“What would ‘they’ think?”

Study about the effect of HIV-related stigma on retention in care in rural South Africa

Sub-study of the ITREMA-project, Ndlovu Caregroup, Elandsdoorn (South Africa)

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Abstract

Retention in HIV-care among people with HIV in rural South Africa is a major problem. Yet retention in care is crucial to HIV-treatment success and better health outcomes. A possible reason for poor retention-in-care outcomes is the presence of HIV-related stigma. This affects people's motivation to seek care and stay in care. Our understanding of the influence of HIV-related stigma on retention in care is limited. Taking existing quantitative data from the ITREMA-trail in rural Elandsdoorn, this study used logistic regression analyses and mediation, moderation and conditional process analyses (Hayes, 2017) to study the direct and indirect relations between HIV-related stigma and retention in care, operationalized as loss to follow-up. Also, statistical mediation by mental health problems and moderation by different coping styles were studied. The outcomes of analyses showed that there is a significant positive relation between HIV-related stigma and loss to follow-up. This relation is mediated by mental health problems. Furthermore, there was some evidence that the relations between HIV-related stigma and loss to follow-up, and between stigma and mental health problems, are moderated by coping styles. Task-oriented coping and avoidance-oriented coping styles strengthened the direct and indirect relation between HIV-related stigma and loss to follow-up. One of the recommendations based on this study is to pay more attention to the mental health and HIV-related stigma of people with HIV to prevent loss to follow-up.

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Preface

First of all I want to say thank you to Ndlovu Care Group for the opportunity to do my internship and conduct my research in their organization. The power of the team of Ndlovu Care Group has inspired me and I look back to a rewarding and thought-provoking time in South Africa. Thank you to Dr. Prof. Tempelman, who has founded the organization and uses his inspiring personality and ambition to help and develop the disadvantaged communities in Elandsdoorn. Furthermore, I want to say thank you to Dr. Hermans. His supportive supervision and critical view during the internship helped me to develop myself as independent academic professional. Also special thanks for the supervision of Prof. de Wit, who helped me in writing and analysing my thesis. His knowledge and ambition in the field of HIV inspired me. Last, many thanks for all the support of Natasja van der Meer. We started as fallow interns, but we finished our internship as good friends.

Sena Ebbers
Utrecht, June 2018

Introduction

With over 7.1 million people with HIV (PHIV), South Africa has the highest percentage of infected people in the world, namely 12% of the total population (Shisana et al, 2014; UNAIDS, 2017). HIV-treatment is crucial for increasing the life expectancy and wellbeing of PHIV, and for preventing new HIV infections. The percentage of treated PHIV in South Africa has increased in the last few years, mainly through international and governmental interventions and policies (UNAIDS, 2017). The South African government's policy has made HIV-testing and treatment eligible for all HIV-positive citizens. However, despite these international and national policies, currently only 56% of the HIV-positive population in South Africa is being treated. Moreover, only 63% of PHIV who have initiated HIV-care remain in care after three years (Fox & Rosen, 2010).

One possible explanation for the low percentage of PHIV in South Africa who are being treated is stigma. Stigma is a major barrier to improving the health of PHIV (Link & Phelan, 2001; Mahajan, et al., 2008; Hatzenbuehler, Phelan & Link, 2013). Various South African studies have found a negative relation between HIV-related stigma, testing behaviour, care seeking behaviour and treatment adherence (Brown, Trujillo & Macintyre, 2003; Corno & De Walque, 2013; Katz et al., 2013; Mahajan et al., 2008). One explanation for these relations is that people who experience HIV-related stigma tend to have less social support and feel ashamed of their status (Katz et al., 2013). Knowledge about the relation between stigma and retention in care, when HIV-treatment has already started, is limited. However, it is known that retention in care is critical for treatment success and prevents treatment resistance (Gardner et al., 2011).

The focus of this study is on the relation between stigma and retention in care. It examines whether the degree of stigma attached to HIV in South African society is related to a higher percentage of HIV-infected people who stop treatment. The study includes mental health and coping as mediating and moderating factors. The study was undertaken in a rural, resource-limited setting in South Africa. Although HIV-related morbidity and mortality rates have decreased in South Africa, limited evidence suggests that PHIV experience specific barriers to managing HIV (Bor et al., 2013). Furthermore, little evidence is available about the impact of HIV-related stigma in rural resource-limited settings in South Africa compared to urban settings (Welz et al., 2007).

HIV and treatment

The Human Immunodeficiency Virus (HIV) is a virus which attacks the immune system of the human body and causes chronic disease. HIV can be treated with antiretroviral therapy (ART) (AIDSinfo, 2018) to suppress the viral load (VL) of HIV in the blood (Aidsmap, 2017). ART has to be taken lifelong and consistently to avert treatment resistance and improve health. Without ART, HIV can lead to death (Ramadhani et al., 2014).

Rural South African context

The HIV-epidemic in South Africa shows heterogeneous infection rates and is mainly found in rural resource-limited settings (RRLS). In 2012, HIV prevalence was 5% in urban settings and 17% in rural settings (Shisana et al., 2012). RRLS are characterized by a lack of individual and social financial funds and resources, less developed infrastructure and fewer skilled healthcare personnel than in urban areas. About 40% of the South African population lives in RRLS (Wools-Kaloustian et al., 2006).

In 2016, there were 270,000 new HIV-infections and 110,000 AIDS-related deaths in South Africa (UNAIDS, 2018). Viral suppression is still a major problem in the country. Of all PHIV, 44% are not on ART, and 38% of those on ART do not take their medication properly, which results in low viral suppression (UNAIDS, 2018). In addition, low retention in HIV-care is a major obstacle to sustaining long-term treatment success (Fox & Rosen, 2010).

Retention in care

Retention in care (RIC) refers to the sustained engagement of PHIV in medical care and clinic visits, once care has started (Messeri et al., 2002). Rosen, Fox and Gill (2007) extended the definition for PHIV in RRLS to include the following: the patient has to be alive and on ART at the end of the follow-up period. This study uses the concept of loss to follow-up (LTFU) as an indication of RIC, whether the patient is still in care or has become lost (Bryan et al., 2013).

Retention in HIV care is important for the ongoing receipt of ART and HIV-supervision during clinic visits; the latter provides social support to help patients with their treatment (Geng et al., 2010). Furthermore, RIC is conditional on successful ART and minimizes the risks of treatment resistance (Fleishman et al., 2012; Thompson et al., 2012). Low retention in care and missed clinic visits are associated with treatment failure (Geng et al., 2010; Ulett et al., 2009) and increased mortality, compared to patients in care (Mugavero et al., 2009; Tripathi et al., 2011).

Research shows that several psychological and social factors are related to RIC; these include mental health problems (MHP) and HIV-related stigma (HRS). PHIV who experience more HRS may experience difficulty remaining in care (Giordano et al., 2007; Goulet et al., 2005; Samet et al., 2003).

HIV-related stigma

Erving Goffman (1963) developed a social theory to explain the relation between stigma and health outcomes. He defined stigma as the situation of the individual or social group that is disqualified from full social acceptance, based on social, behavioural or physical characteristics that differ from the dominant group norms. In the case of PHIV, they are regarded as socially unacceptable and therefore infected individuals are excluded.

Steward et al. (2008) adapted a *conceptual model* to explain the interactive social process of stigma, based on the *hidden distress model* of Scambler (1989), which divides stigma into *enacted stigma, felt normative stigma, internalized stigma* and *vicarious stigma*. *Enacted stigma* is related to discrimination and refers to the experience of unfair treatment because of the HIV-positive status. *Felt normative stigma* addresses personal awareness of stigma, such as the prevalence of stigmatizing attitudes and the perceived norm about stigma. *Internalized stigma* refers to the extent to which PHIV accept their stigmatized position as valid. *Self-stigma* is the result of internalized stigma. This can result in shame and expectation of discrimination, which might stop people from seeking care (Scambler, 1998). Non-stigmatized individuals might internalize HRS as prejudice towards PHIV. Lastly, the model includes *vicarious stigma*: the perceptions of enacted stigma, which are often shaped by discrimination against other PHIV. This refers to the stories that stigmatized people hear about experienced stigma, which creates the feeling of discrimination.

These four forms of stigma interact with each other. According to the findings of Steward et al. (2008*), enacted-* and *vicarious stigma* influence *felt normative stigma*. Felt normative stigma is strongly shaped by stories people hear about stigmatized people who experience discrimination. They become aware of their lower status because of the experienced (indirect) discrimination. Furthermore, *enacted stigma, felt normative stigma* and *internalized stigma* are related to higher levels of depression. When PHIV internalize social stigma, the likelihood of mental illnesses, such as depression and anxiety, increases (Lee, Kochman & Sikkema, 2002). Because of discrimination and lower social status, people might feel excluded and develop negative feelings about themselves, which can result in depression. In addition, *internalized HIV-related stigma* has the potential to affect individual behaviour, such as not taking ART or

accepting HIV-care services because of shame (Chesney & Smith, 1999). Furthermore, internalized HRS negatively affects PHIV's self-esteem (Crocker et al., 1998). Mental health problems are directly related to internalized HRS and HIV-treatment behaviour (Lee, Kochman & Sikkema, 2002). This research focuses on the individual behaviour of PHIV regarding RIC and uses the concept of *internalized stigma*. The following section will address the concept of mental health and its relationship with HIV-related stigma and RIC.

Mental health

The World Health Organization (2001) defines mental health as people's wellbeing and ability to cope with daily life. Mental health problems (MHP) caused by internalized HRS are distress, depression and anxiety (Pascoe & Smart, 2009). According to Kroenke & Spitzer (2002), depression is the main MHP associated with internalized HRS.

Various studies in different developing countries confirm the relationship between HRS and MHP. Steward et al. (2011) conducted a study in India about the relationship between HRS and MHP. They found that internalized HIV-related stigma is directly associated with depression symptoms among PHIV. Symbayi et al. (2007) carried out a study in South Africa among PHIV, which confirmed the conclusion of Steward et al.

Furthermore, MHP are seen as significant barriers to HIV-care because they can predispose PHIV to avoid seeking HIV care (Thompson et al., 2011). Gonzalez et al. (2011) conducted a meta-analysis of 95 studies and found a relation between depression symptoms and non-adherence to ART. Their findings show that depression is significantly linked to low health outcomes and HIV-care engagement. PHIV with MHP are less willing to be tested for HIV and more frequently do not adhere to treatment (Thompson et al., 2012). Rooks-Peck et al. (2018) conducted a systematic review; their meta-analyses confirmed this relation and concluded that PHIV experience more MHP, and this is related to poor RIC.

In addition, coping influences the relationship between internalized stigma and mental health. Coping is important for adjusting and adapting to the social environment and managing internalized HRS (Clark et al., 1999. Miller & Major, 2000; Steward et al., 2008).

Coping

Lazarus and Folkman (1984) define coping as cognitive and behavioural efforts to deal with specific external and internal stressors. The behaviour of stigmatized PHIV depends on coping-styles used in daily life to manage psychological distress from HRS and these can vary greatly. Endler and Parker's (1994) Coping Inventory in Stressful Situations (CISS) model

distinguishes three coping styles: task, emotion and avoidance-oriented coping. *Task-oriented coping* is problem-focused and refers to efforts to solve a particular problem. *Emotion-oriented coping* refers to direct actions to modify emotional responses to stressors. It also includes reframing the problem so negative emotional feelings and stress are no longer evoked (Mattlin, 1990). *Avoidance-oriented coping* is the name given to activities and cognitions that avoid the stressors, such as denying a situation or losing hope (Lazarus & Folkman, 1984). It also includes indirect efforts to deal with the stressor by keeping distance from a situation, avoiding the problem or undertaking distracting activities to reduce feelings of stress (Roth & Cohen, 1986).

Task-oriented coping and emotion-oriented coping are active problem-focused coping styles in which the person actively wants to reduce stressors from internalized HRS. In contrast, avoidance oriented-coping is a passive coping style in which PHIV avoid a situation with the aim of reducing stress. Active coping is linked to better self-related general health, mental health and self-esteem (Namir et al., 1990; Rabkin et al., 1993). People with an active coping style are more able to address and solve a problem, such as seeking or continuing care. In contrast, a passive coping style is related to psychological distress, depression and anxiety because the person suppresses negative feelings (Schmitz & Crystal, 2000; Fleishman et al., 2000; Pakenham & Rinaldis, 2001).

Persons et al. (2010) suggest a relation between avoidance-oriented coping, shame and low healthcare-seeking behaviour, whereby the motivation to seek healthcare and accept social support decreases. Beer et al. (2009) and Moneyham et al. (2010) conducted qualitative study to investigate barriers to retention in HIV care. They concluded that coping ability has a major influence on RIC of PHIV. Those who experience difficulty in coping with HIV-related stigma are more likely to quit treatment.

Research question

The research question was: *To what extent are internalized HIV-related stigma and loss to follow-up related, and to what extent do mental health and coping strategy influence this relationship?*

The research question was divided into four sub-questions:

1. To what extent are internalized HIV-related stigma and loss to follow-up related?
2. To what extent do mental health problems mediate the positive relation between internalized HIV-related stigma and loss to follow-up?

3. To what extent does coping (task, emotion, and avoidance-oriented coping) moderate the positive relation between internalized HIV-related stigma and loss to follow-up?
4. To what extent does coping moderate the positive relation between internalized HIV-related stigma and mental health problems?

Hypotheses

The following hypotheses were tested:

H1: There is a positive relation between HRS and LTFU, which means that PHIV who experience more internalized HRS are more likely to become LTFU;

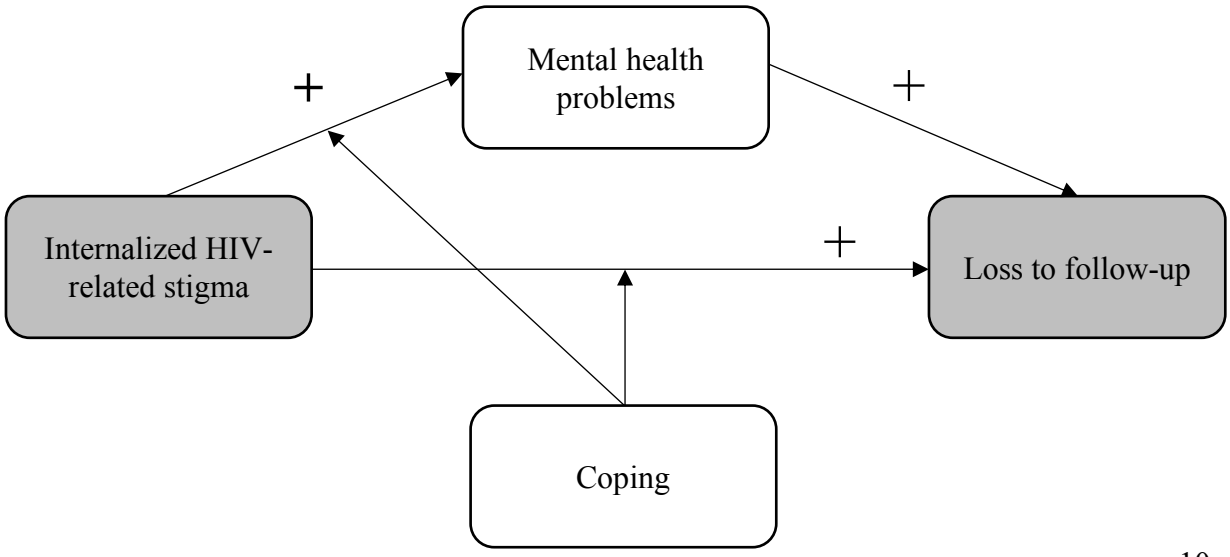
H2: MHP mediate the positive relation between HRS and LTFU in such a way that PHIV who experience a lot of HRS are more likely to develop MHP, which increases their likelihood of becoming LTFU;

H3: Task and emotion-oriented coping moderate the positive relation between HRS and LTFU in such a way that the relationship between HRS and LTFU is stronger at low levels of task and emotion-oriented coping. Moreover, a high level of avoidance-oriented coping strengthens the positive relation between HRS and LTFU;

H4: Task and emotion-oriented coping moderate the positive relation between HRS and mental health problems in such a way that the relationship between HRS and MHP is weaker with higher levels of task and emotion-oriented coping strategies and stronger with lower levels of task-oriented coping strategies. In contrast, higher levels of avoidance-oriented strategies weaken the relation between HRS and LTFY, and between HRS and MHP.

Figure 1.

Conceptual model



Control variables

The study included the control variables age, gender, personal income and distance to clinic. These variables are related to RIC and confound the relationship between internalized HIV-related stigma and loss to follow-up. Hinkin (2004) found that older age is associated with higher treatment adherence and RIC. Concerning gender, women are more likely to stay in care than men (Kranzer et al., 2010; Cornel, McIntyre & Myer, 2011). In addition, lower personal income, unemployment and rural residence are associated with higher treatment failure, such as loss to follow-up (Namusobya et al., 2013). Concerning distance to the clinic, Coetzee et al. (2011) found that PHIV more often attend a clinic in another neighbourhood out of fear of stigmatization. According to Geng et al. (2010), transportation and distance to clinic are major barriers to RIC.

Method

Itrema-study

The research conducted was a sub-study of the Intensified Treatment Monitoring Accumulation (ITREMA) study. The ITREMA-study started in June 2015 and continues until January 2019, and follows 501 participants with HIV (Wensing, 2017). The study is a Randomized Control Trial that evaluated an intensified HIV-treatment monitoring strategy intended to decrease ART-resistance and failure among PHIV in rural South Africa. The ITREMA-project used a combination of clinical, psychological and sociological perspectives to analyse the risk factors that are related to drug resistance and treatment failure.

The ITREMA-study was being conducted at the Ndlovu Medical Centre in rural Elandsdoorn (South Africa). The clinic combined private and public care, and HIV-treatment for approximately 3,600 patients. The ITREMA-study participants attended the medical centre for ART. On their first clinical visit, they completed the ITREMA-baseline questionnaire, which included questions about socio-demographic characteristics and social factors related to HIV, such as HRS and MHP. The present study used the data from this questionnaire to answer the research question.

Research population

This study used a research group of 501 participants with a positive HIV-status. All participants were over 18 and had started ART treatment within the previous 12 months. People

whose medical condition was unstable or were unable to participate in the whole study were excluded from the ITREMA-study. The participants all lived in the Elandsdoorn area.

Operationalization

Stigma

To measure internalized HRS, the ITREMA-baseline questionnaire combined the *AIDS-related stigma scale* of Kalichman and Simbayi (2003) and the questionnaire devised by Herek, Capitanio and Widaman (2002). These questionnaires focus on internalized stigma and the attitude of people towards PHIV. The questionnaire consisted of 13 statements such as: people who have AIDS are dirty; most people become HIV positive by being weak or foolish; would you mind if people knew if your family member has HIV/AIDS? Responses to the items were scored on a 4-point Likert scale, ranging from "strongly disagree" (1) to "strongly agree" (4). The final score was the average score of the answers (1 to 4), divided by the 13 items. The questionnaire has a Cronbach's alpha of .87, indicating good internal reliability.

Mental health problem

The Patient Health Questionnaire 9 (PHQ-9) was used to measure symptoms of depression among PHIV (Kroenke et al., 2001). The questionnaire included a 9-item scale. Participants had to answer the following question for several symptoms: "Over the last 2 weeks, how often have you been bothered by any of the following problems?" The answers were given on a 5-point Likert scale ranging from "not at all" (0) to "a lot" (5). An example of a symptom was "little interest or pleasure in doing things". The questionnaire had a Cronbach's alpha of .78, indicating good internal reliability.

The final 'PHQ-score' was the sum-score of the answers on the items, divided into five categories indicating severity of depression: 1-4 refers to no symptoms of depression, 5-9 mild symptoms, 10-14 moderate depression, and 15-20 moderately severe depression (Kroenke et al., 2001).

Coping styles

The Coping Inventory for Stressful Situations (CISS-21) from Endler et al. (2004) was used to measure the use of different coping styles. CISS-21 distinguishes three coping styles: task, emotion, and avoidance-oriented coping. The questionnaire investigated which coping style a person preferred during a stressful situation. Each item used a 5-point Likert scale; score 1 corresponded to "not at all" and score 5 corresponded to "very much". Each coping style had a

total score, ranging from 7 to 35. A high score was related to a high prevalence for the specific coping style.

The questionnaire consisted of 21 questions: 7 items per coping style. First, *task-oriented coping* had a Cronbach's alpha of .88, indicating good internal reliability. An example of an item was: "Focus on the problem and see how I can solve it". Second, *emotion-oriented coping* had a good internal reliability with a Cronbach's alpha of .74. An example of an item was: "Blame myself for being too emotional in the situation". Third, *avoidance-oriented coping* had a Cronbach's alpha of .74, indicating good internal reliability. An example of an item was: "Take some time off and get away from the problem". The questionnaire had an overall Cronbach's alpha of .81, indicating good internal reliability.

Loss to follow-up

The concept *loss to follow-up* (LTFU) was used as an indication of retention in care. A participant was LTFU when he or she had not visited the clinic for more than 90 days after the last scheduled clinical visit date. The study included defaulted and deceased participants in the definition of LTFU, since death is a possible outcome of LTFU if a participant has quit treatment and stopped taking medication. Furthermore, the research included participants who were initially loss to follow up, but re-entered care after being lost. Finally, every participant was rated as being either *in care* (1) or *loss to follow-up* (2).

Control variables

Gender was coded as men (1) and women (2). *Age* was taken to be the age of the participant on completion of the baseline questionnaire. There was a normal age distribution among the population. To explore the possibly confounding factor of *distance to the clinic*, the physical distance from the patient's home area to the clinic was measured in kilometres, based on the shortest route on Google Maps (2018). Distance to clinic was negatively skewed. For this reason, this study divided the variable into two categories: participants who live less than 30 kilometres from the clinic (1) and participants who live more than 30 kilometres from the clinic (2). *Personal income* was measured by asking the individual participants how many Rands they earned per month, including public benefits. The outcomes of the variable were not normally distributed. For this reason, the variable was divided into two categories: participants who had no personal income (1) and participants who had any income, i.e. more than 1 Rand per month (2).

Statistical analysis

The study used a quantitative research approach. *SPSS Statistics version 25* was used to analyse the data. Socio-demographic characteristics of the sample population were arrived at using descriptive statistical methods, such as cross-tabs and univariate logistic regression analyses. The assumptions of logistic regression, i.e. independency of errors, linearity, multicollinearity and homoscedasticity, were evaluated. Furthermore, mediation, moderation and conditional process analyses with PROCESS macro version 2 of Hayes (2017) were conducted to analyse the relation between *HRS* and *LTFU,* and the effects of the mediating variable *mental health problems* and moderating variables *coping* (task, emotion and avoidance-oriented coping). Based on the univariate logistic regression analysis, the significant control variables were included in the multivariate analyses.

Assumptions

Prior to the analyses, the assumptions of logistic regression analysis were evaluated. First, the results showed that the error terms of the included variables were independent. Second, the relation between the logit of LTFU (dependent variable) and HRS (independent variable) was linear. Third, there was no multicollinearity between the factors; none of the factors had a variance inflation (VIF) above 10. Fourth, the data had no remarkable outliers.

Results

Descriptive statistics of the sample

The research sample comprised 501 participants. As shown in table 1, the majority were female (71.1%), whereas 29.9% were male. The age range of the sample was between 18 and 71 years old, the average being 42.7 (*SD* = 10.3). Participants lived between 1 and 181 kilometres from the clinic. The average distance was 38.4 kilometres (*SD*= 34.4). About 50.1% of the participants lived less than 30 kilometres from the clinic and 49.1% more than 30 kilometres away. Regarding personal income, participants earned between 0 and 300,000 Rand per month. The mean was 2,472 Rand per month (*SD* = 4115). About 50.1% of the sample had no personal income and 49.9% had some personal income of more than 1 Rand per month.

Concerning the dependent variable *loss to follow-up*, 423 (84.4%) participants were in care and 78 (15.6%) participants were lost to follow-up. With regard to the independent variable HRS, the rate ranged from 1.0 to 2.3 and had a mean score of 1.36 (*SD*= 0.41*)*. Furthermore, for the mediating variable MHP, 90.8% of the sample had no symptoms of depression. The mean score was 1.15. For the mediating variable coping, *task-oriented coping* had the highest mean score of 24.1 (*SD*= 7.90), *emotion-oriented coping* 18.1 (*SD*= 5.06), and *avoidance-oriented coping* 16.15 (*SD*= 5.86).

The frequencies and mean scores of the factors were determined concerning "in care" and "loss to follow-up" in table 1. Furthermore, the differences of the factor scores were tested using a univariate regression analysis. It was noticeable that men were significantly more likely to become LTFU, compared to women (*OR*= 1.95, 95% *CI* [1.17, 3.15]). Furthermore, a younger age was correlated with more LTFU (*OR*= .92, 95% *CI* [.90, .95]). Regarding personal income, participants with no income were more likely to become LTFU than participants with some income (*OR*= 2.20, 95% *CI* [1.49, 4.51]). Moreover, a high stigma value was significantly correlated with LTFU (*OR*= 2.59, 95% *CI* [1.49, 4.51]. In addition, mental health problems increased the likelihood of becoming LTFU (*OR*= 2.73, 95% *CI* [1.62, 3.48]).

Table 1.

Statistics of the univariate regression analyses and distributions with LTFU

	OR	**95% *CI***		**In care**	**LTFU**	**Total**
				n(%) / *M(SD)*	n(%) / *M(SD)*	n(%) / *M(SD)*
		Upper	Lower			
Gender	1.92**	1.17	3.15			
Female (ref)				306 (87.2)	45 (12.8)	149 (29.9)
Male				117 (78.0)	33 (22.0)	351 (70.1)
Age	.92***	.90	.95	*43.85 (9.92)*	*36.12 (10.13)*	*42.65 (10.33)*
Distance to clinic	1.27	.78	2.06			
< 30 km (ref)				208 (82.9)	43 (17.1)	25 (50.1)
< 30 km				215 (86.0)	35 (14.0)	250 (49.1)
Personal income	2.20***	1.32	3.67			
No income (ref)				207 (79.6)	53 (20.4)	260 (51.9)
Any income				216 (89.6)	25 (10.4)	241 (48.1)
HIV-related stigma	2.59***	1.49	4.51	*1.33 (.41)*	*1.50 (.32)*	*1.36 (.41)*
Mental health problems	2.73***	1.62	3.48	*1.10 (.41)*	*1.41 (.80)*	*1.15 (.50)*
Task-oriented coping	.97	.92	1.01	*26.36 (6.92)*	*24.91 (6.55)*	*26.13 (6.88)*
Emotion-oriented coping	1.00	.95	1.05	*18.06 (5.07)*	*18.00 (4.98)*	*18.05 (5.06)*
Avoidance-oriented coping	1.01	.97	1.05	*16.10 (5.79)*	*16.45 (6.23)*	*16.15 (5.86)*

Note. The significance levels were*:* * $p<.05$, ** $p<.01$, *** $p<.001$. OR is the odds ratio of the variable; 95% *CI* is the confidence interval of the odds ratio; M is the mean score of the variable; SD is the standard deviation from the mean score; n is the number of participants.

Control variables

As shown in table 1, gender, age and personal income were significantly related to the outcome variable LTFU. The multivariate models therefore included gender, age and personal income as control factors, since they influenced the outcome variable LTFU.

Moderated mediation

Moderated mediation logistic regression analyses were performed using Hayes' (2017) PROCESS macro model 8 to assess the conditional direct and indirect effect of HRS on LTFU, mediated by MHP and moderated by task, emotion, and avoidance-oriented coping. The analyses were performed separately per coping style and included the control variables gender, age and personal income.

Moderation by coping

The outcomes of the analysis showed that the moderated mediation model with task-oriented coping was significant (*b*= .03, *SE*= *.01,* 95% *CI* [.01, .05]); HRS was conditionally related to LTFU, with MHP as mediator. The conditional effect depended on the value of the moderator task-oriented coping. As shown in table 2, HRS had a conditional direct effect on LTFU; when the value of task-oriented coping was high (6.89 above the mean score), the direct relation between HRS and LTFU was significant ($Z(493) = 2.61$, $p = .01$, 95% *CI* [.36, 2.54]). In addition, HRS had a significant conditional indirect effect on LTFU. When task-oriented coping had a mean score above 0, the relation between HRS and mediator MHP was significant (*b*= .03, *SE*= .01, 95% *CI* [.01, .05]). This indicated that HRS was directly and indirectly related to LTFU, depending on the value of the moderator task-oriented coping. The indirect relations between HRS and MHP, moderated by task-oriented coping, are shown in figure 1.

With regard to the analysis with emotion-oriented coping as moderator, the direct and indirect effects between HRS and LTFU with MHP as mediator were not significant (*b*= .02, *SE*= .01, 95% *CI* [-.00, .05]). Furthermore, the moderated mediation model with avoidance-oriented coping as moderator was not significant either (*b*= .00, *SE*= .01, 95% *CI* [-.01, .02]).

Table 2.

Conditional direct and indirect effects of HRS on LTFU for different values of moderator task-oriented coping

	Task-oriented coping	r^2	**95% *CI***	
			Lower	**Upper**
Direct effect	-6.89	-.16	-.01	.70
	.00	.65	-.04	1.33
	6.89	1.45*	.36	2.54
Indirect effect	-6.89	.00	-.10	.10
	.00	.18*	.05	.40
	6.89	.36*	.12	.73

Note. * $p < .05$. Values for the moderators are the mean and plus/minus one standard deviation from the mean.

Discussion

The aim of the study was to gain an understanding of the moderated and mediated relations between HRS and LTFU. The research question was: *to what extent are internalized HRS and LTFU related, and to what extent do MHP and coping strategy influence this relationship?*

First, the statistical analyses showed that HRS and LTFU were significantly correlated. This indicated that PHIV who experienced more HRS were more likely to become LTFU. HRS might stop PHIV from continuing ART because of a lack of social support and feelings of shame (Katz et al., 2013; Persons et al., 2010). Furthermore, internalized HRS decreases self-esteem, which influences the motivation to continue ART (Crocker et al., 1998). This supported the first hypothesis concerning the relation between HRS and LTFU.

Second, the relation between HRS and LTFU was fully mediated by MHP, confirming the second hypothesis. PHIV who experienced more HRS were more likely to develop MHP, characterized by symptoms of depression, which resulted in poorer RIC outcomes. PHIV who experienced HRS possibly felt excluded from the dominant social group, which might lead to shame and loneliness. This could result in feelings of depression because of the lack of social acceptance (Katz et al., 2013). MHP might impede PHIV from remaining in care because of their socially devalued position (Rooks-Peck et al., 2018).

With regard to the third hypothesis, only task-oriented coping had a significant effect on the direct relation between HRS and LTFU. In contrast with the hypothesis, which predicted that

task-oriented coping would have a protective effect, a high value of task-oriented coping was associated with more LTFU. This indicated that PHIV with a robust task-oriented coping style were more likely to become LTFU because of HRS. Furthermore, emotion-oriented coping and avoidance-oriented coping did not moderate the direct and indirect effect of HRS on LTFU, mediated by MHP. This means, emotion and avoidance-oriented coping styles did not influence the relationship between HRS and LTFU.

Fourth, only task-oriented coping moderated the effect of HRS on MHP. In contrast with the fourth hypothesis, PHIV with a robust task-oriented coping style were associated with more MHP. Task-oriented coping did not protect PHIV against developing symptoms of depression, rather it increased the chance of them developing symptoms of depression because of HRS. Concerning emotion- and avoidance-oriented coping, these had no significantly moderated effect on the mediator MHP. Different values of emotion- and avoidance-oriented coping did not change the effect of HRS on MHP. The absence of the influence of avoidance-oriented coping on the relation between HRS and MHP could be the result of avoiding HRS-stressors in the short term, while MHP occur after long-term suppression of HRS-stressors (Schmitz, Crystal, 2000; Fleishman, Sherbourne, Crystal, Collins, Marshall, Kelly, et al., 2000; Pakenham & Rinaldis, 2001).

Limitations

The study had some limitations. The first limitation concerns the representation of the rural South African population. The research conducted included 501 participants living in the rural neighbourhoods of Elandsdoorn. The sample might be not representative of the rural South African population as a whole since it only included Elandsdoorn.

The second limitation concerned the distribution of the outcomes of HRS. The majority of the sample experienced little HRS. The low distribution of the HRS-scores could be the result of socially desirable answers being given in the ITREMA social baseline questionnaire. HIV is still a complex and delicate issue for South Africans. People might find it difficult to talk about it and experience feelings of shame. This would increase the chance of participants providing socially desirable answers to items in the questionnaire. In addition, the results showed that task-oriented coping strengthened both indirect and direct relations between HRS and LTFU, in contrast with the hypothesis. This might be the reason for the low distribution of the HRS-scores, which decreased the effect size. Furthermore, emotion-oriented coping had no effect. In line with the issue of socially desirable answers, PHIV might find it more difficult to talk about their emotions and feelings concerning HIV and therefore give the 'easiest and most desirable' answer

to questions. In addition, the participants of the study received their HIV-treatment at the same clinic. This might have influenced their answers if they believed that 'wrong answers' would negatively influence their treatment and relationship with the caregiver.

The third limitation was the language of the ITREMA social baseline questionnaire. The questionnaire was conducted in English. The majority of the population in Elandsdoorn speak Zulu or Sepedi. The counsellor who carried out the questionnaire translated the questions into the language of the participant. This might have biased the answers given.

The fourth limitation was the accuracy of the measurement of the variables. The ITREMA social baseline questionnaire was completed when the participants entered the ITREMA-study. However, it was possible that participants experienced more HRS or developed MHP after entering the study. The longitudinal effect of the factors on LTFU were not taken into account. It might be that task-oriented coping had a protective effect on MHP and LTFU in the long term, but showed the reversed effect in the short term.

The fifth limitation was the definition of LTFU. There was no clear definition of LTFU in the literature, which made measuring LTFU difficult. In some cases of LTFU, it was not clear whether a patient had defaulted or was in treatment at another clinic. This study included deceased patients who had been LTFU for more than 90 days. In some cases, death was the outcome of LTFU since patients had stopped taking medication. However, the definition also included patients who had been LTFU for more than 90 days and yet returned into care after that.

Practical implications and further research

The results showed that MHP, and depression in particular, played a major role in RIC. HIV-related policies and intervention should not only focus on the physical health of PHIV, but also on their mental health. Preventing and addressing the symptoms of depression among PHIV might help to improve RIC outcomes. Furthermore, internalized HRS is significantly related to more LTFU. Interventions and policies should focus on the prevention of internalized HRS. Talking about HIV in focus groups might help PHIV to make the issue negotiable, so they feel more accepted and valued in the society. This might supress the feeling of stigmatization among PHIV. In addition, men showed a significant higher prevalence of LTFU than women. Intervention and policies should focus in particular on the RIC of men, due to their higher risk being LTFU. For example, men could obtain more intensified HIV-counselling than women, with emphasis on possible barriers concerning RIC. Moreover, PHIV with no income were more likely to become LTFU. Interventions such as job-market orientation trainings or supervision in finding a job might increase the retention in care of PHIV.

The research conducted showed that task-oriented coping strengthened the direct and indirect effects between HRS and LTFU, mediated by MHP. Furthermore, emotion and avoidance-oriented coping had no effect on either the direct or indirect relationships between HRS and LTFU. These results did not confirm the hypotheses, which predicted that task-oriented coping and emotion-oriented coping would have a protective effect against MHP and LTFU. This opposite effect could be the reason for the low distribution of HRS-scores in the sample. This low distribution might have been the result of socially desirable answers. Further research could implement a mixed-method to probe participants more deeply on questions concerning HRS and MHP. Interviews could provide information about and understanding of the experiences and feelings of the participants and could be a positive addition to the research. Moreover, further research could focus on the concept of LTFU, since it included deceased, defaulted participants and potential transferred-out patients. This would give a better understanding of the factors within LTFU.

Conclusion

Based on the findings, it can be stated that HRS does influence the RIC of people in rural Elandsdoorn. This relation is mediated by MHP, characterized by symptoms of depression. Furthermore, task-oriented coping moderated the direct relationship between HRS and LTFU, and the indirect relation between HRS and MHP. In contrast with the expectations, task-oriented coping strengthens the direct and indirect relations instead of protecting PHIV against MHP and LTFU. Further research on the effect of task-oriented coping on RIC is needed to better understand the moderating effect of task-oriented coping. It can be concluded that interventions should focus on HRS and MHP to improve retention of care of PHIV in rural Elandsdoorn.

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