Introduction

In the age of undetectability and wide usage of ART, stigma – felt, anticipated, or enacted - remains a persistent feature in the lives of almost half of people living with an HIV diagnosis.

This is often internalised and manifests through feelings of guilt, self-blame, low self-esteem and shame. As a result, the quality of life for people who are living with HIV (PLWHIV) is negatively affected, with one-in-three people surveyed expecting to be gossiped about, or be rejected sexually because of their status.

This qualitative research aimed to further explore the lived experiences of people living with HIV reported in the 2015 StigmaSurvey UK.

Methods

• 40 semi-structured interviews were carried out with a representative sample of people living with HIV.

• The interviews explored why people have negative feelings towards themselves in relation to their HIV status and to better understand various forms of experienced stigma.

• The researcher who conducted these interviews is herself HIV positive. It is her status that afforded her a common ground with interviewees. The methods employed in the analyses of the data were pre-determined themes and inductive analyses.

RESULTS

• The resounding response from the interviews was that: self, anticipated or experienced stigma is a complex process. It varies over time and is manifested in various situations, ranging from disclosing status to a new partner to discussing diagnosis with healthcare professionals and employees.

• The majority of people (90%) felt they experienced anticipated stigma, primarily because of a perceived lack of knowledge and misconceptions about HIV within the wider population. This impacted on their psychological well-being.

• Moreover, culture, religious ideologies and sexuality were barriers to being open about ones status and this can perpetuate and exacerbate stigma.

• Even if some people do seek solace within the HIV sector, fear of rejection from sexual partners or family is still a lived reality.

• Both women and men described instances when their HIV status was used to elicit power against them resulting in shame and guilt.

Conclusions

Stigma, especially anticipated, is a lived reality for nearly all of those who were interviewed, with the level of anticipation being at its most acute when wishing to discuss ones status with a potential sexual partner because of fear of being rejected, this is even when undetectable. Voices of people living with HIV heard through this research strengthen and contextualise the findings of the StigmaSurveyUK 2015. Findings should influence educational programs and inform national policy to reduce HIV related stigma and discrimination.