Primum Non Nocere – The Urgency of Eliminating Stigma in Health Settings

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Political commitments to address stigma in health settings

- 2030 Agenda for Sustainable Development: “Leave no one behind”

- 2016 Political Declaration on Ending AIDS:
  - Promote non-discriminatory access to health care
  - Eliminate HIV-related stigma and discrimination by 2020

- UNAIDS strategy: target on eliminating HIV-related discrimination with a particular focus on health care
Stigma and discrimination: Definitions

- **Stigma** refers to beliefs and/or attitudes. Stigma is a dynamic process of devaluation that significantly discredits an individual in the eyes of others, such as when certain attributes are seized upon within particular cultures or settings and defined as discreditable or unworthy.

- **Discrimination** refers to any form of arbitrary distinction, exclusion or restriction affecting a person, usually (but not only) because of an inherent personal characteristic or perceived membership of a particular group. It is a human rights violation. In the case of HIV, discrimination can be based on a person’s confirmed or suspected HIV-positive status.
Manifestations of stigma and discrimination in health settings

- Denial of health-care services
- Provision of poorer quality care
- Physical and verbal abuse
- Mandatory HIV testing without consent or appropriate counselling
- Forced or coerced sterilization of women living with HIV
- Health providers minimizing contact with, or care of, PLHIV
- Requiring third-party authorizations for the provision of services
- Demands for additional payment for infection control
- Isolation of people living with HIV
- Lack of privacy
- Breaches of confidentiality
Experiences of stigma and discrimination in health settings

• Experiences of care:
  • ¼ of PLHIV reported experiencing discrimination in health care
  • 1 in 3 women living with HIV reported experiencing at least 1 form of discrimination related to their sexual and reproductive health in health care settings
  • In 7 of 31 countries with accessible data, 1 in 5 people living with HIV reported that a health care worker had disclosed their HIV status without consent

• Denial of care:
  • 1 in 5 people living with HIV reported having been denied health care

Percentage of people living with HIV who experienced discrimination in health-care settings, countries with available data, 2012–2017

Impacts of stigma and discrimination in health settings

- Discrimination in health settings is a violation of human rights
  - Right to health
  - Right to non-discrimination
  - Right to privacy
  - Right to liberty and security of the person
  - Right to freedom of expression and information

- Stigma and discrimination deter uptake of health services

- They impede achievement of UHC, 90-90-90 and epidemic control
Figure 2. Examples of stigma and discrimination that create gaps across the HIV testing and treatment cascade

Examples of barriers specific to one step of the cascade

- Fear of lack of confidentiality among health-care workers undermined HIV testing uptake in sub-Saharan African countries (3, 17).
- Men who have sex with men and transgender women in New York City who feared HIV stigma were less likely to have had an HIV test in the previous six months (4).

Barriers that exist across the cascade

- People living with HIV who experienced high HIV stigma were 2.4 times more likely to present late for HIV care (pooled analysis of 10 studies) (1).
- HIV-related stigma inhibits uptake of services to prevent mother-to-child transmission (38-42).
- Fear of disclosing HIV-positive status to their male partner and stigma identified as key barriers to initiating lifelong treatment among pregnant women living with HIV in three districts in Uganda (20).

- Stigma or fear of stigma leading to non-disclosure undermine treatment adherence by compromising social support mechanisms (20, 22, 23).

- Societal fear of HIV infection.
- Negative attitudes towards key populations.
- Stigmatizing attitudes and practices among health-care workers towards people living with HIV, people at high risk of HIV infection and caregivers.
- Denial of health services to people living with HIV and marginalized groups.
- Lack of family and community support.
Impacts of stigma and discrimination in health settings

- Care seeking
  - 1 in 5 people living with HIV reported avoiding going to a local clinic or hospital due to HIV status (feared facing stigma and discrimination)
  - People living with HIV who perceive high levels of HIV-related stigma are 2.4 times more likely to delay enrolment in care until they are very ill

- Retention in care:
  - Coercive treatment and lack of confidentiality erode trust in services and reduce retention in care

- Treatment adherence:
  - Perceived discrimination in healthcare settings negatively impacts ART adherence, first through internalized HIV stigma, and then through depressive symptoms

Layering of stigma

- HIV status
- Gender
- Sexual orientation and gender identity/expression
- Engagement in drug use/sex work
- Age
- Poverty
- Immigration status
Percentage of key populations who reported having avoided health-care services in the past 12 months due to stigma and discrimination, countries with available data, most recent data, 2013–2017.

Impacts of stigma and discrimination in health settings

• Stigma and discrimination have a detrimental effect on health outcomes
  • Physical health
  • Mental health

• They negatively affect well-being and quality of life
  • Internalized stigma
  • Depression
  • Negative self-image
  • Disclosure concerns
  • Stress
Drivers of stigma and discrimination in health settings

• Discriminatory laws and policies
• Discrimination is often driven by stigma – negative underlying beliefs
• Stigma is rooted in communities and health workers come from these same communities
• Inadequate training and protocols
• Over-stretched systems and insufficient supplies
Stigma against health workers

- Health workers living with HIV
- Health workers providing services for people living with HIV
- Health workers providing services for key and/or vulnerable populations
Addressing stigma and discrimination in health settings

- Continued measurement of stigma and discrimination in health settings and testing of effective interventions
- Legal protection against discrimination
- Health system strengthening: human resources, infrastructure, supply chain etc.
- Patients’ rights education
- Capacity building on health workers’ rights and responsibilities
- Functional and accessible mechanisms for redress
- Human rights-based, people-centred, health services
Rights-based, people-centred multi-sectoral action

- Human rights provide a useful framework
- Participation of people living with HIV and other key and vulnerable populations must be central
- Actions must be multi-sectoral
- Collaboration is key
- Build on existing experience… and tailor it to local settings
Ongoing global initiatives

- Agenda for Zero Discrimination
  - ‘Equal Health for All’ virtual community of practice
  - www.ZeroHIVDiscrimination.com – online repository of tools

- Global Partnership for Action to End All Forms of HIV-related Stigma and Discrimination

- International Federation of Medical Students’ Associations: Declaration of Commitment to Eliminate Discrimination in Health-care Settings (2016)

- People living with HIV Stigma Index

- Global AIDS Monitoring reports
THANK YOU

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