Stigma Reduction Interventions in People Living with HIV to Improve Health-Related Quality of Life

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Word count: 3108 (3707 including boxes)
Abstract word count: 150

Abstract

As UNAIDS 90-90-90 targets for people living with HIV are increasingly being reached in many contexts, health-related quality of life (HRQoL), the ”fourth 90”, warrants special attention. HIV-related stigma and discrimination remain major barriers for overall HRQoL despite impressive clinical and virological improvements in HIV care. We reviewed original publications examining the impact of interventions to reduce stigma as experienced by people living with HIV in all income settings between 2010-2018. Our search identified a lack of well-designed intervention studies that documented stigma reduction and few studies that specifically assessed the impact of stigma on HRQoL. Further, few interventions targeted discrimination from providers outside HIV-specific care or involved people living with HIV in both the design and implementation. Lastly, evidence on methods to reduce stigma among several underrepresented key populations and geographic regions was limited and research on intersectional stigma, i.e. the convergence of multiple stigmatized identities, needs further attention.

Keywords: Review, HIV, fourth 90, stigma, discrimination, intervention, quality of life, health-related quality of life, non-communicable diseases, mental well-being, intersectional stigma

Key Message Panel

- HIV-related stigma and discrimination remain major obstacles for reaching good health-related quality of life (HRQoL).
- Despite considerable efforts to combat HIV-related stigma and discrimination, the effects experienced by people living with HIV are insufficiently evaluated and documented.
- There is a lack of well-designed intervention studies that document stigma reduction.
- Few interventions specifically assessed the impact of HIV stigma on HRQoL
- Few interventions involved people living with HIV in either the design or implementation, although the existing evidence shows the importance of this for relevant and sustainable impact
- Evidence remains scarce on methods to reduce HIV stigma among several key populations and in many geographic regions.
- Further research is required on how to address intersectional stigma for populations disproportionally affected by HIV, and on how to prevent discrimination from healthcare providers outside HIV-specific care, a growing concern to reach the 4th 90 as it undermines health seeking for mental health disorders and other comorbidities.

Introduction

With effective antiretroviral therapy delivering high levels of sustained virological suppression, health-related quality of life (HRQoL) among people living with HIV warrants special attention. The UNAIDS 90-90-90 targets for epidemic control (i.e. that by 2020, 90% of all people living with HIV will know their status, 90% of people diagnosed with HIV infection will receive sustained antiretroviral therapy (ART), and 90% of those receiving ART will be virally suppressed) are increasingly being reached in many contexts.[1,2] However, these "three 90s" do not account for many remaining concurrent challenges among people living and ageing with HIV who still experience suboptimal HRQoL with regards to their mental, sexual and physical well-being.[2]

The addition of a "fourth 90" that includes improved HRQoL for people living with HIV requires solutions that go beyond ART and viral suppression. Impressive clinical and virological progress over the past two decades has resulted in significant advancements in both clinical treatment outcomes and HIV prevention options. Today, convincing evidence that the risk of HIV transmission approaches negligible levels when people are virally suppressed on ART has revolutionized public health communication related to the risk of HIV transmission.[3] Stigma, however, can negatively impact the happiness, self-esteem, sexual and social relationships and the sense of purpose among those living with HIV.[4] Previous research has shown that HIV-related stigma and discrimination are strongly associated with self-assessed overall quality of life (QoL) and mental well-being.[5-13] Fear of stigma and discrimination can also inhibit health seeking behaviour and is a major obstacle for timely diagnosis[14], prevention efforts[15,16] and linkage to care and support[17-19] not only for HIV, but also for mental health disorders and other concurrent conditions, many of which are associated with ageing with HIV. HIV associated stigma remains a major human rights challenge and addressing HIV-related stigma and discrimination will be necessary to achieve the goal of ending AIDS as a public health threat by 2030.[20]

Stigma

Goffman's often cited definition of stigma describes it as "an attribute that is deeply discrediting, that reduces the bearer from a whole person to a tainted, discounted one".[21] More recently, it has been argued that stigma is constructed by a variety of psychological and societal

factors, and "…exists when elements of labelling, stereotyping, separating, status loss and discrimination co-occur in a power situation that allows the process to unfold".[22]

HIV associated stigma is closely related to societal power structures, legal frameworks, and intersecting prejudices experienced by many of the sub-populations disproportionally affected by HIV.[23] It may serve a human need to categorize things and to "hold social structures in place, maintain boundaries and inequalities between groups of people and between those who have power and those who do not" (see Box 1 for an expanded description of the process of stigma).[24,25] People living with HIV often encounter intersectional stigmas, i.e. the convergence of multiple stigmatized identities due to intersecting prejudices related to affiliations to marginalized groups such as ethnic identity, sexual orientation, gender, or moralizing societal views attributed to certain characters or behaviours such as substance use, sex work, poverty or incarceration.[26] Turan et al. recommended researchers to avoid over-simplified categorization and to analyze multiple identities in greater depth in order to increase evidence for interventions that target intersectional stigmas.[26] Earnshaw and colleagues designed the HIV Stigma Framework, validated with empirical data, which clearly outlines mechanisms and consequences for stigma for HIV prevention and intervention.[27] Birbeck and colleagues build on this framework recognizing the drivers, manifestations and outcomes of health-related stigma and discrimination that cut across disease contexts, enabling a more unified approach, beyond individual conditions, that could guide future stigma reduction interventions.[28] Similarly, Stangl et al. recently proposed a cross-cutting theoretical "Health Stigma and Discrimination framework" that could be applied across a range of stigmatizing health conditions, including HIV, while also accounting for intersectional stigma.[29]

Box 1. Description of the Process of Stigma[23]

Stigma drivers: individual-level factors that may originate from lack of knowledge of HIV, prejudices and use of stereotypes and cognitive processes which help us to make sense of the world
Stigma facilitators: societal-level factors that maintain stigma including laws and regulations, cultural and gender norms and economic status
Intersecting/intersectional stigma: the convergence of multiple stigmatized identities due to intersecting prejudices related to affiliations to marginalized groups (e.g. migrants, ethnic or sexual minorities) or certain behaviours (substance use, sex work, etc)
Stigma manifestations: the immediate results affecting how stigma is exhibited or experienced by individuals and groups and including anticipated, enacted and internalized stigma

At an individual level, stigmatization in the form of prejudices and negative attitudes towards people living with HIV can materialize into discriminatory actions, such as job or housing refusal or social exclusion at the workplace, in school or in other social environments.[22] Structural discrimination due to HIV stigma includes physical and social structures that inhibit or limit people living with HIV from equal opportunities to obtain employment, work or residence permits, to get married, to travel, or being denied parental rights such as assisted fertilisation or adoption.[22,30] Recently, UNAIDS formed a global partnership for action aiming to eliminate all forms of HIV stigma and discrimination, recognizing the importance of addressing the multiple stigmatizing experiences (intersectional stigmas) of key populations, such as sex workers, people who inject drugs, men who have sex with men (MSM), transgender people, people in prisons and other closed settings and, in some social contexts, women, young people, migrants, refugees and internally displaced people.[20]

Stigma Reduction Interventions and Health-Related Quality of Life (HRQoL)

Working towards improved HRQoL and the ”fourth 90” requires validated tools to monitor long-term progress as well as targeted interventions to reduce the stigma experienced among people living with HIV. We also need to better understand which stigma reducing interventions to invest in beyond the healthcare setting since HIV-related stigma and discrimination may occur in every area of social life and at multiple levels, including inside families, communities, schools and workplaces and within the justice system.[20] In 2014, UNAIDS published a resource-kit for high-impact stigma reduction programming, stating that “every national response should be based on an evidence-informed understanding of HIV-related stigma”.[31]

Based on the "People Living with HIV Stigma Index" and stigma reports from more than 50 countries,[32,33] UNAIDS proposed that programming at all levels (legal and policy-, law enforcement-, institutional-, community- and individual level)[31] should address HIV stigma.

Consistent with intersectional stigma frameworks and acknowledging the multiple prejudices and stigmas experienced by many key populations living with HIV, the UK-based National AIDS Trust (NAT) concluded that the complex nature of HIV-associated stigma makes it "unlikely that any one-dimensional intervention will have a meaningful impact".[25] In line with UNAIDS, NAT recommended that governments design evidence-based interventions to reduce stigma at all levels through a comprehensive combination approach where all strategies are constructed with the following questions in mind: "Where (which setting/context?), What (needs to change?) and How (should this be done?)"[25]

To date, there have been several helpful reviews of stigma reduction interventions to guide future work in this area. The availability of effective interventions to reduce HIV stigma was reviewed in 2011, but only two out of 19 selected publications included people living with HIV, and most were deemed to be of poor validity due to shortcomings in the study designs.[34] A more complete review of current interventions on the stigmatization process published in 2013[23] found that most studies only addressed one socio-ecological level or one single domain of stigma, and largely had focused on stigma drivers (individual level) and facilitators (societal level), while few studies included people living with HIV.[23] More recently, in 2017, Mak et al. reviewed a broad array of HIV stigma interventions aimed to reduce negative attitudes towards people living with HIV[35] and found small significant reductions by interventions targeting stigma at multiple levels: community members, healthcare workers, and students.[35] Another recent review by Pantelic et al. on reduction of HIV self-stigma in low-and middle-income countries observed that structural-level interventions such as ART provision, economic strengthening and social empowerment, as well as cognitive behavioural therapy at individual level, lead to the most consistent self-stigma reductions.[36] However, interventions aimed to improve health awareness, stigma coping and behavioural change appeared ineffective.[36] Lastly, in 2019, Rao and colleagues reviewed multi-level stigma reducing interventions for numerous stigmatizing conditions (HIV, mental health, leprosy, etc.) across a broad variety of populations and socio-ecological levels but did not analyze the effect on stigma experienced by people living with HIV themselves.[37]

While prior reviews have rarely focused on stigma experienced by people with HIV and HRQoL, it is clear most interventions conducted so far have used information-based approaches.[23] Corrigan has argued that educational interventions alone rarely change attitudes, but mainly teach people to suppress their negative attitudes,[38,39] and that health awareness campaigns have little effect on self-stigma, consistent with recent findings.[36] To address this problem, individual-level interventions have incorporated personal contact as a mechanism to affect attitude change. Personal contact "humanizes" a person with a stigmatized condition and subsequently reduces individual-level manifestations of stigma, i.e. the immediate results of stigma on people living with HIV and their overall HRQoL.[23, 37,40]

Views on which stigma reduction strategies to implement may differ between people living with HIV, who often prioritize wider-context stigma reduction interventions,[40] and researchers and providers, who rank behavioural interventions higher.[40] Further, people living with HIV can provide unique insight into their vulnerabilities and needs with respect to HIV-related stigma and HRQoL. Thus, for sustainable interventions to effectively reduce manifestations of stigma among people living with HIV, more interventions need to involve people living with HIV in the design, implementation and evaluation of intervention programs.[28,41] Involving people living with HIV in stigma reduction interventions may also help us reach the "fourth 90".[42]

Current Review

We provide a narrative focused review of stigma reduction interventions that have implications for HRQoL for people living with HIV across all income settings. We focused on individual-level interventions that target manifestations of stigma, i.e. the immediate effects of stigma on people living with HIV. We examined recent interventions that targeted enacted, anticipated, and internalized stigma among people living with HIV. The overarching goal was to increase our knowledge about which, and to what extent, current individual-level stigma reduction interventions have been effective. Furthermore, we set out to: 1) assess whether current programmes are designed in collaboration with people living with HIV; 2) identify gaps in targeting of certain key populations, settings or regions; and 3) provide recommendations to increase the coverage of effective interventions and fill any knowledge gaps for stigma reduction interventions with implication for HRQoL (see Box 2 for a description of search strategy and selection criteria used in the review process). A detailed description of the review process can be found in the Appendix (Table 1 and Table 2, page 2).

Box 2. Search Strategy and Selection Criteria

This narrative review begun as a systematic review in order to identify studies that fulfilled the following specific criteria:

1) a study population including people living with HIV

2) an intervention aimed to reduce HIV stigma and/or discrimination

3) an assessment of the effect of the intervention in terms of reducing HIV-stigma affecting people living with HIV.

We conducted a systematic search of five major databases: MEDLINE through PubMed, CINAHL, PsychINFO, Web of Science, and the Cochrane Library. A broad search strategy was used including combinations of keywords and/or MeSH terms for the three key terms "HIV", "stigma" and "intervention". We restricted our search to studies published between 2010-2018, English language studies, and studies with an abstract and full text available. In addition to databases, we searched for relevant articles in the reference lists of identified systematic reviews.

Risk of bias in included articles was assessed with validated quality assessment tools for each design; for randomized controlled trials (RCTs) and cluster randomized studies, we used the National Institutes of Health (NIH) tool *Quality assessment of controlled randomized trials* [43] and studies with pre-post designs were assessed with the NIH tool *Quality assessment tool for Before-After (Pre-Post) studies with no control group.*[44] Qualitative studies were assessed using a checklist designed and recommended by the Swedish Agency for Health Technology Assessment and Assessment of Social Services.[45] A detailed search strategy and risk of bias assessment can be found in the Appendix.

The Impact of Interventions to Reduce Experienced HIV Stigma by Study Design

Our search yielded 27 records[46-72] representing various study designs in low-, middle-, and high-income settings (Table 1). The majority of studies were conducted in North America, Sub-Saharan Africa and Asia. Importantly, there were no studies from North- or West Africa, South America, Australia and the Pacific region nor Europe.

Quasi-Experimental Approaches

Among studies performing quasi-experimental designs, one study found that empowerment and educational radio programmes significantly reduced the stigma in groups of people living with HIV in Tamil Nadu, India.[62] Another study in Ethiopia evaluated a large-scale intervention over 7 years that included non-healthcare professionals who offered integrated home-based care and support for families and orphans, stigma reduction, and income generating activities at community level and found positive changes in community attitudes toward people living with HIV and improved QoL among people living with HIV.[65]

Qualitative or Mixed-Methods Approaches

Intervention studies with qualitative designs indicated favourable intervention effects. Initial workshops for people living with HIV focused on understanding HIV stigma, personal strengths and disclosure management were often followed by workshops for partners, children and friends;[55] peer support groups;[60] or small support teams of neighbours, relatives, and friends (so-called "micro-clinics") trained together to provide psychosocial and adherence support in countries such as Uganda[60] and Kenya.[69] One study that examined a patient-centred holistic care intervention among adults living with HIV in Kenya found that simple mechanisms for support, compassion and improved communication in routine care increased self-esteem, stigma resilience and increased confidence to disclose HIV status.[58]

RCT and Pre- and Post-Test Approaches

In studies with a quantitative design, perceived stigma was often assessed through self-administered questionnaires to participants living with HIV. Many studies showed statistically significant reductions in perceived stigma across all participants, [47,50,54,57,64,67,70,71] while few found varying impact depending on gender[56] or provider category.[59] One study in the US found that the effect of a group-based behavioural intervention among youth on HIV awareness, coping skills and contact with other youth sustainably reduced stigma among young males across all four dimensions of stigma manifestations (personalized stigma, disclosure concerns, negative self-image and concern with public attitudes about people living with HIV), while young females only experienced a temporary decline in personalized stigma and increased stigma across the other three types of stigma manifestations.[56] Moreover, another study found that a community support initiative in South Africa through 'treatment buddies' decreased the stigma experienced by people living with HIV, while stigma increased when a healthcare professional provided the support.[59] Research in Uganda found mixed results in clients'

experiences of enacted stigma at the healthcare facility level following a "creativity intervention" aimed at generating a more caring attitude between staff, peers and people living with HIV.[63] Lastly, a study conducted in the US evaluated the potential stigma reducing impact of a patient-centred mental health program for under-served adults living with HIV based on active decision-making and individualized care plans including a range of therapeutic services following a comprehensive biopsychosocial assessment at enrolment. Although the evidence was rated as being of poor quality in our review, self-reported stigma appeared to decrease across the three dimensions in the HIV Stigma Scale: distancing, blaming and discrimination.[54]

In contrast, several studies using either an RCT or a pre- and post-test design showed no statistically significant reductions in stigma among people living with HIV,[46,48,51,61,68] although some authors said they observed important stigma reductions "in practice"[52,66] or trends indicating stigma reduction.[49] For example, one study described that stigma appeared to decline following a peer-led video and writing intervention among African-American women living with HIV.[53] On a similar note, in Vietnam, a separate study found no reductions in stigma following peer-led support visits, but they did see improved QoL 12 months post intervention among patients with severely immunosuppressed condition.[72]

Types of HIV-Related Stigma Interventions, Target Groups and Settings

The majority of the included papers described interventions that targeted specific groups living with HIV such as women,[47,53,64,67] children/families,[49,56,60,70,71] ethnic subgroups[51,53,67] or key populations such as adolescents[49,56] and MSM,[46,68] while only two included people living with HIV with other comorbidities, i.e. chronic pain[58] or mental health issues.[54] Some interventions were multi-level, including community members, social networks, family members/caregivers and healthcare workers.[48,55,57,60,69,71] Most interventions were delivered by therapists or healthcare professionals and included individual or group sessions with people living with HIV, while some were peer-led or community-based. Table 1 describes the target groups, implementers and interventions in detail (Table 1).

Approximately half of the included studies reported some involvement of people living with HIV. Among these studies, people living with HIV were described as being involved in various stages of the intervention design,[49] the intervention implementation (i.e. as peer-educators) [48,52,55,56,59,66,69] or both. [51,53,60,62,67,72]

About half of the included studies broadly mentioned the relationship between stigma and QoL in the introduction or discussion section, but few studies assessed the impact of the intervention on both stigma and HRQoL.[50,65,72] These studies found that QoL improved after the stigma reducing interventions.

Knowledge Gaps

The majority of the stigma and discrimination reducing interventions that have been evaluated were quantitative in nature, with only two mixed-methods studies and four qualitative studies. All interventions relied to some extent on participants' ability and willingness to express themselves verbally, most often in groups. This may not be the most suitable model for individuals who do not have the capacity or who do not feel comfortable speaking about themselves and their HIV infection in front of others. Teti et al.[73], although not fulfilling the quality requirements of this review, provided an interesting alternative to group sessions by encouraging individual artistic expressions to reduce personalized stigma.[73]

None of the intervention studies included in this review were conducted in north- or west Africa, South America, Australia or the Pacific region nor Europe, despite these regions being home to over a third of all people living with HIV globally.[74] Additionally, settings where the three 90s are largely fulfilled, and with a rapidly growing population who are ageing with HIV, such as western Europe and Australia, were not represented in the literature at all, marking a serious knowledge gap on progress towards HRQoL and the "fourth 90".

This review also found an absence of intervention studies on HIV stigma and discrimination in non-HIV specific healthcare settings, e.g. clinical settings that treat common co-morbidities including care for older people living with HIV, a group with a greater need for healthcare services that go beyond ART.

Furthermore, to date, no published stigma reducing interventions have been evaluated among several important key populations at elevated risk of HIV infection, for example migrants, transgender persons and prisoners, and very few studies focused on people who inject drugs, sex workers, MSM, adolescents and young people. Racial or ethnic subgroups were rarely considered outside of North America. Lastly, more interventions should document any

involvement of people living with HIV in the study design or in other stages of the interventions, since such interventions have often been found to be most effective.

While the effects of stigma reducing interventions may have implications on QoL, very few studies explicitly assessed the impact of the intervention on both stigma and HRQoL.[50,65,72] None of the included interventions specifically targeted intersectional stigma or assessed the effect of the stigma reducing interventions on intersectional stigma commonly experienced by many marginalized populations disproportionally affected by HIV infection.

Conclusions

Our review identified a lack of well-designed intervention studies that document stigma reduction. Of the 27 studies that met our inclusion criteria, only three specifically assessed the impact of HIV stigma on HRQoL, despite knowledge of overall HRQoL being directly related to experiences of stigma among people living with HIV. Further, few interventions explicitly described the inclusion of people living with HIV in both their intervention design and implementation. Lastly, our review highlights a lack of evidence on effective HIV stigma interventions in several large geographic regions and among several key populations.

Further research is warranted on intersectional stigma as well as ways to reduce HIV stigma and discrimination beyond the HIV-specific healthcare setting for people ageing with HIV and people with comorbidities and mental illness, a priority in the strive towards improved HRQoL among people living with HIV. The application of cross-cutting theoretical frameworks for research and interventions to reduce health-related stigma across multiple stigmatized health conditions should also be further explored in the context of HIV.[28,29] Reducing stigma and improving HRQoL are imperative for reaching the "fourth 90" and Sustainable Development Goals 3 and 10 (good health and wellbeing for all and reduced inequalities through decreased vulnerability, marginalization and discrimination),[75] as well as achieving more equitable health at the global level.

Box 3. Recommendations for Future Policy and Research

- HRQoL measures need to be consistently included in HIV-related stigma interventions.
- Meaningful inclusion of people living with HIV in the design, development, implementation and interpretation of stigma reducing interventions is required if interventions are to be effective.
- More evidence is needed to address stigma among older people living and ageing with HIV, including those with comorbidities who are seeking services additional to their HIV specific care.
- Future evaluations of the efficacy of new policies and stigma interventions among neglected sub- and key populations, including those facing intersecting stigma, are needed.
- The absence of contextual evidence required to design effective stigma reducing interventions for people living with HIV in north- or West Africa, South America, Australia and the Pacific region and Europe, should be addressed through additional research.
- Interventions must be contextualized to the setting and sub-population, and tailored to account for variation in verbal ability and willingness to participate in group sessions, which may vary between different sub-groups and individuals living with HIV.
- Innovation in civil society involvement that addresses HIV stigma beyond traditional peer-support programs and healthcare settings is required. This must be adequately resourced to enable effective and rigorous evaluation that can then enable sharing of best practice.
- Future research must take a combination approach that looks at HIV associated stigma through a multi-level (individual, structural, etc.) and intersectional lens, ideally using existing validated tools and frameworks to enable cross study comparisons.

Authors' Contributions

GZA, AME, LEE and VS conceptualized the study. MR led the review process and identified the first search results. DR placed the review in the context of previous stigma reviews. All authors reviewed identified records. Quality assessment was carried out by AME, LEE, GZA and MR. The paper was drafted by GZA, AME, LEE and ME and revised by GZA, AME, DG and DR. All authors read and approved the final version of the manuscript.

Conflict of Interest

The authors declare that they have no conflict of interest.

References

1. UNAIDS. 90-90-90: An ambitious treatment target to help and the AIDS epidemic: UNAIDS, 2014.
2. Lazarus JV, Safreed-Harmon K, Barton SE, et al. Beyond viral suppression of HIV–the new quality of life frontier. *BMC Med* 2016; **14**(1): 94.
3. UNAIDS. Undetectable = Untransmittable Public Health and Viral Load Supression. 2018. https://www.unaids.org/en/resources/presscentre/featurestories/2018/july/undetectable-untransmittable (accessed 2019-08-04 2019).
4. Rueda S, Mitra S, Chen S, et al. Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. *BMJ Open* 2016; **6**(7): e011453.
5. Fuster-Ruizdeapodaca MJ, Molero F, Holgado FP, Mayordomo S. Enacted and internalized stigma and quality of life among people with HIV: the role of group identity. *Qual Life Res* 2014; **23**(7): 1967-75.
6. Holzemer WL, Human S, Arudo J, et al. Exploring HIV stigma and quality of life for persons living with HIV infection. *J Assoc Nurses AIDS Care* 2009; **20**(3): 161-8.
7. Rao D, Chen WT, Pearson CR, et al. Social support mediates the relationship between HIV stigma and depression/quality of life among people living with HIV in Beijing, China. *Int J STD AIDS* 2012; **23**(7): 481-4.
8. Rydstrom LL, Wiklander M, Naver L, Ygge BM, Eriksson LE. HIV-related stigma and health-related quality of life among children living with HIV in Sweden. *AIDS Care* 2016; **28**(5): 665-71.
9. Reinius M, Wiklander M, Wettergren L, Svedhem V, Eriksson LE. The Relationship Between Stigma and Health-Related Quality of Life in People Living with HIV Who Have Full Access to Antiretroviral Treatment: An Assessment of Earnshaw and Chaudoir's HIV Stigma Framework Using Empirical Data. *AIDS Behav* 2018.
10. Slater LZ, Moneyham L, Vance DE, Raper JL, Mugavero MJ, Childs G. The multiple stigma experience and quality of life in older gay men with HIV. *J Assoc Nurses AIDS Care* 2015; **26**(1): 24-35.
11. Nobre N, Pereira M, Roine RP, Sintonen H, Sutinen J. Factors associated with the quality of life of people living with HIV in Finland. *AIDS Care* 2017; **29**(8): 1074-8.

12. Niderost S, Imhof C. Aging With HIV in the Era of Antiretroviral Treatment: Living Conditions and the Quality of Life of People Aged Above 50 Living With HIV/AIDS in Switzerland. *Gerontol Geriatr Med* 2016; **2**: 2333721416636300.
13. Zeluf-Andersson G, Eriksson LE, Schönnesson LN, Höijer J, Månehall P, Ekström AM. Beyond viral suppression: the quality of life of people living with HIV in Sweden. *AIDS Care* 2019; **31**(4): 403-12.
14. Gesesew HA, Gebremedhin AT, Demissie TD, Kerie MW, Sudhakar M, Mwanri L. Significant association between perceived HIV related stigma and late presentation for HIV/AIDS care in low and middle-income countries: A systematic review and meta-analysis. *PLoS One* 2017; **12**(3): e0173928.
15. Fortenberry JD, McFarlane M, Bleakley A, et al. Relationships of stigma and shame to gonorrhea and HIV screening. *Am J Public Health* 2002; **92**(3): 378-81.
16. Maughan-Brown B, Nyblade L. Different dimensions of HIV-related stigma may have opposite effects on HIV testing: evidence among young men and women in South Africa. *AIDS Behav* 2014; **18**(5): 958-65.
17. Rintamaki LS, Davis TC, Skripkauskas S, Bennett CL, Wolf MS. Social stigma concerns and HIV medication adherence. *AIDS Patient Care STDS* 2006; **20**(5): 359-68.
18. Sayles JN, Wong MD, Kinsler JJ, Martins D, Cunningham WE. The association of stigma with self-reported access to medical care and antiretroviral therapy adherence in persons living with HIV/AIDS. *J Gen Intern Med* 2009; **24**(10): 1101.
19. Sweeney SM, Vanable PA. The association of HIV-related stigma to HIV medication adherence: a systematic review and synthesis of the literature. *AIDS Behav* 2016; **20**(1): 29-50.
20. UNAIDS. Global Partnership for Action to Eliminate All Forms of HIV-Related Stigma and Discrimination: UNAIDS, 2018.
21. Goffman E. Stigma; notes on the management of spoiled identity: Englewood Cliffs, N.J. : Prentice-Hall, [1963]; 1963.
22. Link BG, Phelan JC. Conceptualizing stigma. *Annu Rev Sociol* 2001; **27**: 363-85.
23. Stangl AL, Lloyd JK, Brady LM, Holland CE, Baral S. A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013: how far have we come? *J Int AIDS Soc* 2013; **16**(3 Suppl 2): 18734.
24. Doods C. Evidence of HIV-related stigma among African people in the UK Information-sharing meeting - Black African migrants, National AIDS Trust; 2014.
25. National AIDS Trust. Tackling HIV stimga: what works? Using the global evidence base to reduce the impact of HIV stigma.: National AIDS Trust, 2016.
26. Turan JM, Elafros MA, Logie CH, et al. Challenges and opportunities in examining and addressing intersectional stigma and health. *BMC Med* 2019; **17**(1): 7.
27. Earnshaw VA, Smith LR, Chaudoir SR, Amico KR, Copenhaver MM. HIV stigma mechanisms and well-being among PLWH: a test of the HIV stigma framework. *AIDS Behav* 2013; **17**(5): 1785-95.
28. Birbeck GL, Bond V, Earnshaw V, El-Nasoor ML. Advancing health equity through cross-cutting approaches to health-related stigma. *BMC Med* 2019; **17**(1): 40.
29. Stangl AL, Earnshaw VA, Logie CH, et al. The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Med* 2019; **17**(1): 31.
30. UNAIDS. Act to change laws that discriminate UNAIDS, 2019.
31. UNAIDS. Reduction to HIV-related stigma and discrimination.: UNAIDS, 2014.

32. Stigma Index. The people living with HIV stigma index. http://www.stigmaindex.org/ (accessed 18/1 2019).
33. GNP Plus. Global network of people living with HIV. https://www.gnpplus.net/ (accessed 18/1 2019).
34. Sengupta S, Banks B, Jonas D, Miles MS, Smith GC. HIV interventions to reduce HIV/AIDS stigma: a systematic review. *AIDS Behav* 2011; **15**(6): 1075-87.
35. Mak WWS, Mo PKH, Ma GYK, Lam MYY. Meta-analysis and systematic review of studies on the effectiveness of HIV stigma reduction programs. *Soc Sci Med* 2017; **188**: 30-40.
36. Pantelic M, Steinert JI, Park J, Mellors S, Murau F. 'Management of a spoiled identity': systematic review of interventions to address self-stigma among people living with and affected by HIV. *BMJ Global Health* 2019; **4**(2): e001285.
37. Rao D, Elshafei A, Nguyen M, Hatzenbuehler ML, Frey S, Go VF. A systematic review of multi-level stigma interventions: state of the science and future directions. *BMC Med* 2019; **17**(1): 41.
38. Corrigan PW, Penn DL. Lessons from social psychology on discrediting psychiatric stigma. *Am Psychol* 1999; **54**(9): 765-76.
39. Penn DL, Corrigan PW. The effects of stereotype suppression on psychiatric stigma. *Schizophr Res* 2002; **55**(3): 269-76.
40. Fredericksen RJ, Edwards TC, Merlin JS, et al. Patient and provider priorities for self-reported domains of HIV clinical care. *AIDS Care* 2015; **27**(10): 1255-64.
41. Bogart LM, Uyeda K. Community-based participatory research: partnering with communities for effective and sustainable behavioral health interventions. *Health Psychol* 2009; **28**(4): 391-3.
42. UNAIDS. Policy Brief: The Greater Involvement of People Living with HIV (GIPA), 2007.
43. National Institute of Health. Quality assessment of controlled randomized trials. https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools (accessed 19/12 2018).
44. National Institute of Health. Quality assessment tool for Before-After (Pre-Post) studies with no control group. https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools (accessed 19/12 2018).
45. Swedish Agency for Health Technology Assessment and Assesment of Social Services (SBU). Mall kvalitativ forskningsmetodik. https://www.sbu.se/sv/var-metod/ (accessed 19/12 2018).
46. Adam BD, Murray J, Ross S, Oliver J, Lincoln SG, Rynard V. hivstigma.com, an innovative web-supported stigma reduction intervention for gay and bisexual men. *Health Educ Res* 2011; **26**(5): 795-807.
47. Barroso J, Relf MV, Williams MS, et al. A randomized controlled trial of the efficacy of a stigma reduction intervention for HIV-infected women in the Deep South. *AIDS Patient Care STDS* 2014; **28**(9): 489-98.
48. Batey DS, Whitfield S, Mulla M, et al. Adaptation and Implementation of an Intervention to Reduce HIV-Related Stigma Among Healthcare Workers in the United States: Piloting of the FRESH Workshop. *AIDS Patient Care STDS* 2016; **30**(11): 519-27.
49. Bhana A, Mellins CA, Petersen I, et al. The VUKA family program: piloting a family-based psychosocial intervention to promote health and mental health among HIV infected early adolescents in South Africa. *AIDS care - psychological and socio-medical aspects of AIDS/HIV* 2014; **26**(1): 1-11.

50. Bhatta DN, Liabsuetrakul T. Efficacy of a Social Self-Value Empowerment Intervention to Improve Quality of Life of HIV Infected People Receiving Antiretroviral Treatment in Nepal: A Randomized Controlled Trial. *AIDS Behav* 2017; **21**(6): 1620-31.
51. Bogart LM, Mutchler MG, McDavitt B, et al. A Randomized Controlled Trial of Rise, a Community-Based Culturally Congruent Adherence Intervention for Black Americans Living with HIV. *Ann Behav Med* 2017; **51**(6): 868-78.
52. Chidrawi HC, Greeff M, Temane QM, Doak CM. HIV stigma experiences and stigmatisation before and after an intervention. *Health Sa Gesondheid* 2016; **21**: 10.
53. DeMarco RF, Chan K. The Sistah Powah structured writing intervention: a feasibility study for aging, low-income, HIV-positive Black women. *Am J Health Promot* 2013; **28**(2): 108-18.
54. Farber EW, Shahane AA, Brown JL, Campos PE. Perceived stigma reductions following participation in mental health services integrated within community-based HIV primary care. *AIDS Care* 2014; **26**(6): 750-3.
55. French H, Greeff M, Watson MJ. Experiences of people living with HIV and people living close to them of a comprehensive HIV stigma reduction community intervention in an urban and a rural setting. *SAHARA J* 2014; **11**: 105-15.
56. Harper GW, Lemos D, Hosek SG, Adolescent Med Trials Network HIV. Stigma Reduction in Adolescents and Young Adults Newly Diagnosed with HIV: Findings from the Project ACCEPT Intervention. *AIDS Patient Care STDS* 2014; **28**(10): 543-54.
57. Li ATW, Fung KPL, Maticka-Tyndale E, Wong JPH. Effects Of HIV stigma reduction interventions in diasporic communities: insights from the CHAMP study. *Aids Care-Psychological and Socio-Medical Aspects of Aids/Hiv* 2018; **30**(6): 739-45.
58. Lowther K, Harding R, Simms V, et al. Effect of participation in a randomised controlled trial of an integrated palliative care intervention on HIV-associated stigma. *AIDS care - psychological and socio-medical aspects of AIDS/HIV* 2018: 1-9.
59. Masquillier C, Wouters E, Mortelmans D, le Roux Booysen F. The impact of community support initiatives on the stigma experienced by people living with HIV/AIDS in South Africa. *AIDS Behav* 2015; **19**(2): 214-26.
60. Mburu G, Ram M, Skovdal M, et al. Resisting and challenging stigma in Uganda: the role of support groups of people living with HIV. *J Int AIDS Soc* 2013; **16**(3 Suppl 2): 18636.
61. Moitra E, Chan PA, Stein MD. Open Trial of an Acceptance-Based Behavior Therapy Intervention to Engage Newly Diagnosed HIV Patients in Care: Rationale and Evidence of Feasibility and Acceptability. *Behav Modif* 2015; **39**(5): 670-90.
62. Nambiar D, Ramakrishnan V, Kumar P, et al. Knowledge, stigma, and behavioral outcomes among antiretroviral therapy patients exposed to Nalamdana's radio and theater program in Tamil Nadu, India. *AIDS Educ Prev* 2011; **23**(4): 351-66.
63. Neema S, Atuyambe LM, Otolok-Tanga E, et al. Using a clinic based creativity initiative to reduce HIV related stigma at the Infectious Diseases Institute, Mulago National Referral Hospital, Uganda. *Afr Health Sci* 2012; **12**(2): 231-9.
64. Nyamathi A, Ekstrand M, Salem BE, Sinha S, Ganguly KK, Leake B. Impact of Asha intervention on stigma among rural Indian women with AIDS. *West J Nurs Res* 2013; **35**(7): 867-83.
65. Okello FO, Stuer F, Kidane A, Wube M. Saving the sick and improving the socio-economic conditions of people living with HIV in Ethiopia through traditional burial groups. *Health Policy Plan* 2013; **28**(5): 549-57.
66. Prinsloo CD, Greeff M, Kruger A, Khumalo IP. HIV stigma experiences and stigmatisation before and after a HIV stigma-reduction community "hub" intervention. *Afr J AIDS Res* 2017; **16**(3): 203-13.

67. Rao D, Desmond M, Andrasik M, et al. Feasibility, acceptability, and preliminary efficacy of the unity workshop: an internalized stigma reduction intervention for African American women living with HIV. *AIDS Patient Care STDS* 2012; **26**(10): 614-20.
68. Rongkavilit C, Wang B, Naar-King S, et al. Motivational interviewing targeting risky sex in HIV-positive young Thai men who have sex with men. *Arch Sex Behav* 2015; **44**(2): 329-40.
69. Salmen CR, Hickey MD, Fiorella KJ, et al. "Wan Kanyakla" (We are together): Community transformations in Kenya following a social network intervention for HIV care. *Soc Sci Med* 2015; **147** 332-40.
70. Simoni JM, Yang JP, Shiu CS, et al. Nurse-delivered counselling intervention for parental HIV disclosure: results from a pilot randomized controlled trial in China. *AIDS* 2015; **29 Suppl 1**: S99-S107.
71. Smith Fawzi MC, Eustache E, Oswald C, et al. Psychosocial support intervention for HIV-affected families in Haiti: implications for programs and policies for orphans and vulnerable children. *Soc Sci Med* 2012; **74**(10): 1494-503.
72. Van Tam V, Larsson M, Pharris A, et al. Peer support and improved quality of life among persons living with HIV on antiretroviral treatment: a randomised controlled trial from north-eastern Vietnam. *Health Qual Life Outcomes* 2012; **10**: 53.
73. Teti M, Pichon L, Kabel A, Farnan R, Binson D. Taking pictures to take control: Photovoice as a tool to facilitate empowerment among poor and racial/ethnic minority women with HIV. *J Assoc Nurses AIDS Care* 2013; **24**(6): 539-53.
74. WHO. Global Health Observatory data repository: Number of people (all ages) living with HIV - Estimates by WHO region. 2018.
75. UNAIDS. The AIDS response in the 2030 agenda for sustainable development: joint work, shared gains 2019. https://www.unaids.org/en/AIDS_SDGs.