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**The impact of community support initiatives on the stigma experienced by people living with
HIV/AIDS in South Africa**

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ABSTRACT

In the current context of human resource shortages in South Africa, various community support interventions are being implemented to provide long-term psychosocial care to persons living with HIV/AIDS (PLWHA). However, it is important to analyze the unintended social side effects of such interventions in regards to the stigma felt by PLWHA, which might threaten the successful management of life-long treatment. Latent cross-lagged modeling was used to analyze longitudinal data on 294 PLWHA from a randomized controlled trial (1) to determine whether peer adherence support (PAS) and treatment buddying influence the stigma experienced by PLWHA; and (2) to analyze the interrelationships between each support form and stigma. Results indicate that having a treatment buddy decreases felt stigma scores, while receiving PAS increases levels of felt stigma at the second follow up. However, the PAS intervention was also found to have a positive influence on having a treatment buddy at this time. In addition, a treatment buddy mitigates the stigmatizing effect of PAS, resulting in a small negative indirect effect on stigma. The study indicates the importance of looking beyond the intended effects of an intervention, with the goal of minimizing any adverse consequences that might threaten the successful long-term management of HIV/AIDS and maximizing the opportunities created by such support.

KEYWORDS

- Peer adherence support
- Treatment buddy
- Stigma
- Unintended social side effects
- South Africa

1. INTRODUCTION

As a result of consistent access to antiretroviral treatment (ART), persons living with HIV/AIDS (PLWHA) now face life with HIV/AIDS as a chronic medical condition, rather than an acute, fatal disease (1, 2). The scale-up of ART has raised adult life expectancy in populations with high HIV prevalence (3) and this has in turn “given new meaning to past challenges” (4: p. 231). To successfully fight the HIV/AIDS epidemic in the long term, HIV/AIDS requires psychosocial care in addition to biomedical care to ensure long-term adherence and patient retention (5-7). Given the growing number of patients requiring treatment and support (8), it is becoming increasingly important to empower ART patients to take responsibility for their own treatment (9). Sustaining long-term retention in care (10), maintaining long-term adherence (11, 12), empowering patients (9) and improving the health-related quality of life of those living with HIV (13, 14) are therefore important yet challenging goals in the durable and sustainable response to the HIV and AIDS epidemic.

Although the need for such additional psychosocial care for patients on ART is widely acknowledged, it is also clear that the South African health system is experiencing human resource shortages (11, 15-17). For instance, Hontelez et al. (2012) estimated that an additional 2,200 nurses, 3,800 counselors and 300 doctors would be required in order to guarantee universal access to HIV treatment to all patients with a CD4 cell count of ≤ 350 cells/ μ l in South Africa (18). This tension between supply and demand has led to “task shifting” as part of an overall strategy that includes measures to increase, retain and sustain health staff (11, 16). This strategy refers to “a process of delegation whereby tasks are moved, where appropriate, to less specialized health workers” (15: p. n.p). As the delegation of tasks from doctors to non-physician clinicians (*Type I*) and from the latter to nurses (*Type II*) does not appear to be a sufficient solution to the human resource crisis, a new line of research has been investigating the shifting of tasks to lay community providers and counselors (*Type III*) and to PLWHA themselves (*Type IV*) (15, 19, 20). This strategy was highlighted when the mobilization of communities was identified as one of the five Priority Work Areas in the *Treatment*

2.0 framework for action (2011) by the Joint United Nations Programme on HIV/AIDS (UNAIDS) Secretariat and World Health Organization (WHO) (21).

A broad array of community support initiatives (*Type III*) can be identified (22-24), representing a continuum that stretches from informal activities (9), including members of a PLWHA's social network who volunteer to act as treatment buddies (9, 22, 25), to peers who are paid by health professionals to function as team members (26) and more formal community health workers (CHW) (9, 22, 25). In order to improve the long-term success of ART by sustaining long-term retention in care (10) and maintaining long-term adherence (11, 12), treatment buddies and peer adherence supporters are mobilized. Furthermore, both of these community support initiatives could prompt PLWHA to take more responsibility themselves (6, 19, 27). Nominating a "treatment buddy" to assist PLWHA with adherence issues is one way of helping them manage their own illness (9). This type of supporter is usually someone with close personal ties to the patient, who is aware of the patient's status and can remind and support the patient once ART has commenced (9, 25, 28, 29). Peers can also be mobilized to empower patients (9). The relative success of the ART scale-up has resulted in a growing pool of PLWHA (19). As a consequence of their shared concerns and the shared experience of disease management in the specific context of their communities, the latter community support initiatives are linked in their credibility and identification with PLWHA (26, 30).

Two recent review studies conducted by Bärnighausen et al. (2011) and by Wouters et al. (2012) indicate that receiving psychosocial support from the community can significantly improve treatment outcomes (19, 31). Mobilizing the community reduces the impact of human resource shortages and moves support closer to PLWHA, ensuring it is thus better tailored to local needs (19, 20, 32, 33). Community support initiatives have been identified as a promising strategy for bridging the gap between the patient and health care programs (19). Besides their impact at the community level, local services provided by community support initiatives have proven to be very effective means of

affording psychosocial support (19, 20, 34, 35), improving health-seeking behavior among PLWHA (15, 36), enhancing quality of life (30), ameliorating defaulter tracing (19), empowering patients (19), contributing to psychological and immunological improvements (30) and enhancing adherence to treatment (15, 19, 20, 28, 37).

Despite these positive results, Nyblade et al. (2003) argue that while people with HIV/AIDS might be cared for by their family, community volunteers and health care providers, this care can come with stigma (38). A similar view is expressed in the conceptual model developed by Holzemer et al. (39). Actions that are carried out with good intentions, such as saving lives, can be perceived as stigmatizing by PLWHA (1). To the best of our knowledge, to date there is very little research on the social consequences of adherence intervention. In a qualitative study, O’Laughlin et al. (2012) found that having a treatment partner combats HIV-related stigma (29). The limited research on the unintended social side effects of community support heightens the need to investigate whether community support initiatives that aim to improve treatment have an influence on the stigma felt by PLWHA. HIV is particularly stigmatizing because it is a sexually transmitted infectious disease which is associated with sexual behavior, perceived personal responsibility and negatively regarded social groups (40-43). HIV-related stigma intensifies the challenges of life-long treatment (44, 45), as this “powerful social force” (41: p. 46) has a negative effect on HIV-preventive behaviors (42, 43, 46), quality of life (39, 46-48), disclosure (49, 50), mental health outcomes (51) and adherence to treatment (25, 39). Two main types of stigma can be identified in the literature: external stigma, which consists of negative attitudes expressed to PLWHA (52), and internal stigma, which results from the internalization of AIDS stigmatizing beliefs (53). Internalized stigma is particularly harmful (54), as it can lead to fear about accessing services, sexual risk behavior and psychological consequences, among other outcomes (55-57). As internalized stigma interferes with HIV prevention, treatment and care (58), this article will focus on this type of stigma, investigating the unintended

social side effects of community support for PLWHA in order to provide long-term quality care, treatment and support in a context of human resource shortages.

This study utilizes secondary data analyses from a randomized controlled trial (RCT) entitled “Effective AIDS Treatment and Support in the Free State” (FEATS). The overarching goal of the parent project was to investigate actual AIDS treatment and support in settings where free ART had already been introduced. With regard to the primary research aim of this RCT, when comparing CD4 cell counts in the peer adherence support (PAS) group to the control group, the results are statistically significant, with higher CD4 counts in the intervention group (CONSORT statement in 59). Despite this positive effect, the above-mentioned lack of research on the unintended social side effects of community support heightens the need to investigate whether PAS that improves treatment adherence has an impact on the stigma felt by PLWHA. The first aim of this article is therefore to determine whether PAS intervention and treatment buddying have an impact on the stigma felt by PLWHA.

Both PAS and treatment buddies can be found on the “care continuum” – which is a framework developed by the WHO that represents the range of comprehensive services provided by various actors to the PLWHA, from hospitals to the individual/home, across a continuum (5). Seen on this continuum, peer adherence supporters and treatment buddies differ not only in their degree of formality but also in their strength of ties. However, the linkage mechanisms among different caregiving activities are an aspect of the care continuum that remains poorly defined (60). In fact, as Ogden (2006) notes, “the peer support domain is completely unlinked to the rest of the continuum” (60: p. 337). Within the current scientific research surrounding the substitution and complementarity of more formal support (e.g. peer support), and more informal support (e.g. treatment buddying), there is a debate about whether the use of one form of support goes hand in hand with the partial or complete withdrawal of the other kind of support (substitution models), or whether two kinds of

support can be provided alongside one another (complementarity models). In this regard, the second aim of this article is to analyze the interrelationships between each of these community support forms and their effect on stigma.

2. METHODS

STUDY

The data analyzed for this study were drawn from the “Effective AIDS Treatment and Support in the Free State” (FEATS) study. A full description of this RCT can be found in the CONSORT (Consolidated Standards Of Reporting Trials) statement of the overarching FEATS study (CONSORT statement in 59). This study, which was conducted by the Centre for Health Systems Research & Development at the University of the Free State (UFS), is recorded in South Africa’s national trial register (DOH-27-0907-20250) and has been recognized by the United States National Institutes of Health (NCT00821366). Ethical approval was granted by the UFS Faculty of Health Sciences Ethics Committee (ETOVS 145/07). Written informed consent to participate in the randomized controlled trial and to access patient files during the collection of clinical data was obtained from study participants before interviews began.

SAMPLE

Study participants were selected from twelve public ART clinics across five districts in the Free State Province of South Africa (Lejweleputswa; Motheo; Thabo Mofutsanyana; Fezile Dabi; Xhariep). Patients were required to meet the following three selection criteria: being at least 18 years old, having commenced ART in the previous five weeks, and residing in the town or village where the health facility in question was located. Clinical data were obtained from the National Health Laboratory Services Data and through access to patient files. Participants were asked to complete surveys at Baseline, Follow-up 1 and Follow-up 2. Baseline data collection for this longitudinal survey was conducted between October 2007 and October 2008 among 630 PLWHA. The next round of data

collection was carried out between March and December 2009, with 397 completed interviews. The third interview round was carried out between February and July 2010 among 294 participants. The interviews at Baseline took on average 51 minutes, at Follow-up 1, 36 minutes and Follow-up 2, 31 minutes. The diminishing interview length can be explained by the fact that the questionnaire was shortened, in part due to resource constraints. The questions were asked in one-on-one interviews. Before obtaining written informed consent from participants the trained interviewers emphasized the fact that the data would remain confidential and be anonymous to the researchers conducting the data analysis. The patient interviews included questions on HIV testing, treatment adherence, side effects of treatment and stigma. Attrition was primarily due to mortality among study participants and unknown whereabouts (61), with no statistically differential attrition occurring as a function of stigma experienced (t-test: 0.209, $p = 0.834$). Attrition analysis determines that with regard to the control variables only one significant difference was found: those who completed all three rounds had a higher average real per capita monthly household expenditure at the start of the study (t-test: 2.214, $p = 0.027$), in comparison to those who left the study.

PEER ADHERENCE SUPPORT INTERVENTION

All patients were receiving ART and the associated support provided by the public sector ART program described in the National Treatment Guidelines for ART for Adults (62), based on the following criteria: CD4 cell count below 200 cells/ μ l irrespective of stage, OR WHO Stage IV AIDS-defining illness, irrespective of CD4 count, AND expressed willingness and readiness by the patient to adhere to ART. The following treatment regimens were used in the public sector: regimens 1a (d4T/3TC/efavirenz), 1b (d4T/3TC/NVP), and 2 (AZT/ddI/lopinavir/ritonavir). Following the baseline survey, patients recruited into the study were randomly assigned – using a Zelen-type double randomized consent design – to a control group, to a group who received additional PAS or to group of patients who received PAS and nutritional support (i.e. two 400 g cans of meatballs and spaghetti in tomato sauce a week). A Zelen-type double randomized consent design was adopted in the RCT

component of the study. Within such a design, study participants are only offered the treatment to which they are randomly assigned and can accept or reject treatment. Such a study design is appropriate where: blinding is not practicable or possible; the use of classic randomization and informed consent procedures significantly threatens internal validity; the interventions are highly attractive; the control group receives standard care; and/or the study focuses on a clinically relevant objective or objectives and offers important new insights (63-65). The experiment was implemented in October/November 2008. Experimental subjects were enrolled in the intervention for 11.7 months on average. Patients received an average of 7.6 visits from the peer adherence supporter each month.

Before conducting the RCT, the research team assessed the acceptability of the PAS intervention by means of focus group discussions carried out with ART staff and lay workers. Furthermore, telephone interviews were conducted with 22 randomly selected public sector ART clients and approximately 70 clients of dieticians at facilities in the Free State province who had recently started taking ART. Despite the fact that all respondents were very positive about the idea of the PAS intervention, they expressed concern that the intervention would lead to their HIV status being inadvertently disclosed. As confidentiality is of crucial importance in view of HIV/AIDS-related stigmatization (66), in the actual study the interviewers did not conduct interviews with the households of ART patients they had interviewed personally. Moreover, the household survey was introduced to the respondents as a provincial survey of household health and welfare, in which each household had been selected to participate on an entirely random basis. This decision was taken to ensure a careful balance between confidentiality and reality. Visits from peer adherence supporters took place at times and locations chosen by the ART patients receiving the support, whether at home, work or elsewhere (67).

The peer adherence supporters were PLWHA who had been on ART for at least 12 months. In order to avoid involving lay health workers who were already working for the government or an NGO, peer

adherence supporters were excluded if they had received related training. Theoretical and practical training on HIV/AIDS, ART, adherence, infection control at home and nutrition was based on material developed by the University of the Free State's School of Nursing (67). Peer adherence supporters were paid a monthly stipend of USD 100, conditional on performance (61). When visiting the patient, the peer adherence supporter provided help with adherence and discussed any reasons why this could be difficult, such as stigma. They identified possible ART side effects and took action as appropriate. When necessary, the patient was referred to the clinic. Other topics, such as unemployment benefits or pensions, were also discussed.

Almost all peer adherence supporters were female (98%), and the majority had a higher secondary education degree (Grade 10, 20%; Grade 11, 34%; Grade 12, 38%). The mean age of the peer adherence supporters was 35.8 years. At the close of the intervention, the majority of the 52 peer adherence supporters (55.6%) had already been on ART for five years. When asked how often they experienced difficulty in taking their own ART medication, 95.6% reported never experiencing any difficulty. The majority of the peer adherence supporters (98%) reported that their meetings with PLWHA took place at the PLWHA's home (61).

MEASURES: HIV-RELATED STIGMA

Internalized stigma was operationalized using an adaptation of Berger's HIV stigma scale presented by Wright et al. (55). This shortened version was developed to make the measurement instrument less burdensome for PLWHA. More specifically, negative self-image – which is a negative evaluation of the self based on a person's HIV/AIDS status (68) – was assessed using the following three items on a four-point Likert scale (1: strongly disagree; 2: disagree; 3: agree; 4: strongly agree): 1. I feel that I am not as good a person as others because I have HIV; 2. Having HIV/AIDS makes me feel unclean; 3. Having HIV/AIDS makes me feel that I'm a bad person. Table I shows the means and standard deviations of the items from the negative self-image scale. Confirmatory factor analysis was used to

examine the latent structure of the negative self-image scale. In order to evaluate whether the resulting parameter estimates were good measures of their latent constructs, we included items which had factor loadings above the 0.40 threshold (69). All of the factor loadings were above 0.60. Following the method described by Hatcher (1994), the composite reliability of the scales was calculated. A score above 0.70 indicates a reliable scale (70). At both follow-ups, the composite reliability of this negative self-image factor was found to be above the 0.70 threshold recommended (Follow-up 1: 0.86; Follow-up 2: 0.88).

Table I. Means and distribution of the items of the negative self-image scale

	Follow-up 1	Follow-up 2
I feel that I am not as good a person as others because I have HIV	1.59 (SD: 0.80)	1.52 (SD: 0.753)
Having HIV/AIDS makes me feel unclean	1.46 (SD: 0.680)	1.43 (SD: 0.677)
Having HIV/AIDS makes me feel that I'm a bad person	1.45 (SD: 0.685)	1.43 (SD: 0.652)

MEASURES: TREATMENT BUDDY

Treatment buddying lies at the informal end of the support continuum. Data on treatment buddying were collected using the question: ‘Have you since the previous interview had a treatment buddy help you to see that you take your ARV medication?’. Of the PLWHA we interviewed, 32.8% and 26.7% responded affirmative at Follow-up 1 and Follow-up 2, respectively. The vast majority of treatment buddies were female (74.8%)¹ and their average age was 32.2 years old (SD: 14.46).¹ The percentage of treatment buddies on ART increased from 23.2% at Follow-up 1 to 67.3% at Follow-up 2. Eight in ten PLWHA were being visited by their treatment buddy at home at the first follow-up.¹ In 94.5% of cases, this person – who originated from the social network of the PLWHA – was not being remunerated for their support.¹ Half of the treatment buddies were partners or children of the PLWHA. It emerged that 8.8% of the PLWHA we interviewed had confused their peer adherence

supporter with their treatment buddy;¹ in order to avoid bias, we excluded these cases from the analyses. Other treatment buddies were found to originate from the direct social environment of the PLWHA (sibling, parent, friend or neighbor).¹

MEASURES: CONTROL VARIABLES

Previous research has indicated that the following background characteristics are often associated with stigma felt by the PLWHA. Demographic data (46, 71, 72) include sex, age and highest education level attained. We also included health-related measures, as they have been demonstrated to impact on ART outcomes in previous studies (46, 56, 73): Baseline CD4 count; CD4 cell count at Follow-ups 1 and 2; ART duration in days; presence or absence of side effects; and intermittent use of ART. A third group of variables included in the study consisted of family-related confounders (39, 74): the total number of household members, sex and education level of household head, real per capita monthly household expenditure (standardized), and whether or not the PLWHA lived in informal housing, as households can also be a potential source of stigma. The final control variables concerned whether or not the patient was attempting to keep his or her HIV positive status a secret (46, 51), and the presence or not of anxiety and depression (46, 56).

To select our control variables, we examined the relationship between the above-mentioned control variables and negative self-image and having a treatment buddy at both follow-ups. Preliminary analysis revealed that the anxiety and depression scale was significantly associated with negative self-image at the first follow-up ($\beta = 0.234$, $p = 0.000$). Negative self-image at the second follow-up is significantly associated with baseline health (CD4 cell count at baseline: $\beta = -0.167$, $p = 0.015$). The presence of side effects, receiving nutritional support as provided in the study, and living in an informal house were significantly associated with having a treatment buddy at the first follow-up, with the respective parameters: $\beta = 0.172$, $p = 0.003$; $\beta = 0.152$, $p = 0.010$ and $\beta = 0.148$, $p = 0.018$. At

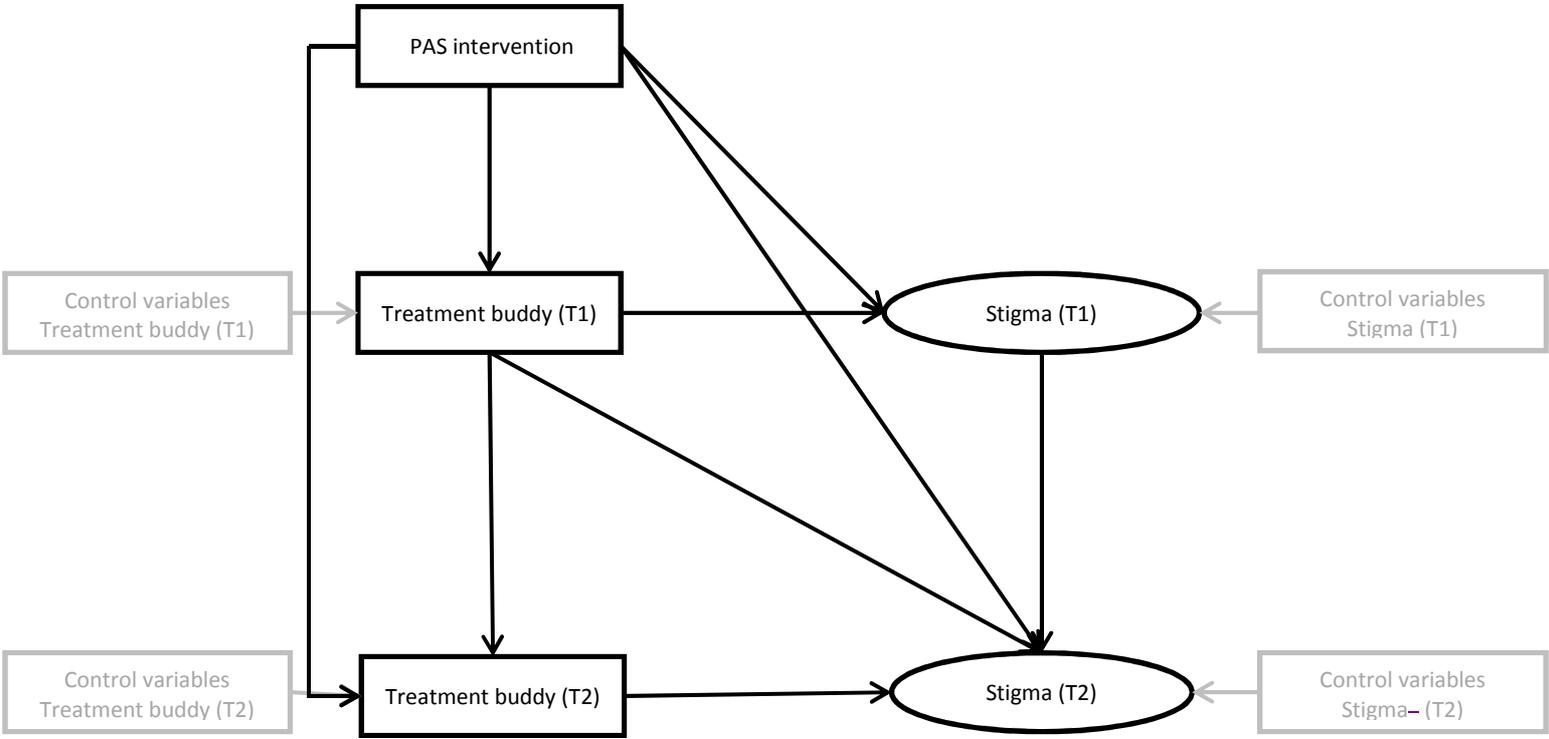
¹ Information not available at Follow-up 2.

the second follow-up, trying to keep HIV a secret and receiving nutritional support as provided in the study was significantly associated with having a treatment buddy ($\beta = -0.137, p = 0.018$; $\beta = 0.185, p = 0.003$). These characteristics were therefore included as control variables in the subsequent analyses.

ANALYSIS

In order to investigate both research aims, latent cross-lagged modeling was performed using Mplus version 7. Data exploration was carried out using SPSS version 20. Since the Shapiro-Wilk Test of Normality indicated that our sample deviated from the normality assumption, the models were estimated using MLR, a robust estimator for non-normal data (75). Using the chi-square difference test adapted for MLR estimation (76), we found that the latent stigma factor to be fully metric invariant over time (Satorra-Bentler scaled chi-square difference test TRd: 4.4288, $p = 0.400$). Consequently, all factor loadings were set equally across the two rounds (77). Furthermore, the measurement error associated with a Follow-up 1 latent factor item correlated with the measurement error associated with the corresponding Follow-up 2 item (78). For the sake of simplicity, error correlation paths are not shown in Figure 1. At the second follow-up we used two dummy variables to control for whether or not the patient completed the whole scheme of the experiment. To analyze the interrelationships between each of these community support forms and stigma (second research aim), a specific indirect effect was estimated to examine whether having a treatment buddy mediates the effect of PAS on stigma felt by PLWHA. The model was estimated based on the observed exogenous variables. Missing data theory applies only to endogenous dependent variables. The adequacy of the models was evaluated based on Hu and Bentler's cutoff criteria (1999), in which two of the following three criteria must be met for a satisfactory global model fit to be attained: comparative fit index (CFI) $\geq .95$, root mean square error of approximation (RMSEA) $\leq .06$, and standardized root mean square residual (SRMR) $\leq .08$. (79).

Figure 1. Latent cross-lagged model of the impact of community support initiatives on the stigma felt by PLWHA



3. RESULTS

Table II. Descriptive statistics

Control variables (time constant)					
Sex (Female)		75.1 %	N: 259		
Education level	No formal education	3.1 %	N: 259		
	Primary education	25.5 %			
	Some secondary education	50.5 %			
	Completed secondary education	17.4 %			
	Tertiary education	3.5 %			
Age (years)		38.97 (SD: 9.34)	N: 260		
		Baseline	Follow-up 1	Follow-up 2	Test statistic
Internalized stigma					
Sum score of internalized stigma		n.a.	4.53 (SD: 1.99) N: 258	4.21 (SD: 1.79) N:258	T-test T: 2.043 P: 0.042
Control variables (time changing)					
CD4 cell count		141.17 (SD: 92.2) N: 236	326.29 (SD: 198.70) N:253	377.97 (SD: 213.85) N:256	F-test F: 118.259 P: 0.000

Treatment duration in days		39.32 (SD:34.86) <i>N</i> :262	499.63 (SD:85.40) <i>N</i> :260	815.53 (SD:83.79) <i>N</i> :264	F-test F:7737.413 P: 0.000
Intermittent use of ART (yes)		n.a.	8.4 % <i>N</i> : 261	9.4 % <i>N</i> : 265	McNemar test P: 0.678
Side effects (yes)		30.9 % <i>N</i> : 262	7.7 % <i>N</i> : 259	7.6 % <i>N</i> : 263	Chi ² test Chi ² : 72.271 P: 0.000
Nutritional support		n.a.	23.7 % <i>N</i> : 194	23.7 % <i>N</i> :194	McNemar test P: 1.000
Keep HIV status a secret (yes)		n.a.	44.0 % <i>N</i> :257	44.0 % <i>N</i> :257	McNemar test P: 1.000
Anxiety and depression index		10.35 (SD:6.69) <i>N</i> :252	5.79 (SD: 5.76) <i>N</i> :258	4.80 (SD: 5.371) <i>N</i> :261	F-test F: 62.77 P: 0.000
Household size		3.40 (SD:2.06) <i>N</i> : 265	3.22 (SD: 1.93) <i>N</i> : 246	3.16 (SD:1.96) <i>N</i> : 265	F-test F: 1.023 P: 0.360
Sex of household head (Female)		66.8 % <i>N</i> : 262	65.2 % <i>N</i> : 247	66.4 % <i>N</i> : 259	Chi ² test Chi ² : 0.160 P: 0.923
Education level of household head		<i>N</i> :259	<i>N</i> :246	<i>N</i> :251	Chi ² test Chi ² : 2.974 P: 0.936
	No formal	6.6 %	5.3 %	7.6 %	

	education				
	Primary education	37.5 %	37.8 %	32.7 %	
	Some secondary education	42.0 %	43.9 %	45.4 %	
	Completed secondary education	12.4 %	11.4 %	13.1 %	
	Tertiary education	1.5 %	1.6 %	1.2 %	
Informal housing (yes)		20.4 % <i>N: 265</i>	15.2 % <i>N: 244</i>	15.5 % <i>N: 265</i>	Chi ² test Chi ² : 3.154 P: 0.207
Real per capita monthly household expenditure		1018.96 (SD: 986.34) <i>N: 259</i>	886,94 (SD: 662.86) <i>N:242</i>	869.53 (SD: 1148.16) <i>N:262</i>	F-test F: 1.7866 P: 0.155

Table II provides an overview of the sample statistics. Analysis of the covariates across study arms revealed significant differences between the respondents who underwent the intervention and those of the control group concerning the following control variables: sex of household head (Baseline: Chi²: 9.332, p = 0.001; Follow-up 1: Chi²: 7.018, p = 0.006); keep HIV a secret (Follow-up 2: Chi²: 3.259, p = 0.046); anxiety and depression index (Follow-up 2: T-test: -2.45, p = 0.015); real per capita monthly household expenditure (Follow-up 2: T-test: 2.192, p = 0.030). A significant difference was found for the average sum score of internalized stigma (T-test: 2.043, p: 0.042) from 4.53 (SD: 1.99) at Follow-up 1 to 4.21 (SD: 1.79) at Follow-up 2. Moreover, testing the differences in control variables between Baseline, Follow-up 1 and Follow-up 2, the F-test and the post-hoc Tukey test

revealed a significant difference in the score on the anxiety and depression index between Baseline and both follow-ups (F-test: 62.77, $p = 0.000$). Furthermore, the results reveal that there is a significant difference in treatment duration days between the three waves (F-test: 7737.413, $p = 0.000$). Similar results can be found for the average CD4 cell count, with significant differences between the three waves (F-test: 118.259, $p = 0.000$). A significant difference was found for the side effects experienced (Chi² test: 72.271, $p = 0.000$). No significant differences were found for the other control variables between the three waves.

Descriptive analysis revealed that 38.97 years (SD: 9.34) was the mean age in the sample. The majority of the patients interviewed were female (75.1%). When assessing the highest level of education achieved, 3.1% of patients had no formal education, 25.5% had completed primary education, 50.5% enjoyed some secondary education, 17.4% had completed secondary education and only 3.5% had completed tertiary education. At ART initiation, mean CD4 cell count was 147.17 (SD: 92.2). From Follow-up 1 the CD4 cell count increased to 326.29 (SD: 198.70), whereas the average CD4 cell count on Follow-up 2 was 377.97 (SD: 213.85). At Baseline, patients had been on ART for an average of 39.32 (SD: 34.86) days. At Follow-up 1 the average duration of their treatment was 499.63 days (SD: 85.40), while at Follow-up 2 they had been taking their medication for about two years on average (average: 815.53, SD: 83.79). At Follow-up 1, less than one out of ten respondents (8.4%) indicated that they had interrupted their treatment at least once, while 9.4 percent indicated this at Follow-up 2. The PLWHA who reported side effects decreased from Baseline (30.9%) to Follow-up 1 (7.7%) and then remained stable at 7.6% at Follow-up 2. People receiving nutritional support remained stable (23.7%) at both follow-ups. The mean household size remained relatively stable over time (Baseline: 3.40 [SD: 2.06]; Follow-up 1: 3.22 [SD: 1.93]; Follow-up 2: 3.16 [SD: 1.96]). The average per capita monthly household expenditure was higher at Baseline (1018.96 [SD: 986.34]) than at Follow-up 1 (886.94 [SD: 662.86]) and Follow-up 2 (869.53 [SD: 1148.16]). At Baseline, 20.4% of the PLWHA lived in an informal house, compared to 15.2% at Follow-up 1 and

15.5% at Follow-up 2. The percentage of PLWHA who tried to keep their HIV secret remained stable (44.0%). The score on the anxiety and depression index decreased, from 10.35 (SD: 6.69) at Baseline, to 5.79 (SD: 5.76) at Follow-up 1 and 4.80 (SD: 5.371) at Follow-up 2. At Baseline, 66.8% of the household heads were female, compared to 65.2% at first follow-up and 64.4% in the subsequent follow-up. Less than one out of ten household heads had no formal education (Baseline: 6.6%; Follow-up 1: 5.3%; Follow-up 2: 7.6%). The majority of the heads of the household had primary (Baseline: 37.5%; Follow-up 1: 37.8%; Follow-up 2: 32.7%) or some secondary education (Baseline: 42.0%; Follow-up 1: 43.9%; Follow-up 2: 45.4%). At Baseline, 12.4% of the household heads had obtained a Grade 12 certificate, in comparison with 11.4% at Follow-up 1 and 13.1% at Follow-up 2. Of the household heads, 1.5%, 1.6% and 1.2%, respectively, had completed tertiary education at Baseline, Follow-up 1 and Follow-up 2.

Table III illustrates analyses examining the influence of PAS and having a treatment buddy on felt stigma over time. As indicated by the CFI (0.950), SRMR (0.047) and RMSEA (0.043) in Table III, a good model fit was found. To give a clear overview of the main effects of the analysis, the results of the control variables are not shown in the table. The significant control variables are discussed below. None of the dummy variables controlling for whether or not the patient completed the whole scheme of the experiment were significant. First, we will determine the factors that influence having a treatment buddy. Our findings indicate that experiencing side effects of ART encourages persons living with HIV/AIDS to seek support from a treatment buddy at the first follow-up ($\beta = 0.130$, $p = 0.038$). Keeping HIV a secret has a negative effect on seeking the support of a treatment buddy at the second follow-up ($\beta = -0.125$, $p = 0.029$). Table III demonstrates that the PAS intervention has a positive influence on seeking a treatment buddy ($\beta = 0.265$, $p = 0.007$) at the second follow-up. This finding indicates that external support can stimulate the uptake of informal support. Second, with regard to the influence on negative self-image, our results show that the autoregressive path from the latent negative self-image factor at Follow-up 1 to its Follow-up 2 counterpart has a coefficient of

0.130 ($p = 0.045$). At the first follow-up, the anxiety and depression index had a positive influence on feeling stigmatized ($\beta = 0.265$, $p = 0.000$). The CD4 cell count at Baseline was negatively associated with stigma felt at Follow-up 2 ($\beta = -0.122$, $p = 0.036$). Furthermore, the study shows that receiving PAS significantly increased the level of stigma experienced at the second follow-up ($\beta = 0.311$, $p = 0.001$). In addition, results indicate that having a treatment buddy produces a destigmatizing effect on the PLWHA ($\beta = -0.149$, $p = 0.009$). The specific indirect effect produced by having a treatment buddy at Follow-up 2 is small and negative but nevertheless a significant effect ($\beta = -0.039$, $p = 0.046$). This indirect effect indicates that through the stimulation of treatment buddy uptake, PAS has a small negative effect on the level of stigma experienced. Having a treatment buddy has a destigmatizing effect on the PLWHA and might protect them against the stigmatizing influence of receiving treatment adherence support. The squared multiple correlation coefficient (R^2) for the model predicting the search for a treatment buddy was 0.141 at the first follow-up and 0.095 at the second. The amount of explained variance in negative self-image was 7.6% at Follow-up 1, compared to 10.5% at Follow-up 2.

Table III. Standardized model results from cross-lagged model of impact of community support on stigma over time ($N = 267$)²

² Model is controlled for variables discussed in the measures section.

	Beta	p-value
Follow-up 1		
Treatment buddy		
Treatment buddy (Baseline)	0.284	0.000
PAS intervention	0.109	0.117
Negative self-image		
Treatment buddy (Baseline)	-0.050	0.486
Treatment buddy (Follow-up 1)	-0.049	0.483
PAS intervention	0.038	0.543
Follow-up 2		
Treatment buddy		
Treatment buddy (Follow-up 1)	0.128	0.050
PAS intervention	0.265	0.007
Negative self-image		
Negative self-image (Follow-up 1)	0.130	0.045
Treatment buddy (Follow-up 1)	-0.005	0.935
Treatment buddy (Follow-up 2)	-0.149	0.009
PAS intervention	0.311	0.001
Model fit		
CFI	0.950	
RMSEA	0.043	
SRMR	0.047	

4. DISCUSSION

Given the growing number of patients requiring long-term treatment and support (8), it is becoming increasingly important to sustain long-term retention in care (10), maintain long-term adherence (11, 12) and empower ART patients to take responsibility for their own treatment (9). Psychosocial care is indispensable in responding to the challenges of living with HIV/AIDS as a chronic illness (5). In a climate of “task shifting” (11, 16), mobilizing the community has become an important strategy in providing such encompassing treatment (19, 32, 33). Both PAS and treatment buddying have been found to address these needs. Although considerable research has been devoted to analyzing the impact of community support initiatives on positive outcomes, such as adherence and quality of life, very little attention has been paid to the unintended social side effects of such community support. In this regard, the double aim of this article was [1] to analyze whether the PAS intervention and having a treatment buddy influence the stigma felt by PLWHA; and [2] to investigate the interrelationships between each form of community support and stigma.

In regards to the first aim, our results show that receiving PAS increased feelings of stigma at the second follow-up. This might be explained by the fact that emphasizing anonymity and confidentiality – as done in this intervention – can paradoxically be counterproductive (1, 80). In this regard, De Cock et al. (2002) state that “the quest for secrecy promotes rather than breaks the destructive silence around HIV/AIDS” (80: p. 69). This study provides scientific support to the warning given by Rodriguez-García et al. (2013), who drew attention in the 2013 World Bank report to the idea that community interventions can have unintended adverse consequences, such as exacerbating experienced levels of stigma (81). Moreover, we might expect the stigmatizing effect to become even greater, since peer adherence supporters stated in the post-intervention evaluative focus group discussions that reasons given for withdrawal from the study included fear of disclosure, feelings of shame and concerns about what the neighbors would say, among other things. Furthermore, results indicated that the anxiety and depression index had a positive influence on feeling stigmatized. This

finding is consistent with the results of a meta-analysis by Logie and Gadalla (2009) (46). Previous research has shown that PLWHA who feel anxiety, depression and alienation are also more likely to feel stigmatized (57).

In line with previous research that has identified the establishment of a support group as effective in reducing stigma (30, 46), this quantitative study demonstrates that seeking a treatment buddy also leads to the diminishment of stigma. O’Laughlin et al. (2012) obtained similar results in their qualitative research on the social consequences of treatment partnering in Tanzania (29). The destigmatizing effect of having a treatment buddy might be explained by the fact that treatment buddies socialize with PLWHA in public (25, 29), compare HIV/AIDS to other less stigmatized diseases (25), publicly criticize individuals who stigmatize PLWHA (29) and challenge the myths surrounding HIV/AIDS (25). At the same time, a treatment buddy mitigates the stigmatizing effect of PAS, resulting in a small negative indirect effect on stigma. These results suggest that informal caregiving is an important factor in the prevention of adverse consequences such as stigma.

There are a broad array of community support initiatives, which can be represented on a continuum that stretches from informal to more formal activities. Peer adherence supporters and treatment buddies differ not only in their degree of formality but also in their strength of ties. Treatment buddies are an example of strong informal ties, which are intimate ties that tend to be multi-stranded and regularly maintained. Peer adherence supporters exemplify weak formal ties, as they are non-intimate ties which tend to be single-stranded and infrequently maintained (82, 83). When peers are professionalized, their mutual identification, credibility and commonality with patients diminishes, as their accountability to the target population shifts to the health care system (84). As our results show, care provided by untrained, unremunerated persons who have strong personal ties to the PLWHA has a different, unintended social side effect from care provided by trained, paid peers from outside the patient’s social network. This study provides scientific support to Ogden’s (2006)

claim that it is important to make “clear distinctions between care that is provided through formal structures (e.g. clinical and non-clinical care provided in the home by volunteer lay providers) and care provided in the home that is not supported through formal programs (non-clinical care which is provided by family members, friends and neighbors)” (60: p. 339).

With regard to the second aim of this study, namely to investigate the interrelationships between each of the two forms of community support in question and stigma, our results indicate that receiving support from a peer adherence supporter stimulates the uptake of assistance from a treatment buddy. These results are relevant to the current scientific debate surrounding the substitutability or complementarity of formal and informal support. Substitution models are based on the assumption that the use of one form of support goes hand in hand with the partial or complete withdrawal of another kind of support; complementarity models, meanwhile, state that the two kinds of support can be provided alongside one another. In Western gerontological studies, where these models have their roots, more evidence has been found to support the latter assumption (85). Our results, which suggest that the search for informal support can be stimulated by formal support, are also more consistent with the complementarity view. HIV/AIDS may isolate PLWHA from the communities they depend on (29, 30). Like those of other studies, our results are promising in that patient use of psychosocial support may facilitate the rebuilding of their social network of informal support (14, 30).

One of the strengths of this study is that it measures stigma as a latent construct over time, since stigma is a social construct that might change dynamically over the illness trajectory (49, 71). Moreover, this research provides a novel look at community support interventions. However, this study is one of the first to investigate the unintended social side effects of community support interventions and the interrelationship between different kinds of community support. Further research is required to replicate this study in other settings. Furthermore, results indicate that

experiencing side effects of ART encourages persons living with HIV/AIDS to seek support from a treatment buddy. This might be explained by the fact that experiencing side effects could make HIV/AIDS more visible (e.g. Lipodystrophy) and might make the PLWHA feel more ill, which could stimulate the search for support (58). Inspired by these results, further research should explore in greater depth the relationship between disease progression and the usage of support. A number of limitations should also be acknowledged. First, the absence of a random sample limits the generalizability of our interpretations. Large-scale studies that use a random sample are thus an important research priority. Second, a lack of additional information on treatment buddies at the second follow-up means that there is some possibility of overlap; although, this is highly unlikely since we excluded respondents who confused their peer adherence supporter with a treatment buddy at Follow-up 1. Third, we could not control the analysis for baseline rates of stigma, as two out of three factor loadings were below the 0.40 boundary line (69) and this factor did not show configural invariance over time (77). It is recommended that future research replicates this study while also incorporating baseline stigma into the analyses to control for its effect and to investigate differences in rates of stigmatized feelings pre and post intervention. A fourth limitation relates to the way in which stigma was approached in this study. Stigma is particularly harmful when society's negative views are adopted and internalized by PLWHA (54); analyzing the impact of PAS on such a negative self-image is therefore important. Various types of stigma have been described (39, 46), however, and this study relies on a latent construction of only one type. Further research is required to investigate the influence of community support initiatives on the multiple forms of stigma. Moreover, as it was not possible to operationalize the psychosocial mechanisms (86) of receiving peer adherence support and having a treatment buddy using the FEATS data, future research could make interesting progress by analyzing the pathways along which social support is offered. Furthermore, as articulated by O'Laughlin et al. (2012), qualitative research could help to further uncover other social consequences of treatment intervention for HIV/AIDS (29).

These results have both theoretical and practical implications. With regard to the theoretical aspect, this study links peer support to other care received by PLWHA. This result provides impetus to respond to the research need surrounding the “care continuum” framework, to link the peer support domain to the different caregiving activities on the continuum (5, 60). Examining the linkage among different types of care is important as it may help reduce costs by allowing greater efficiency (87) and may provide opportunities for promoting related health care, such as the screening of family members for tuberculosis and other infectious diseases (60, 87). Regarding the implications for policy and practice, these results imply that when evaluating an intervention it is important to look beyond its aimed effects. On the one hand, unintended adverse consequences should be taken into account, such as enhanced stigma, which might threaten the successful management of life-long treatment challenges. On the other hand, unintended positive social side effects deserve attention in any comprehensive evaluation of interventions. For instance, the study provides further support to the idea that it is worthwhile to focus on stimulating informal psychosocial care through formal care initiatives.

5. CONCLUSIONS

As various community support interventions are now being implemented with the aim of improving the lives of those living with HIV/AIDS, it is important to analyze their unintended positive and negative social side effects. The resulting knowledge may provide opportunities to minimize the adverse consequences threatening the successful long-term management of HIV/AIDS and to maximize the positive social side effects, taking optimal advantage of the opportunities created by this support. More research is required to explore other unintended positive and negative social side effects of such support in order to provide long-term quality care, treatment and support in a context of human resource shortages.

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