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ORIGINAL PAPER

Beyond the Diagnosis: Exploring Illness Identity in HIV and Its Impact on Health Outcomes

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Abstract

This study utilizes the illness identity framework to investigate the incorporation of HIV into a sense of self and how varying degrees of integration influence key patient-reported outcomes. Using baseline data from the SINAKO Cluster Randomised Controlled Trial, we analysed responses from 316 adults living with HIV (PLHIV) attending 12 healthcare facilities in the Cape metropole, South Africa. Respondents completed assessments on four illness identity dimensions (rejection, acceptance, engulfment, and enrichment) alongside measures for depression and anxiety symptoms, stigma, medication adherence, and self-management. Regression analyses with robust standard errors assessed associations between illness identity and patient-reported outcomes, controlling for gender, age, and illness duration. Longer illness duration was associated with acceptance and enrichment. There was no evidence of an association between gender or education level and illness identity, while age showed a weak positive association with acceptance. Higher engulfment scores correlated with greater depression and anxiety symptoms, increased stigma, and poorer treatment adherence and self-management. Higher enrichment scores were associated with better self-management and lower stigma. Higher rejection scores were associated with heightened negative self-image. Acceptance did not show unique associations with any outcome. This study highlights the vital role of illness integration in shaping health outcomes among PLHIV in resource-limited, high-prevalence settings. Strategies that rapidly identify those in an engulfment state early in the illness trajectory and foster adaptive illness integration, specifically enrichment, could improve outcomes for PLHIV.

Keywords HIV · Illness identity · Psychosocial well-being · ART adherence · Stigma · Self-management

Introduction

With HIV well-established as a manageable chronic illness [1–3], the idea of living well with HIV becomes increasingly relevant to the treatment and care of people living with HIV (PLHIV). This is conceptualised as the best possible state of health that could be attained by individuals, regardless of the illness [4]. Living well is a subjective but transformative experience, and the concept extends beyond just increasing life expectancy to advocating for an improved quality of life [4]. Fundamental to living well is the integration of the chronic illness into the person's sense of self and identity [5–8]. This integration or incorporation of chronic illness is described as a continuous effort by those affected to reconcile the duality of self; merging the past non-ill self with the present chronically-ill self, and creating a new identity that is well adapted to living with chronic illness [5, 9–11]. When individuals living with chronic illness incorporate illness into their sense of self, they deeply acknowledge its

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presence and accommodate it within their lives, developing themselves alongside the illness, rather than embracing and living for the illness [7, 12]. Achieving good clinical outcomes and overall well-being despite illness and ultimately living well with a chronic condition is profoundly rooted in integration [13–15].

Important indicators such as linkage to and retention in HIV care [16, 17], timely ART initiation post-diagnosis [18] and rates of advanced HIV disease [19] continue to fall short of optimal targets, highlighting persistent gaps in HIV care and a need for deeper exploration. Despite this, a growing body of research has pointed to a connection between care outcomes and integration of HIV into a sense of self. Notably, delayed acceptance or a protracted denial phase following HIV diagnosis, may result from affected individuals' inability to incorporate HIV into their sense of self [20, 21]. This may mean engagement in care is deferred [20, 22] allowing asymptomatic illness to progress to advanced disease before those affected present for care [19, 23]. Lack of illness integration into a sense of self may explain why some PLHIV find positive health behaviours such as adherence to ART challenging [24–26]. Other research demonstrates that those experiencing *negative HIV centrality* (the degree to which HIV is negatively interpreted as central to identity and therefore not integrated), are more likely to report worse psychological wellbeing [27–29], internalised stigma [28], post-traumatic stress disorder (PTSD) symptoms, poor relationships with significant others and inadequate treatment adherence [29, 30].

In contrast, incorporating or integrating HIV into self and identity is argued to be an important precursor for PLHIV's successful engagement in their own care and treatment [21]. PLHIV who successfully navigate identity transitions, transformation and reformation following an HIV diagnosis are more likely to report better ART adherence, sustained illness management [31, 32], self-efficacy and a sense of control over both illness and life [23, 32–35] than those who do not exhibit integration. They also show an ability to cope with HIV-related stigma and ultimately live well with HIV [23]. Although insightful, the existing research on HIV, identity, and integration is largely qualitative [36, 37] and often limited to specific aspects of integration [27], rather than examining the full continuum from non-integration to full incorporation. This highlights the need for robust quantitative assessment of the relationship between the extent of HIV integration into sense of self and the associated health outcomes. To address the gap, this study draws upon the concept of illness identity in chronic illness [38, 39] to contribute to understandings about how the degree of HIV integration or incorporation into a sense of self and identity impacts outcomes.

Theoretical Framework

The concept of illness identity is underpinned by *identity integration*; a primary concept within Erikson's 1968 theory of lifespan development [40]. The theory posits that a coherent sense of self is achieved when various aspects of oneself have been seamlessly integrated. The state of harmony among the different self attributes in turn brings a sense of regularity and stability, conditions critical for optimal psychological functioning [38, 40, 41]. The Illness Identity framework has discerned four measurable constructs or dimensions; *engulfment*, *rejection*, *acceptance* and *enrichment* [12, 38]. The *engulfment* and *rejection* states capture the lack of integration into self of the chronic illness by the individual. With *engulfment*, illness becomes central to the individual's identity and interrupts other life areas such as work and social relationships. With *rejection*, illness is perceived as a threat or unacceptable to the self. In these states, individuals living with chronic illness may disregard self-management activities as demanded by their chronic illness and these states may potentially explain behaviours such as poor adherence to treatment [12, 39, 42]. *Acceptance* and *enrichment* on the other hand, represent more adaptive components of illness integration. *Acceptance* is the degree to which individuals accept their chronic illness as a part of themselves, regardless of other social roles and identities. Those who accept do not have their lives dominated by their illness and are able to achieve some level of normality in their lives, including self-management of their illness [12, 38]. *Enrichment* represents the degree to which having a chronic illness has enriched the sense of self and resulted in positive life changes, including personal growth [12, 39]. The enrichment state is associated with a number of better health outcomes including better health related quality of life [43, 44].

Against this backdrop, the present study seeks to address a critical yet underexplored question: how does the extent of HIV integration into a sense of self shape key health outcomes among adults living with HIV in a high-prevalence, resource-limited setting? We hypothesise that (1) maladaptive illness identity dimensions (engulfment and rejection) will be associated with lower wellbeing scores, higher internalised stigma, poorer ART adherence, and worse self-management; (2) adaptive illness identity dimensions (acceptance and enrichment) will be associated with higher wellbeing scores, lower internalised stigma, better ART adherence, and better self-management, and (3) greater time since HIV diagnosis (illness duration) will be associated with more adaptive illness identity dimensions.

To comprehensively explore and address these questions, this study had two main objectives. We first separately examine the relationship between demographic factors

(gender, age and education level) and illness identity, as well as between an illness-specific variable (duration of illness/time since diagnosis) and illness identity. This provides insight into the differences between individuals who have successfully navigated the identity transformations since HIV diagnosis and integrated HIV versus those who have not yet incorporated HIV into their sense of self. To investigate how varying extents of HIV integration into a sense of self influence key patient-reported outcomes, we then examine the association between the illness identity framework and the following outcomes: depressive and anxiety symptoms, HIV-related stigma (negative self-image), medication adherence, and self-management. We focus on these specific outcomes given that PLHIV are disproportionately affected by poor mental health and stigma [45, 46], both of which could undermine treatment adherence and wellbeing [47, 48]. Moreover, in the absence of a cure, adherence and effective self-management remain pivotal to achieving optimal health outcomes [49]. Given the complex interplay between mental health, stigma, and adherence, understanding these associations could therefore guide a shift toward more person-centred HIV care approaches that recognize the critical role of illness integration in improving patient outcomes. Hence, we hypothesize that applying the illness identity framework and its associated measures (engulfment, rejection, acceptance and enrichment) may provide valuable insights into the factors influencing divergent health outcomes among individuals living with HIV. Specifically, this approach may help shed some light on why some individuals achieve optimal well-being and successfully adapt to their illness, while others experience challenges that contribute to suboptimal health outcomes.

Methods

Data Sources, Setting, Collection and Participants

The current study utilized data collected from participants within the baseline phase of the SINAKO cluster randomised control trial. The trial was set in five sub-districts of the Cape Metro health district in the Western Cape, South Africa- Khayelitsha, Klipfontein, Mitchell's Plain, Eastern, and Western. These districts are characterized by high HIV prevalence rates- for example the 2017 HIV prevalence rate among pregnant women in Khayelitsha ranged from 29.5% to 34.3% [50, 51]. The trial engaged community healthcare workers in delivering the intervention which was aimed at enhancing HIV competence among PLHIV and within their households. Details of the SINAKO trial protocol and intervention have been documented elsewhere [52, 53]. Twelve healthcare facilities from across the five sub-districts were randomised into six clusters per trial arm. To be included in the study, participants had to be 18 years of age or older with a confirmed HIV diagnosis. The study's fieldworkers recruited and enrolled into the study 316 individuals living with HIV who were visiting the trial health facilities (136 and 180 participants assigned to the control and intervention arms respectively). For data collection, the fieldworkers conducted interviews with participants at either the health facility or at the participant's home. Data collection activities occurred between 6th May 2020 and 11th May 2021.

Measures

Individual Level Demographic and Illness Specific Variable

Individual level demographic variables included age (in years, centred), gender (0 = male, 1 = female) and education level (0 = none to secondary and 1 = matric to university). An illness specific variable, time since diagnosis (hereafter called illness duration), (0 = diagnosed with HIV more than six months ago, 1 = diagnosed with HIV less than six months ago), was also included.

Illness Identity

We used the adapted 20 item illness identity questionnaire (IIQ), specifically validated for HIV as a chronic illness in the current study's context [54]. The original 25 item IIQ was developed, validated and used in a Belgian context with diabetes as a chronic illness [12]. The scale had also been previously used to explore a number of other chronic illnesses including refractory epilepsy (RE) [44], congenital heart disease (CHD), multisystem connective tissue disorders (MSDs) [38] and inflammatory bowel disease (IBD) [43]. The IIQ has four illness identity subscales mirroring the dimensions: engulfment, rejection, acceptance and enrichment. Participant responses are captured on a five-point Likert scale ranging from "strongly disagree" to "strongly agree".

Depression and Anxiety

To screen for depression and anxiety, we administered the patient health questionnaire-9 (PHQ-9) and the generalized anxiety disorder questionnaire-7 (GAD-7) respectively [55, 56]. The PHQ-9 is a nine-item self-report questionnaire, with nine criteria on which the diagnosis of depressive disorder is based [57]. The GAD-7 self-report questionnaire has seven-items with seven criteria for generalized anxiety disorder diagnosis. Both scales are on a 4-point Likert scale with participants requested to respond to statements such as "Not being able to control or stop worrying" (GAD-7) or "little

interest or pleasure in doing things" (PHQ-9). Responses ranged from "Not at all" to "nearly every day". The reliability and validity of both scales (PHQ-9 and GAD-7) as measures of depression and anxiety is well established [55, 56]. Higher scores meant increasing frequency of reported symptoms.

HIV-related Stigma

For HIV related stigma, we used the six item negative self-image subscale from the validated and widely used 40-item HIV stigma scale by Berger, Ferrans and Lashley [58]. The negative self-image subscale represents negative feelings that PLHIV can have about themselves because of HIV. Sample items include "Having HIV makes me feel unclean" and are graded on a 5-point Likert scale with responses ranging from ranging from "strongly disagree" to "strongly agree". Higher scores meant higher levels of negative self-image.

Self-Management

We adapted and used eight items from the validated Partners in Health scale [59, 60] and the Self-Management screening tool [61]. The items measure different aspects of self-management ranging from knowledge of illness and treatment to self-efficacy and locus of control. Sample items included "I understand what will happen if I don't take my ARVs every day" and "I feel confident that I can meet my health and life goals". Items are graded on a 5-point Likert scale where responses ranged from strongly disagree" to "strongly agree", with higher scores representing better self-management.

Self-Reported ART Adherence

We used the extensively used AIDS Clinical Trials Group (ACTG) Adherence Questionnaire [62, 63] to estimate adherence to medication. The use of individual measures of ART adherence is valid and reliable, e.g. the average 4-day recall item of the ACTG adherence questionnaire; however, adherence is a multidimensional concept and there is as yet no 'gold standard' for measurement of ART adherence. We therefore decided to create a composite measure of ART adherence to improve assessment of adherence estimation [63]: we consequently computed a "total adherence" scale variable using the sum scores of four items from the ACTG questionnaire measuring different ART adherence behaviours: (1) *how often did you not take your ART medications on time*, (2) *during the past 4 days*, *on how many days have you missed taking all of your doses*, (3) *how closely did you follow your specific schedule over the last 4 days* and (4) *how would you rate your ART adherence in the past month*. The first 3 items are graded on a 5-point Likert scale with responses ranging from "never" to "all of the time"; the fourth item was responded to on a scale of 0–10, with 10 representing perfect adherence and 0 representing worst adherence.

Table 1 Reliability statistics for all scales

Scale	Alpha (α)	AVE	CR
Rejection	0.71	0.63	0.84
Acceptance	0.86	0.78	0.91
Engulfment	0.90	0.62	0.92
Enrichment	0.92	0.68	0.94
Household HIV competence	0.80	0.56	0.86
Anxiety	0.87	0.56	0.90
Depression	0.85	0.49	0.88
Stigma	0.93	0.74	0.94
Self-management	0.81	0.46	0.86
Adherence	0.60	0.48	0.77

AVE = Average Variance Extracted; CR = Composite Reliability

Statistical Analysis

Statistical analysis was performed using IBM SPSS Statistics (Version 30.0.0.0). We initially computed descriptive statistics of the characteristics of participants. To estimate internal consistency and reliability of all the scales that we used, we estimated the average variance extracted (AVE) which should be ≥0.5 and composite reliability (CR) which should be ≥0.7. Although the CR is a less biased estimate of reliability than Cronbach's Alpha, we also calculated the Cronbach's alphas for all scales. Composite reliability for all the scales were all above 0.7 (Table 1). Alphas for all but one scale (adherence: α = 0.6) were also above 0.7 and demonstrated that the scales were acceptable with good reliability [64].

We conducted three different multivariate analyses of variance (MANOVAs) to examine mean-level differences in illness identity based on gender (male or female), illness duration (coded 0 = diagnosed with HIV more than six months ago, 1 = diagnosed with HIV less than six months ago) and education level (coded 0 = none to secondary and 1 = matric to university). Pearson correlation coefficients were calculated between age and the four illness identity dimensions.

To explore associations between illness identity and patient-reported outcomes (depressive and anxiety symptoms, HIV-related stigma, self-management and self-reported ART adherence), we calculated Pearson correlation coefficients as descriptive measures of bivariate association. For multivariable analysis, we estimated ordinary least squares (OLS) regression models. In all four regression analyses we controlled for age, gender and illness

duration. In addition, we corrected for the influence of clinic fixed effects by implementing dummy coding [65, 66]. To account for potential heteroskedasticity and clustering of observations within clinics, we used heteroskedasticity- and cluster-robust standard errors [67]. This approach allowed for examination of the unique contribution of each illness identity dimension.

Table 2 Demographic and HIV-related characteristics of participants ($N=316$)

Variable	*n* (%)
Gender	
Female	262 (82.9)
Male	54 (17.1)
Race	
Black	267 (84.5)
Coloured/White/Asian	49 (15.5)
Age, M (SD)	35 (10)
Education level	
None to secondary education	247 (78.2)
Matric to university education	69 (21.8)
Employment[a]	
Employed	112 (61.5)
Unemployed/pensioner	70 (38.5)
Relationship status	
In a relationship	213 (67.4)
Not in a relationship	103 (32.6)
Number of biological children	
None	52 (16.5)
One or two	171 (54.1)
Three or more	93 (29.4)
How HIV was acquired	
Born with HIV	2 (0.6)
Sexual partner(s)	268 (84.8)
Injecting drugs	0 (0.0)
Taking care of someone living with HIV	12 (3.8)
Other	34 (10.8)
Illness duration (time since HIV diagnosis)	
More than six months ago	232 (73.4)
Less than six months ago	84 (26.6)
ART history	
First on ART	175 (55.4)
Previously used ART	141 (44.6)
Household members living with HIV (excluding participant)	
None	194 (64.5)
One or more	107 (35.5)
Household members who have died from HIV	
None	280 (89.5)
One or more	33 (10.5)

[a] Employment data available for $n=182$ participants; remaining participants had missing data

Results

Characteristics of Participants

Table 2 presents the demographic characteristics of the study participants. A total of 316 PLHIV were enrolled, with the majority being female ($n=262$, 83%) and a smaller male proportion ($n=54$, 17%). The mean age of participants was 35 years (SD = 10). Education level of participants varied, with 78% ($n=247$) having no formal education or only up to secondary school, while 22% ($n=69$) had completed matric or held a university degree. Of those who self-reported on employment status, 62% ($n=112$) were employed, whereas 38% ($n=70$) were unemployed. Additionally, 67% ($n=213$) of participants were in a relationship, while 33% ($n=103$) were not. Regarding illness duration, 73.42% ($n=232$) of the participants had been living with HIV for more than six months, whereas 26.58% ($n=84$) had been living with HIV for six months or less at the time of data collection.

Role of Demographic and Illness Specific Variables

We calculated Pearson correlation coefficients between age and the four illness identity dimensions to assess the relationship of age and illness identity. Only the acceptance subscale showed a weak positive and significant association with age, $r(316)=0.11$, $p=0.04$. There was not a significant association between age and the other three illness identity subscales; *engulfment*, *rejection* and *enrichment* (Table 3).

We performed three different MANOVAs to examine the role gender, education level and illness duration in illness identity. Table 4 presents MANOVA results for illness identity based on gender, education level and illness duration. With the first MANOVA for gender and four illness identity subscales, there was not a significant difference between males and females when considered jointly on the variables: *rejection*, *acceptance*, *engulfment* and *enrichment*. Similarly, with the second MANOVA for education level and the four illness identity subscales, there was also not a significant difference between participants who had no and up to secondary school education and those with matric and up to university education when considered jointly on the variables *rejection*, *acceptance*, *engulfment* and *enrichment*. The final MANOVA for illness duration (recent diagnosis of less than six months ago or old diagnosis of more than six months ago) and the four illness identity subscales showed significant multivariate effects. A separate ANOVA was then conducted with each dependent variable, with each ANOVA evaluated at an alpha level of 0.025. There was a significant difference between PLHIV with longer illness duration and those with shorter illness duration on *acceptance*: $F(1, 314)=12.90$, $p<0.001$, Partial $\eta 2=0.039$, with those with

Table 3 Pearson correlations among key study variables

Variable	2	3	4	5	6	7	8	9	10
1. Rejection	−0.11 *0.05*	0.00 *0.97*	0.04 *0.53*	−0.10 *0.75*	−0.10 *0.59*	0.13* *0.024*	−0.10 *0.86*	0.07 *0.22*	−0.11 *0.06*
2. Acceptance	–	−0.16** *0.000*	0.72** *0.000*	−0.11 *0.26*	−0.10 *0.45*	−0.16** *0.000*	0.52** *0.000*	0.22** *0.000*	0.11* *0.045*
3. Engulfment		–	−0.15** *0.000*	0.26** *0.000*	0.29** *0.000*	0.73** *0.000*	−0.15** *0.000*	−0.14** *0.000*	−0.11 *0.11*
4. Enrichment			–	−0.11 *0.06*	−0.11 *0.11*	−0.16** *0.000*	0.58** *0.000*	0.26** *0.000*	0.08 *0.15*
5. Anxiety				–	0.73** *0.000*	0.19** *0.001*	−0.11 *0.31*	−0.12** *0.001*	−0.10 *0.45*
6. Depression					–	0.19** *0.001*	−0.11 *0.13*	−0.12** *0.002*	−0.10 *0.44*
7. Stigma						–	−0.15** *0.000*	−0.13** *0.000*	−0.12** *0.003*
8. Self-management							–	0.22** *0.000*	0.12* *0.032*
9. Adherence								–	0.00 *0.98*
10. Age									–

r values above diagonal; p-values in italics below r. Diagonal (–) = self-correlation

* $p < 0.05$. ** $p < 0.01$

Table 4 MANOVA results for illness identity dimensions by gender, education level, and illness duration

Effect	Wilks' Λ	F	df (hyp)	df (error)	*p*-value	Partial η²
Gender	0.99	0.47	4	311	0.760	0.006
Education level	0.99	1.11	4	311	0.351	0.014
Illness duration	0.57*	4.66	4	311	0.001	0.057

* $p < 0.05$

longer illness duration scoring higher (M = 12.92) than those with shorter illness duration (M = 12.048). We also found a significant difference between PLHIV with longer illness duration and those with shorter illness duration on *enrichment*: F (1, 314) = 12.75, $p < 0.001$, Partial η2 = 0.039, with those with longer illness duration (M = 30.32) scoring higher than those with shorter illness duration (M = 28.46). There was not a significant difference between PLHIV with longer illness duration and those with shorter illness duration on *rejection*: F (1, 314) = 3.34, $p = 0.07$, Partial η2 = 0.01 and on *engulfment* F (1, 314) = 2.32, $p = 0.128$, Partial η2 = 0.007.

Associations between Illness Identity and Patient-Reported Outcomes

Correlations Among Study Variables

Table 3 presents the correlations among key study variables. *Engulfment* demonstrated a positive association with anxiety symptoms, depressive symptoms, and stigma, while showing a negative relationship with self-management and treatment adherence. Similarly, *rejection* was positively correlated with stigma. In contrast, both *acceptance* and *enrichment* were negatively associated with stigma but positively correlated with self-management and adherence to treatment, suggesting a more adaptive illness identity is linked to better health outcomes.

Regression Analyses

Table 5 presents the results of the regression analyses, highlighting significant associations between the illness identity dimensions of engulfment, rejection, acceptance and enrichment and all evaluated patient-reported outcomes, including anxiety and depression symptoms, HIV-related stigma, self-management, and self-reported ART adherence. The outcome variables were each separately regressed onto the illness identity variables (engulfment, rejection, acceptance and enrichment) while controlling for gender, age, illness duration and the effect of clinics as clusters. The results indicated that illness identity was significantly associated with all the patient reported outcomes we evaluated; anxiety ($R^2 = 0.1442$, $F(18,297) = 2.98$, $p < 0.001$), depression ($R^2 = 0.1167$, $F(18,297) = 3.31$, $p < 0.001$), stigma ($R^2 = 0.640$, $F(18,297) = 29.33$, $p < 0.001$), self-management ($R^2 = 0.1442$, $F(18,297) = 13.07$, $p < 0.001$) and adherence ($R^2 = 0.1214$, $F(18,297) = 4.483$, $p < 0.001$). The findings also indicated that *engulfment* was consistently associated

Table 5 OLS regression analyses predicting outcomes from illness identity dimensions, controlling for age, gender, and illness duration

Anxiety				
$F(18, 297)=2.98$, $p<0.001$, $R^2=0.144$				
Predictor	B	SE	95% CI	p-value
Rejection	0.008	0.071	[−0.133, 0.148]	0.915
Acceptance	0.292	0.165	[−0.032, 0.616]	0.077
Engulfment	0.191**	0.054	[0.085, 0.296]	<0.001
Enrichment	0.044	0.084	[−0.209, 0.121]	0.602
Depression				
$F(18, 297)=3.31$, $p<0.001$, $R^2=0.117$				
Predictor	B	SE	95% CI	p-value
Rejection	−0.032	0.071	[−0.172, 0.109]	0.655
Acceptance	0.359	0.206	[−0.047, 0.765]	0.082
Engulfment	0.263**	0.061	[0.144, 0.382]	<0.001
Enrichment	−0.028	0.089	[−0.204, 0.148]	0.757
Stigma				
$F(18, 297)=29.33$, $p<0.001$, $R^2=0.640$				
Predictor	B	SE	95% CI	p-value
Rejection	0.188**	0.069	[0.052, 0.325]	0.007
Acceptance	−0.229	0.196	[−0.614, 0.156]	0.243
Engulfment	0.461**	0.052	[0.358, 0.563]	<0.001
Enrichment	−0.342**	0.076	[−0.492, −0.191]	<0.001
Self-management				
$F(18, 297)=13.07$, $p<0.001$, $R^2=0.144$				
Predictor	B	SE	95% CI	p-value
Rejection	0.002	0.009	[−0.015, 0.019]	0.802
Acceptance	0.038	0.023	[−0.006, 0.082]	0.094
Engulfment	−0.019**	0.007	[−0.033, −0.006]	0.005
Enrichment	0.045**	0.011	[0.023, 0.067]	<0.001
Adherence				
$F(18, 297)=4.48$, $p<0.001$, $R^2=0.121$				
Predictor	B	SE	95% CI	p-value
Rejection	0.049	0.067	[−0.083, 0.181]	0.463
Acceptance	−0.011	0.147	[−0.300, 0.279]	0.942
Engulfment	−0.181**	0.056	[−0.291, −0.070]	<0.001
Enrichment	0.088	0.071	[−0.052, 0.228]	0.218

B = unstandardised regression coefficient; SE = standard error; CI = confidence interval. Age, gender, and illness duration were included as covariates in all models (coefficients not shown)

** $p < 0.01$

with all the outcomes. Higher levels of *engulfment* were associated with higher anxiety (B = 0.191, SE = 0.054, $p < 0.001$) and depressive symptoms (B = 0.263, SE = 0.061, $p < 0.001$), as well as higher stigma (B = 0.461, SE = 0.052, $p < 0.001$). Additionally, *engulfment* was associated with poorer self-management (B = −0.019, SE = 0.007, $p = 0.005$) and lower adherence to ART (B = −0.181, SE = 0.056, $p < 0.001$). *Rejection* was associated with higher stigma (B = 0.188, SE = 0.069, $p = 0.007$) but did not show significant relationships with other outcomes. This finding suggests that individuals in the *rejection* state may be experiencing more profound stigma-related distress. In contrast, *enrichment* was linked to more favourable outcomes. Higher *enrichment* levels were associated with higher self-management (B = 0.045, SE = 0.011, $p < 0.001$) and lower stigma (B = −0.342, SE = 0.076, $p < 0.001$), suggesting a protective role. Finally, *acceptance* did not demonstrate significant associations with any of the assessed outcomes, indicating a more neutral role in illness identity within the current sample of PLHIV.

Discussion

There is a scarcity of research examining the detailed relationship between the degree of HIV integration into a sense of self and identity and health outcomes. In response, this study deployed the illness identity framework to explore the extent of HIV integration in adults living with HIV in Cape Town, South Africa, including both those recently diagnosed and those who had been living with the condition for a longer duration. The influence of gender, age, education level and illness duration on illness identity were investigated. The relationship between different illness identity dimensions and key health outcomes, including mental health (depression and anxiety symptoms), stigma, self-management, and treatment adherence were also examined. The findings demonstrate that illness identity is an important construct in chronic illness, particularly as it pertains to outcomes [38, 39, 43, 68]. The study also provides important insights into the role of illness integration among adults living with HIV, with important implications for both theoretical understandings and practical interventions.

Demographic and Illness Specific Variables and Illness Identity

Gender did not significantly influence illness identity of PLHIV in the current study, however, high female representation in the study may have impacted this finding and is a potential limitation. These findings are aligned with previous research that explored illness identity in patients living with refractory epilepsy (RE) [44], congenital heart disease (CHD), multisystem connective tissue disorders (MSDs) [38] and inflammatory bowel disease (IBD) [43]. However, we identified a single study that showed differences in illness identity among people living with diabetes based on gender [12]. Higher education level has been associated with better adaptation to chronic illness and better health behaviours in other studies [69–71], although there was no evidence of an association with illness identity in this study.

Age was only weakly positively associated with *acceptance* and not correlated with the other illness identity dimensions in the current study, with older individuals scoring higher on *acceptance* than younger individuals.

Previous illness identity literature however presents divergent evidence. Older patients living with MSD and CHD scored higher on *rejection* [38], within a sample of patients living with RE, age was negatively associated with *rejection* [44] and in a sample of patients living with IBD age was not related to illness identity [43]. Conflicting findings on age-related differences in illness identity may stem from a myriad of factors including developmental and life stage of the individual, social, and illness-specific factors. One possible explanation is that participants in some of the previous studies were adolescents, young or emerging adults who may still be exploring and developing their personal and social identities [12, 44], and therefore having to additionally integrate illness into their identity created significant identity challenges [12, 72–74]. In contrast, older individuals may have a more stable sense of self and thus a proclivity to accept their illness. Another plausible reason for the disparity may lie in the nature of the chronic illness rather than the age of the individual; for example, some illnesses are more visible and therefore perceived by others—and may be subject to stigma [75, 76]. For some individuals living with a highly stigmatised illness such as HIV, preoccupation with the illness, onward transmission, and its perceived impact on a sense of self or identity are heightened [77], potentially presenting integration challenges.

Differences across chronic illnesses may therefore relate to the degree to which a condition is visible, socially moralised, or perceived as identity-threatening. Certain conditions such as IBD may be more concealable and less socially moralised in some settings, potentially altering the extent to which the illness becomes central to one's sense of self. These illness-specific social meanings may therefore help explain why associations between socio-demographic variables and illness identity differ across conditions. Individual demographic factors may not necessarily be strong determinants of illness identity and the process may be driven by other factors such as psychological and or social factors [5]. These findings may therefore underscore the argument for customised illness identity interventions that consider factors beyond chronological age, gender or education level.

One of the more important findings of this study is the significant association of duration of illness with illness identity. Individuals who had been living with HIV for periods longer than six months exhibited higher levels of *acceptance* and *enrichment* than those with a more recent diagnosis who had been living with HIV for less than six months. The finding suggests that as time progresses, individuals may develop a more integrated sense of self in relation to their illness. Although there was no association found between illness duration and illness identity in a cohort of patients living with IBD [43], our finding is aligned with evidence from studies exploring RE and MSD [38, 44]. This supports theories suggesting that, although not as linear as described here, chronic illness adaptation follows a trajectory where individuals are initially challenged by their diagnosis but over time may develop a more integrated sense of self, accommodate and live reasonably well with their illness [5, 10, 34, 68]. This finding suggests that the immediate and early post-diagnosis period is a critical window for intervention. The implication is that recently diagnosed individuals should be prioritized, a critical undertaking in the context of the universal test and treat (UTT) strategy, which emphasizes rapid linkage to care and early treatment initiation following an HIV diagnosis [78], to guarantee improved health outcomes [79, 80]. Therefore, interventions that promote more adaptive illness identity states should be implemented promptly after diagnosis. These could facilitate early linkage to care and improve health outcomes early in the illness trajectory [81].

Illness Identity and Health Outcomes

A remarkable finding of this study is the consistent association of *engulfment* with mental health and self-care behaviours. *Engulfment*, characterized by HIV negatively dominating or as central to one's sense of self, was associated with higher levels of reported symptoms of anxiety and depression, and with stigma, as well as lower scores for reported self-management and ART adherence. This aligns with previous research indicating that when a chronic illness becomes central to a person's identity in a negative way, it can lead to poor outcomes including heightened psychological distress, maladaptive coping and poor self-management behaviours [29, 30, 38, 44]. Although not a novel finding, as Onu and colleagues demonstrated similar effects of HIV centrality [27], our study contributes by situating centrality within the illness identity framework and all the states; specifically *engulfment*, and also highlights its relational position and comparative impact alongside the other states; *acceptance*, *enrichment* and *rejection*. From a healthcare provider stance, identifying individuals in the *engulfment* state is therefore crucial for targeted support and intervention. At a practical level, implementing routine screenings for *engulfment*-related state could help identify individuals who may require targeted support.

In contrast to *engulfment*, *enrichment* emerged as an adaptive illness identity state. This result is in line with previous studies [38, 43, 44, 82]. The finding that PLHIV who reported higher levels of *enrichment* demonstrated better self-management and experienced lower level of self-stigma, expands the realm of knowledge and offers a significant contribution to literature on illness identity in HIV. While existing research has alluded to the importance of *acceptance* in facilitating health-seeking behaviours and

engagement with care [81, 83–85], this study extends current understandings by illustrating the distinct and inimitable value of enrichment as a more empowered and adaptive illness identity state. Enrichment reflects not just accommodation or acceptance of the illness, but a positive redefinition and possible transformation of the self, informed by living with HIV. In doing so, it supports patient-empowerment perspectives that recognize the role of personal growth and meaning-making in shaping long-term health behaviours and outcomes [8, 15, 86]. The association between *enrichment* and improved self-management suggests that individuals who ultimately derive a sense of purpose or growth from living with HIV may be better equipped to navigate the complexities and demands of long-term living with HIV, its treatment and care. Additionally, the inverse relationship between *enrichment* and stigma underscores the potential of the enrichment state to buffer against internalized stigma; that remains a persistent barrier to HIV care engagement. This result is also consistent with previous literature [77]. Together, these findings contribute a novel empirical angle within the context of HIV in a high-burden setting. By implication, interventions should not only target acceptance, but could foster opportunities for individuals to move toward *enrichment* [29, 87]. Collectively, these findings elevate illness identity as a critical construct, underscoring full illness integration as vital to achieving optimal health outcomes. In alignment with previous illness identity in diabetes and IBD literature [12, 43], we found that *enrichment* was unrelated to depression and anxiety. A possible reason for the lack of association is that inasmuch as post-traumatic growth, a characteristic of *enrichment*, has been demonstrated to be associated with better mental health, this relationship is mediated by centrality; the extent to which individuals negatively define themselves by their illness in a sample of PLHIV [29]. Negative HIV centrality by itself is associated with poor mental health outcomes. Therefore, greater HIV centrality appears to amplify the mental health benefits of post-traumatic growth [29]. Thus, for the current sample of PLHIV, the centrality of HIV may possibly not be high enough to link enrichment or post-traumatic growth with improved mental health outcomes.

Acceptance was not associated with any of the health outcomes we assessed. This is in contrast to previous evidence from studies exploring chronic illnesses such as RE, CHD and MSD that have shown *acceptance* as an adaptive state related to outcomes such as better quality of life and psychological functioning [38, 44, 82]. Our finding however is consistent with a study that explored illness identity in IBD [43] and suggests that in the case of HIV, acceptance alone may not be sufficient for promoting reporting of improved mental health symptoms, ART adherence and self-management. One possible explanation is that *acceptance* state serves as a transitional stage toward *enrichment* rather than an endpoint. This aligns with research suggesting that illness integration processes are complex, non-linear and often unfold iteratively. Individuals may initially struggle to come to terms with their diagnosis (*acceptance*) before going through substantial and consistent identity work to develop a more empowered and growth-oriented perspective (*enrichment*) [5, 6, 8, 68, 88].

Finally, these findings highlight an association between *rejection* and stigma, indicating that the *rejection* state in HIV may be largely driven by stigma. Consistent with previous literature, this result supports the idea that individuals who struggle to integrate HIV and other chronic illnesses such as diabetes into their sense of self may experience heightened internalized stigma [36, 37, 89]. Internalised stigma, remains one of the most significant barriers to treatment adherence and well-being among PLHIV [90]. Therefore, our findings suggest that addressing internalised stigma may be pivotal in reducing stigma-related rejection in HIV. Interventions such as cognitive behavioural therapy have been shown to mitigate internalised HIV stigma [91, 92] and could therefore play a critical role in alleviating *rejection*. Coherent with previous illness identity studies of individuals living with MSD, CHD, IBD, and diabetes [12, 38, 43], the *rejection* state in adults living with HIV in the current study was unrelated to reported symptoms of depression and anxiety. A possible explanation for this finding is that PLHIV could deliberately distance themselves from HIV and use this as a strategy to preserve their psychological well-being [36]. Although, previous studies have demonstrated *rejection* to be associated with poor treatment adherence and self-management [12, 82, 93, 94], we did not find the same association in the current study. In a recent review we conducted, we found that HIV-related *rejection* is not necessarily tied to poor treatment adherence; some PLHIV may acknowledge the lifesaving benefit of ART adherence and maintain effective care routines without incorporating HIV into their identity [95]. This ambiguity could be explained by the "holding on" phenomenon in chronic illness, where pre-illness self-representations are preserved and are complemented by learning to control illness and treatment adherence, thereby separating oneself from the illness. The problem with holding on is argued to be that it is rather disempowering as it overlooks the uncontrollable aspects of chronic illness [15].

Strengths, Limitations and Suggestions for Future Research

To our knowledge, no study has explicitly investigated the entirety of the illness identity construct specifically in the context of HIV as a chronic illness, making this research a

crucial contribution to the field. From a theoretical perspective, our findings extend literature on and underscore the importance of illness identity as a key concept in understanding the adaptation to living with HIV as a chronic illness. Moreover, the associations between illness identity dimensions and health outcomes provide critical insight into the reasons for divergent health outcomes attained by PLHIV in relation to envisaged ART program targets. The associations also highlight the need for going beyond just the routine biomedical approach at the provider-patient interface and appreciating patients' illness identities. Insights from this study could also inform interventions that aim to promote adaptive illness identities.

This study is not without limitations. Notably, this study used cross-sectional baseline data: we cannot therefore draw conclusions around causality. Further research exploring changes over time is needed. Additionally, the sample size was determined based on the primary outcomes of the trial rather than the specific hypotheses examined in this article. Consequently, no a priori power analysis was conducted for the present analyses, and the study may have been underpowered to detect small effect sizes. Furthermore, participants were recruited via the twelve health facilities that participated in the SINAKO trial, as a result, this might have introduced sample bias. Participants recruited while visiting healthcare facilities who are actively seeking care may differ in some ways from participants recruited via other means such as home or community settings. As such, it may be argued that those actively seeking care may not necessarily be in *rejection* state, for instance. Future studies exploring illness identity in HIV could endeavour to attain a diverse and representative sample of PLHIV, randomly recruited from within communities. The sample size was also relatively small; replication with a larger sample of PLHIV would therefore be beneficial. Together, these factors limit the generalizability of our findings however, implementation of the suggested adjustments in future studies could improve the possibility of generalizability of findings. Furthermore, almost all measures that we used were self-reported. Whilst self-reported variables are appropriate in studies such as the current one, recall bias may have been introduced. To minimise this possibility, future studies could corroborate self-reported data with information (e.g. date of first diagnosis) from objective data sources such as patients' medical records. Furthermore, measures such as adherence to ART could be triangulated with more objective measures such as viral load data from patient files in future research. Lastly, a fairly large proportion of participants in our study were female, which may have affected the results. Future studies could endeavour to attain a representative sample of both females and males. Future research should explore longitudinal trajectories of illness identity to better understand how individuals move from the initial turmoil stages after diagnosis to acceptance and enrichment, this with the aim of possibly informing the design of future interventions.

Conclusion

This study provides compelling evidence that illness identity plays a pivotal role in HIV care, shaping outcomes and well-being of PLHIV. While demographic factors such as gender and education were not related to illness integration, findings suggest that being *engulfed* by HIV is the primary driver of poorer outcomes and that with *enrichment*, better outcomes could be envisioned. Incorporating these insights into clinical practice, psychosocial support programs and intervention design could foster a more holistic and person-centred approach to HIV care that recognizes illness integration as a crucial determinant of resilience, self-management, and living well with HIV.

Author Contributions NS, EW, CM and LK participated in the conceptualization of the study. NS performed the statistical analysis, interpreted the results and drafted the manuscript. All authors critically reviewed and revised the manuscript. All authors read and approved the final manuscript.

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Data Availability The data that support the findings are part of the SINAKO cluster-randomised controlled trial (Pan African Clinical Trial Registry, PACTR201906476052236), a study on HIV competent households in South Africa [41, 42] and could be made available upon reasonable request from the authors.

Declarations

Ethics Approval and Consent to Participate This study is part of the SINAKO cluster randomised control study, for which ethics approval has been obtained [52]. Approvals for the research were obtained from the Western Cape Department of Health and the City of Cape Town, and ethical clearance was granted by the University of the Western Cape's Biomedical Research Ethics Committee (BM19/4/6) and the Ethical Committee for the Social Sciences and Humanities of the University of Antwerp (SHW_17_64). It is the intention of the authors to publish the results of the study in a peer-reviewed journal and present them at relevant scientific events.

Competing Interests None.

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