingness to disclose
- Disclosure should be a personal choice which is tailored to the needs of the individual woman. Disclosure should feel like a safe event where the woman is fully supported
- Beneficial disclosure describes a situation where a person living with HIV informs people of their status so that this knowledge can help prevent spreading the virus e.g. when status is shared with a sexual partner to help plan against onward transmission, or when HIV status is shared with family and friends to obtain support
- Women can be motivated to disclose their HIV status for a number of reasons which include enhanced quality of life, to gain support from their social network and also potentially from counseling as well as out of concern for partner's health
- Initiatives are available to help support women who wish to disclose their HIV status

These include:

- counselling approaches such as role-play
- mediated disclosure
- community initiatives such as community forums and support groups
- policy and programme approaches including training healthcare workers in HIV management
- Disclosure to children is an important decision, while there are times where it is suitable to disclose to children there can be occasions where it isn't. These include not wanting the child to worry and wanting them to have a carefree childhood. The World Health Organization has developed guidance on disclosure to children

### **HIV-related stigma can be measured**

- Evaluating anti-stigma campaigns and identifying the most appropriate approaches to combat stigma mean that it is important to be able to measure the impact of any interventions
- The People Living with HIV Stigma Index provides tools to assess trends in the stigma and discrimination experienced by those living with HIV. The index is composed of a survey to collect information about the experiences of people living with HIV related to stigma, discrimination and their rights. The design of The People Living with HIV Stigma Index mean that it can be adopted for independent use or it can be used in the group setting

### **There are strategies to help overcome stigma and discrimination**

- The greater involvement of people living with HIV (GIPA) is a principle that aims to recognise the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives
- Peer support can be beneficial for women, through providing mutual support and helping them realise that they are not alone; there are a range of peer support groups available
- Healthcare professionals should be supported to recognise the impact of stigma on healthcare outcomes. Research has shown that people with HIV can often experience stigma and discrimination through the healthcare system and that this is predictive of greater distrust, weaker treatment benefit effects and poor treatment adherence

## **Initiatives have been developed to support women in combating stigma and discrimination**

- A number of anti-stigma campaigns have previously been implemented by international organizations such as AVERT, the International Community of Women Living with HIV/AIDS, the International HIV/AIDS Alliance. National organisations including AIDES in France and Lifeboat in Germany have also developed campaigns.

## **Discussion guide**

Consider the following questions when completing this module – the questions can be used for both reflective self-learning purposes and as a guide to discussion as part of a group learning experience.

### **Identifying stigma and discrimination in women living with HIV**

Challenges in relation to stigma and discrimination can be experienced across all stages of a woman's life and in a number of different situations. Experiences of stigma and discrimination are linked with emotional wellbeing and can potentially result in reduced treatment adherence and increased risk taking behavior.

- What are the different types of stigma that can be experienced?
- What different aspects of health and wellbeing can be influenced by stigma?
- Which population groups are likely to be involved in each of the different types of stigma?
- Which groups of women living with HIV might be more likely to experience stigma and discrimination? Is there a 'vulnerable' type?
- How can those women at high risk of experiencing stigma and/or discrimination be identified?
- How can a woman be supported to take steps to counteract against stigma, or to discuss treatment and care options with their healthcare professional?
- How can a woman be supported to access care and continue to fully adhere to treatment despite any stigma or discrimination that may be experienced?

### **Considering disclosure in women**

Disclosure is a decision that women need to consider at all stages during their life; each situation being unique and requiring consideration of a number of factors. Supporting disclosure should be tailored to the individual needs of each woman.

- What are the positive effects of disclosure?
- What are the situations where a woman might be encouraged or may feel motivated to disclose?
- If a woman decides to disclose how can they be supported with this?
- What factors should be considered when deciding on when and how to disclose to a child?
- What resources are available for guidance on disclosing to children?

### **Support for women with HIV who are experiencing stigma**

- How does stigma manifest itself during the different life stages in women, and how can these be overcome?
- What social support can be offered to a woman when discussing experiences of stigma?  
How can women access these services?
- What coping strategies could be used or suggested by a healthcare professional to support women experiencing stigma?
- How can healthcare professionals be supported to recognise and react to stigma?