50+ STIGMA IN MIGRANT SOCIETIES

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EPIDEMIOLOGY OF HIV IN EUROPE

- DEVELOPMENT AND DISTRIBUTION OF **EFFECTIVE ARVS** HAS RESULTED IN **BETTER HEALTH OUTCOMES** AND **IMPROVED LIFE EXPECTANCY FOR PLHIV**[1] – **IN EUROPE APPROX 840,000 PLHIV ARE OVER AGE OF 50**[2]**.**

- **LACK OF TARGETED PREVENTION STRATEGIES** LEADS TO OLDER PEOPLE **VULNERABLE TO NEW HIV INFECTIONS** – **12.9% NEW INFECTIONS IN WESTERN EUROPE IN OVER 50s**[3].
- INCREASED **MIGRATION EXPANDED DEMOGRAPHIC PROFILE** OF PLHIV IN EUROPE – **37% HIV DIAGNOSES IN PEOPLE NOT NATIVE TO EUROPE**[4].
- **CHANGING NEEDS** OF PEOPLE LIVING WITH HIV[5].

STIGMA OF OVER 50s BME WITH HIV

- AIM: **TO IDENTIFY CAUSES OF STIGMA; UNDERSTAND THE IMPACTS OF STIGMA; AND PROPOSE THREE STRATEGIES TO REDUCE STIGMA AND SUPPORT THOSE AFFECTED BY STIGMA.**
- RESEARCH METHODOLOGY: **PAPER QUESTIONNAIRES; ONE-TO-ONE AND GROUP DISCUSSIONS WITH 16 OVER 50s SERVICE USERS OF AFRICAN HIV SUPPORT GROUP IN SOUTH EAST LONDON.**

WHAT IS STIGMA?

"Stigma is an adhesive that cannot be removed but stuck with for life, whereby HIV is an added disease that cannot be removed." Coach, 50 year old Nigerian.

- **STIGMA** IS A TYPE OF NEGATIVE, DISTINGUISHING LABEL THAT STEMS FROM VIEWING OTHERS AS LESS VALUABLE THAN THE MAJORITY[6]. IT CAN BE PERCEIVED OR ENACTED.
- **DISCRIMINATION** IS STIGMA PUT INTO PRACTICE, DISPLAYED THROUGH UNFAIR BEHAVIOUR, DISRESPECT AND CRUELTY[7].

CAUSATIVE FACTORS FOR STIGMA

HIV-RELATED STIGMA

- **ERRONEOUS FEAR OF CONTAGION OF HIV THROUGH CASUAL CONTACT**[8], EXHIBITED BY NON-SPECIALIST HEALTHCARE PROFESSIONALS WHO USE HEIGHTENED HYGIENIC PRECAUTIONS; AS WELL AS THE WIDER COMMUNITY, INCLUDING BME:

"…I've seen them break a cup after another woman with HIV had used it…They even said 'Look how she was sitting on that chair, you can catch HIV if you sit on that chair now'." Leyla, 50 year old Tanzanian woman describes treatment of PLHIV within her circle of friends.

- **ASSUMPTIONS ABOUT LIFESTYLE**[9] CHOICES OF PLHIV, E.G. PROMISCUITY, MSM.

- **NEGATIVE REPRESENTATION OF PLHIV** IN MAINSTREAM MEDIA[10]:

"We always hear about cancer on TV but nothing about us who are living with HIV. Why is nobody talking about how brave we are?" Arthur, 50 year old from Nigeria.

CAUSATIVE FACTORS FOR STIGMA

AGE-RELATED STIGMA

- **LESS VALUE ATTRIBUTED TO OLDER PEOPLE**[11]. PARTICIPANTS REPORTED BEING PATRONISED, NOT LISTENED TO, AND DENIED ADVANCED MEDICIAL APPROACHES:

"I keep telling him [doctor] I got pain but my feeling is he don't want to waste no time with me because am old and probably going to die soon." Anna, 68 year old Ugandan.

- **STEREOTYPICAL VIEW OF SEXUALITY OF OLDER PEOPLE**[12] THAT IMPEDES EARLY HIV DIAGNOSES, AND LACK OF SERVICES FOR OVER 50s.

- **GREATER EXPECTATIONS PLACED ON OLDER PEOPLE** TO HAVE KNOWLEDGE AND SKILLS TO PROTECT SEXUAL HEALTH[13]. CAN ALSO LEAD TO SELF AGE-RELATED STIGMA:

"When I found out I thought 'Father Lord, what have I done?…I always teaching my kids be careful and now here I am…I felt too ashamed" Honey, 58 year old Jamaican, diagnosed 2013.

CAUSATIVE FACTORS FOR STIGMA

RACE-RELATED STIGMA

- **DISTORTED ASSESSMENT** THAT BME PEOPLE DO NOT SHARE SAME MORALS AND VALUES OF HOST COMMUNITY AND ARE A **BURDEN ON PUBLIC SERVICES**[14].

- PARTICIPANTS REPORTED **COMMUNICATION IMPLIED THEY WERE LESS ABLE TO UNDERSTAND CONSEQUENCES AND INSTRUCTIONS** DUE TO RACE.

- RACE-RELATED STIGMA ALSO **OCCURS BETWEEN VARIOUS BME COMMUNITIES**[15]:

"When I had started dating a West Africa man, his friend told him, 'Beware, you know those East African people are all full of the AIDS…" Sarah, 54 year old Kenyan.

- CAN OCCUR IF INTENTIONS ARE HONOURABLE - IF SERVICES THAT ARE DESIGNED FOR BME PEOPLE **IGNORE THE LANGUAGE, CULTURAL AND NEEDS-BASED COMPLEXITIES** EXISTING BETWEEN DIFFERENT ETHNIC GROUPS[16].

THE IMPACT OF STIGMATISING BEHAVIOURS

SELF-CONCEPT

- ALL PARTICIPANTS REPORTED THAT **STIGMA HAS AN EFFECT ON THEM AND HOW THEY FEEL**.

- THIS INCLUDES **GUILT, DECREASED CONFIDENCE, LESS VALUABLE AND LESS MOTIVATION** TO CARE ABOUT SELF.

"Stigma makes me not able to feel much important, that I am not able to contribute more." Coach, 50 years old, Nigerian man.

- IMPACT OF STIGMA **DEVASTATING AND LONG-LASTING**[17].

- **AFFECTS SELF-IMAGE**, **EVALUATION OF SELF-WORTH** AND VALUE TO OTHERS, AND **INCREASES SELF-BLAME**[18].

THE IMPACT OF STIGMATISING BEHAVIOURS

COMMUNITY INTERACTIONS

- **STIGMATISING ATTITUDES AND BEHAVIOURS HAVE MIGRATED** WITH PEOPLE FROM BME COMMUNITIES, AFFECTING SOCIAL RELATIONSHIPS AND LONELINESS[19]:
  "People talk behind other people's backs. One lady from my church, everybody was talking she had AIDS. I don't want to become her…I don't have a large social group." Kate, 51 year old Nigerian lady.

- **OBSTACLES TO SEEKING COMPANION** INCLUDE DISCLOSURE CONCERNS, FEELING TOO OLD, ASSOCIATING SEX WITH HIV, AS WELL AS PRIOR NEGATIVE EXPERIENCES[20]:
  "When I disclosed he was fine…but when we broke up he started harassing me, telling me I had given him AIDS. I know I didn't but for weeks I was so stressed, thinking he was going to tell everybody. I don't want to disclose again so now stay alone." Leyla

- **UNABLE TO RELY ON TRADITIONAL SUPPORT NETWORKS**[21] HAS LEFT OPLHIV ANXIOUS ABOUT THE FUTURE AND HIGHLIGHTS NEED FOR FORMAL COMMUNITY SUPPORT:
  "I am worried about growing older with HIV as I might not be able to meet my daily activities of living leaving me unable to cope, and I have nobody to ask for help." Sarah, who had only disclosed to her one sister in Kenya.

THE IMPACT OF STIGMATISING BEHAVIOURS

HEALTH AND SOCIAL CARE OUTCOMES

- STIGMA HAS **INCREASED THE BURDEN OF ATTENDING TO HIV-RELATED NEEDS**[22] – CONCEALING MEDICATION OR ENTERING HIV CLINIC.

- **STIGMA ENACTED BY NON-HIV SPECIALIST HCP**, MOSTLY DOCTORS AND NURSES, INCLUDES **JUDGEMENT AND PRIVACY VIOLATIONS**, LEADS TO NON-DISCLOSURE:
  "In hospital after an operation I heard two nurses talking that I had HIV. I am sure the other patients could hear and it made me feel so bad. I couldn't say anything as I thought if I made a complaint they would treat me even worse." Wendy, 66, Ghanaian.

- STIGMA CAUSES PATIENTS TO **FEEL HUMILIATED, LESS POWERFUL** AND **CONCERNED ABOUT CARE WILL RECEIVE AS THEY GROW OLDER WITH HIV**:
  "I am worried about getting older and staying in old people's homes, where it seems everything is shared. I don't think there will be enough confidentiality." Clare, 50 year old Ugandan woman.

STRATEGIES TO OVERCOME STIGMA

PUBLIC ENGAGEMENT

- NEED TO **SEEK PUBLIC OPINION REGARDING** OPLHIV FROM BME COMMUNITIES TO UNDERSTAND MOTIVES FOR STIGMATISING BEHAVIOURS[23].

- PUBLIC INFORMATION CAN **ALTER HIV NARRATIVE**, CHALLENGE MYTHS, AND **INCREASE VALUE** ATTRIBUTED TO BME COMMUNITIES AND OLDER PEOPLE[24].

- MORE **LEGISLATION TO PROTECT PEOPLE** FROM DISCRIMINATION; **OPPORTUNITIES TO SEEK JUSTICE** WITHOUT FEAR OF RECRIMINATIONS; AND TO **ENFORCE POLICY**.

- **CREATIVE ENGAGEMENT** - SURVEYS, POSTERS, TV COMMERCIALS, AND **POSITIVE PORTRAYAL** OF OPLHIV FROM BME COMMUNITIES IN MAINSTREAM MEDIA.

- TO BE EFFECTIVE, REQUIRES **DIVERSE USE OF LANGUAGE, IMAGERY AND DELIVERY** TO TARGET **INTRICATE NEEDS** OF VARIOUS AUDIENCES[25].

STRATEGIES TO OVERCOME STIGMA

TRAINING HEALTH AND SOCIAL CARE FRONTLINE STAFF

- TO DISPEL CONTAGION MYTHS, ENHANCE LISTENING SKILLS, IMPROVE CONFIDENTIALITY AND APPRECIATE PSYCHO-SOCIAL RESPONSES TO HIV DIAGNOSIS.

- DEVELOP **CULTURAL AWARENESS** AND **COMPREHEND COMPLEX INFLUENCES** ON EMOTIONAL AND PHYSICAL WELL-BEING[26] – STIGMA, ADHERENCE, MONITORING, DIET: ***"Ramadhan is necessary for us Muslims…but my doctor told me it is not possible because I eat my pills with food. She didn't understand how important it is to me…is shameful in my community if I don't fast."*** Leyla

- **'CULTURALLY SPECIFIC SUPPORT TEAMS'**[27] WITHIN HEALTH AND SOCIAL CARE SETTINGS THAT **INCLUDE EXPERT PATIENTS** CAN ADVISE AND SUPPORT PRACTITIONERS AND SERVICE USERS.

- MUST **REFLECT BME COMMUNITIES WITH HIGH AND LOW HIV PREVALENCE** TO AVOID FURTHER ALIENATION[28].

STRATEGIES TO OVERCOME STIGMA

PATIENT INVOLVEMENT

- NECESSARY TO **INCLUDE THE VOICES OF OPLHIV FROM BME COMMUNITIES** IN ALL STIGMA-REDUCING STRATEGIES TO UNDERSTAND NEEDS AND EMPOWER PATIENTS[29].

- **PATIENT PARTICIPATION GROUPS** ALLOW SERVICE USERS TO REPORT ON SERVICES, ADVISE POLICY, PROVIDE TRAINING, AND IMPROVE ACCOUNTABILITY[30].

- **PATIENT VOICES IN PUBLIC ENGAGEMENT STRATEGIES INVALUABLE** TO REPRESENT REAL FACE OF HIV, ALTER STIGMATISING ATTITUDES, FOSTERING ADMIRATION. BARRIERS – STIGMA SURROUNDING HIV CAN PROHIBIT OPLHIV FROM BME COMMUNITIES SPEAKING OPENLY[31].

- **PEER SUPPORT** – SHARED EXPERIENCES, COPING STRATEGIES, IMPROVED EMOTIONAL HEALTH[32]: ***"After my friend found my medication and started to use this information I feel the need to talk to people who understand me."*** Apple, 50, diagnosed 2004.

- MUST **INCORPORATE INTRICATE NEEDS INTO DESIGN AND DELIVERY**, INCLUDING AGE, ETHNIC GROUP, ENVIRONMENT CREATED, TREATMENT ROUTINES, DIETARY REQUIREMENTS AND TRANSPORT PROVISIONS[33].

CONCLUSION

- NEED TO **RECOGNISE** OVER 50S FROM BME ARE LIVING WITH HIV; A **WILLINGNESS** TO RESEARCH EXPERIENCES OF STIGMA; **MOTIVATION** TO INVEST IN THE RESOURCES TO CHALLENGE STIGMA AND INCREASE SELF-ESTEEM.

- **HIV, AGE AND RACE-RELATED STIGMA** PERMEATES LIVES OF OPLHIV FROM BME COMMUNITIES IN EUROPE.

- STIGMA HAS A **DEVASTATING IMPACT** OF **SELF-CONCEPT**, **COMMUNITY INTERACTIONS** AND **HEALTH AND SOCIAL CARE OUTCOMES**.

- I PROPOSE THREE STRATEGIES TO REDUCE STIGMA AND EMPOWER PATIENTS: **PUBLIC ENGAGEMENT**, **TRAINING HEALTH AND SOCIAL CARE FRONTLINE STAFF**, AND **PATIENT INVOLVEMENT**.

ENDNOTES

1. Emlet, 2007: 740; Grov et al, 2010: 630
2. UNAIDS, 2014
3. Lazarus and Nielsen, 2010
4. Cairns, 2015
5. Grov et al, 2010: 631
6. Goffman, 1963: 3
7. Emlet, 2007: 741
8. Herek et al, 2002: 11
9. Green, 2009: 64; Emlet, 2007: 748
10. Cullen, 2003: 68
11. AGE UK, 2011: 70
12. Emlet, 2007: 749
13. Emlet, 2006: 786
14. O'Brien and Khan, 2002: 102, 106
15. O'Brien and Khan, 2002: 105
16. O'Brien and Khan, 2002: 107

ENDNOTES

17. Emlet, 2007: 741
18. Green, 2009: 58
19. O'Brien and Khan, 2002: 105
20. Shippy and Karpiak, 2005: 246
21. Shippy and Karpiak, 2005: 253; Emlet, 2007: 748
22. Emlet, 2007: 747
23. Robinson and Lorenc, 2012: 2
24. Robinson and Lorenc, 2012: 8
25. O'Brien and Khan, 2002: 109
26. Emlet, 2007: 749; O'Brien and Khan, 2002: 115
27. Seibert et al, 2002
28. O'Brien and Khan, 2002: 109; Robinson and Lorenc, 2012: 2
29. Sabatier, 2002: 87, 98; Emlet, 2007: 749
30. Robinson and Lorenc, 2012: 7
31. Robinson and Lorenc, 2012: 5, 8
32. Sabatier, 2002: 94, 99, Shippy and Karpiak, 2005: 252
33. O'Brien and Khan, 2002: 108, 111; Shippy and Karpiak, 2005: 246, 247

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