



Published in final edited form as:

AIDS Behav. 2022 June ; 26(6): 1892–1904. doi:10.1007/s10461-021-03540-1.

Perceptions about local ART adherence norms and personal adherence behavior among adults living with HIV in rural Uganda

Jessica M. Perkins^{1,2,*}, Bernard Kakuhihikire³, Charles Baguma³, Justin D. Rasmussen⁴, Emily N. Satinsky⁵, Allen Kiconco³, Justus Kananura³, Carolyn M. Audet^{2,6}, Mark J. Siedner^{5,7,8,9}, Jessica E. Haberer^{5,8}, David R. Bangsberg^{3,10}, Alexander C. Tsai^{3,5,8,9}

¹Peabody College, Vanderbilt University, Nashville, TN, USA

²Vanderbilt Institute of Global Health, Vanderbilt University Medical Center, Nashville, TN, USA

³Mbarara University of Science and Technology, Mbarara, Uganda

⁴Duke University, Durham NC, USA

⁵Center for Global Health, Massachusetts General Hospital, Boston MA USA

⁶University of Witwatersrand, Johannesburg, South Africa

⁷Division of Infectious Diseases and Medical Practice Evaluation Center, Massachusetts General Hospital, Boston, MA, USA

⁸Harvard Medical School, Boston, MA, USA

⁹Mongan Institute, Massachusetts General Hospital, Boston MA USA

¹⁰Oregon Health & Science University-Portland State University School of Public Health, Portland, OR, USA

Abstract

Although misperceived norms often drive personal health behaviors, we do not know about this phenomenon in the context of antiretroviral therapy (ART) adherence. We conducted a cross-sectional study including all persons living with HIV (PLWH) on ART across eight villages

*Corresponding author: PMB 90, 230 Appleton Place, Vanderbilt University, Nashville, TN 37203-5721 USA; jessica.m.perkins@vanderbilt.edu; Phone: (615) 875-3289.

Author contributions: JMP conceived of and designed the study. JMP, BK, JDR, AK and JK participated in the data collection. JMP wrote the first draft. JMP, BK, CB, JDR, ENS, AK, JK, CMA, MJS, JEH, DRB, and ACT participated in interpretation of the data and provided critical revisions. ACT provided study oversight. All authors read and approved the final manuscript.

Conflicts of interest/Competing interests: The authors have no relevant financial or non-financial interests to disclose.

Ethical approval: Approval was obtained from the ethics committees of Massachusetts General Hospital, Mbarara University of Science and Technology, and Vanderbilt Human Research Protections. The study also received clearance from the Uganda National Council of Science and Technology and the Research Secretariat in the Office of the President of the Republic of Uganda. The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

Consent to participate: Written informed consent or a thumbprint indicating consent to participate was obtained from each participant.

Consent to publish: Written informed consent or a thumbprint indicating consent to have related data published was obtained from each participant.

Availability of data and code: Data and code available upon request.

in one parish in a rural region of southwestern Uganda. We used surveys to measure personal reports of ART adherence (not missing any doses of ART in the past 7 days was considered optimal adherence whereas missing doses was considered sub-optimal adherence) and perceived norms about the local ART adherence norm (whether or not each individual thought ‘most other PLWH on ART in this parish’ missed any doses in the past 7 days). Multivariable Poisson regression models were used to estimate the association between perceived norms and personal adherence. Among 159 PLWH on ART (95% response rate), 142 (89%) reported no missed doses. However, 119 (75%) thought most individuals in this population of PLWH on ART were sub-optimally adherent. This misperception about the local ART adherence norm was prevalent in every subgroup of PLWH. Misperceiving the local ART adherence norm to be sub-optimal adherence was associated with a reduced likelihood of optimal adherence among married PLWH (adjusted relative risk [aRR] = 0.83, 95% confidence interval [CI] 0.71–0.97). The association was similar but imprecisely estimated for all PLWH (aRR = 0.91, 95% CI 0.82–1.01). Interventions to correct misperceived ART adherence norms as a stand-alone intervention or as a complement to other adherence promotion programs may influence ART adherence behavior and perhaps reduce HIV-related stigma.

Resumen

Aunque las normas mal percibidas impulsan los comportamientos personales de salud, no sabemos acerca de este fenómeno en el contexto de la terapia antirretroviral (TAR). Este estudio transversal incluyó a todas las personas que viven con el VIH (PVVS) y con TAR en ocho pueblos de una parroquia en una región rural del suroeste de Uganda. Utilizamos encuestas para medir los informes de adherencia personal al TAR (no faltar ninguna dosis de TAR en los últimos 7 días se consideró como acción óptima; mientras que faltar las dosis se consideraron como acción subóptima) y las normas percibidas sobre la norma local de adherencia al TAR (si cada individuo pensó o no que 'la mayoría de las otras PVVS en esta parroquia omitieron alguna dosis en los últimos 7 días). Usamos modelos multivariados de regresión de Poisson para estimar la asociación entre las normas percibidas y la adherencia personal. De las 159 PVVS con TAR (tasa de respuesta del 95%), 142 (89%) reportaron que no faltaron ninguna dosis. Sin embargo, 119 (75%) pensaron que la mayoría de los individuos en esta población de PVVS con TAR eran subóptimamente adherentes. Esta percepción incorrecta sobre la norma local de adherencia al TAR fue prevalente en todos los subgrupos de PVVS. La percepción incorrecta de que la norma local de adherencia al TAR era subóptima se asoció con una menor probabilidad de adherencia óptima entre las PVVS casadas (riesgo relativo ajustado [aRR] = 0,83; intervalo de confianza [IC] del 95% 0,71-0,97). La asociación fue similar pero imprecisamente se estima para todas las PVVS (aRR = 0,91; IC 95% 0,82-1,01). Las intervenciones para corregir las normas mal percibidas de TAR, como una intervención independiente o como un complemento de otros programas de promoción de la adherencia, pueden influir en el comportamiento de la adherencia al TAR y tal vez reducir el estigma relacionado con el VIH.

Keywords

Antiretroviral therapy; Descriptive norms; Social networks; Social norms; Stigma

INTRODUCTION

For persons living with HIV (PLWH), high and consistent levels of adherence to HIV antiretroviral therapy (ART) are important for maintaining HIV-1 RNA viral suppression (1), increasing life expectancy (2, 3), and reducing HIV transmission risk (4). In Uganda, viral suppression rates remain below "95-95-95" targets (5, 6). Systematic reviews have found sex, current substance use, depressive symptoms, social support, HIV-related stigma, trust/satisfaction with health care workers and HIV care providers, structural access barriers, and other factors to correlate with ART adherence (7, 8). However, no studies have assessed perceived norms about ART adherence as a driver of personal ART adherence among adults in sub-Saharan Africa. Changing perceptions about local ART adherence norms may be an understudied intervention opportunity to improve rates of ART adherence.

Conceptual Framework

Empirical studies of social influence and social conformity have clearly demonstrated that others' attitudes and behavior can affect one's own attitudes and behavior (9-12). Additionally, individuals think and behave in ways that match what they believe to be social norms, that is, the typical attitudes and behavior among most others, especially in contexts of uncertainty (13-16). Based on empirical evidence, the Focus Theory of Normative Conduct differentiated between perceptions about what most others think ought to be done (i.e., injunctive norms) and perceptions about what most others do (i.e., descriptive norms) as separate constructs in driving individual behavior (13). At the same time, Social Norms Theory distinguished what an individual thinks are the typical or most common behaviors and attitudes (i.e., perceived norms) from the behaviors and attitudes that are actually the most common behaviors and attitudes (i.e., actual norms) among individuals within a specific social referent group (14).

This distinction between perceived and actual norms also arose from empirical research (primarily of substance use in high-resource settings). Studies found that individuals often believed harmful behaviors and attitudes were more common (among peers in their social reference groups) than they actually were and they believed protective behaviors and attitudes were rarer (among peers in their social reference groups) than they actually were (17). Moreover, misperceptions existed in all settings even though settings differed in the strength of their actual norms (i.e., varying prevalence of behavior and attitude). Follow-up studies also then found that these misperceptions mattered as individuals' norm perceptions often predicted individuals' own behaviors (17, 18). Moreover, even after adjusting for actual norms of behavior within that same social referent group, perceived norms were still strongly associated with personal behavior (19).

The social norms approach to behavior change builds on these theories and empirical studies by focusing on changing misperceived norms (14, 19-26). This class of intervention emphasizes conveyance of information about existing health-promoting norms to people who may misperceive or be unaware of these norms. The goals are to nudge uptake of positive or health-promoting behavior and attitudes among some individuals, support ongoing positive behaviors and attitudes among others, and reduce the extent to which norms are misperceived. Additionally, increased (accurate) awareness of local norms creates

opportunity for more conversation about, support for, and/or tolerance of desired health behaviors and attitudes within the general population, which may in turn cause further uptake of desired behaviors and reduction of risk behaviors and/or attitudes.

Specifically, individuals may take up the desired behavior after experiencing cognitive dissonance with their own prior behavior upon learning the true local norms. Others may be supported to take up the desired behavior (or may be prevented from engaging in risk behavior) by individuals who learn true local norms. Additional individuals may be less likely to discontinue engaging in a health-promoting behavior that is the norm based on both of these reasons. Thus, with this class of intervention, multiple intrapersonal and interpersonal processes related to changes in perceived norms among different groups of individuals may drive changes in personal behavior (14, 24, 27). Experimental studies have found that interventions communicating what most people within a salient referent group actually do have changed individuals' perceptions about which behaviors and attitudes are most common, which, in turn, has led to changes in personal behavior and overall population rates of behavior (19, 28-32).

Perceived Norms and HIV Prevention in Sub-Saharan Africa

Emerging literature from sub-Saharan Africa suggests behavioral (or attitudinal) norms may be widely misperceived and that these misperceptions may similarly influence personal behaviors. Several studies have found that adults tend to overestimate the prevalence of health risk behaviors among peers in their social reference groups and underestimate the prevalence of health promotion behaviors, in relation to HIV testing, HIV stigma, condom use, sexual partner concurrency, substance use, mosquito net use, and parental discipline (33-44). These studies also indicate that the behaviors individuals perceive to be typical or normative among peers are associated with their own engagement in the same behavior. Several field experiments regarding other topics in sub-Saharan Africa find associations between changes in perceived norms and changes in individual attitudes and behaviors (45-49).

Studies based on objective measures of ART adherence often show that most PLWH in care achieve high adherence (though overall adherence rates are still below target) (50, 51). Many PLWH may be unaware that other PLWH achieve such high adherence rates, however. Salient information available in the local context (i.e., verbal and non-verbal cues) influences the formation of perceived norms (52). Cues suggesting that high adherence is normative among PLWH peers may not be widely disseminated in local environments for several reasons. First, HIV-related stigma often prevents discussion about HIV serostatus, prevention behavior, and ART regimens with partners and social ties (53-57). Second, conditional on there being any "everyday discussion" about ART, then PLWH may be more likely to discuss challenges related to taking ART and missing doses rather than everyday (adherent) dose-taking behavior. Both factors will tend to obscure everyday conversation about high adherence behavior being the norm, leading to the possibility that non-adherence will be incorrectly perceived as typical or normative behavior and therefore inferred as the norm (27, 58, 59). Third, the media often highlight and sensationalize information about risky behaviors, noncompliant individuals, and rates of disease incidence.

These exaggerations provide cues suggesting that many people are not engaging in health promoting behavior even if in reality most people are engaging in health promoting behavior. These cues could contribute to incorrect norm perceptions (60-65).

No studies exist on the extent of misperceived ART adherence norms in sub-Saharan Africa. However, one qualitative study among youth in Uganda concluded that providing peer adherence levels in text message reminders to youth on ART could help motivate personal adherence (66). Similarly, a randomized control trial in Tanzania found that an intervention including a visual image depicting the level of clinic attendance and ART adherence among PLWH at that clinic was associated with individual attendance and adherence (67). Additionally, a study of PLWH in the U.S. found that perceived ART adherence norms among friends and family modified the association between HIV-related stigma and personal ART adherence (68). If PLWH on ART do not know local adherence rates or mistakenly believe missing ART doses is common in their local PLWH community, then there would be an opportunity for a social norms approach to improve adherence in that community.

The Current Study

For this secondary data analysis, we obtained data on all adult PLWH living in eight villages in Rwampara District of southwestern Uganda; these data were taken from a larger parent study that enrolled all adult residents in the area (regardless of HIV status). The present study addresses the gap in knowledge about misperceived norms as drivers of ART adherence in two ways. First, we assess the level of self-reported ART adherence in a population-based sample of PLWH on ART in a rural, HIV-endemic setting in sub-Saharan Africa where most PLWH are on ART. We then compare the aggregated level of individuals' self-reported ART adherence to their perception about the 'local ART adherence norm' (i.e., adherence level among most other PLWH on ART who live in the area). Second, we estimate the association between individuals' perception about the local ART adherence norm and personal ART adherence.

METHODS

Study Setting

To select a site for the parent study, study investigators engaged with local officials and collaborators in an iterative process to identify a rural parish containing multiple villages that would be amenable to ongoing research and intervention activities. Study investigators subsequently chose the targeted parish due to its tractable population size and geographic terrain, the local leaders' welcoming of the study team, the relatively little presence of non-governmental organizations, and the similarity to rural contexts across Uganda and sub-Saharan Africa in general. The parish contains eight villages and is about 260 km southwest of Kampala, the largest city in Uganda, and about 20 km from its closest commercial hub, Mbarara Town which had an estimated population of 195,013 in 2014 (69). Most residents in Uganda (and many PLWH elsewhere in sub-Saharan Africa) live in outlying rural areas like this study context where the local economy features small village communities and agricultural and small-scale trading and enterprise. Household food and water insecurity are common, and access to electricity is rare (70-72). Prior to starting study activities, the study

team held several community sensitization meetings in collaboration with local leaders to inform parish residents about the study and elicit feedback about the study design (73). The parent study included a census enumerating all parish residents aged 18 years and older.

Study Population

All persons aged 18 years and older who permanently resided within the parish during the period of data collection were eligible for participation in the parent study (53). The parent study was designed to measure the prevalence of health-related outcomes, typical local norms for a variety of behaviors and attitudes, and existing social connections between all adults within the parish. During the data collection period, the parish contained a total of 1795 permanent resident adults who were eligible for study participation. The present study on ART adherence of PLWH focuses on the data from participants in the parent study who reported themselves to be HIV-positive.

Data Collection Procedure

Using the census enumeration, trained research assistants who spoke the local language (Runyankole) attempted to recruit all eligible adult residents into the parent study by traveling to their homes or places of employment to make contact. Multiple attempts were made over the course of the data collection period to contact residents who were not easily available. To invite a resident into the study, a research assistant typically approached a resident one-on-one and explained that they were eligible to participate in a study about health and wellbeing. Research assistants then obtained written informed consent or a thumb print and a witness signature from all residents who opted to participate. A research assistant then collected data from a consenting participant using a computer assisted, survey-based interview tool. The process lasted 45-90 min and was typically completed in one sitting. All data used for the secondary data analyses presented here were collected in 2016-2018 through one interview with each participant.

The interview involved typical survey interview questions that had been written in English, translated into Runyankole, and then back-translated to English. Question piloting, translation, and testing followed an iterative process to ensure high fidelity. Additionally, the interview involved recording social network connections between adults in the parish because the parent study was also designed as a sociocentric (i.e., whole-population) network study (53, 74, 75). Specifically, five questions (i.e., 'name generators' (76)) elicited participants' nominations of people with whom the participant spent leisure time, exchanged emotional support, discussed financial matters, discussed health matters, and exchanged food. These questions had also gone through an iterative pilot testing and translation process. Participants were instructed to name up to six adults who were permanent residents of the parish in response to each name generator. An additional question asked married/cohabiting participants to name their spouse. This study design permitted the linkage of data between participants if the nominated persons also participated in the study. Nominations in response to each name generator question were confirmed using photographs. The combination of nominated persons across the name generator questions then represented the set of direct network ties to a participant (77). All nominees within a participant's set of

network ties (hereafter referred to as alters) who were also study participants represented a participant's personal network in this study.

Measures

Personal ART Adherence.—Participants who indicated that they were HIV-positive also reported whether they were taking ART, and, if so, then the number of doses of ART they had missed in the past 7 days. Due to skewness, participant responses were classified into two categories: no missed doses (i.e., optimal adherence) versus 1 or more missed doses (i.e., sub-optimal adherence). This binary indicator was our primary outcome.

Perceptions about Most Others' ART Adherence.—Prior studies have elicited perceptions about a behavioral norm (i.e., the behavior exhibited by the majority of individuals within a defined social referent group) by adapting questions eliciting personal reports of behavior (33, 38, 78-80). Following this precedent, we therefore asked each participant on ART how many doses of ART most *other* PLWH on ART in their parish had missed in the past 7 days. Response options included “none”, “a few”, “most”, “all doses”, or “don't know”. Participants who thought that most others did not miss any doses were classified as perceiving optimal adherence to be the local ART adherence norm. Participants with any other response were classified as perceiving sub-optimal adherence to be the local ART adherence norm.

We used “other PLWH on ART in this parish” as the social referent group (81) for the purposes of eliciting perceived norms about ART adherence for two reasons. First, pilot testing suggested that this description was an easily understood population subgroup with whom participants identified in this context. Additionally, choosing the social referent group to be the same as the targeted participant group meant that we could directly compare the aggregated rate of ART adherence behavior in this group to participants' perceptions about the local ART adherence level for this same group. This comparison would allow us to assess the extent to which the local ART adherence norm was misperceived or accurately perceived. This comparison technique to identify norm misperceptions has been used in this context and elsewhere in studies of social norms (33, 38).

Additional Factors.—We also collected data about age, formal schooling, having symptoms of probable depression (measured using the Hopkins Symptom Checklist) (82), consuming alcohol 2+ times per week, time since HIV-positive diagnosis, marital status, participant-reported spousal HIV serostatus, and participant-reported spousal knowledge of the participant's HIV status. Finally, we created a trichotomous variable to represent a participant's connectedness to other PLWH on ART in their personal network. To do so, we used alters' self-reports about their personal HIV-status and ART adherence. Participants' personal networks were categorized into one of three mutually exclusive groups: (a) the network included no HIV-positive alters; (b) the network included 1 or more HIV-positive alters who either reported not being on ART or reported sub-optimal adherence to ART; or (c) the network included 1 or more HIV-positive alters, *all* of whom reported optimal ART adherence. We created this variable because not accounting for exposure to alter behavior in

the analyses might have biased the relationship between perception and behavior away from the null.

Analysis

We assessed the distribution of perceptions about the local ART adherence norm in the entire sample of PLWH on ART and across subgroups of PLWH on ART. To estimate the association between personal adherence behavior and perceptions of the local ART adherence norm, we first fitted a modified Poisson regression model with robust estimates of variance. We specified personal optimal adherence (vs. sub-optimal adherence) as the outcome and one's perception about the local ART adherence norm as the primary explanatory variable, adjusting for other factors. With a binary dependent variable, the modified Poisson regression model has been shown to yield estimated incidence rate ratios that can be interpreted straightforwardly as relative risk ratios (83). We then fit another multivariable model with only married PLWH because the couple dyad represents a critical source of ART adherence support in sub-Saharan Africa (84, 85). This second model also adjusted for participant-reported spousal serostatus.

Ethical Considerations

Ethical approval for the parent study was granted by the Partners Human Research Committee at Massachusetts General Hospital and the Research Ethics Committee at the Mbarara University of Science and Technology. Clearance for the parent study was also obtained from the Uganda National Council of Science and Technology and the Research Secretariat in the Office of the President. Vanderbilt Human Research Protections Program approved secondary data analyses for the current study.

RESULTS

Among 1626 adults who participated in the parent study (representing a 91% response rate from all resident adults in the parish), 167 (9.3%) reported themselves to be HIV-positive. Among these PLWH, 159 (95%) reported being on ART. Most PLWH on ART were women (103 [65%]), most (95 [60%]) were married, and most (116 [73%]) were diagnosed with HIV more than five years prior to data collection. Additionally, most (121 [76%]) PLWH on ART nominated at least one alter who reported themselves as HIV-positive. Among 95 married PLWH on ART across 70 distinct households, 90 (95%) individuals reported that their spouse knew about their positive HIV serostatus and 72 (76%) reported that their spouse was also HIV positive.

In terms of personal ART adherence, 142 of 159 (89%) PLWH on ART reported not missing any doses in the past 7 days. Moreover, the majority of PLWH on ART in every subgroup reported not missing any doses in the past 7 days (Table 1). Thus, optimal adherence was reported by most PLWH on ART in this parish.

In terms of perceptions of ART adherence among others, 40 of these same 159 PLWH on ART (25%) thought that most PLWH on ART in this population had not missed any doses in the past 7 days. However, 65 (41%) thought most had missed a few doses in the past 7 days, 14 (9%) thought most had missed most doses, and 2 (1%) thought most had missed all

doses. Thirty-eight (24%) reported not knowing how many doses most PLWH on ART had missed in the past 7 days. Thus, in total, 119 (75%) PLWH on ART misperceived the local ART adherence norm, incorrectly believing that most PLWH on ART in this population were sub-optimally adherent. The prevalence of misperceiving the norm ranged from 61 to 88% across subgroups (Table 2).

The first multivariable Poisson regression model indicated that PLWH on ART who incorrectly believed that sub-optimal adherence was the local ART adherence norm (compared with those who correctly thought optimal adherence was the norm) were less likely to report optimal adherence themselves, though the estimate was imprecise (adjusted relative risk [aRR] = 0.91; 95% confidence interval (CI) 0.82-1.01; P = 0.092). The model including married participants only, and additionally adjusting for participant-reported spousal serostatus, indicated that misperceiving the norm was associated with personal sub-optimal adherence behavior (aRR = 0.83; 95% CI 0.71-0.97; P = 0.022) (Table 3). No other factors were associated with ART adherence in either model.

DISCUSSION

In this study of personal ART adherence behavior within a population-based sample of adult PLWH on ART living in eight villages in rural Uganda, we report two key findings. First, most PLWH on ART in this population did not know that optimal adherence was the local ART adherence norm, incorrectly believing that most PLWH on ART in this same population were sub-optimally adherent to their ART regimens. This finding is consistent with prior research demonstrating pervasive misperceptions about other kinds of behavioral norms in Uganda, South Africa, and elsewhere (19, 33, 34, 38, 39, 80, 86-93). This work builds on those studies by demonstrating the extent of misperceived ART adherence norms within an entire population of PLWH on ART. Additionally, results may be generalizable to comparable contexts as this population is similar to other populations in rural, sub-Saharan Africa where HIV is endemic and most PLWH are on ART.

Second, our results provide evidence that there is a negative association between optimal ART adherence and the extent to which an individual believes that most other PLWH on ART in his or her community are not optimally adherent, especially among married PLWH on ART. These findings are consistent with findings from a study in China among HIV-positive men who have sex with men (94). Men who perceived that most PLWH with a similar CD4 count were on ART were themselves more likely to report a behavioral intention to initiate ART use. Similarly, another study in the southern U.S. found that PLWH with low ART adherence were more likely than those with high ART adherence to perceive that PLWH commonly skip taking their ART medication when consuming alcohol (95). The current findings from Uganda are also consistent with studies on other topics indicating that perceived norms about others' health-promoting and health-risk behavior influence personal health behavior (19, 20, 23, 96-107). Taken together, and in light of earlier work, the findings of our study suggest an opportunity for both a population-wide intervention and a targeted intervention to correct misperceived norms and improve ART adherence rates (as long as effective ART is available) (26, 108).

Promoting information about accurate local adherence norms within a population where norm misperception was present could help increase optimal ART adherence rates in multiple ways. First, PLWH on ART with sub-optimal adherence who had misperceived the norm might improve their own adherence rates upon learning true rates. Even if misperceived norms had not previously influenced adherence behavior for some of these individuals (perhaps, for example, among some single adults in this parish), learning accurate adherence norms might then encourage them to pursue optimal adherence and, if applicable, find ways around any ART-related challenges. For example, new norms information could prompt PLWH to talk with their PLWH peers or supporters about how to overcome barriers to adherence, which may be useful if effective interventions to address other significant barriers to adherence (e.g., concurrent depression) are available. At the same time, correcting misperceived norms among PLWH on ART who were already virally suppressed could support their maintenance of long-term adherence.

Additionally, disseminating information about accurate local ART adherence norms among both PLWH and the larger community might also help reduce HIV-related stigma and secrecy around ART treatment, which could thereby improve adherence at the personal level (55), and also increase adherence at the population level by motivating others to get tested and linked to care if HIV-positive. Relatedly, this new information could motivate those PLWH who know their positive status but are not on ART to subsequently try to link to care (assuming treatment is available to them). It could also prompt greater interpersonal communication between partners or within households about HIV prevention, serostatus disclosure, and adherence more generally. Additionally, partners and other supporters who are aware of ART routines might be more likely to assist PLWH with reaching and maintaining high adherence. Together, these reinforcement processes might then continue to validate what PLWH have learned about local adherence norms (52).

Several methods exist to disseminate accurate information about local norms (52). First, social norms marketing campaigns target a general population and provide information about accurate local norms (96, 102, 109, 110) (e.g., “79% of seniors in the graduating class of 1998 expressed the opinion that students should not drink to an intoxicating level that affects academic work or other responsibilities”) (111). Second, personalized normative feedback targets individuals typically exhibiting the undesired behavior and provides information about individual behavior in relation to behavioral norms within specific reference groups (99, 104, 112, 113) (e.g., “You prescribed far more treatments -- 188% more -- than similar prescribers within your state”) (113). Third, focus groups target a group of individuals and encourage discussion about their norm perceptions versus local norms, and encourage a deeper process of social reality testing to weaken the power of misperceived norms (114-117). Fourth, highlighting existing positive behaviors among opinion leaders can act as a social norm cue and increase the visibility and salience of the actual norm and contribute to reducing misperceptions (118).

Based on this study, example messages include “Most single / married men living with HIV in your village are on ART and take all of their ART doses each week” or, “Most women / men aged 18-30 who are HIV-positive in your village are on ART and take all their doses each week.” They could be distributed via stand-alone radio and other public

formats, and/or be packaged with the delivery of other HIV-related interventions, such as peer counseling and adherence clubs, financial incentive programs, SMS-based adherence support, or couples-based support programs (66, 119-123). Health care providers could also communicate local norm information when interacting with newly diagnosed individuals or when patients come to an HIV-clinic for follow-up care. Local norms could also be visually depicted at the entrances to clinics (67).

The findings from this study are subject to several limitations. First, the direction of causality could not be determined. Second, our data on HIV serostatus and ART adherence data were derived from self-report. However, objectively measured adherence rates from this region are similar to those reported in this study (50, 51). Moreover, even if the actual prevalence of sub-optimal adherence was twice that reported here, weekly optimal adherence would still be the norm for this population. Thus, our primary finding that PLWH on ART underestimated the commonness of optimal adherence among the local population of PLWH on ART would not change. Third, this study did not assess injunctive norms, personal attitudes, or behavioral intentions about ART adherence, which may be important components in a behavioral pathway. Future research should assess the extent to which injunctive norms about ART adherence are misperceived and whether they also influence adherence behavior. Finally, we did not elicit perceived norms about other salient reference groups, nor did we elicit perceived norms about behavior in specific ART-related situations (e.g., whether most PLWH on ART miss any doses under specific scenarios, whether most disclose being on ART to partner and friends, what steps most take to overcome barriers to ART when present). Replication of this investigation using a wider set of ART adherence behavior and perceived norm measures with a larger population of PLWH who represent a more diverse adherence spectrum is warranted.

Conclusions

Most PLWH on ART across eight villages in rural Uganda reported optimal adherence to their weekly ART routine. However, optimal adherence rates were still below the 95-95-95 goals, indicating a need for intervention. At the same time, few PLWH on ART in these villages were aware that optimal adherence was the local ART adherence norm. This gap between perception and reality among many PLWH represents a novel opportunity to conduct a social norms-based intervention to inform PLWH about local accurate ART adherence norms. Changing their misperceptions might lead to an increase in personal optimal adherence and, ultimately, an increase in overall complete ART adherence rates. Initial evidence indicated an association between individuals' perception about the local adherence norm and their own adherence, especially among married PLWH on ART.

ACKNOWLEDGEMENTS

We thank the HopeNet cohort study participants, without whom this research would not be possible. We also thank members of the HopeNet study team for research assistance; in addition to the named study authors, HopeNet and other collaborative team members who contributed to data collection and/or study administration during all or any part of the study were as follows: Owen Alleluya, Patience Ayebare, Dickson Beinomugisha, Bridget Burns, Patrick Gumisiriza, Clare Kamagara, Elizabeth Namara, Phionah Ahereza, Juliet Mercy, Patrick Lukwago Muleke, Rhina Mushagara, Rumbidzai Mushavi, Elijah Musinguzi, Moran Owembabazi, Sarah Nabachwa, Immaculate Ninsiima, Mellon Tayebwa, and Dagmar Vo echovská. We also thank Roger Hofmann of West Portal Software Corporation (San Francisco, CA, USA), for developing and customizing the Computer Assisted Survey Information Collection

Builder software program used to collect the survey and social network data. We also thank Claire Evans who contributed research assistance in finalizing the manuscript.

Funding:

This study was funded by grants from Friends of a Healthy Uganda and U.S. National Institutes of Health (NIH) R01MH113494 to ACT. This work was also partially supported by the NIH-funded Tennessee Center for AIDS Research (P30 AI110527). JMP acknowledges salary support from NIH K01MH115811. JEH acknowledges salary support from NIH K24MH114732.

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Table 1.

Antiretroviral therapy (ART) adherence among PLWH living in eight villages in southwest Uganda (N = 159)

	Persons living with HIV and on ART		Self-reported optimal adherence*	
	N	(%)	n	(%)
Sex				
Women	103	(65%)	94	(91%)
Men	56	(35%)	48	(86%)
Age				
18-39 years	54	(34%)	48	(89%)
40-49 years	59	(37%)	54	(92%)
50+ years	46	(29%)	40	(87%)
Education				
None/some primary	88	(55%)	80	(91%)
Completed primary or more	71	(45%)	62	(87%)
Symptoms indicative of probable depression				
Probable depression	33	(21%)	29	(88%)
No probable depression	126	(79%)	113	(90%)
Alcohol consumption				
Consumes alcohol 2+ times per week	23	(14%)	18	(78%)
Consumes alcohol less often or never	136	(86%)	124	(91%)
Time since HIV diagnosis ^a				
Diagnosed within past 12 months	6	(4%)	5	(83%)
Diagnosed 1-5 years ago	36	(23%)	30	(83%)
Diagnosed > 5 years ago	116	(73%)	106	(91%)
Marital status and participant-reported spousal HIV status ^a				
Not married or cohabiting	63	(40%)	57	(90%)
Has a spouse who is HIV-positive	72	(45%)	64	(89%)
Has a spouse with an HIV-negative/unknown status	23	(14%)	20	(87%)
Self-reported HIV status and ART adherence among alters in participant's personal network				
Network contains at least 1 HIV-positive alter, all of whom reported optimal ART adherence*	107	(67%)	97	(91%)
Network contains no HIV-positive alters	38	(24%)	34	(89%)
Network contains at least 1 HIV-positive alter who either reported not being on ART or reported sub-optimal ART adherence*	14	(9%)	11	(79%)

* Optimal adherence was defined as not missing any ART doses in the past 7 days. Sub-optimal adherence was defined as missing 1 or more ART doses in the past 7 days.

^aOne participant was missing a response.

Table 2.

Perception of the local ART adherence norm among PLWH living in eight villages in southwest Uganda (N = 159)

	Thought most PLWH on ART in this population were optimally adherent*		Did not think most PLWH on ART in this population were optimally adherent*	
	n	(%)	n	(%)
Sex				
Women	22	(21%)	81	(79%)
Men	18	(32%)	38	(68%)
Age				
18-39 years	11	(20%)	43	(80%)
40-49 years	15	(25%)	44	(75%)
50+ years	14	(30%)	32	(70%)
Education				
None/some primary	23	(26%)	65	(74%)
Completed primary or more	17	(24%)	54	(76%)
Symptoms indicative of probable depression				
Probable depression	4	(12%)	29	(88%)
No probable depression	36	(29%)	90	(71%)
Alcohol consumption				
Consumes alcohol 2+ times per week	9	(39%)	14	(61%)
Consumes alcohol less often or never	31	(23%)	105	(77%)
Time since HIV diagnosis				
Diagnosed within past 12 months	1	(17%)	5	(83%)
Diagnosed 1-5 years ago	7	(19%)	29	(81%)
Diagnosed > 5 years ago	32	(28%)	84	(72%)
Marital status and participant-reported spousal HIV status				
Not married or cohabiting	17	(27%)	46	(73%)
Has a spouse who is HIV-positive	18	(25%)	54	(75%)
Has a spouse with an HIV-negative/unknown status	5	(22%)	18	(78%)
Self-reported HIV status and ART adherence among alters in participant's personal network				
Network contains at least 1 HIV-positive alter, all of whom reported optimal ART adherence*	28	(26%)	79	(74%)

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	Thought most PLWH on ART in this population were optimally adherent* n	(%)	Did not think most PLWH on ART in this population were optimally adherent* n	(%)
Network contains no HIV-positive alters	10	(26%)	28	(74%)
Network contains at least 1 HIV-positive alter who either reported not being on ART or reported sub-optimal ART adherence*	2	(14%)	12	(86%)

* Optimal adherence was defined as not missing any ART doses in the past 7 days. Sub-optimal adherence was defined as missing 1 or more ART doses in the past 7 days.

Table 3.

Multivariable Poisson regression model estimating the association between perception of the local ART adherence norm and optimal adherence among married PLWH on ART in rural Uganda (n = 95)

Variables	Population of married participants		Optimal ART adherence*		
	n	aRR (95% CI)	aRR (95% CI)	Test-statistic ^a	p-value
Perception of local ART adherence norm					
Did not think that most PLWH on ART were optimally adherent	72 (76%)	0.83 (0.71, 0.97)	0.83 (0.71, 0.97)	-2.29	0.022
Thought that most PLWH on ART were optimally adherent	23 (24%)	REF	REF		
Sex					
Women	52 (55%)	1.10 (0.87, 1.38)	1.10 (0.87, 1.38)	0.81	0.417
Men	43 (45%)	REF	REF		
Age (in years)	mean = 42 (s.d. = 10)	1.00 (0.99, 1.01)	1.00 (0.99, 1.01)	-0.85	0.394
Education					
None/some primary	45 (47%)	REF	REF		
Completed primary or more	50 (53%)	0.94 (0.82, 1.08)	0.94 (0.82, 1.08)	-0.87	0.382
Symptoms indicative of probable depression					
Probable depression	21 (22%)	0.98 (0.84, 1.15)	0.98 (0.84, 1.15)	-0.22	0.828
No probable depression	74 (78%)	REF	REF		
Alcohol consumption					
Consumes alcohol 2+ times per week	15 (16%)	1.04 (0.81, 1.33)	1.04 (0.81, 1.33)	0.28	0.779
Consumes alcohol less often or never	80 (84%)	REF	REF		
Time since HIV diagnosis					
Diagnosed within past 12 months	5 (5%)	0.94 (0.68, 1.30)	0.94 (0.68, 1.30)	-0.38	0.701
Diagnosed 1-5 years ago	25 (26%)	0.92 (0.79, 1.07)	0.92 (0.79, 1.07)	-1.06	0.290
Diagnosed > 5 years ago	65 (68%)	REF	REF		
Marital status and participant-reported spousal HIV status					
Has a spouse who is HIV-positive	72 (76%)	1.05 (0.89, 1.23)	1.05 (0.89, 1.23)	0.55	0.584
Has a spouse with an HIV-negative/unknown status	23 (24%)	REF	REF		
Self-reported HIV status and ART adherence of alters in participant's personal network					
Network contains no HIV-positive alters	19 (20%)	1.30 (0.71, 2.36)	1.30 (0.71, 2.36)	0.85	0.396

Variables	Population of married participants		Optimal ART adherence*		
	n	aRR (95% CI)	Test-statistic ^a	p-value	
Network contains at least 1 HIV-positive alter who either reported not being on ART or reported sub-optimal ART adherence*	10 (11%)	REF			
Network contains at least 1 HIV-positive alter, all of whom reported optimal ART adherence*	66 (69%)	1.16 (0.61, 2.20)	0.45	0.651	

aRR adjusted relative risk ratio, *CI* confidence interval

* Optimal adherence was defined as not missing any ART doses in the past 7 days. Sub-optimal adherence was defined as missing 1 or more ART doses in the past 7 days.

^a Associated test statistic for p-Value is z-score.