EFFECT AND PROCESS EVALUATION OF A PEER-DRIVEN HIV SELF-STIGMA REDUCTION INTERVENTION (RESET WORKSHOP) AMONG PEOPLE LIVING WITH HIV IN THE NETHERLANDS

Juni 2023

Background

Introduction

HIV-related self-stigma is associated with poorer health outcomes, reduced quality of life and less access to HIV care and treatment for people living with HIV (PLHIV) worldwide ((UNAIDS, 2007; Earnshaw et al., 2013; Mahajan et al., 2010). PLHIV living in the Netherlands still experience stigmatizing responses in a variety of settings (Stutterheim, Bos & Schaalma, 2008; Stutterheim et al., 2022). Unfortunately, programs that effectively target self-stigma among PLHIV remain scarce. The majority of interventions that target stigma focus on public stigma and discrimination of PLHIV. However, many PLHIV internalize societies' negative view of them and accept its validity (Stutterheim et al., 2012), a phenomenon called self-stigma (Bos et al., 2013). Self-stigma can manifest itself in feelings such as shame, self-blame, and worthlessness. Research shows that self-stigma negatively affects various aspects of the quality of life and psychological wellbeing of PLHIV (Herek et al., 2013; Lyimo et al., 2014; Stutterheim et al., 2012; Overstreet et al., 2013).

Research highlights a number of strategies to reduce self-stigma including, but not limited to, enhancing social and peer support (Sommerland et al., 2017), planning coping responses (Dobson et al., 2019; White et al., 2015; Mittal et al., 2012), improving psychological flexibility through counseling or Acceptance and Commitment Therapy (Livingston et al., 2012), building skills and resilience (Pantelic et al., 2019), and other empowerment techniques (Stangl et al., 2013; Dimaggio et al., 2017; Stutterheim et al., 2023). Many of these strategies find their theoretical basis in techniques from psycho-education and cognitive behavioral theories (Roozen et al., 2020; Ma et al., 2019). Necessary components for stigma interventions targeting those who experience stigma themselves are a combination of education, contact with peers, and training coping skills. Similarly, Corrigan et al. (2011) stated that contact with peers is a fundamental aspect of a stigma reduction intervention. Education is important to counter misinformation and define (self)stigma; contact with peers is important to share experiences and normalize HIV; and training coping skills is important to help PLHIV navigate ways to deal with negative feelings regarding HIV and stigmatizing situations.

Unlike HIV-related discrimination, self-stigma remains understudied, with no well-established and theoretically sound self-stigma interventions targeting PLHIV (Pantelic et al., 2019; France et al., 2019). Interventions yield more promise to be effective when systematically developed and grounded in theory and evidence (Roozen et al., 2020; De Bruin et al., 2009; Stutterheim et al., 2023). The RESilience & Empowerment Training (RESET) is a Dutch face-to-face group workshop for PLHIV aimed at reducing self-stigma comprising three weekly sessions of 2.5 hours each. The intervention has been developed by a Dutch research team consisting of stigma researchers, PLHIV, and HIV health care professionals (HIV doctors and nurses from OLVG Hospital). RESET was designed in close collaboration with PLHIV, enhancing the likelihood that the intervention could successfully be adopted and implemented in the future. In this report we share the findings from the effect evaluation of RESET as well as the process evaluation regarding the implementation of the program.

Needs assessment

Summary of results

This needs assessment consisted of a three studies; a literature review and two empirical studies. The results of these studies provide the context for the RESET intervention, including the population, setting, and community that will enable us to make concrete program goals.

The literature review (study 1) examines associations (causes and consequences) of self-stigma in a systematic review format. The quantitative study (study 2) presents a stigma model in which the relationships between different types of stigma and the interplay with various (mental) health outcomes are examined. This was done by measuring the short HIV stigma Scale (Den Daas et al, 2017), which is examined yearly among all 3000 HIV patients in the OLVG hospital, to factors such as age, time since diagnosis, gender, sexual orientation, and cultural background. In a complementary qualitative study, 37 interviews were held with PLHIV (men and women with a migration background and men who have sex with men) to examine the specific needs among these groups related to self-stigma. The focus in the interviews was on themes such as 'public beliefs about HIV, 'manifestations and consequences of self-stigma and disclosure concerns' and 'coping strategies'.

Participatory self-stigma workgroup

Alongside these studies, a participatory workgroup has been established, consisting of PLHIV (hello gorgeous Foundation), stigma researchers (Open University and Maastricht University, RIVM), and HIV health care professionals (OLVG doctors and nurse specialist). During the past year we have met several times to discuss practical issues and progress of our studies. This team will stay involved with the project and will actively participate in the future adoption and implementation of the self-stigma intervention.

STUDY 1 SYSTEMATIC REVIEW

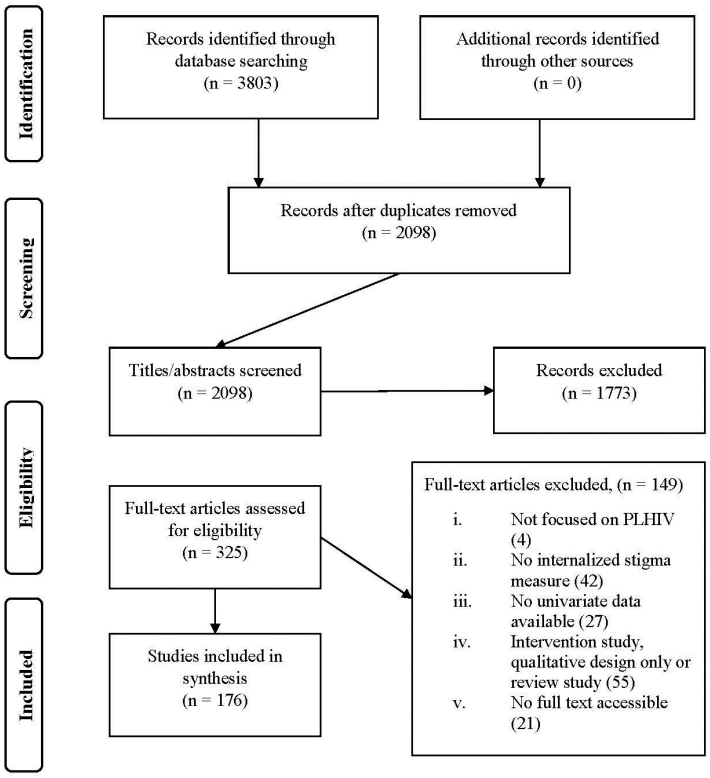
Objective of study[1]

Internalized HIV stigma is prevalent and research on internalized HIV stigma has increased during the past 10 years. The aim of this systematic review was to synthesize research on internalized HIV stigma and relationships with various health-related variables in order to better inform the development of interventions aimed at reducing internalized HIV stigma.

Methods

We reviewed 176 studies with a quantitative design reporting correlates that were peer-reviewed, published in English before January 2021, drawn from PubMed, PSYCHINFO, Web of Science, EBSCO, and Scopus.

Figure 1 *Prisma flowchart*



[1] Van der Kooij, Y.L., den Daas, C., Bos, A.E.R., Willems, R.A. & S.E. Stutterheim (2023). Correlates of internalized HIV stigma: a comprehensive systematic review, AIDS Education and Prevention, 35(2), 158–172, 2023.

Results

Synthesis showed consistent associations between internalized stigma and negative psychological (e.g., depression, anxiety), social (e.g., lack of social support, discrimination, nondisclosure, and intersecting stigmas), and health (e.g., substance use, treatment nonadherence, negative clinical HIV outcomes) variables.

Conclusion

This review provides a comprehensive overview of correlates of internalized HIV stigma. In line with earlier research this review confirms the well-established relationship between internalized HIV stigma and poor psychosocial and health outcomes (e.g., depression, anxiety, lack of social support, nondisclosure, and treatment nonadherence). The review further draws attention to (less studied) relations between internalized HIV stigma and intersecting stigmas, as well as sociodemographic factors (e.g., socioeconomic vulnerability and marginalized key populations). We call for more longitudinal research, and a broader socioecological approach to (internalized) stigma in general.

STUDY 2 QUANTITATIVE STUDY

Objective of study[2]

Self-stigma negatively affects quality of life of people living with HIV (PLHIV) to various degrees. When PLHIV internalize the experience of public stigma they might incorporate this into their self-image, which can result in negative mental and physical health outcomes. This current study is part of a Value Based Healthcare Project in which HIV-related stigma and various quality of life outcomes for PLHIV are measured. The objective of this study was to examine the relationships among perceived public stigma, experienced stigma and self-stigma, and a set of quality of life outcomes.

Methods

This study used a cross sectional design and included a sample of 1704 PLHIV in the Netherlands. Participants were recruited from the OLVG hospital, one of the largest HIV treatment centers in the Netherlands. Participants were eligible for the study if they were at least 18 years of age and if they were able to fill in the survey in Dutch or English. Demographic characteristics (age, gender, region of origin, HIV transmission route, and time since diagnosis) were retrieved from medical records. Surveys were filled in online or, for those without internet access, with pen and paper in the hospital. Eight concepts were measured with a set of adaptations of validated surveys including stigma (i.e. self-stigma, perceived public stigma, experienced stigma) (Berger Stigma scale), social support (SSL12-I) and six quality of life outcomes; depression and anxiety (HADS), disclosure concerns, sleeping difficulties (SCL90-Sleep), sexual problems, self-esteem (SISE) and general health level (SF-12).

Results

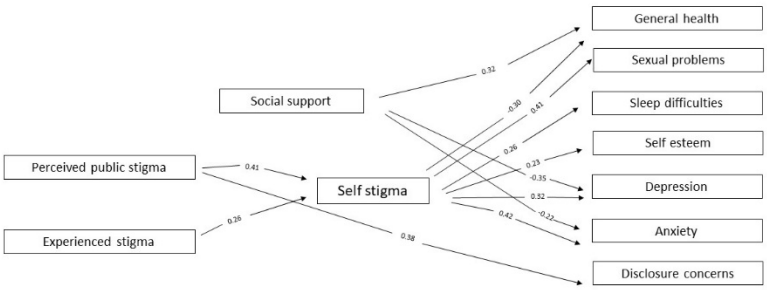
Most of the 1704 participants included in the sample were male (94%). Ages ranged from 21 to 84, with a mean age of 50.7 years (SD = 10.9), and the mean time since diagnosis was 11.8 years (SD = 7.9). The majority of the participants had acquired HIV through same sex intercourse (87%). The sample was culturally diverse; more than half of the participants were born in the Netherlands (62%), and 37% of the participants had a migration background (most

[2] Van Der Kooij, Y. L., Kupková, A., Den Daas, C., Van Den Berk, G. E., Kleene, M. J. T., Jansen, H. S., ... & Stutterheim, S. E. (2021). Role of self-stigma in pathways from HIV-related stigma to quality of life among people living with HIV. AIDS Patient Care and STDs, 35(6), 231-238.

represented regions were: the Caribbean/ South America, Eastern Europe, and Sub-Saharan Africa).

Bivariate analyses showed that self-stigma was significantly and positively related to other types of stigma (perceived public stigma $r = 0.55$, $p < 0.01$, experienced stigma $r = 0.47$, $p < 0.01$). All domains of quality of life outcomes revealed significant correlations with self-stigma. Disclosure concerns, depression, anxiety, sexual problems, and sleeping difficulties showed a positive relation to self-stigma (i.e. r ranging from 0.31 to 0.48, $p < 0.01$). Finally, self-esteem, general health, and social support showed a negative correlation to self-stigma ($r = 0.29, 0.40, 0.29$, $p < 0.01$).

Figure 3. *Stigma mediation model with standardized parameters*



A structural equation model was tested to examine a stigma mediation model. Figure 3 illustrates our model with standard coefficients of all pathway effects that were significant. The final model in our study revealed that the indirect effects through self-stigma of both public and experienced stigma on quality of life outcomes are larger than the direct effects of public and experienced stigma on quality of life outcomes.

Conclusion

The current study shows how the process of stigma impacts quality of life of PLHIV. The findings demonstrate that self-stigma mediates the effects of public and experienced stigma on quality of life outcomes, suggesting that self-stigma in PLHIV is important to address. Programs to effectively target self-stigma among PLHIV are however still scarce. Understanding the determinants of self-stigma and the context in which self-stigma occurs could inform future interventions to reduce HIV-related stigma and its harmful effects.

STUDY 3 QUALITATIVE STUDY

Objective of study[3]

The objective of this study was to better understand the process of HIV related self-stigma for two groups of key populations living with HIV and to identify the specific needs for these groups. Outcomes of this study will contribute to the development of an intervention aimed to reduce the negative consequences of self-stigma and improve the wellbeing of people living with HIV.

Methods

For this qualitative study, 37 semi structured interviews were carried out between December 2018 and May 2019 with PLHIV (men and women with migration backgrounds and men who have sex with men). Participants were purposively recruited through the OLVG hospital in Amsterdam, one of the largest HIV treatment centers in the Netherlands. PLHIV were eligible to participate if they were over the age of 18, diagnosed with HIV, and belonged to one of the subgroups (men/women with a migration background or MSM). The interviews were held in Dutch, English, Spanish or French language and the interviewers were also PLHIV. The interviews focused on manifestations of self-stigma and disclosure concerns, perceived public beliefs, and coping mechanisms of PLHIV.

Results

18 women with a migration background, 10 MSM with a migration background, and 9 Dutch MSM participated in this qualitative research. In table 1 the rest of the study demographics are shown. The mean age of our participants was 42.2 years. Most of the MSM were single and were employed, while the majority of the women with a migration background were unemployed, living on social welfare and were in a relationship. Almost half of the participants (43.2%) had disclosed their HIV status to less than 10 people.

Table 1. *Demographics (n=37)*

		N	%
Sex	Male	19	51.4
	Female	18	48.6
Sexual orientation	Heterosexual	17	46.0
	Homosexual	18	48.6

[3] Analysis of the data is still ongoing, presented here are preliminary findings.

	Bisexual	2	5.4
Relationship status	Single	21	56.8
	Relationship/married	13	35.1
	Divorced/widowed	3	8.1
Level of education	University degree	9	24.4
	Some college	19	51.3
	High school or less	7	18.9
	None	2	5.4
Employment situation	Employed	17	46.0
	Not employed	16	43.2
	Volunteer work	4	19.8
No. of people told about HIV	Less than 10	16	43.2
	10 to 30	8	21.6
	More than 30	10	27.0
	Everyone	2	5.4
	Unknown	1	2.8
Years of living with HIV	Average 11.4	-	-

Perceived public beliefs about HIV

Participants were asked about the views of people in their community about HIV and PLHIV in general. A distinction was often made between people who were more or less informed (or educated) about HIV.

- "There is still a lot of unawareness around HIV, "people still associate HIV with images of death, AIDS and Africa, or being a sinner" [male participant, age 25)
- "It's more normal now, people have more information and know you can live a normal healthy life" [female participant, age 22)

Self-stigma and disclosure concerns

Participants often mentioned that self-stigma is a process and different to everyone. For some it was heavily related to their personal background and intersected with negative feelings about HIV but also their sexual orientation, traumatic events in the past or their cultural background. Frequently recurring manifestations of self-stigma that were mentioned were: negative self-image, self-isolation, feelings of depression and anxiety, fear for intimacy, and self-blame.

- "I still feel shame… especially when someone finds out… It's the name of it, the mark you receive…. Which is horrible and also very… sad" (male participant, age 25)

Disclosure concerns and anticipated stigma remained a very important issue for most of the participants; being extra careful telling others, fears of gossip and losing friends and family. Consequently, this would lead to less social support and help seeking behavior.

- "I think you have to be careful who you decide to share your information with. Peoples' words and opinions can influence you" (female participant, age 47)

Coping and empowerment

During the interviews participants were asked about their way of coping with negative feelings about themselves regarding HIV or negative reactions they received. Some of the mentioned strategies are listed below:

- Seeking social support (contact with other PLHIV)
- Self-care (healthy lifestyle and proper use of medication) or self-healing (spiritual practices, mindfulness)
- Educating oneself and others about HIV to feel more empowered
- Seeking psychological help (therapy; psychologist/ psychiatrist)

Conclusion

Findings of this qualitative study contribute to deeper knowledge of the concept of HIV-related self-stigma. Accounts of PLHIV showed that self-stigma is a complex issue and highly dependent on personal, social, and contextual factors. When designing interventions to target self-stigma and its negative consequences, special attention should be given to the intersection of these different factors that play a role in the lives of different populations living with HIV.

Conclusion and recommendations

The results of these studies together provide a foundation for the further development and implementation of an intervention targeting HIV-related self-stigma and negative health related outcomes. Our findings from the literature review suggest that HIV-related self-stigma appears to be associated with a multitude of different psychological and social health related outcomes (e.g. psychological distress, self-esteem, social isolation, treatment adherence). Further, in our quantitative study of 1704 PLHIV in the Netherlands we found that self-stigma has a mediating role in the relationship between different types of stigma (i.e. perceived public stigma, experiences stigma) and quality of life outcomes. Finally, interviews with 37 PLHIV showed how complex the process and manifestations of HIV-related self-stigma are in the lives of PLHIV, and therefore in need of an intervention targeting self-stigma at different levels (individual, community, structural).

Practical implications for the development of a self-stigma intervention:

- Target intervention at multiple levels
- Focus not only on self-stigma but also on root causes behind it
- Give special attention to empowerment of PLHIV by strengthening their coping mechanisms (e.g. though education, social support, psychological help)

Intervention development

We used the The Intervention Mapping (IM) approach consisting of six steps to develop the RESET intervention. IM is a approach for developing effective behavior change interventions in a systematic way (Bartholomew et al., 2016), and offers a sound framework for the development, implementation, and evaluation of stigma reduction interventions (Stutterheim et al., 2023). The first step was conducting a needs assessment in which data were gathered to gain a thorough understanding of self-stigma in PLHIV. We ascertained determinants of behaviors and environmental conditions for self-stigma that lead to poor health and quality of life (see Table 1). In our needs assessment we conducted a systematic review, a large survey study, and interviews and focus group discussions with PLHIV.

The second step was to determine program outcomes and objectives for PLHIV and their social environment. Following the needs assessment we determined multilevel program objectives. For the individual level (PLHIV), behavioral objectives were increasing positive beliefs about HIV and expecting positive reactions towards one's HIV status. For the environmental level, objectives were providing a supportive environment for PLHIV (social support, linkage to accurate HIV information channels and culturally sensitive support networks) and decreasing intersectional stigmas in the community. Specific behavioral determinants at the individual and environmental level such as knowledge, attitude, social norms, skills, and self-efficacy were targeted (Table 2 shows a Change Matrix).

Table 1 *Logic model of problem*

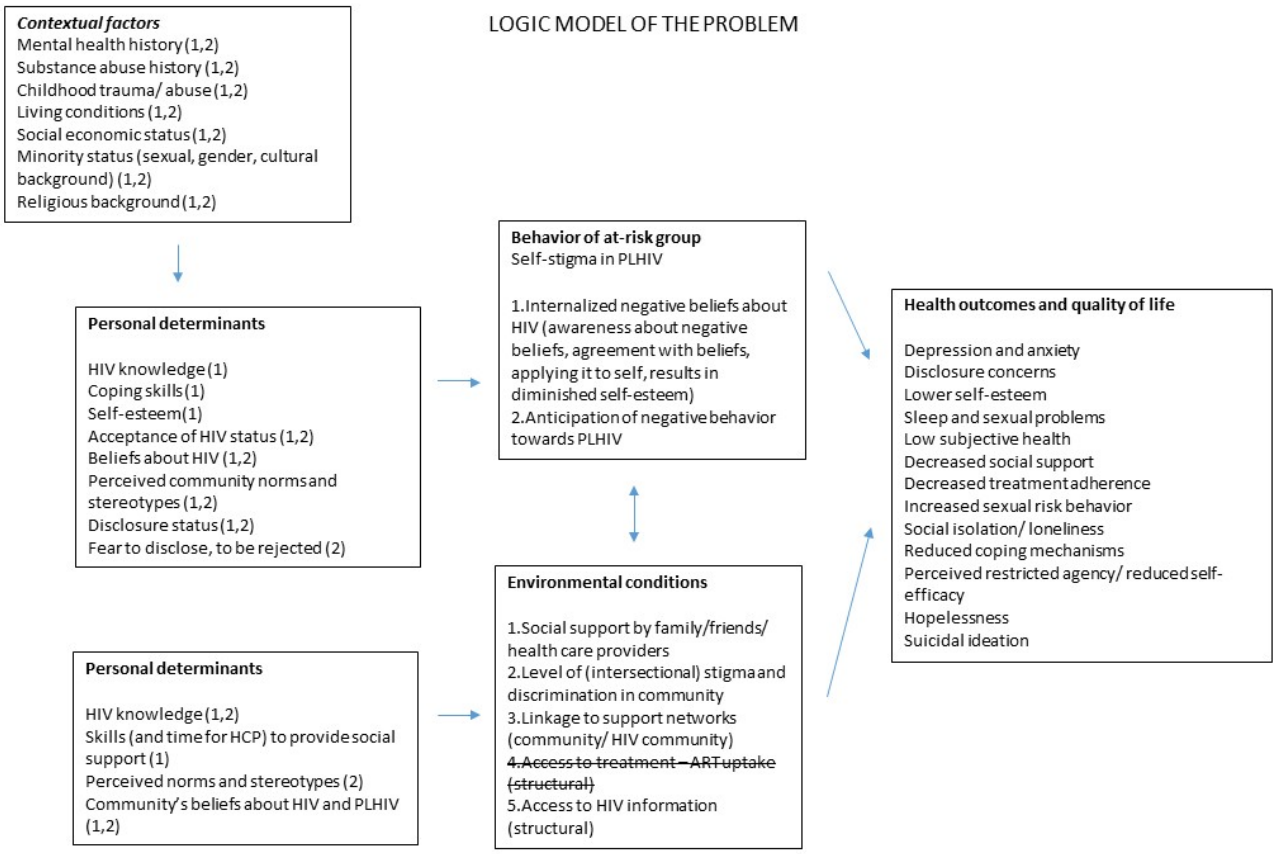


Table 2 *Example of one of the Change Matrices for RESET (Stutterheim et al., 2022).*

Description of targeted individual/group	*Awareness/Risk perception*	*Outcome expectations/Attitude*	*Subjective norm*	*Self-efficacy/Skills*	*Public stigma*
BO1: PLHIV internalize positive beliefs about HIV					
PO1.1: PLHIV acquire accurate information about HIV.	A.1.1.: List the channels that provide information on HIV.	OE1.1a: Describe that PLHIV can and do live long and healthy lives. OE.1.1.b: Describe that PLHIV can have healthy children. OE.1.1.c: Describe how when you take your medication correctly, HIV is not transmissible. OE.1.1d: Describe the benefits of having accurate HIV knowledge. A.1.1: Express positive feelings about acquiring accurate information about HIV.	SN.1.1: Explain that other PLHIV that have accurate knowledge of HIV feel more empowered.	SE.1.1: Express confidence in being able to acquire accurate HIV information. S.1.1: Demonstrate the ability to acquire accurate HIV information.	
PO1.2: PLHIV reject stereotypes about PLHIV.	Aw.1.2: List common stereotypes about HIV. RP.1.2.a: Explain that HIV is no longer a terminal disease. RP.1.2.b: Explain that, with good adherence, PLHIV cannot transmit HIV to others. RP.1.2.c: Explain that PLHIV cannot transmit HIV to others during social contact.	A.1.2: Express positive feelings towards rejecting stereotypes in order to improve self-image.	SN.1.2: Explain that other PLHIV that successfully rejected stereotypes feel better about themselves.		PS.1.2.a: Explain that PLHIV are not to be blamed for acquiring HIV; PS.1.2.b: Explain that PLHIV are not morally deviant.
PO1.3: PLHIV cope adaptively with HIV diagnosis and negative feelings.	Aw.1.3: Identify coping skills that advantageous (e.g. selective disclosure, seeking social support, self-care, activism, external attribution, positive reappraisal).	A.1.3: Express positive feelings towards applying adaptive coping skills as an effective way of dealing with HIV stigma.	SN.1.3: Explain that other PLHIV have successfully applied adaptive coping skills.	SE.1.3: Express confidence in applying adaptive coping skills. S.1.3: Demonstrate the ability to apply adaptive coping skills.	

PO1.4: PLHIV accept HIV status.		A.1.4: Express positive feelings about accepting one's HIV status. OE.1.4: Recognize that accepting one's HIV status contributes to more self-esteem.	SN.1.4: Explain that many PLHIV accept their HIV status.	SE.1.4: Express confidence to accept one's HIV status. S.1.4: Demonstrate the ability to accept one's HIV status.	PS.1.4: Appraise negativity from others as something that results from ignorance.
PO1.5: PLHIV view HIV status as only one part of broader identity.		A.1.5.a: Recognize that one's identity is a social category which consists of many different parts, and HIV is only one part of it. A.1.5.b: Express positive feelings towards viewing HIV as only one part of a broader identity is empowering.	SN.1.5: Explain that other PLHIV that view HIV as only one part of their identity are more empowered.		
PO1.6: PLHIV demonstrate self-esteem and self-confidence in living with HIV.				SE.1.6: Express confidence in being able to demonstrate self-confidence and self-esteem. S.1.6: Demonstrate the ability to present self with self-confidence and self-esteem in living with HIV.	PS.1.6 Assess negativity about HIV in society as something that results from ignorance.

Note: BO = behavioral objective; PO = performance objective; Aw = awareness; RP = risk perception; A = attitude; OE = outcome expectation; SN = social norm; SE = self-efficacy; S = skills; PS = public stigma

The third step was to select theory-based methods and corresponding practical applications. Methods and applications for our intervention derived from both social cognitive theories as well as empowerment theories. The fourth step was producing the program. In this step we created the RESET workshop and its activities (more details are given in the next section 'Intervention Description'). Following this, in step five we planned for adoption, implementation, and maintenance of the program. The intervention was developed in a collaborative manner between PLHIV, stigma researchers, and health care professionals. PLHIV were involved at the start of the project (from planning and design to implementation of the program). The website (https://reset.hellogorgeous.nl/) was created for participants to sign up, for information about the program, and to share results. Materials to deliver the program were also created and translated in English to be made available online (both trainers handbook and workbook for participants) for adoption of the program. In the final sixth step we created a plan to evaluate the program (effect and process evaluation).

Figure 1 *Website page RESET intervention*

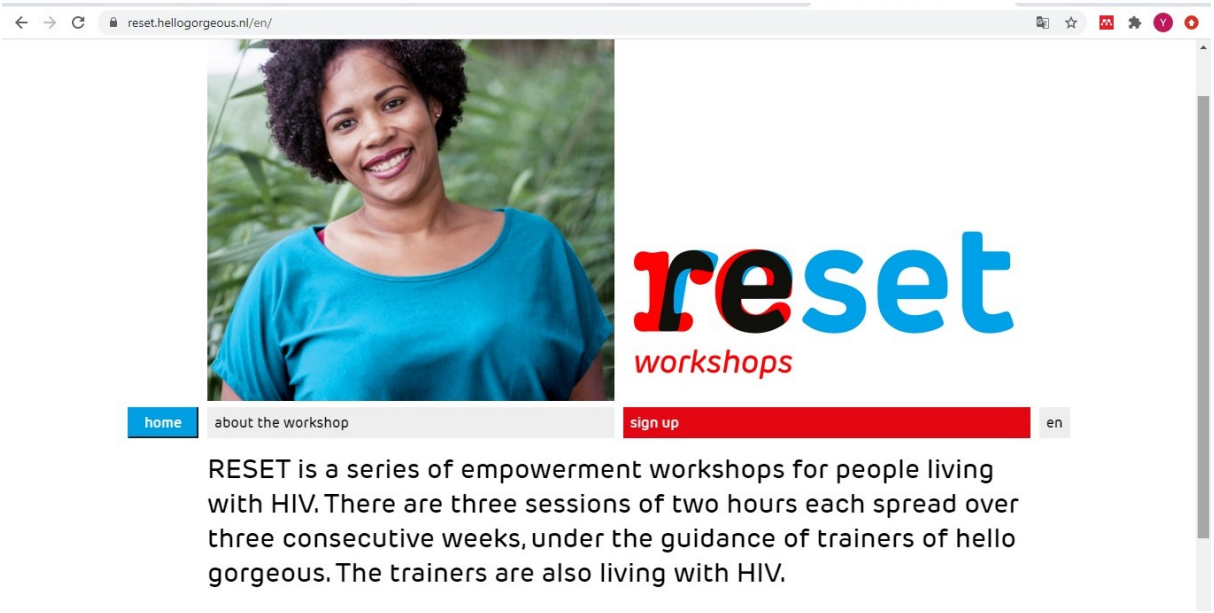


Figure 2 *Example from RESET handbook: first session activities*

Session 1	**Stigma education and awareness**			
Activities	Content	Targeted determinants	Time	Materials
1.1 Five questions introduction	Getting to know each other; discuss house rules; privacy participants		10 minutes	None
1.2 Stereotypes	Explore negative associations with HIV	Knowledge, attitude, norms	20 minutes	Flipcharts/ post its
1.3 Knowledge Quiz	HIV educational game to target misbeliefs about HIV	Knowledge	20 minutes	Question cards
BREAK			10 minutes	
1.4 Introducing stigma	Movie and psychoeducation; what is stigma, which types exist, exercise in small groups on stigmatizing situations	Knowledge, attitude, norms	15 minutes	Laptop, beamer, flipchart
1.5 Effects of stigma	Movie and psychoeducation; what are the effects on someone who is being stigmatized	Knowledge, attitude, norms	20 minutes	Laptop, beamer, flipchart
1.6 Self-stigma experiences	Movie and psychoeducation; what is self-stigma, how does it affect someone, discuss personal experiences in small groups	Knowledge, norms	20 minutes	Laptop, beamer, flipchart
Homework exercise	Try to notice times during which you feel less worthy than others because of HIV. Write this down and bring it with you to the next workshop session.			

Intervention description

Content of workshops

RESET (Resilience & Empowerment Training) is a face to face group intervention designed to target self-stigma in PLHIV and improve their wellbeing. Participants included in the intervention group receive three workshop sessions of 2.5 hours each.

Session 1 HIV and stigma	The first session focuses on education and awareness of self-stigma and its effects, and targeting misbeliefs and stereotypes about HIV.
Session 2 Coping and self-esteem	The second session focuses on helping participants to identify and cope with negative feelings about HIV, and boosting their self-esteem.
Session 3 Disclosure and empowerment	The last session explores ways to cope with negative reactions to HIV status from others, discusses pros and cons of HIV status disclosure, and provides tools to empower participants.

Design

The design of our intervention is based on the Intervention Mapping method for developing effective public health interventions. The intervention program has been co-designed with PLHIV and is adapted according to the needs of PLHIV living in the Netherlands during different focus group discussions and a pilot session. The intervention consists of a three week workshop and was delivered in group format of 5 to 8 PLHIV per group and 2 facilitators living with HIV. After each session, homework exercises were assigned to facilitate change from one session to the next (Basco & Rush, 2007). Facilitators are people from hello gorgeous foundation, a grass roots organization that aims to normalize living with HIV and combats HIV-related stigma. The facilitators are experienced in giving workshops and focus group discussions with PLHIV. Besides that facilitators received a training for trainers session supervised by two psychologists from the Open University and Maastricht University.

Social cognitive theory and empowerment principles

The intervention is based on the principles of social cognitive theories (SCT) and includes active learning amongst peers. SCT combines determinants of behavior with methods for behavior change (Clark et al., 2014; Young et al., 2015). SCT provides opportunities for social support by instilling self-efficacy, activating performance, and uses observational

learning, reinforcements and modeling to achieve behavior change. The intervention also includes principles of empowerment theories. Empowerment on the individual level includes perceived efficacy and people taking control over their own lives (Zimmerman, 2000). Lastly insights from cognitive behavioral therapy were used to create different intervention activities (Hofmann et al., 2012).

Peer support

Our group intervention uses techniques such as role playing, modeling of behaviors through video, social support, and contact with peers. The facilitators delivering the intervention are PLHIV. The facilitators will function as a role model and a resource for coping strategies. A method for addressing psychosocial distress in people with chronic illnesses (such as HIV) involves trained peers who share a diagnosis to provide social support and other assistance (Marino et al., 2007). Peer support has further proven to provide ways to easily relate to needs and concerns of a targeted group (Doull et al., 2017; Mburu et al., 2013). PLHIV in the workshop will find new contacts with other PLHIV, and are able to share methods of coping, as well as learn new skills from each other. Group identification (the feeling of strong ties to a socially defined group of people) has also proven effective in reducing the effects of stigma on people with a chronic illness (Corrigan et al., 2013).

Methods

Recruitment & participants

70 PLHIV were recruited through Dutch HIV treatment centers (OLVG and DC Clinics) and HIV organizations (hello gorgeous, Hiv Vereniging, and Shiva) for participation in the intervention and evaluation between January 2021 and December 2022. Participants were eligible to participate when meeting the following criteria: a) having a diagnosis of HIV; b) being 18 years or older; c) being enrolled in HIV care in the Netherlands; d) able to speak Dutch or English. Participants were excluded from participation in case of a serious medical, psychiatric or cognitive disease that would interfere with participation (e.g. severe clinical depression with risk of suicide or people with a serious drug or alcohol problem).

In total 13 workshops were held, of which 8 at OLVG Spuistraat and 5 at DC Clinics. Informed consent was obtained prior to participation in the workshop.

Medical ethical approval

Ethical approval for this study was granted (R20.074, NL752509.100.20) by the Medical Research Ethics Committees United (MEC-U) in the Netherlands.

EFFECT EVALUATION

Outcome measures

For the effect evaluation, participants completed questionnaires at baseline, post-intervention and at three months follow-up. No control group was included. The primary outcome was self-stigma (HSS, Berger et al., 2001); secondary outcomes were self-esteem (RSES, Rosenberg, 1965), quality of life (WHOQOL-BREF 1998), resilient coping (BRCS, Sinclair & Wallston, 2004), and empowerment (ESR, Rogers et al., 2010).

HIV-related self-stigma was measured using an adapted version of the 40-item HIV stigma scale developed by Berger, Ferrans & Lashley (2001), namely the 32-item HIV stigma scale (Bunn et al., 2007). The 32-item scale measures negative self-image, disclosure concerns, public attitudes, and enacted stigma. Answers are provided on a 4-point Likert scale ranging from 1 to 4, with higher scores indicating greater stigma. This scale is a frequently used measure of HIV-related stigma and is considered both valid and reliable (Bunn et al., 2007; Berger et al., 2001).

Self-esteem was measured using the single-item Self-Esteem Scale (SISE) (Robins, Hendin, & Trzesniewski, 2016), namely "I have high self-esteem" with scores ranging from 1 to 7. A higher score indicates more self-esteem. The scale has demonstrated high construct validity (Robins et al., 2016).

Quality of Life was measured with the WHOQOL-BREF scale (WHO Group, 1998). This measurement produces scores on the patients' self-reported judgement of four different domains of QOL including physical health, psychological health, social relationships, and environmental factors (financial resources, health care). Answers are provided on a 5-point Likert scale, with higher scores indicating better QOL.

Resilient coping was measured with the four-item Brief Resilient Coping Scale (BRCS) (Sinclair & Wallston, 2004). The scale is designed to explore tendencies to cope with stress in highly adaptive manner. Answers are provided on a 5-point Likert scale ranging from 1 to 5, with higher scores indicating higher resilience. The scale is a frequently used one and is considered both valid and reliable for various types of populations (Kocalevent et al., 2017; Sinclair & Wallston, 2004).

Empowerment was measured using a 28-item Empowerment Scale (Rogers, 2010). The scale operationalizes the construct of personal empowerment from a person's perspective. Answers are provided on a 4-point Likert scale ranging from 1 to 4, with higher scores indicating feeling more empowered. High internal consistency for the scale has been reported (Rogers et al., 2010; Wowra & McCartner 1999).

Analyses

Post-intervention and follow up effectiveness after three months were evaluated with one-sided paired samples t-tests. Participants filled in questionnaires online between September 2021 and April 2023.

PROCESS EVALUATION

A process evaluation was also conducted in which 13 participants, facilitators, and implementers were interviewed between December 2022 and March 2023. Data were analyzed using process-related themes of recruitment, reach, context, implementation, dose-delivered, and fidelity. Participants' satisfaction scores and feedback from the evaluation forms were also reviewed.

Results effect evaluation

Participant characteristics

109 PLHIV showed their interest in participating in RESET during the time of recruitment (between January 2021 and December 2022). In total 70 participants took part in the RESET intervention and study. 68 participants completed all 3 weekly sessions of RESET. 2 participants dropped out due to sickness and a family emergency. 70 participants completed the baseline questionnaire, 67 participants completed the post-intervention questionnaire, and 65 participants completed the 3 month follow up questionnaire.

The average age of the participants was 49 years, ranging from 22-76. 81.4% of the participants were male, and 74.3% were Dutch. Further participant details are included below in Table 3.

Table 3 *Characteristics of participants (baseline N=70)*

Variable		**Mean**	**Range**
Age		*49*	*22 to 76*
Variable	**Category**	**N**	**Percentage**
Gender	Female	12	17.1%
	Male	57	81.4%
	Non-binary	1	1.4%
Cultural background	Dutch	52	74.3%
	Migration background European	7	10%
	Migration background non-European	9	12.8%
	Unknown	2	2.9%
Sexual identity	Homosexual	54	77.1%
	Heterosexual	12	17.1%
	Bisexual	3	4.3%
Level of education	High school	8	11.4%
	Higher education (MBO)	13	18.6%
	Higher education (HBO, WO)	47	67.1%
	Other	2	2.9%
Currently employed	Yes	42	60%
	No	28	40%
In a relationship	Yes	28	40%
	No	42	60%
Years living with HIV	Less than 2 years	3	4.3%
	2 to 10 years	30	42.9%
	10 to 20 years	18	25.7%
	More than 20 years	19	27.1%

Significant changes across both primary and secondary outcome measures were reported by participants after taking part in the intervention. Comparing baseline (t0) and post-intervention (t1), participants reported a significant reduction in self-stigma ($p < .001$, $d = .67$) and improvement in self-esteem ($p < .001$, $d = .47$), resilience ($p < .001$, $d = .36$), and empowerment ($p = .022$, $d = .31$). No significant differences post-intervention (t1) compared to baseline (t0) were reported for quality of life.

Follow up scores (t2) significantly improved at 3 month time point compared to baseline (t0) for self-stigma ($p < .001$, $d = 53$) and self-esteem ($p < .001$, $d = 78$). Empowerment scores also significantly improved at 3 month follow up (t2) but with a relatively low effect size ($p = .03$, $d = .22$). No significant differences at 3 month follow up (t2) compared to baseline (t0) were found for resilience ($p = .09$, $d = .70$) and quality of life ($p = .05$, $d = .26$). The results of the t-tests can be found in Table 4 (supplementary document tables t-tests).

Results process evaluation

13 respondents were included in the process evaluation, 8 RESET participants and 5 facilitators and implementers of RESET. The effect evaluation showed that after participating in RESET, participants reported significant changes across different areas of their lives. This process evaluation looks at the implementation of RESET to better understand the study's findings. Data from the process evaluation give us a deeper understanding of the impact of the RESET workshops as well as the strengths and limitations of the intervention.

Recruitment, reach, and context

Participants for the RESET workshop were recruited through different channels. Doctors and nurses of a large HIV treatment centre (OLVG) promoted the intervention among their patients during regular patient visits. Various HIV community organizations (Hiv Vereniging, Hello Gorgeous, Shiva) further helped to recruit participants through online channels (website, newsletters, magazine, social media). Problems with recruitment were common during the implementation phase, and less participants than anticipated were included in the intervention. 70 participants participated in RESET, of which 17% identified as female, and 23% had a migration background.

Contextual factors that impeded recruitment were COVID-19 and access to harder to reach populations (PLHIV with a migrant background and women). During COVID-19 there were fewer onsite hospital visits for PLHIV at OLVG. This resulted in fewer opportunities for doctors and nurses to discuss HIV-related stigma and refer patients to the RESET workshop. Interviews with participants, recruiters, and facilitators also revealed that during COVID-19 fear for physical contact and group activities as well as general low motivation to participate in activities were common. Also for harder to reach populations, recruitment difficulties were reported such as language barriers, safety and privacy concerns. The workshop was delivered in Dutch and English and for some PLHIV with a migrant background their level of Dutch or English was not sufficient. Also for those PLHIV with high levels of stigma or those who were not open about their status engaging in a group workshop with others and unknown facilitators was not an option.

Implementation, dose-delivered, fidelity

Of the 70 participants that completed the first session, only 2 dropped out during the following sessions. Originally we planned to deliver 20 workshops. With less participants recruited than expected, 13 workshops were delivered. Based on participant evaluation forms, participants gave a 8.6 satisfaction score (range between 1 and 10) for their participation in the RESET workshop. According to the workshop facilitators, participants were generally very engaged and enthusiastic during workshops.

Workshop facilitators were able to deliver all workshop sessions according to the guidelines of our trainers handbook during the 13 workshop rounds. However, both facilitators and participants reported that there was not enough time to go through all activities without feeling rushed. This sometimes resulted in not having enough time for all participants to share their story or talk more in depth about certain topics (often mentioned shame/ guilt). Also, homework exercises were not always completed by all participants when there was not enough time to explain the exercise fully. Group sizes varied between 4 and 8 participants. All participants took part in the activities in each session (ranging from educational videos, group discussions, and role plays). When the size of a workshop group was relatively small, some activities had to be adjusted accordingly to the amount of participants (e.g. discussions in pairs became group discussions).

The peer leader model and workshop set-up created a safe space for discussions about HIV and stigma. Workshop facilitators, also PLHIV, were successful in encouraging participants to share their experiences with living with HIV. For example, the first session used an educational video screening targeting stereotypes about HIV. This activity together with a knowledge quiz about HIV and group discussions appeared to be effective in creating a positive attitude towards living with HIV, which may have contributed to an improved self-image. Engaging in the role play activities also appeared to be effective in building skills and self-efficacy to disclose and/or cope with negative reactions. The purpose of the role plays was to practice disclosure of HIV status or dealing with possible stigmatizing situations in daily life among peers in the group. Participants shared that practicing with these situations during role plays helped them in interactions with friends and family in daily life and for some in sharing their story for the first time with others.

Impact of workshop

During interviews, participants spoke about the (positive) impact RESET had on their lives. Many participants shared that the activities from the workshop and meeting other PLHIV helped them in their acceptance of HIV, building more self-esteem, and creating a more positive mentality in general:

"I learned that I can step up for myself. It is easier for me to set boundaries now, to say I will not accept this. You learn to feel worthy of yourself again". Participant RESET

"I realise now that I am more than that (HIV). It is about who I am and not about the virus that I have" Participant RESET

Changes were also reported in outlook surrounding living with HIV as well as improved interactions with family and friends. Many participants spoke to more people in their social network about HIV and stigma and how this affected them. Others reported that they realised that overcoming self-stigma also helps to mitigate stigma from other people:

"The effect of a workshop like this for the outside world can be pretty big too" Participant RESET

"Working on HIV stigma helped me to be more positive… When you are more open (about your status), you get different reactions from others too". Participant RESET

RESET also contributed to participants feeling more empowered in other aspects of life. Several participants described how they did not disclose their HIV status to others prior to RESET (or relatively to few others). After participating in RESET however, they felt more empowered and confident to discuss their HIV status with others:

"RESET was a life changing moment, for the first time I was brave enough to open up to my children about my HIV. I also went to the Power of Love (event) for the first time in my life. Practicing disclosure and thinking about the response helped me, also in realising that I mostly created the stigma myself." Female participant RESET

Some participants shared that they felt more confident about their HIV, which helped them in meeting new people (dating), participating more in social activities, and feeling less isolated in general. Other participants felt more empowered after participating in RESET to use new knowledge and skills to educate others or support other PLHIV:

"After participating in RESET I have signed up to become a buddy for people who were recently diagnosed with HIV." Participant RESET

"Sharing my story can inspire others. I think it is very important to organize workshops like this to educate and raise awareness that can fill those gaps in other people" Participant RESET

<u>Strengths of the workshop</u>

The peer-led workshop model was mentioned as one of the strengths of the workshop by almost all participants. Facilitators were well received and did a good job creating a safe space to talk among peers. All participants reported feeling comfortable sharing about their life among peers inside their group:

"I felt safe knowing that the workshop leaders were also living with HIV. Because of this I felt less ashamed and strengthened because they know how I feel, since we share the same experience." Participant RESET

In addition to that, most participants indicated that the workshop provided them with peer support and the possibility to meet others with HIV (sometimes for te first time), learn from each other, and share experiences:

"RESET provided me with a lot of positivity in life. Just to be able to talk to others and feel less lonely". Participant RESET

"Participating was very empowering because of the chance to meet peers, people with the same condition, that go through the same. That was very special and I realized how much that is needed also." Participant RESET

Another strength that was often mentioned was the diverse and mixed groups (in terms of age, years living with HIV, gender, and sexual orientation, and level of openness). Sharing the same condition but also having a different background gave participants more perspectives and contributed to self-acceptance:

"*Diverse groups felt right. It was about acceptance, something we all have to go through. Being trans or not, everybody has to go through the same process. That is the same for everyone living with HIV. It was beautiful to share with people from different walks of life"* Participant RESET

At the same time participants also shared the importance of having role models that they could easily identify with. Women especially said it was important to them to be able to recognize themselves, and therefore it was necessary that there was at least one other woman in the group (either facilitator or participant; this was the case in each workshop).

Limitations of workshop and recommendations for future adoption

Overall participants reported lack of time to go through the program as a limitation, resulting in less space for participants to fully share their experiences and emotions throughout the workshop. The need for more time to reflect on themes such as shame and guilt and its effect on self-stigma was also mentioned by a few participants. Most participants recommend to add another session or evaluation day (a few months after the program) to see how far people have come since the program. Having another day to look back at the program also gives participants a chance to stay connected and work on personal goals.

Another limitation that was mentioned by a few participants was that sometimes there was too much focus on disclosure and call for activism in order to overcome self-stigma. Also, participants reported that for future workshops more attention could be paid to the ongoing process of self-stigma and how public or experienced stigma may influence feelings of self-stigma over the years.

"Something I missed in the workshop was that because of (negative) reactions of others self-stigmatizing thoughts can get under your skin again". Participant feedback form

Recommendations for future adoption of the program concerning recruitment and reach of the targeted population:

Facilitators, implementers, and participants all pressed that future recruitment initiatives should include a broader network of HIV treatment centres throughout the country. Promoting RESET and providing information about the program could be included during yearly meetings of the association of HIV doctors and nurses. A personal way of recruiting participants for RESET is important according to most PLHIV and HIV nurses that we spoke to. The only way to reach PLHIV without a solid network and high levels of self-stigma and/or who are not open about their status is through their HIV doctor or nurse:

"For those that are not active in the HIV community, their HIV doctor or nurse is the only one that can inform them about activities such as RESET and to check in with them or ask them about whom they disclosed to". Participant

Education about HIV-related stigma issues and sensitivity towards privacy related issues are highly important as well:

"If someone is scared or has a lot of stigma, their HIV nurse should talk to them about RESET or refer to someone to talk to anonymously. However, not everyone is comfortable enough to talk about stigma. You first have to do some educating, also among health care personnel." Participant

For those harder to reach populations (e.g. people with a migration background, women) making use of a peer counsellor within hospitals that pays special attention to creating a safe space and is able to talk about privacy concerns during recruitment would be of added value. Also with regard to the implementation, having a more diverse pool of workshop facilitators and diverse role models in general is important. To reach more PLHIV with a migration background, closely working together with community organizations such as Shiva and Mara is also crucial.

Finally, more attention could also be paid to using a more personal recruitment approach online. Using testimonials of prior participants to share their experience with RESET, availability of a promotion video, and visibility of workshop facilitators and ways to get in touch before participating.

CONCLUSION

The results of our evaluation study indicate that the RESET workshop reduces HIV self-stigma, and positively impacts self-esteem, empowerment, and resilience. With some adjustments to the program, RESET is promising for further implementation. Future adoption of the program should include an extra follow up session, pay more attention to the themes shame and guilt and the link between perceived public stigma and self-stigma. Future recruitment of PLHIV for the program could be improved by expanding collaborations with different HIV health care centers, as well as working with a set of diverse peer counsellors.

Hello gorgeous has updated the workshop content based on this evaluation study and will continue with RESET from September 2023 onwards.

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