Reduced Adherence to Antiretroviral Therapy among HIV-infected Tanzanians Seeking Cure from the Loliondo Healer

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Abstract

The predictors for seeking alternative therapies for HIV-infection in sub-Saharan Africa are unknown. Among a prospective cohort of 442 HIV-infected patients in Moshi, Tanzania, 249 (56%) sought cure from a newly popularized religious healer in Loliondo (450 kilometers away), and their adherence to antiretrovirals (ARVs) dropped precipitously (OR=0.20, 95% CI, 0.09–0.44, p<0.001) following the visit. Compared to those not attending Loliondo, attendees were more likely to have been diagnosed with HIV more remotely (3.8 vs. 3.0 years prior, p<0.001), have taken ARVs longer (3.4 vs. 2.5 years, p<0.001), have higher median CD4+ lymphocyte counts (429 vs. 354 cells/mm^3, p<0.001), be wealthier (wealth index 10.9 vs. 8.8, p = 0.034), and receive care at the private versus the public hospital (p=0.012). In multivariable logistic regression, only years since the start of ARVs remained significant (OR, 1.49, 95% CI, 1.23–1.80). Treatment fatigue may play a role in the lure of alternative healers.

Keywords

HIV/AIDS; antiretroviral therapy; adherence; faith healing; traditional healing; Global Health; Africa

Introduction

In 2010 more than 5 million persons living with HIV/AIDS in sub-Saharan Africa were receiving antiretroviral therapy, and this number is estimated to increase substantially (1). While antiretroviral adherence in resource-poor settings is as good as, if not better than, that in North America (2–5), adherence may decline over time (3; 6–8).

Well-documented reasons for incomplete antiretroviral adherence in low-resource settings include limited financial resources, transportation barriers, and user fees (9–16); younger age (4; 13); complexity of antiretroviral dosing and side effects (4; 14); stigma and lack of disclosure (11; 13; 17–19); depression (6; 18; 20–22), and active substance abuse (18; 21–23). The influence of traditional or spiritual healers, however, is unclear. Extant reports involve relatively small numbers of individuals reporting sporadic contact with various healers (24–27). None describes a mass phenomenon where a population quickly and suddenly believes in the healing powers of an individual and acts on that belief.

In August 2010 in the remote village of Sumunge, in Loliondo, Tanzania a retired Lutheran minister began offering a one-dose herbal cure for HIV and other chronic illnesses (28). The remedy, for which he charged 500 Tanzanian shillings (approximately 0.31 US dollars), was prepared by saying a prayer, boiling the root of the Mugariga tree (*Carissa spinarum*), cooling the brew, and dispensing it in cups to participants. As media reports spread across Tanzania and East Africa, tens of thousands of individuals sought healing, and by March 2011 traffic to the village was backed up for 15 kilometers (29). As part of the Coping with HIV/AIDS in Tanzania (CHAT) study (30), a longitudinal cohort study initiated in 2008 to explore associations between psychosocial characteristics, HIV medication adherence, and health outcomes among HIV-infected individuals in Moshi, Tanzania we observed a high proportion of study participants traveling to Loliondo to receive the cure. We describe Loliondo attenders and non-attenders and corresponding antiretroviral adherence rates.

Methods

HIV-infected individuals, ages 18–64, were enrolled from Kilimanjaro Christian Medical Centre (KCMC, a private zonal referral hospital, N=228) and Mawenzi Regional Hospital (a public facility, N=271) between November 2008 and October 2009. Participants were followed longitudinally using in-person surveys and clinical exams semi-annually and HIV RNA levels annually. Survey instruments included sociodemographic data as well as information on religion and spirituality, beliefs about and interactions with non-traditional healers, self-reported health status (SF-8), HIV testing history, and household assets. The survey instruments were translated from English into Kiswahili and back-translated into English to confirm translation validity. Trained interviewers recorded participant responses using Entryware version 6.4 (Techneous, Vancouver, British Columbia).

This analysis is restricted to participants taking antiretroviral therapy at their last study visit prior to the widespread popularity of the Loliondo healer (N=441). Participants reporting no missed doses in the previous 3 months were considered adherent.

Trends for the general popularity of the Loliondo healer were estimated using Google Insights for Search (www.google.com/insights/search/), which computes the number of searches for a given term relative to the total number of searches over time. For data presented, the term "Loliondo" was used. Loliondo attendance among CHAT participants was captured initially through a follow-up question for clients reporting interactions with traditional healers. Starting in June 2011 patients were asked explicitly if they had personally sought healing at Loliondo from Babu Mwasapile. Loliondo attenders were asked about transportation costs, if they believed that 'drinking from the cup' improved or healed their HIV, and if they were advised to stop taking their medications.

During the third wave of surveys (completed by August 2010), participants were asked about involvement in both organizational and non-organizational religious activity: "How often do you attend church or other religious meetings?" and "How often do you spend time in private religious activities, such as prayer, meditation or study of holy scriptures?" (31). Additionally, participants were asked how important for healing is each of the following: faith healing by religious leaders, medical doctors, personal prayer and spirituality, traditional healers, witchdoctors, and herbalists.

Participants were asked to rate their health over the past 4 weeks during semi-annual surveys. At annual clinical assessments, HIV RNA levels were obtained per study protocol and CD4+ lymphocyte counts were abstracted from clinical records. A wealth index consisting of 8 assets and 3 characteristics of the living environment was constructed by applying to each component variable its estimated contribution to the 2010 Tanzania Demographic and Health Survey wealth index (R^2 0.9452, Kilimanjaro Region).

Student's t-tests and logistic regression were used to assess the significance of differences in sociodemographic characteristics, spirituality, health status, HIV medication history and treatment outcomes between Loliondo attendees and non-attendees. The association between Loliondo attendance and adherence was analyzed using a random-effects logistic regression model, where individual-level adherence was modeled as a function of the number of quarters since respondents' Loliondo visit, as well as a linear function of time, the effect of which was allowed to differ between Loliondo attendees and non-attendees.

Results

Among 442 CHAT participants on antiretroviral therapy, 249 (56%) reported visiting Loliondo and 240 indicated specifically that they "drank from the grandfather's cup." Shown in Panel A of the figure is the proportion of participants, by Loliondo attendance status, reporting complete adherence to antiretroviral therapy during the previous three months. Temporal trends in the number of participants who traveled to Loliondo parallel those of Google searches for "Loliondo" (Panel C). During the second quarter of 2011, following the height of the healer's popular appeal, adherence rates dropped sharply among

Loliondo attenders versus non-attenders, but at subsequent observations, adherence patterns were comparable. The effect of Loliondo attendance on adherence was significant for the first quarter after participants' Loliondo visit (OR = 0.20, 95% confidence interval, 0.09 to 0.44, p<0.001, compared to pre-Loliondo values). We examined rates of virologic failure (increase in HIV RNA level to > 400 copies/ml) among 376 participants who had viral load measurements both before and after the rise in popularity of the Loliondo healer during late 2010. There was no difference in the rate of virologic failure between Loliondo attendees (10/214, 4.7%) vs. non-attendees (9/131, 6.9%, p=0.467). As shown in Panel B of the figure, the rate of virologic suppression below 400 HIV RNA copies/ml was lowest (71%) among Loliondo attendees reporting incomplete adherence during the second quarter of 2011.

In bivariate analysis (see table), Loliondo attenders were more likely than non-attenders to be older (43.2 vs. 40.8 years, p = 0.003), widowed (34.1% vs. 23.3%, p=0.013), and Lutheran (30.6% vs. 21.2%, p=0.027). No differences were found with respect to spiritual practices or beliefs regarding healing. While Loliondo attenders vs. non-attenders perceived no significant differences with respect to their health and had similar nadir CD4+ lymphocyte counts, Loliondo attenders were more likely to have been diagnosed with HIV more remotely (3.8 vs. 3.0 years prior, p<0.001), to have been on antiretroviral therapy longer (3.4 vs. 2.5 years, p<0.001), and to have higher median CD4+ lymphocyte counts (429 vs. 354 cells/mm^3, p<0.0001). Loliondo attenders were wealthier than non-attenders (10.9 vs. 8.8, p = 0.034, using predicted wealth index), and attendance was more common among patients of the private referral hospital (p=0.012). In multivariable logistic regression, only years since start of antiretroviral therapy was significant (OR, 1.49, 95% CI, 1.23–1.81).

The median transportation cost to attend Loliondo was 80,000 Tanzanian shillings (IQR 60,000 –100,000, 51 US dollars, N=241). One quarter of Loliondo attenders (57/234) believed that the treatment improved or healed their HIV infection. Twelve of 226 (5%) reported being advised to stop taking their HIV medications. Of 12 who reported discontinuing medications, 6 resumed medications within two weeks.

Discussion

The majority of participants taking antiretrovirals in this cohort from Northern Tanzania sought an herbal cure for HIV from a spiritual leader. Visiting the healer was associated with a significant, but impermanent, decline in antiretroviral adherence. Treatment fatigue appeared to play a significant role in the lure of the healer, as duration of antiretroviral use was independently associated with attendance. Other factors, including those not measured, likely played a role. Being older, widowed, and Lutheran (the denomination of the healer), having been diagnosed with HIV longer ago and engaged in HIV care for longer, attending a particular clinic, and having higher predicted wealth were each associated with Loliondo attendance in bivariate analysis. Prior measures of spirituality and beliefs about divine healing did not predict attendance. The possibility of cure, even from a healer outside of one's religious tradition, was so attractive that many patients were willing to incur significant costs, travel for hours, and disrupt years of sustained ART adherence. Insignificant decreases in virologic suppression among Loliondo attenders, including the

subgroup reporting incomplete adherence, were noted. That these changes were insignificant is likely a function of both resumed adherence and the temporal disconnect, at the individual patient level, between Loliondo attendance, adherence assessments and viral load measurements.

The interaction between religiosity and adherence to antiretroviral adherence in sub-Saharan Africa is complex. For example, Zou et al. found that 81% of 438 urban and rural Tanzanian church-goers believed that HIV could be cured by prayer; however, a large majority of respondents (94%) indicated they would start antiretrovirals if diagnosed with HIV infection (32). Kisenyi, in a cross-sectional study of 220 Ugandan patients on antiretroviral therapy, found higher adherence levels correlated with greater behavioral religiosity (33). On the other hand, rare instances of HIV-infected patients discontinuing antiretrovirals as a result of belief of healing through spiritual means have been clearly documented (24). Less is known about the appeal of herbal remedies. In Uganda, one third of 401 patients on antiretroviral therapy reported using herbal medicines, primarily to treat symptoms such as fever or cough; lower antiretroviral adherence was associated with use of herbal medicine, but it did not appear that patients were taking herbal medications explicitly as a substitute for HIV therapy (34).

The combination of faith healing and traditional herbal medicine offered by the widely-publicized Loliondo healer presented an attractive opportunity for people facing a lifetime of medication to maintain health. The significant decline in adherence associated with Loliondo attendance highlights the marketability of hope for a true HIV cure, especially among those who have taken antiretroviral therapy for longer, and underscores the importance of ongoing patient education regarding alternative therapies.

We note several limitations of this report. As an observational study, we identify associations but cannot invoke causality. Multiple key measures, including adherence to antiretroviral therapy and Loliondo attendance were self-reported, raising the possibility of social desirability bias. Identical adherence questions, however, were asked repeatedly, and it is unlikely that respondents would provide socially desirable answers during one survey over another. In addition, adherence was measured solely using self-reports. It also possible that some who reported not attending Loliondo did actually attend. However, given the popularity of the healer (29), the absence of stigma attached with attendance, and an emphasis on confidentiality during the survey process, it seems doubtful that participants would mischaracterize participation to surveyors. Finally, the data were collected using structured survey instruments, and qualitative interviews were not performed.

The findings from this study have implications for researchers, policy makers, and care providers. Further research is needed to understand the trade-offs patients make in seeking the uncertainty of a one-time cure in exchange for adherence to proven life-saving medications. Would the lure have been the same if a physical element (namely, drinking from the cup) had not been present? Was the perceived cure thought to be effected more by the herbal drink or by divine healing? What social dynamics led to the rapid rise and then the rapid decline in popularity of the healer? Why did adherence rates improve with continued observation? Robust, mixed-methods techniques and interdisciplinary research

will be required to answer these and other questions. Policy makers should consider ways to engage spiritual and religious leaders in respectful dialogue that seeks bidirectional understanding of the theological, social, and medical issues at stake for HIV-infected individuals who seek alternate therapies. Finally, findings from this this study have implications for HIV providers and others caring for patients with chronic diseases. Medical providers are rarely trained to engage patients about religious beliefs and spiritual practices, much less probe patients' interactions with various healers. In the US, physicians are divided regarding how best to broach the topic (35). Healthcare providers may hold stereotypes about the "kind of patient" who holds particular beliefs and therefore refrain from conversations about the beliefs and practices. The provision of care to patients who are drawn to non-medical cures requires awareness, sensitivity, and compassion to negotiate effective and acceptable treatment strategies within that patient's worldview.

Conclusion

More than half of the HIV-infected patients in this cohort participated in a highly publicized religious healing activity, and participation was temporally associated with decreased antiretroviral adherence. Only the duration of time since starting antiretroviral therapy was independently associated with participation. Recognizing and addressing the lure of alternative cures for HIV infection and their impact on adherence is critical to the continued success of HIV care and treatment programs in resource-poor settings.

Acknowledgments

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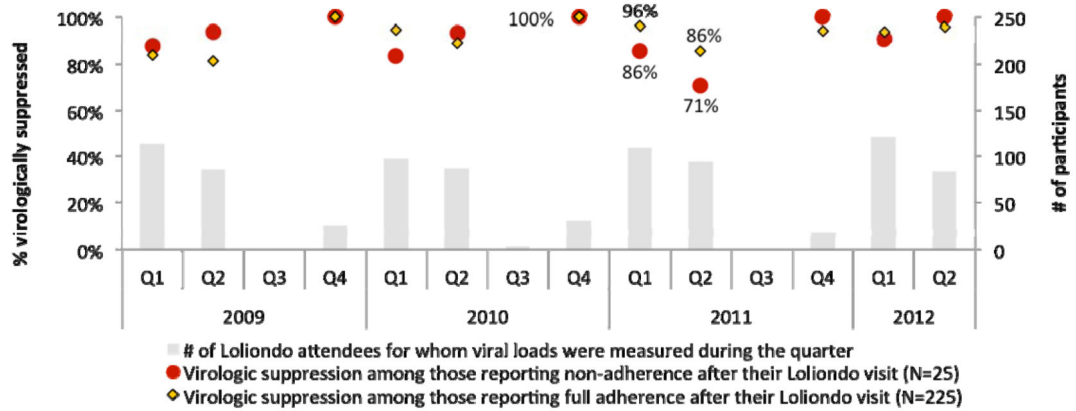
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A. Self-reported adherence among Loliondo attendees and non-attendees (N=442)

Self-reported adherence in the past 3 months, Loliondo attendees (N=249)
Self-reported adherence in the past 3 months, Loliondo non-attendees (N=193)
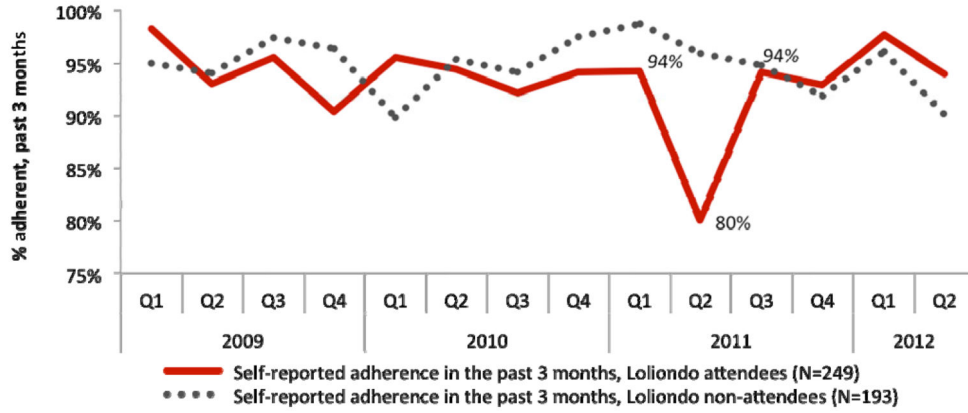
B. Virologic suppression (HIV RNA level < 400 copies/ml) among Loliondo attendees (N=230)

# of Loliondo attendees for whom viral loads were measured during the quarter
Virologic suppression among those reporting non-adherence after their Loliondo visit (N=25)
Virologic suppression among those reporting full adherence after their Loliondo visit (N=225)

C. Loliondo popularity and attendance

Number of Loliondo attendees
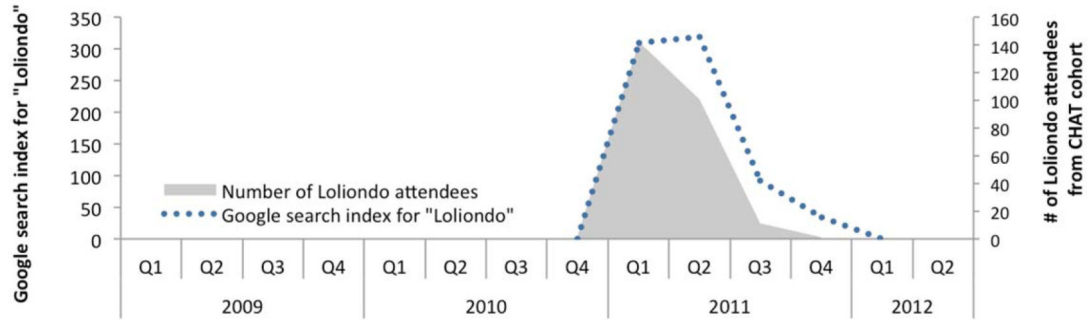Google search index for "Loliondo"

Figure.
Self-reported 3 month antiretroviral adherence rates among a cohort of HIV-infected patients in Kilimanjaro Region, Tanzania (panel A); virologic suppression among Loliondo attendees, by self-reports of adherence (panel B); temporal trends in internet Google searches for "Loliondo" and in visits to the Loliondo healer among the cohort (panel C).

Table

Predictors for visiting the Loliondo healer among 442 HIV-infected persons taking antiretroviral therapy in the Kilimanjaro Region, Tanzania.

		N	Bivariate comparisons			Multivariate model (N=355)	
			Attended Loliondo	Did not attend Loliondo		Odds Ratio	
			Mean (SD) or %	Mean (SD) or %	p-value		[95% CI]
Socio-demographics	Female	442	70.3	65.8	0.317	1.162	[0.657 – 2.055]
	Age	442	43.2 (8.6)	40.8 (7.9)	0.003	1.023	[0.992 – 1.055]
	Secondary education	441	21.0	19.7	0.742	1.352	[0.679 – 2.691]
	Urban residence	441	39.5	46.6	0.134	0.823	[0.494 – 1.370]
Marital status	Married	442	35.3	40.9	0.230	ref	
	Widowed	442	34.1	23.3	0.013	1.417	[0.750 – 2.679]
	Divorced	442	16.9	21.2	0.244	1.367	[0.682 – 2.737]
	Single	442	13.7	14.5	0.798	1.674	[0.770 – 3.636]
Religion	Catholic	441	42.7	43.0	0.956	ref	
	Lutheran	441	30.6	21.2	0.027	1.767	[0.962 – 3.247]
	Muslim	441	19.0	25.9	0.081	0.804	[0.421 – 1.538]
	Other	441	7.7	9.8	0.419	0.605	[0.260 – 1.410]
Spirituality	Frequency of church/religious service attendance	410	0.9 (0.3)	0.9 (0.3)	0.988	0.819	[0.411 – 1.633]
	Frequency of time spent in private religious activities	410	0.4 (0.5)	0.4 (0.5)	0.342	1.010	[0.536 – 1.904]
Importance for healing of:	Faith healing	408	2.4 (1.3)	2.3 (1.2)	0.549	1.216	[0.963 – 1.535]
	Medical doctors	410	4.1 (0.6)	4.0 (0.6)	0.414	0.866	[0.574 – 1.307]
	Personal prayer	410	3.1 (1.2)	3.2 (1.0)	0.591	0.878	[0.685 – 1.126]
	Traditional healers	410	1.1 (0.4)	1.0 (0.2)	0.481	0.916	[0.408 – 2.055]
Health	SF-8™ Score	442	1.5 (0.4)	1.6 (0.6)	0.066	1.024	[0.587 – 1.787]
	Nadir CD4+ lymphocyte count (cells/mm^3)	439	158.7 (158.2)	144.1 (112.5)	0.279	omitted	
	Most recent CD4+ lymphocyte count (cells/mm3)	439	429.2 (223.3)	354.1 (195.1)	<0.001	1.000	[0.998 – 1.001]
	Years since diagnosis	441	3.8 (1.9)	3.0 (1.7)	<0.001	omitted	
	Years since start of ART	407	3.4 (1.7)	2.5 (1.4)	<0.001	1.489*	[1.229 – 1.805]
	WHO stage 3 or 4	436	66.8	70.9	0.362	0.615	[0.352 – 1.074]
Cohort	KCMC	442	53.0	40.9	0.012	ref	
	Mawenzi	442	47.0	59.1	0.012	0.929	[0.459 – 1.881]

| | N | Bivariate comparisons | | | Multivariate model (N=355) | |
| | | Attended Loliondo | Did not attend Loliondo | | Odds Ratio | |
		Mean (SD) or %	Mean (SD) or %	p-value		[95% CI]
Predicted wealth index	408	10.9 (9.4)	8.8 (9.3)	0.034	1.022	[0.993 – 1.052]

SF-8™, Short Form 8 (a self-reported measure of health); WHO, World Health Organization; KCMC, Kilimanjaro Christian Medical Centre. Nadir CD4+ lymphocyte count and years since diagnosis were omitted from multivariate logistic regression because of collinearity;

*
indicates significance at p<0.001.