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AMERICAN PSYCHOLOGICAL ASSOCIATION

Stigma and Health

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ISSN: 2376-6972

2024, Vol. 9, No. 2, 173–180
https://doi.org/10.1037/sah0000475

Exploring the Relationship Between Anticipated Stigma and Community Shared Concerns About HIV on Defaulting From HIV Care in Rural South Africa

Erica N. Browne[1], Marie C. D. Stoner[1], Chodziwadziwa Kabudula[2], Mi-Suk Kang Dufour[3], Torsten B. Neilands[4], Hannah H. Leslie[4], Rebecca L. West[4, 5], Dean Peacock[6], F. Xavier Gómez-Olivé[2], Kathleen Kahn[2], Audrey Pettifor[2, 7], and Sheri A. Lippman[2, 4]

[1] Women's Global Health Imperative, RTI International, Berkeley, California, United States
[2] Medical Research Council/Wits Rural Public Health and Health Transitions Research Unit (Agincourt), Faculty of Health Sciences, School of Public Health, University of the Witwatersrand, Johannesburg
[3] Division of Biostatistics, School of Public Health, University of California, Berkeley
[4] Department of Medicine, University of California, San Francisco
[5] Department of Global Health, Boston University School of Public Health
[6] Sonke Gender Justice, Johannesburg, South Africa
[7] Department of Epidemiology, Gillings School of Global Public Health, University of North Carolina at Chapel Hill

Although stigma has been associated with people living with HIV defaulting from care, there is a gap in understanding the specific impact of individual stigma and community-level concern about HIV on defaulting. This is a secondary analysis of a unique data set that links health facility–based medical records to a population-representative community survey conducted in 2018 in rural Mpumalanga province, South Africa. We used the parametric g-formula to estimate associations among individual anticipated stigma, low perceived community and local leader concern about HIV, and defaulting from care in the prior year. In addition, we estimated the population-level effects of intervening to reduce stigma and increase concern on defaulting. Among 319 participants on treatment, 42 (13.2%) defaulted from care during the prior year. Anticipated stigma (risk ratio [RR] 1.22, 95% confidence interval, CI [0.72, 2.74]), low perceived concern about HIV/AIDS from community leadership (RR 1.12, 95% CI [0.76, 3.38]), and low shared concerns about HIV/AIDS in the community (RR 1.37, 95% CI [0.79, 3.07]) were not significantly associated with default. Hypothetical population intervention effects to remove the individual anticipated stigma and low community concerns yielded small reductions in default (~1% reduction). In this sample, we found a limited impact of reducing anticipated stigma and increasing shared concern about HIV on retention in care. Future studies should consider the limitations of this study by examining the influence of other sources of stigma in more detail and assessing how perceptions of stigma and concern impact the full HIV testing and care cascade.

Clinical Impact Statement

In a high HIV-prevalent rural community in South Africa, we found that anticipated stigma and the perceived level of concern about HIV in the community and from leadership had a small influence on people living with HIV defaulting from care over a 1-year period. Future analyses should examine how perceptions of stigma and concern impact engagement in care among patients in other regions, who are less established in care, or not yet in care.

Keywords: stigma, HIV care, defaulting from care, population intervention effects, South Africa

Supplemental materials: https://doi.org/10.1037/sah0000475.supp

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This article was published Online First August 31, 2023.

Erica N. Browne https://orcid.org/0000-0003-2069-6589

This research is supported by the United States National Institute of Mental Health (Grants R01MH110186 to Audrey Pettifor and R01MH103198 to Sheri A. Lippman/Audrey Pettifor). The Agincourt Health and Demographic Surveillance Site and census data collection is supported by the South African Medical Research Council and the University of the Witwatersrand, as well as the Wellcome Trust, United Kingdom (Grants 058893/Z/99/A; 069683/Z/02/Z; 085477/Z/08/Z; and 085477/B/08/Z). The contents are solely the responsibility of the authors and do not necessarily represent the views of the funding institutions.

The authors would like to thank the study participants and study team, the Medical Research Council/Wits Rural Public Health and Health Transitions Unit (Agincourt) staff, the community engagement/Learning, Information dissemination and Networking with Community team, and the data unit. They also would like to thank Megan Lewis at RTI International for her support. The authors have no conflicts of interest to disclose.

Mindful that our identities can influence our approach to science, the authors wish to provide the reader with information about our backgrounds. With respect to gender, when the article was drafted, eight authors self-identified as women and four authors as men. With respect to race, 10 authors self-identified as White, one as Black, and one as mixed Asian and White.

continued

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As of 2019, there are 20.7 million people living with HIV (PLHIV) in East and Southern Africa, and approximately one third live in South Africa (The Joint United Nations Programme on HIV/AIDS, 2019). Of the 7.5 million PLHIV in South Africa, 85%–92% were aware of their HIV status, and 70% were on antiretroviral therapy (ART; The Joint United Nations Programme on HIV/AIDS, 2019). However, a substantial number of PLHIV on ART default from care, leading to increased mortality, ongoing HIV transmission, and acquired medication resistance. A meta-analysis in 2015 estimated that among South African adults initiating ART, 77% were retained in care at 12 months, 75% at 24 months, and 63% at 72 months (Fox & Rosen, 2015). More recent data from UNAIDS show that there has been a 30% increase in PLHIV in South Africa who had started treatment but are no longer receiving it (The Joint United Nations Programme on HIV/AIDS, 2021). In rural northeastern South Africa, 41% of patients on ART were lost to follow-up between April 2014 and July 2017 (Ambia et al., 2019). Despite the need to increase retention in care to achieve the UNAIDS 95-95-95 goals, lack of routine monitoring of individuals who default from care has led to a gap in understanding how to prevent defaulting from care (Ambia et al., 2019; Chalker et al., 2008; Mugglin et al., 2012). Understanding characteristics associated with patients who default could help identify future at-risk patients and inform targeted interventions to improve retention and patient outcomes.

Several studies have found that multilevel measures of stigma and community attitudes and concern about HIV can influence the utilization of HIV services and retention in HIV care, but much of the evidence is qualitative and somewhat contradictory (Brault et al., 2022; Chirambo et al., 2019; Evangeli et al., 2014; Green et al., 2020; McGuire et al., 2010; Miller et al., 2010; Mukumbang, 2021; Treves-Kagan et al., 2017; Zuch & Lurie, 2012). For example, two studies in Malawi found that when individuals anticipated feeling devalued or discriminated against (i.e., anticipated stigma) or experienced stigma (i.e., enacted stigma), they were more likely to default from treatment; two other studies in South Africa found that anticipated stigma was not a primary driver of defaulting (Chirambo et al., 2019; Evangeli et al., 2014; McGuire et al., 2010; Miller et al., 2010). Yet, according to the Framework Integrating Normative Influences on Stigma (FINIS), individual anticipated stigma is further impacted by one's larger cultural content, which can ultimately influence decisions to engage in social interactions such as attending medical appointments (Green et al., 2020; Pescosolido & Martin, 2015). A study examining both community concerns with public attitudes about PLHIV and individual anticipated sigma used FINIS to conclude that having a high degree of perceived community concerns was a barrier to self-reported desire to see a doctor every 6 months for HIV care when PLHIV anticipated negative treatment by health care workers (Green et al., 2020). Therefore, it is possible that both individual anticipated stigma and community concerns influence defaulting from care, but these are rarely studied together in a single population. Population-based quantitative studies are needed to provide a more nuanced understanding of the relationships between individual perceptions of stigma, perceptions of HIV in the community, and defaulting from care (McGuire et al., 2010).

To this end, we used a unique data resource from rural South Africa that combines clinical records with a population-based survey from a community mobilization study to assess associations between multilevel measures of stigma and community HIV-related concerns on defaulting from care. We hypothesized that both anticipated stigma and community concern would influence retention in care according to the FINIS framework. In addition, we estimated the population intervention effects of hypothetical interventions to improve stigma and concern on reducing default.

Method

Settings and Procedure

Our study is a secondary analysis that includes data linked from health facility–based medical records to a population-representative community survey conducted between 2015 and 2018 in the Agincourt Health and Demographic Surveillance Site (AHDSS) of the rural Bushbuckridge subdistrict of Mpumalanga province, South Africa (Lippman et al., 2017). The community mobilization intervention was developed to address social barriers to engagement in HIV care to improve linkage to and retention in HIV care and prevent new HIV diagnoses by mobilizing around treatment as prevention. Results of the intervention, which involved community-based workshops and activities that encouraged participants to become actively involved in HIV prevention both in their own lives and in their communities, have been described elsewhere. We use the trial's population-based survey conducted at the end of the intervention in 2018 in this analysis. The survey aimed to capture 75 residents aged 18–49 years in all AHDSS villages, including 15 study villages and 12 nonstudy villages, and were conducted using computer-assisted personal interviewing. Indicators collected include self-reported information on social barriers to care, including stigma, as well as shared concerns around HIV, sexual risk behavior, and HIV testing and disclosure. Eligibility criteria included being 18–49 years of age, spending most nights at the home residence, and having lived in the study area for at least 9 of the past 12 months. One individual was interviewed per household, and no financial compensation was provided for participation in the study per study site policy. After eligibility was confirmed, informed consent procedures were conducted in Shangaan (local language) or English, depending on the participant's preference, and surveys were conducted in participants' households.

In addition to the community surveys, we continuously collected data on HIV testing, and care visits conducted at the nine health

Chodziwadziwa Kabudula, Rebecca L. West, Dean Peacock, F. Xavier Gómez-Olivé, Kathleen Kahn, Torsten B. Neilands, Audrey Pettifor, and Sheri A. Lippman performed the research. Audrey Pettifor, Torsten B. Neilands, and Sheri A. Lippman designed the research study. Erica N. Browne, Mi-Suk Kang Dufour, and Hannah H. Leslie analyzed the data. Erica N. Browne and Marie C. D. Stoner wrote the article. All authors have read and approved the final article.

Correspondence concerning this article should be addressed to Erica N. Browne, Women's Global Health Imperative, RTI International, 2150 Shattuck Avenue, Suite 800, Berkeley, CA 94704, United States. Email: ebrowne@rti.org

facilities in the AHDSS study area participating in the Clinic-Link system. Clinic-Link is an electronic system designed to capture patient-level information from the health facilities and link clinical records of residents receiving care in the area to their AHDSS census record. Trained data capturers stationed at the clinics obtained consent to link clinic records to the census and then searched the AHDSS database for a match based on several personal identifiers. Once a patient was linked, their medical information was abstracted and linked to AHDSS household and demographic information, which could also be linked to responses in the community survey (Kabudula et al., 2014).

The Institutional Review Boards at the University of North Carolina–Chapel Hill and the University of California, San Francisco, and the Human Research Ethics Committee at the University of the Witwatersrand in South Africa approved this study.

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Analysis Sample

This analysis includes participants from the final community survey conducted between August and December 2018 who were linked to the Clinic-Link database. Individuals who were recorded on clinic records as HIV positive and on ART during the year prior to the survey (i.e., eligible to default) were included in the analysis.

Measures

The primary outcome was defaulting from care within a 1-year period, between August 2017 and July 2018 constructed from the Clinic-Link data set. Default was constructed using medication dispensation data and was defined as a PLHIV who had been prescribed ART, with ≥90 days elapsed since the date of last prescription and no return visit or refill issued (per South African national guidance; Department of Health Republic of South Africa, 2016).

The exposures in our analysis included individual anticipated stigma and two measures of perceived community concern about HIV from the survey—one was concern among community members and the other among local leaders. Anticipated HIV stigma was measured using a nine-item scale adapted from the UNAIDS general population survey: Department of Health Services AIDS module and previously used in Botswana (Weiser et al., 2006) that includes questions assessing expectations of discrimination should one become HIV positive or reveal an HIV-positive status (e.g., "You would be treated badly at work or school" and "You would be disowned from or neglected by your family"). Participants provided responses to each item using a 3-point Likert scale (2 = *very likely*, 1 = *somewhat likely*, or 0 = *unlikely*; Cronbach's α was .89). Scores from each item were initially summed (possible range 0–18) but because the distribution of the continuous score was heavily skewed toward zero (i.e., the majority of the sample reported no anticipated stigma), the measure was instead dichotomized as any versus no anticipated stigma. There were no clear breaks or instructions from the scale to define low, medium, or high levels of stigma, thus we did not want to make assumptions about the functional form of the stigma measure. The decision to dichotomize was consistent with prior analyses using the same data (Treves-Kagan et al., 2017) and with how the measure has been used previously (Weiser et al., 2006). Participants were classified as reporting any anticipations of stigma if they responded "very likely" or "somewhat likely" to any of the nine questions (i.e., score > 0).

Community-shared concern about HIV/AIDS is an 18-item subscale of the Community Mobilization Measure designed to capture whether the participant perceives members of the community to (a) consider HIV as important, problematic, and mutable; (b) be aware of the impacts of HIV in their village; and (c) believe they can work together to improve outcomes (e.g., "People in your village consider HIV/AIDS an important issue" and "People in your village believe that HIV impacts the community"; Lippman et al., 2017). Participants indicated agreement with each item on a 3-point scale that ranged from *do not agree at all* to *agree a lot* (α = .97). Leaders' concern about HIV/AIDS was measured by the level of agreement with four items (e.g., "The village leaders work to prevent the spread of HIV" and "The village leaders are concerned about access to HIV care and treatment") on the same 3-point scale (α = .97). Each individual's responses were averaged to create composite scores (range 1–3), with a higher score indicating a perception of greater shared concern. Mean scores for both perceived community and leaders' shared concerns were dichotomized to increase interpretability and defined as low level of shared concern (yes/no) with a mean score < 2.0, representing less than "somewhat agreement" with all scale items.

Potential confounders for all models were selected based on prior literature, theory, and reviewing exposure, confounder, and outcome relationships with directed acyclic graphs (Supplemental Figure 1). To assess model specification, we compared the probability of default predicted by the model with the observed prevalence of default in the data to ensure that they were similar and adjusted functional form of covariates and interactions if needed (Naimi et al., 2017). We tried to ensure that we were accounting for all potential interactions with the exposure because estimation with the g-formula is improved with saturation (Chatton et al., 2020; Naimi et al., 2017; Schisterman et al., 2017); we excluded interactions that caused convergence issues or had zero sample in a given cell. Measures included the following: age (cubic), sex, educational attainment (as completed high school or less than high school education), earned income in the past 3 months, any alcohol use, marital status, discussed getting HIV tested with a partner before last test, time since HIV diagnosis (within past 5 years vs. >5 years ago), tuberculosis diagnosis, treatment from a larger community health center (vs. a primary care health clinic), and treatment clinic's service readiness based on facility audit in 2018 (Leslie et al., 2020; lower, moderate, high). To assess the assumption of positivity, we examined covariates to ensure that there were exposed and unexposed individuals within all confounder levels (Ahern et al., 2009; Robins et al., 2000).

Statistical Analysis

We described the demographic characteristics of those who did and did not default from care in the analytic data, reporting percentages and frequencies for categorical measures and medians with the interquartile range for continuous measures. Next, we used the parametric g-formula to estimate associations between exposures and outcomes. To implement the parametric g-formula, we used the following steps: (1) we modeled the adjusted association for each exposure–outcome relationship using logistic regression, including confounders mentioned above and interaction terms between confounders and exposures; (2) we used the coefficients in Step 1 to impute the outcome probability for each

individual while setting the exposure to different values (e.g., 0 all unexposed, 1 all exposed, or set to observed value); (3) we averaged these probabilities across the population and divided (for risk ratios) and subtracted (for risk differences) the probabilities under each scenario; and (4) we used bootstrapping to construct 95% confidence intervals based on percentiles (Ahern et al., 2009; Danaei et al., 2013; Edwards et al., 2014; Garcia-Aymerich et al., 2014; Lajous et al., 2013; Naimi et al., 2014; Taubman et al., 2009). To ensure our model in Step 1 was correctly specified, we compared the estimated risk of defaulting from care using the g-formula with the empirical prevalence in the data set.

We used the parametric g-formula to make two different comparisons. First, we estimated how the prevalence of defaulting changes if all were exposed to each measure of stigma or concern versus if all were unexposed, which is analogous to the standard exposed versus unexposed comparison. Second, we estimated how the current prevalence of defaulting from care would change if instead all were unexposed to each measure of stigma or concern (i.e., if we were able to remove the current observed prevalence of each stigma exposure). This second estimate was included to help provide relevant context for how policy to remove the current amount of stigma in this community might expect to influence defaulting from care (Westreich, 2017). To assess if the effect of stigma or concern was greater with an HIV diagnosis in the past 5 years, we used the same model coefficient estimates and parametric g-formula procedure to estimate the effects of stigma or concern among those diagnosed within the past 5 years.

Results

Among the 2,089 participants who completed the 2018 community survey, 311 had a clinic record indicating positive HIV status and a prescription for ART at the start of August 2017. The average age was 36 years (standard deviation, *SD* 7.5, range 18–49), and the majority were female (79%; Table 1). On average, participants had been diagnosed 4 years prior (interquartile range 2–6 years; range 1–14 years). Of the 311 participants, 42 (13.5%) had defaulted from care during the prior year.

Approximately one third of participants who were HIV positive and on treatment (n = 105, 34%) reported anticipated HIV stigma,

Table 1

Characteristics of Participants Who Completed the Survey and Had a Clinic Record for Antiretroviral Therapy Prescription 2017–2018, by Default Status

	Defaulted from care during past year					
	Yes n = 42 (13.5%)		No n = 269 (86.5%)		Total N = 311 (100%)	
Characteristics	*N*	(%)	*N*	(%)	*N*	(%)
Female	37	(88)	209	(78)	246	(79)
Age, years—*M*, *Mdn* (IQR)	32.7, 32	(27–40)	36.4, 37	(32–42)	35.9, 36	(31–42)
Age group						
18–24	6	(14)	22	(8)	28	(9)
25–34	22	(52)	80	(30)	102	(33)
35–44	9	(21)	128	(48)	137	(44)
45–49	5	(12)	39	(15)	44	(14)
Married (legal or traditional)	11	(26)	101	(38)	112	(36)
Currently pregnant	4	(10)	13	(5)	17	(5)
Number of children under age 15—*M*, *Mdn* (IQR)	2, 2	(1–3)	2, 2	(1–3)	2, 2	(1–3)
Educational attainment						
Completed primary or less	5	(12)	37	(14)	42	(14)
Some high school	17	(41)	131	(49)	148	(48)
Completed high school	20	(48)	101	(38)	121	(39)
Any income past 3 months	13	(31)	146	(54)	159	(51)
Any household food insecurity, past month	2	(5)	23	(7)	25	(8)
Any alcohol use	10	(24)	61	(23)	71	(23)
Discussed getting HIV tested with partner before last test	16	(38)	147	(55)	163	(52)
At least one sex partner in past year is living with HIV	7	(17)	84	(31)	91	(29)
From clinical record						
Years since HIV diagnosis—*M*, *Mdn* (IQR)	4.3, 4	(2–6)	4.4, 4	(2–6)	4.4, 4	(2–6)
Diagnosed > 5 years ago	12	(29)	80	(30)	92	(30)
Diagnosed with tuberculosis (prior to August 2017)	11	(26)	73	(27)	84	(27)
Care received at						
Community health center	28	(67)	139	(52)	167	(54)
Primary care health clinic	14	(33)	130	(48)	144	(46)
Readiness score of clinic where care was received						
Lower	6	(14)	55	(20)	61	(20)
Moderate	24	(57)	148	(55)	172	(55)
High	12	(29)	66	(25)	78	(25)

Note. *M* = mean; *Mdn* = median; IQR = interquartile range.

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Table 2
Anticipated HIV Stigma and Perceived Community and Leader Concerns About HIV as a Predictor of Defaulting From Care in Prior Year

	Outcome: Defaulted from care during past year					
	Yes		No		Total	
Stigma exposures	*N*	(%)	*N*	(%)	*N*	(%)
Total	42	(100)	269	(100)	311	(100)
Anticipated HIV stigma						
Any	17	(40)	88	(33)	105	(34)
None	25	(60)	181	(67)	206	(66)
Community shared concerns about HIV						
Low concern (mean score < 2.0)	15	(36)	68	(25)	83	(27)
Moderate to high concern (mean score 2.0–3.0)	27	(64)	201	(75)	228	(73)
Village leaders concern about HIV						
Low concern (mean score < 2.0)	13	(31)	63	(23)	76	(24)
Moderate to high concern (mean score 2.0–3.0)	29	(69)	206	(77)	235	(76)

with a greater proportion among those who defaulted from care (n = 17, 40%; Table 2). Overall, one in four perceived their community (n = 83, 27%) and their village leaders (n = 76, 24%) to have low levels of concern about HIV/AIDS. Among those who defaulted from care, about one in three perceived their community (n = 15, 36%) and village leaders (n = 13, 31%) to have low concerns about HIV.

Considering the traditional causal effect estimates comparing all exposed with all unexposed, all measures of stigma or concern were estimated to have minimal impact on defaulting from care (Table 3). The estimated effect of any anticipated stigma increased the risk of default by 1.12 times, although this was not statistically significant (risk ratio [RR] 1.12, 95% CI [0.74, 3.16]). The estimated risk difference if all current anticipated stigma could be removed from the population was a 0.7% decrease in defaulting (95% CI [−2.2%, 4.2%]).

Perceived low community concerns about HIV/AIDS had the largest association with defaulting from care, with an estimated RR of 1.34; however, this association was also not statistically significant (95% CI [0.88, 3.49]). We estimated that if all current low levels of perceived community concern about HIV/AIDS was removed, defaulting from care would decrease by 1.5% (95% CI [−0.8%, 4.6%]). Low perceived concern about HIV/AIDS from leadership also lacked a statistically significant association with defaulting from care (RR 1.19, 95% CI [0.88, 3.65]). We estimated that if all current low levels of perceived concern about HIV/AIDS from leadership was removed, defaulting from care would decrease by 0.8% (95% CI [−1.4%, 3.8%]).

We explored the effect of anticipated stigma or concern on defaulting from care among the subset who were diagnosed with HIV within the past 5 years to examine if the relationship between stigma and default differed for those diagnosed more recently. The estimated effect of any anticipated stigma on default was similar for those diagnosed in the past 5 years (RR 1.19, 95% CI [0.70, 3.44]) when compared to the estimate in the overall sample. Perceived low concern about HIV/AIDS in the community was estimated to increase the risk of default by 17% (RR 1.17, 95% CI [0.59, 3.67]). Perceived low concern about HIV from leaders was estimated to

Table 3
Estimated Effect of Stigma Exposures on Defaulting From Care (N = 311)

	Exposure					
Effect on outcome: Defaulting from care	Any anticipated stigma		Low community shared concerns about HIV/AIDS		Low leadership concerns about HIV/AIDS	
Exposure effect (standard exposed vs. unexposed comparison)						
Risk all exposed[a], %	14.3		16.1		15.1	
Risk all unexposed[a], %	12.8		12.0		12.7	
Risk difference (RD), % [95% CI]	1.5	[−5.3, 20.3]	4.1	[−2.0, 26.8]	2.4	[−3.3, 29.8]
Risk ratio (RR) [95% CI]	1.12	[0.74, 3.16]	1.34	[0.88, 3.49]	1.19	[0.88, 3.65]
Eliminating each exposure (100% reduction from observed)						
Risk under observed exposed[a], %	13.5		13.5		13.5	
Risk all unexposed[a], %	12.8		12.0		12.7	
Risk difference, % [95% CI]	0.7	[−2.2, 4.2]	1.5	[−0.8, 4.6]	0.8	[−1.4, 3.8]
Risk ratio [95% CI]	1.05	[0.87, 1.45]	1.13	[0.94, 1.48]	1.07	[0.94, 1.34]

Note. Bootstrap 95% confidence interval [CI], based on percentiles.
[a] Not causal effects.

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have a larger association with defaulting (RR 1.31, 95% CI [0.82, 4.68]) compared with the association in the overall sample (RR 1.18, 95% CI [0.92, 3.69]). Similarly, if all current levels of anticipated stigma and concern were removed, defaulting from care for those diagnosed in the past 5 years was estimated to decrease by around 1%.

Discussion

In this study, which used linked medical records to a population-representative community survey, both individual anticipated stigma and perceptions of concern about HIV from the community and community leaders were not associated with defaulting from ART treatment during a 1-year period. Among those who were on ART in the prior year, between 25% and 35% reported anticipated HIV stigma, low perceived community concern, and low perceived concern from leaders. This was similar to what was seen previously among HIV-negative individuals within the same villages (Treves-Kagan et al., 2017). Although individual anticipated stigma and low perceived concerns about HIV/AIDS was somewhat more common among those who defaulted from care, there was limited evidence of an association, and none of the measures were significantly associated with defaulting. Population intervention effects to remove observed levels of individual anticipated stigma and low community concern were estimated to yield small reductions (~1% decrease) in default. Our results suggest that interventions targeted at reducing anticipated stigma and increasing a shared concern around HIV may have only a small impact on retention among those already in care for HIV.

Our results contrast with studies in Malawi that showed associations between anticipated stigma and defaulting from care (Chirambo et al., 2019; McGuire et al., 2010). However, nearly all in the Malawi study had defaulted within the first year of starting ART (McGuire et al., 2010). It is possible that anticipated stigma and perceived low community concern do not have as much of an influence on patients who are already established in care compared with patients who are testing and may not know their status or who have a new HIV diagnosis and are not yet seeking care or just initiating (Danaei et al., 2013). Less time on treatment has been associated with increased default (Lajous et al., 2013). Patients in our study were in care and had been diagnosed 4 years prior on average. Thus, most patients in our study would have initiated treatment before a universal test, and treatment was implemented in September 2016 (ART initiated at the time of diagnosis) and therefore likely started ART with lower CD4 counts. One study found that having an ART-eligible CD4 count at diagnosis significantly improved retention in care for HIV patients in rural South Africa (Gosset et al., 2019). Although we did explore the effects of anticipated stigma and concern on default among those diagnosed within the past 5 years, we had low precision given the low number of defaults ($N = 42$) in our modest sample and could not examine smaller time intervals. Future analyses should compare how the effects of stigma and community concerns or attitudes toward HIV on default vary by time on treatment.

We found that roughly 13% of our sample defaulted in a 1-year period, which is lower than has been reported in some prior studies (approximately 30%–40%; Ambia et al., 2019; Fox & Rosen, 2015; The Joint United Nations Programme on HIV/AIDS, 2021). The lower prevalence of default may be because our sample was predominantly female (75%), and male sex has been associated with increased default (Gosset et al., 2019; Kebede et al., 2021). We were unable to estimate associations stratified by sex given the small number of males who defaulted. Additionally, our study sample excluded those who migrated outside of the study area. Migration and mobility are associated with defaulting from care and may have led to a lower prevalence of default in our analytic sample (Dahab et al., 2008; McGuire et al., 2010).

There are several limitations to our analysis. First, the g-formula relies on the causal assumptions of correctly specified models, consistency, positivity, and exchangeability or no unmeasured confounding (Robins et al., 2000). These assumptions cannot be tested in observed data. However, our estimated prevalence of defaulting from care using the parametric g-formula was equivalent to the observed data, indicating that the models are likely correctly specified. Second, our analysis relies on self-reported information about anticipated stigma and perceived community concerns, which may be misreported because of social desirability bias. Last, anticipated stigma was measured in 2018, which was either coincident or slightly after when defaulting would have occurred (between August 2017 and July 2018). We assumed that anticipated stigma did not change substantially during this time but are unable to assess temporality or make causal claims. Despite these limitations, our study uses a unique data set that links health facility–based medical records to population-representative community survey data in a rural, high-prevalence area, allowing us to assess novel research questions about the associations between multilevel measures of stigma and perceived community concerns on default that have not previously been possible to examine.

Conclusions

In our secondary analysis of a population in care in a high HIV-prevalent rural community in South Africa, we found no association between anticipated stigma or perceived level of community concerns about HIV and default from care. Data indicate that hypothetical interventions with components targeted at reducing stigma and increasing a shared community concern around HIV would likely have a small impact on retention in care. Future analyses should examine how perceptions of stigma and concern impact engagement in care among patients who are less established or not in care.

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Received December 12, 2022
Revision received May 31, 2023
Accepted July 10, 2023 ■

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