

Household HIV competence and illness identity in HIV: Insights from the baseline phase of the SINAKO cluster randomised controlled trial

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Abstract

Background

Illness identity is the extent to which a chronic illness is integrated into one's sense of self. It can significantly impact the health outcomes and well-being of people living with HIV (PLHIV). Because incorporating HIV into one's identity is shaped by social context, particularly the household environment, we hypothesised that household HIV competence would play an important role in shaping key dimensions of illness identity: acceptance, rejection, engulfment, and enrichment.

Methods

Data were drawn from the baseline phase of the SINAKO cluster randomised controlled trial. A total of 316 adults living with HIV, aged 18 to 65 years (mean age = 35.49; 83% women), completed questionnaires evaluating household HIV competence and the four illness identity dimensions. Most participants (73%) had been living with HIV for more than six months. Multiple regression analyses with robust standard errors were conducted to assess associations between household HIV competence and each illness identity dimension, controlling for gender, age, and illness duration.

Results

In adjusted models, there was strong evidence that household HIV competence was associated with two dimensions of illness identity: higher household HIV competence was associated with greater acceptance ($\beta = 0.06$, $p = 0.04$) and lower rejection ($\beta = -0.14$, $p = 0.002$). No evidence was found of an association with engulfment ($\beta = -0.10$, $p = 0.13$) or enrichment ($\beta = 0.10$, $p = 0.05$).

Conclusions

These findings build on the illness identity literature by demonstrating that household HIV competence is uniquely linked to acceptance and rejection among people living with HIV. Recognising the central role of families in shaping the illness experience is vital. Strengthening household HIV competence through targeted family support may reduce rejection and promote acceptance, with the potential to improve long-term health outcomes for those living with HIV.

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BACKGROUND

Structural HIV testing, timely linkage to care, and sustained engagement in HIV services for people living with HIV (PLHIV) are essential components of effective HIV programs [1]. The success of antiretroviral therapies (ART) furthermore relies on lifelong adherence at levels exceeding 95% of prescribed doses [1–3]. High ART adherence levels support improved clinical outcomes in PLHIV and a life expectancy comparable to individuals living without HIV, effectively rendering HIV a manageable chronic condition [1]. Despite global progress, however, in certain high-prevalence settings only 83% of those diagnosed are linked to HIV care, and retention rates after a year on ART may be as low as 46% [4]. Globally, only 65% of adult PLHIV on ART are virally suppressed after three years [5]. HIV related mortality also persists [6, 7]. These outcomes necessitate an understanding of what may be missing from current approaches.

An often overlooked factor contributing to sub-optimal HIV health outcomes is how PLHIV adapt to living with HIV, and how this adaptation intersects with the management of HIV care [8–11]. Adaptation to a chronic condition involves acknowledging a change in situation and incorporating or integrating this change and the illness into their sense of selves and identity, lives, and lifestyles, alongside making practical changes to accommodate it [12–14]. Such incorporation is key to living well with chronic illness [15–17]. This process can be understood and measured through the concept of *illness identity* [18, 19], a concept successfully applied to other chronic conditions [18–21]. In these studies, illness identity was associated with a range of outcomes, including treatment adherence, depression, anxiety, life satisfaction, and overall health-related quality of life (HRQoL) [18–22]. Recent work has shown that this concept is also applicable to HIV [23].

Illness identity can significantly influence overall well-being and health outcomes among PLHIV. Individuals who successfully integrate HIV into their sense of self often report greater empowerment, enhanced self-efficacy, and a stronger sense of control over their illness and their lives [24–28]. They are better able to manage disclosure and cope with HIV-related stigma [24–26, 29]. Furthermore, their illness management and treatment adherence is more internally motivated [30], and they are more likely to sustain engagement in care [27] and ultimately live better with HIV [25]. In contrast, individuals may experience difficulties, such as denial, in integrating HIV into their sense of self, often driven by stigma [31]. This can result in delayed engagement with care, progression to symptomatic illness, and poorer adherence to ART [25, 28, 30], even in the case of readily-available ART [32]. Delays in engaging with care may reflect the need to emotionally or psychologically process diagnosis [33, 34], a process not always accommodated by universal test and treat approaches [35]. Furthermore, the potential trauma of an HIV diagnosis may result in maladaptive internalisation, where HIV may be internalised or over-integrated into memory [28, 36–38]. In such cases, PLHIV may report poor mental health, inadequate ART adherence [36] and poor HRQoL [37]. Incorporation of HIV into a sense of self and identity is therefore an important step for PLHIV [30] and understanding the factors that support successful incorporation is therefore critical.

Illness identity comprises four dimensions; engulfment, rejection, acceptance and enrichment [19]. Engulfment and rejection reflect non-integration of chronic illness, and may explain poor outcomes among PLHIV [18, 22]. In the state of *engulfment*, HIV dominates an individual's sense of self and daily

life, with their identity defined by their positive HIV status. In contrast, in the *rejection* state, HIV is perceived as a threat to the self, and is therefore rejected as part of one's identity. Acceptance and enrichment represent more adaptive forms of integration. *Acceptance* reflects acknowledging HIV as part of one's identity alongside and regardless of other social roles. *Enrichment* represents the degree to which having HIV has either resulted in positive life changes, facilitated personal growth, or strengthened an individual's sense of identity [18, 19, 22].

Adaptation to and integration of HIV, however, does not occur in isolation but is shaped by relationships and interactions within individuals' environments [24, 27, 28, 39–41]. Social support, particularly within the household, plays a critical role in the adaption to living with HIV and successfully managing the illness [42–48]. Recognising the importance of households for HIV management, Masquillier et al. (2016) developed the concept of Household HIV Competency, recognizing that households may function as either health-enabling or health-impeding environments [49, 50]. Households characterized by stigma, exclusion, and violence may hamper the successful integration of HIV into one's life and identity, whereas HIV competent households that create a safe space for disclosure and dialogue, and build solidarity, may support PLHIV to adhere to ART and to remain in care. HIV-competency is therefore characterised by sharing and translating HIV-related knowledge into prevention and treatment behaviour, fostering ownership of HIV and responsibility for safe sexual practices, testing and ART adherence, and being receptive to outside support [46, 49].

A growing body of literature highlights HIV-competent households as health-enabling environments that facilitate disclosure, support, and sustained engagement with care [49–51]. There remains, however, a notable gap understanding how household HIV competence influences adaptive outcomes, particularly in relation to the development of illness identity among PLHIV. While emerging research underscores the importance of illness identity as a critical determinant of self-management and health outcomes [23, 51], the intersection between household HIV-competence and individual illness identity remains underexplored. This study therefore aimed to explore the association between household HIV-competence and the four domains of illness identity, specifically engulfment, rejection, acceptance and enrichment, in adults living with HIV.

METHODS

Data sources, collection and participants

The data for this study was drawn from the baseline phase of the SINAKO (isiXhosa for “we can”) cluster randomised controlled trial. The trial aimed to deploy community healthcare workers (CHWs) to deliver an intervention designed to strengthen HIV competence among PLHIV and their households, and to evaluate its effects on ART adherence and related outcomes. SINAKO was set in five sub-districts of the Cape Metro in the Western Cape, South Africa; Khayelitsha, Klipfontein, Mitchell's Plain, Eastern and Western. These areas are characterised by high HIV prevalence [52], high unemployment, and low socio-economic status [53].

The SINAKO trial protocol and intervention design are published in detail elsewhere [46, 54]. Twelve healthcare facilities served as clusters and were randomised into intervention and control arms (six in each arm). A sample size of 316 adults living with HIV (180 in the intervention arm and 136 in the control arm) were recruited from the relevant facilities and gave written consent to participate. Baseline data collection activities occurred between May 2020 and May 2021. Permission to conduct the research was provided by the Western Cape Department of Health and the City of Cape Town [46]. Ethical approval was obtained from 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).

Measures

Illness Identity

Illness identity was assessed using an adapted illness identity questionnaire (IIQ). The original IIQ was developed, validated and used in a Belgian context for diabetes [19] and later validated for use in this context (PLHIV in South Africa) using the SINAKO data [23]. The IIQ has four illness identity subscales: engulfment, rejection, acceptance, and enrichment, measured across 25 items. Participant responses are captured on a five-point Likert scale ranging from “strongly disagree” to “strongly agree”. Internal reliability of each subscale was assessed using Cronbach's alpha: all were above 0.7, demonstrating that the scales were acceptable with good reliability [55]; rejection $\alpha = 0.71$, acceptance $\alpha = 0.86$, engulfment $\alpha = 0.90$, and enrichment $\alpha = 0.92$.

Household HIV Competence index

Household HIV competence was assessed using a 5-item index representing key attributes of HIV competent households: 1. creation of a safe space for disclosure and dialogue about HIV; 2. building of solidarity (by households and families) to support PLHIV to adhere to ART and remain in care; 3. gaining, sharing and translating HIV-related knowledge into prevention and treatment behaviour; 4. fostering ownership of HIV and responsibility for safe sexual practices, testing and ART; and 5. being receptive to outside support (e.g. by CHWs). Household HIV competency was measured using 16 items developed on the basis of qualitative research [49, 50]. Response options included a six-point Likert scale ranging from ‘completely disagree’ to ‘completely agree’: negatively worded items were reverse coded so that higher scores reflected better HIV household competency. The scale's reliability and validity was demonstrated in previous articles [56, 57]. Participants were asked to indicate agreement with statements on a six-point Likert scale ranging from “completely disagree” to “completely agree”. Certain items were reverse coded so that higher scores reflected favourable household HIV competence. Cronbach's alpha for the household HIV competence index was $\alpha = 0.80$.

Individual-level demographic and illness variables

Individual level demographic and illness specific variables included gender (coded 0 = male, 1 = female), age (in years, centred), and illness duration (coded 0 = diagnosed with HIV six months or more ago, 1 = diagnosed with HIV less than six months ago).

Statistical Analysis

Analysis was conducted using IBM SPSS Statistics Version 29.0.2.0. Descriptive Statistics were computed to summarise participant characteristics. Multivariate analyses of variance (MANOVAs) were conducted to explore mean-level differences in illness identity based on gender and illness duration. Pearson correlations examined associations between age and illness identity dimensions. Multiple regression analyses with robust standard errors were conducted to explore the association between household HIV competence influence and, separately, each dimension of illness identity, while controlling for gender, age and illness duration. Ordinary least squares with cluster-robust standard errors accounted for both heteroscedasticity and clustering of observations at the clinic level [58]. Dummy variables for each facility were included to adjust for between-clinic differences [59].

RESULTS

Characteristics of participants at baseline

Demographic characteristics of participants are presented in Table 1. The sample ($n = 316$) ranged in age from 18 to 65 years ($M = 35$, $SD = 10$) and was predominantly female (83%). At the time of data collection, 232 (73.42%) individuals had been living with HIV for six months or more and 84 (26.58%) had been recently diagnosed and living with HIV for less than six months (Table 1). Most participants 137 (44%) had an income of between one rand and one thousand Rands (equivalent to between 0.055–54.50 US\$), whilst 84 (27%) had no income; 91 (29%) had an income of between one thousand Rands and twenty thousand Rands (equivalent to between 54.50–1090 US\$).

Table 1
Demographic information including participants' household description with HIV related data

Variable	Participants (N = 316) (%)
Age ^a	35(10)
Gender	
Female	262(82.9)
Male	54(17.1)
Race	
Black	267(84.5)
Coloured/White/Asian	49(15.5)
Education level	
None to secondary	247(78.2)
Matric to university	69(21.8)
Relationship	
In a relationship	213(67.4)
Not in a relationship	103(32.6)
Illness duration	
More than six months	232(73.42)
Less than six months	84(26.58)
Personal income	
Nothing	84(26.9)
R1-1000	137(43.9)
R1,000–20,000	91(29.2)
Is participant head of household	
Not household head	182(57.6)
Household head	134(42.4)
Participant's number of children	
One or two children	171(54.1)
3 or more	93(29.4)
None	52(16.5)
Number of people in the household who have died from HIV	
None	280(89.5)
One or more	33(10.5)
Number of other household members living with HIV	
None	194(64.5)
One or more	107(35.5)
Data are shown as mean (SD)	

The role of gender, illness duration and age

There was no statistical evidence of a difference by gender for acceptance, rejection, engulfment and enrichment (Wilk's $\Lambda = 0.994$, $F(4, 311) = 0.440$, $P = 0.78$, Partial $\eta^2 = 0.006$). There was strong evidence of a difference between those with longer illness duration and those with shorter illness duration when considered jointly on acceptance, rejection, engulfment and enrichment (Wilk's $\Lambda = 0.953$, $F(4, 311) = 3.87$, $P = 0.004$, Partial $\eta^2 = 0.047$). There was strong evidence of a significant difference between PLHIV with longer illness duration and those with shorter illness duration on enrichment ($F(1, 213) = 12.73$, $P < 0.001$, Partial $\eta^2 = 0.039$), with those with longer illness duration scoring higher ($M = 30.32$) than those with shorter illness duration ($M = 28.46$). There was also evidence of a difference between PLHIV with longer illness duration and those with shorter illness duration on acceptance ($F(1,$

59.887) = 9.89, $P = 0.002$, Partial $\eta^2 = 0.031$); participants with longer illness duration ($M = 17.116$) scored higher than those with shorter illness duration ($M = 16.131$). There was no evidence of a difference between PLHIV with longer illness duration and those with shorter illness duration on rejection ($F(1, 62.61) = 3.299$, $P = 0.07$, Partial $\eta^2 = 0.010$) and on engulfment ($F(1, 72.900) = 2.326$, $P = 0.13$, Partial $\eta^2 = 0.007$). There was evidence of a weak negative and significant association between age and the rejection subscale ($r(316) = 0.13$, $P = 0.02$), with older individuals reporting lower levels of rejection. There was no other evidence of an association between age and the other three illness identity subscales (Table 2).

Table 2
Pearson's correlation

1. Enrichment	2	3	4	5	6
	-.54**	.72**	-.12*	.08	.14*
	< .001	< .001	.03	.15	.02
2. Engulfment	...	-.54**	.16**	-.09	-.11*
		< .001	.01	.11	.05
3. Acceptance		---	-.28**	.11	.15**
			< .001	.06	.01
4. Rejection			---	-.13*	-.22**
				.02	< .001
5. Age				---	.15**
					.01
6. Household HIV Competence					---

**Correlation is significant at the 0.01 level (2-tailed); *Correlation is significant at the 0.05 level (2-tailed).

Associations between Household HIV Competence and illness identity in HIV

Adjusted regression analyses controlling for gender, age, illness duration, and clinics indicated evidence of an association between household HIV competence and two dimensions of illness identity. Higher household HIV competence was associated with lower levels of rejection ($\beta = -0.14$, $t = -3.11$, $p = 0.002$) and higher levels of acceptance ($\beta = .056$, $t = 2.10$, $p = 0.037$).

There was no evidence of an association between household HIV competence and engulfment ($\beta = -0.096$, $t = -1.52$, $p = 0.13$) or enrichment ($\beta = .095$, $t = 1.941$, $p = .053$). Full regression results are presented in Table 3.

Table 3
Regression analyses with household HIV competence as an independent variable and enrichment, engulfment, acceptance and rejection in HIV as dependent variables, controlling for age, gender and illness duration

Overall regression model	Enrichment $F(15,300) = 2.81$ $p < .001$ $R^2 = .12$				Engulfment $F(15,300) = 2.12$ $p = .009$ $R^2 = .10$				Acceptance $F(15,300) = 2.89$ $p < .001$ $R^2 = .13$				Rejection $F(15,300) = 2.49$ $p = .002$ $R^2 = .11$			
Variable	B	t	LL	UL	B	t	LL	UL	B	t	LL	UL	B	t	LL	UL
Gender	.07	.11	-1.19	1.33	.27	.32	-1.38	1.91	.25	.74	-.42	.92	.00	.01	-1.42	1.43
Age	.00	.01	-.05	.05	-.03	-.82	-.11	.05	.01	.30	-.03	.04	-.02	-.82	-.07	.03
Illness duration	-1.71	-2.74**	-2.94	-.48	.74	1.01	-.71	2.18	-.83	-2.17*	-1.58	-.08	.35	.60	-.79	1.48
HHHC	.10	1.94	.00	.19	-.10	-1.52	-.22	.03	.06	2.10*	.00	.11	-.14	-3.11**	-.23	-.05

CI= confidence intervals (95%), LL= lower level, UL= upper level, HHHC= Household HIV competence, ** $p < .01$; * $p < .05$.

DISCUSSION

This study examined the role of household HIV competence in shaping dimensions of illness identity in HIV (rejection, engulfment, acceptance, and enrichment) among adults living with HIV in South Africa who had recently initiated ART. Hypotheses included 1) lower levels of household HIV competence would be associated with higher levels of rejection, 2) lower levels of household HIV competence would be associated with higher levels of engulfment, 3) higher levels of household HIV competence would be associated with higher levels of acceptance, and 4) higher levels of household HIV competence would be associated with higher levels of enrichment. We furthermore examined associations between age, gender, and illness duration with illness identity dimensions.

The results furthermore indicated that age was weakly associated with rejection, with older participants reporting lower levels of rejection. Other evidence in the literature is inconsistent. While some studies found no association [21], others found a positive correlation between age and rejection, engulfment and enrichment [18]. The findings in this study are consistent with those of a study exploring illness identity among participants with refractory epilepsy [20]. This could possibly be linked to both HIV and epilepsy being highly stigmatised illnesses and the fact that studies have indicated that older PLHIV (more than 55 years) may have lesser overall and internalized stigma than younger PLHIV [60]. Future research could further explore the relationships between age, rejection and stigma.

Consistent with studies that explored illness identity in those with congenital heart disease, multisystem connective tissue disorders [18], refractory epilepsy [20], and irritable bowel disease [21], gender was not related to any of the four illness identity dimensions. This may, however, be due to the small sample size of male participants in this study and therefore warrants consideration in future research.

Illness duration was positively associated with the adaptive dimensions of illness identity in HIV; enrichment and acceptance. PLHIV who have been living with HIV for longer periods scored higher on acceptance and enrichment. This supports existing research that shows that with time PLHIV may move beyond acceptance to full incorporation of HIV into a sense of self and identity [61]. The result is consistent with studies that investigated illness identity in MSD [18] and refractory epilepsy [20].

Importantly, the results indicated that there was evidence of an association between household HIV competence and the acceptance and rejection dimensions of illness identity in HIV. Higher household HIV competence levels were related to greater acceptance and lower rejection scores, suggesting a potentially protective role of household HIV competency. This is important given that the rejection state has previously been linked with poorer health outcomes for people living with chronic illness [18, 22, 62]. One plausible mechanism is that of status disclosure, which has previously been associated with stigmatisation or rejection of the PLHIV by family, severing access to crucial emotional, psychological and instrumental support, with implications for identity transition or integration of HIV [28, 63]. In contrast, HIV-competent households may provide the emotional and social conditions necessary for PLHIV to acknowledge and integrate their diagnosis. Research to engage households and families to support PLHIV's engagement in care supports this [39, 44, 45, 47, 54]. Therefore, household focused interventions supporting household HIV competency could assist PLHIV to integrate HIV into their sense of self and ultimately improve their health outcomes.

Similarly, household HIV competence was positively associated with acceptance. Acceptance has been linked to positive health outcomes for people living with chronic illness, such as reduced depressive and anxiety symptoms [19] and improved self-care [22]. This study's findings align with broader evidence that highlighting the role of family support in facilitating adaptive coping and positive identity transition in the PLHIV [28, 40, 41]. These findings furthermore highlight the concept of HIV competent households as health enabling environments [46, 49]. Together, these findings affirm the argument for interventions to support household competency to facilitate integration and incorporation of and thus improve health outcomes for PLHIV.

In contrast, there was no evidence of an association between household HIV competence and engulfment. In an engulfment state, individuals may define themselves in terms of their illness and find it permeates all aspects of their lives [18, 22]. One possible explanation is the conceptual complexity of engulfment. Related constructs such as HIV centrality suggest that strong identification with HIV can be either maladaptive (overwhelming identity) or adaptive (facilitating growth), depending on how it is experienced [28, 36–38, 64]. Maladaptive HIV centrality or engulfment is associated with poorer outcomes for relationships with significant others, adherence to treatments and mental health [36]. Adaptive, positive centrality of HIV can lead to post-traumatic growth [37]. It is possible that participants interpreted items capturing engulfment in different ways, attenuating observable associations.

There was furthermore no evidence of an association between household HIV competence and enrichment. Enrichment denotes the extent to which chronic illness has enhanced people living with chronic illness' sense of self and facilitated their growth. It is associated with better health outcomes [18, 19] and has been linked with more perceived social support [65]. One possible explanation for the lack of association observed in this study is that enrichment may reflect a more individual, internal process of meaning-making and growth that develops over time and may be less directly influenced by the immediate household environment. Additionally, given that participants in this study had recently initiated ART, they may still have been in earlier stages of adjustment, where positive reinterpretation and growth have not yet fully emerged.

Limitations and future research

This study has several limitations. First, the cross-sectional nature of this analysis and reliance on self-report measures preclude causal inference. Longitudinal and experimental research is needed to examine the relationship between household HIV competence and illness identity and their evolution over time. Second, the relatively small and predominantly female sample may limit generalizability. Future research should explore these dynamics in males living HIV. Third, stigma remains a key aspect of living with HIV, but was not modelled in this study: future studies should explore the potential mediating role of stigma in the relationship between household HIV competence and illness identity. Finally, qualitative research could provide deeper insight into how individuals experience and negotiate illness identity in household contexts. Nevertheless, as far as we are aware, this is the first time that the associations between household HIV competence and illness identity in HIV have been investigated.

CONCLUSION

This study builds on the existing illness identity literature by providing evidence for the role of household HIV competence in illness identity in PLHIV, and specifically its association with acceptance and rejection. These findings underscore the critical role of households and families in shaping the illness

experience and, by extension, health outcomes for PLHIV. Interventions that strengthen HIV competence within households, by fostering supportive, informed, and communicative environments, may reduce rejection and promote acceptance, thereby supporting better long-term outcomes for PLHIV.

Abbreviations

ART
Antiretroviral therapy
CHW
Community healthcare worker
HRQoL
Health-related quality of life
IIQ
Illness Identity Questionnaire
MANOVA
Multivariate analysis of variance
PLHIV
People living with HIV
RCT
Randomised controlled trial
SINAKO
isiXhosa for “we can” – name of the cluster randomised controlled trial

Declarations

Ethics approval and consent to participate

Ethical approval was obtained from the University of the Western Cape's Biomedical Research Ethics Committee (reference: BM19/4/6) and the Ethical Committee for the Social Sciences and Humanities of the University of Antwerp (reference: SHW_17_64). All procedures were conducted in accordance with the Declaration of Helsinki and its later amendments. All participants provided written informed consent prior to participation.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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Author Contribution

Conceptualization: NS, EW, CM, LK
Data curation: NS, LC
Formal analysis: NS, LC
Funding acquisition: EW, CM, LK
Methodology: NS, EW, CM, LK
Project administration: LK, CMS
Supervision: LK, EW
Validation: LC
Writing – original draft: NS
Writing – review & editing: NS, LC, CM, EW, LK

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 are under embargo. The said data will be available on request from the authors upon completion of the trial.

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