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Case Management for People Living with HIV and AIDS in Rwanda:
Evaluation of a "Linkages" Model

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By

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1. ABSTRACT

Case management is an increasingly popular approach to the coordination of care for people living with HIV and AIDS (PLHIV) in Rwanda. CARE International in Rwanda implements a "Linkages" case management model for PLHIV in Nyagatare District, using health facility-based Linkages focal points and community volunteers to achieve three outcomes: (1) promote antiretroviral (ARV) adherence, (2) link clients to needed support services, and (3) bolster psychosocial wellbeing. This evaluation explored outcomes associated with program exposure by utilizing a cross-sectional posttest design with mixed methods, including a quantitative survey among adult Linkages clients on ARVs, focus groups with clients and community volunteers and in-depth interviews with focal points, and a service inventory. Adherence was high among respondents, and having a focal point was associated with an increased likelihood of never skipping medication. Having a community volunteer was not associated with differences in ARV adherence. Among those with a need for services, having a focal point was associated with a significantly higher likelihood of referral for nutritional assistance, counseling, and health insurance and significantly lower risk of unmet need for counseling and health insurance. Though the other analyses examining the relationships between having a focal point or community volunteer and referrals and unmet need were not statistically significant, most were in the anticipated direction. Stigma and marginalization were low among the sample, but there was a high prevalence of depressive symptoms. There were no differences in psychosocial outcomes based on exposure to program personnel. These findings are suggestive that the program is achieving positive outcomes related to ARV adherence and referrals and unmet need for social services among clients but has had little effect on psychosocial wellbeing. Future research on the impact of HIV case management should utilize a pre-post design with a true comparison group and adequate sample sizes.

2. OVERVIEW

The burden of HIV in Rwanda is relatively low compared to other countries in sub-Saharan Africa. As of 2005, Rwanda had a 3% national prevalence, with some variation between urban and rural areas (Institut National de la Statistique du Rwanda & ORC Macro, 2005). Regardless, the task of effectively managing the wellbeing of people living with HIV and AIDS (PLHIV) is challenging given Rwanda's rudimentary and fragmented health and social support systems, shortage of medical personnel, and quantity of PLHIV (Republic of Rwanda, 2003).

To address the myriad needs of PLHIV in a developing country context, the President's Emergency Plan for AIDS Relief recommends the establishment of country-level networks of domestic and international organizations aligned to coordinate care, offer support services, and facilitate referrals for PLHIV (Office of the U.S. Global AIDS Coordinator, 2006). Additionally, Institute of Medicine (2007) calls for strong referral mechanisms and interdisciplinary networks providing community-based care and support. Consequently, case management is an increasingly popular approach to care coordination and support for PLHIV in Rwanda, with several models currently in use by various governmental and non-governmental organizations.

One such model has been implemented by CARE International au Rwanda. Unlike other models in Rwanda, CARE's Linkages" case management model for PLHIV in Nyagatare District has a heavy reliance on lay health workers—community volunteers, many who are PLHIV themselves. The community volunteers work in tandem with health facility-based Linkages focal points (i.e., "case managers") to achieve three primary outcomes: (1) promote antiretroviral (ARV) adherence, (2) link clients to needed support services, and (3) bolster psychosocial wellbeing.

A modest body of literature examines the effectiveness of case management for PLHIV in western society through the use of quantitative methods (Gardner et al., 2005; Husbands et al., 2007; Katz et al., 2001; London, Leblanc, & Anshensel, 1998; Sherer et al., 2002). However, with the exception of one study utilizing qualitative methods to explore case management outcomes in Rwanda (Thurman, Haas, Dushimimama, Lavin, & Mock, in press), a review of the published literature has revealed no other evaluations of case management in developing countries.

The purpose of this research was to determine the effectiveness of CARE's Linkages case management model as it relates to three outcome areas: (1) medication adherence, (2) unmet support service need, and (3) psychosocial wellbeing. This study utilized a mixed method approach comprised of a quantitative survey of Linkages clients; qualitative data collection among clients, community volunteers, and Linkages focal points; and an inventory of support services availability in Nyagatare District.

The results of this analysis will be used to inform efforts to strengthen the Linkages case management model as well as to guide national policy in Rwanda. In particular, the study results will be used to formulate recommendations for CARE regarding how to strengthen its program. Similarly, the findings can guide other program implementers in Rwanda and elsewhere as to considerations for case management for PLHIV, such as the extent to which community volunteers are useful additions to case management in resource-constrained settings. Additionally, the findings can be used to steer evidence-based policy decisions at the national level in Rwanda, for example related to national strategy regarding coordination of care for PLHIV, the expansion of case management models, and the professional training of social workers and nurse case managers. Finally, this research will contribute to the case management literature, particularly concerning the efficacy of HIV case management in a developing country.

3. LITERATURE REVIEW

Case management approach

The case management approach traditionally has been utilized to manage the complicated needs of those with chronic or mental illness in resource-rich countries. Although there are many case management models of care, the core tasks associated with case management typically include: client identification, initial assessment for needed medical or support services, development of a care plan, linkage to service providers, monitoring service delivery, and reassessment for needed medical or support services (Centers for Disease Control and Prevention, 1997). If done correctly, Orwin, Sonnefeld, Garrison-Mogren, and Smith (1994) suggest that case management better connects clients to support services than the client could accomplish alone, although case manager assistance with service arrangement does not always result in uptake by clients (Lehrman, Gentry, Yurchak, & Freedman, 2001).

In the last twenty years, the use of case management has broadened to address the complex support service and health needs of PLHIV. HIV case management is associated with improved usage of primary care services (Cunningham, Wong, & Hays, 2008; Gardner et al., 2005; Huba, Melchior, & Panter, 2000; Sherer et al., 2002), increased uptake of needed support services (London, Leblanc, & Anshensel, 1998), and reduced unmet need for ancillary services (Katz et al., 2001).

Linkages case management model

CARE International au Rwanda's Linkages case management model uses a two-tiered approach to case management. Linkages "focal points" work within health centers to identify clients' needs and link them with appropriate support service providers. Additionally, Linkages focal points supervise community volunteers, who make home visits to PLHIV to monitor their ARV adherence and the possible side effects of treatment, to reassess support service needs, and to address issues related to stigma and psychosocial wellbeing.

The Linkages model appears an amalgam of multiple models of case management (Murphy, Tobias, Rajabiun, & Abuchar, 2003). As with the broker model, where the central duty of the case manager is to connect the client with support services, there is a narrow relationship between the Linkages focal point and client. Visits between the focal point and client are limited in number and duration, particularly due to the high ratio of clients to focal point. The focal point, community volunteer, and health provider form a multifaceted team addressing various aspects of care coordination, as in the full support model. Further, under the Linkages model, case management support is scaled down as the client's needs are met, as in the rehabilitation model. The heavy reliance on community volunteers to perform the bulk of client monitoring and support makes the Linkages model unique to Rwanda, as well as to other models described in the HIV case management literature.

Community volunteers/lay health workers

The literature is replete with examples of community volunteers or lay health workers performing a variety of functions in resource-constrained settings, including health education, first line treatment, referrals to support services or healthcare, HIV counseling and testing, and psychosocial support, and for diverse health issues, such as maternal and child health, tuberculosis, and HIV and AIDS (Han, Lee, Kim, & Kim, 2009; Lewin et al., 2006; Sanjana et al., 2009). Nevertheless, strong evidence of the efficacy of lay health workers is largely absent from the literature, especially for HIV care and support (Lewin et al., 2005; Lewin et al., 2006). The existing evidence suggests that the most effective programs involving lay health workers are those that target specific health outcomes rather than generalist approaches to wellbeing (Lewin et al., 2006).

In addition to filling workforce gaps, there is evidence to suggest that lay health workers are particularly capable of serving as change agents in their communities due to their intimate understanding of the clients they serve and the problems that they face (Ahmed, Fort, Micah, Dickerson, & Belay, 2006). Indeed, clients themselves value the assistance afforded by lay health workers who come from their own communities particularly because of their knowledge of the community and its residents (Baiden et al., 2007).

Social support theory

Substantial empirical evidence indicates that social relationships impact health (House, Landis, & Umberson, 1988), such that the provision of social support is a common tactic to improve the wellbeing of PLHIV, particularly related to their psychosocial needs and medication adherence. For example, in sub-Saharan Africa, community responses to HIV and AIDS include social support groups or associations that can provide psychological support, reduce feelings of stigma, and facilitate income generating activities (Mutangadura, Mukurazita, & Jackson, 1999). Case management also is a promising practice for improving psychosocial wellbeing among PLHIV through referrals for therapy and the fostering of a direct supportive relationship between case manager and client. In fact, in a study of PLHIV in Toronto who were randomized to receive case management versus self-directed care, clients with the highest levels of depression benefited most from case management (Husbands et al., 2007). Moreover, subjective social support (for example, satisfaction with the degree of support provided by friends) has been shown to mediate depressive symptoms among PLHIV (Mavandadi, Zanjani, Have, & Oslin, 2009).

Likewise, there is quantitative evidence to support the notion that social support is associated with medication adherence among PLHIV. (Amberbir, Woldemichael, Getachew, Girma, & Deribe, 2008; Diabeté, Alary, & Koffi, 2007; Schneider, Kaplan, Greenfield, Li, & Wilson, 2004). However, other factors also are predictive. For example, life circumstances such as forgetting, being away from home, being busy, lack of food with which to take medicine, and changes in routines are cited as common reasons for disruption of medication schedules (Amberbir et al., 2008; Chesney et al., 2000; Hardon et al., 2006; Jean-Baptiste, 2008; Reynolds et al., 2004). Likewise, psychosocial issues, such as depression and stigma, tend to reduce medication adherence. In a study of PLHIV in India, Kumarasamy et al. (2005) identified stigma as a barrier to medication adherence. And, in a study of PLHIV in Spain, an interaction between social support and lack of depression predicted ARV adherence (Gordillo, del Amo, Soriano, & Gonzalez-Lahoz, 1999).

A paper by House et al. (1988) called for the development of a social support theory of health promotion that considered the quantity, structure, and content of social relationships. Subsequently, several studies have sought to develop models to explain the role of social support on medication adherence. DiIorio et al. (2009) tested a psychosocial model of ARV adherence that was grounded in social cognitive theory and included variables such as social support, depression, stigma, self-efficacy, and satisfaction with provider. Social support was found to be predictive of reduced depression and increased self-efficacy, which in turn were predictive of adherence. In another evaluation of a social support model of ARV adherence, Simoni, Frick, & Huang (2006) studied the relationship of functional social support (that is, perceived quality of social support) on medication adherence. Four facets of functional support were measured—appraisal, emotional, informational, and spiritual—and the data indicated that social support was related to adherence through its relationship with self-efficacy.

Anderson Behavioral Model of Health Services Use

The Anderson Behavioral Model of health services use theorized that uptake of health services is driven by three coalescing forces: (1) predisposing factors at the individual level, such as socio-demographic characteristics, social supports, and health beliefs; (2) enabling factors, which promote or inhibit uptake, such as the availability of and access to services; and (3) actual need for health services, which is dependent on the medical condition (Anderson, 1995; Anderson & Newman, 1973). Subsequent applications of the model have demonstrated that it is highly predictive of ancillary service usage, as well as unmet needs for services (Calsyn & Winter, 2001; Mitchell & Krout, 1998; Smith, 2003). Interestingly, in a study of service use and unmet needs among families of adults with severe mental illness, Smith (2003) determined that informal social support was a significant predictor of service use, but not unmet need for supportive services. The same study suggested that the mechanism by which social support affects service use may be related to referrals or to a diffusion of positive opinions of available services.

Theoretical framework for the Linkages model evaluation

The present study of the effectiveness of the Linkages Model is guided to a large extent by social support theory and the Anderson model. In brief, the ability of the Linkages case management model to promote ARV adherence, address support service needs, and bolster psychosocial wellbeing likely is predicated upon the Linkages model's ability to offer social support to clients through exposure to focal points and community volunteers. The analysis of outcomes related to medication adherence and psychosocial wellbeing is largely driven by the presumption that the social support afforded by Linkages focal points and community volunteers promotes these outcomes, although the analyses also consider client-level predisposing factors available in the data file. The analysis of the extent to which the Linkages model can reduce unmet need for support services among PLHIV is strongly rooted in the Anderson model, and considers predisposing client characteristics, enabling resources, and the needs of clients.

4. RESEARCH QUESTIONS

Research Question #1: Is there a difference in medication adherence among adult Linkages clients on ARVs based on varying exposures to Linkages personnel? How does medication adherence differ by exposure to Linkages focal points versus community volunteers?

> **Null Hypothesis 1A**: There is no difference in medication adherence between those with a Linkages focal point and those without a Linkages focal point.
>
> **Null Hypothesis 1B**: There is no difference in medication adherence between those with a Linkages community volunteer and those without a Linkages community volunteer.

Research Question #2: Is there a difference in level of unmet need for support services among adult Linkages clients on ARVs based on varying exposures to Linkages personnel? How does unmet need for support services differ by exposure to Linkages focal points versus community volunteers?

> **Null Hypothesis 2A**: There is no difference in level of unmet need for support services between those with a Linkages focal point and those without a Linkages focal point.
>
> **Null Hypothesis 2B**: There is no difference in level of unmet need for support services between those with a Linkages community volunteer and those without a Linkages community volunteer.

Research Question 2.1: To what extent could unmet needs theoretically be met based on service availability?

Research Question 2.2: What are the strengths and weaknesses of the Linkages referral mechanism?

Research Question #3: Is there a difference in psychosocial wellbeing among adult Linkages clients on ARVs based on varying exposures to Linkages personnel? How do levels of stigma, marginalization, and depression differ by exposure to Linkages focal points versus community volunteers?

Null Hypothesis 3A: There is no difference in stigma levels between those with a Linkages focal point and those without a Linkages focal point.

Null Hypothesis 3B: There is no difference in stigma levels between those with a Linkages community volunteer and those without a Linkages community volunteer.

Null Hypothesis 3C: There is no difference in marginalization levels between those with a Linkages focal point and those without a Linkages focal point.

Null Hypothesis 3D: There is no difference in marginalization levels between those with a Linkages community volunteer and those without a Linkages community volunteer.

Null Hypothesis 3E: There is no difference in depression levels between those with a Linkages focal point and those without a Linkages focal point.

Null Hypothesis 3F: There is no difference in depression levels between those with a Linkages community volunteer and those without a Linkages community volunteer.

5. METHODS

As described more thoroughly in the methods sections of the manuscripts found in Appendices A-C, this evaluation utilized a mixed-method, post-test study design that included primary data collection and secondary data analysis. First, a sample of 400 Linkages clients purported to be on ARVs was selected from a database of client intake forms. A June 2009 survey, conducted with clients at their homes, captured data on demographics, perceived health status, medication adherence, psychosocial wellbeing, support service use and unmet service needs, and quality of relationships with Linkages focal points and community volunteers (Appendix D). The instrument primarily contained items used in previous studies among PLHIV or within a developing country context. Cronbach's alpha was calculated for all scales, with alpha greater than 0.60 deemed acceptable. Multivariate analysis was used to determine the most important factors related to key outcomes, with particular focus on whether having a Linkages focal point or community volunteer was predictive of outcomes. Logistic regression was used for dichotomous outcomes (for example, medication adherence, referrals, and unmet need for support services). Ordinary Least Squares regression was used for continuous outcomes (for example, stigma, marginalization, and depression).

Following the survey, research personnel extracted the medical records of participating clients. The medical record extraction sought to obtain information on the most recent CD4 count of clients, date of ARV initiation, and CD4 count at the time of ARV initiation (Appendix E). Using Ordinary Least Squares regression, these data were used in combination with adherence data from the client survey to assess whether medication adherence was predictive of client health outcomes.

Secondary data analysis was completed on two sets of data collected by CARE International in Rwanda as part of their program activities. In October 2009, CARE facilitated a service inventory in Nyagatare District to determine the availability of 10 support services commonly needed among PLHIV: nutritional assistance, home based health care, help around the house, counseling, legal advice, financial assistance, school fee assistance, school material assistance, housing assistance, and health insurance (*mutuelle*). Approximately 70 representatives from direct service providers attended regional meetings at which they completed questionnaires regarding their organization's provision of support services, eligibility criteria for receipt of services, geographic coverage, and the presence of a wait list. Information on service availability was linked to the client survey results regarding need and unmet need for support services to help determine the extent to which the capacity of the service network limited the ability of program personnel to address service needs among clients.

Additionally, in October 2009, CARE collected qualitative data from Linkages clients, community volunteers and focal points to understand (a) the issue of depression and stigma among people living with HIV and AIDS; (b) how the Linkages model works, including the referral process for support services and strengths and weaknesses of the referral mechanism; and (c) what training has been received and is needed by program personnel. Two focus groups were held with clients and two were conducted with Linkages community volunteers in Gatunda and Rukomo sectors. Additionally, in-depth interviews were conducted with two Linkages focal points working in health facilities in the same sectors. Thematic analysis of the transcriptions was conducted.

The full research protocol underwent ethical approval for use of human subjects in biomedical research. Reviews were conducted by doctoral-trained faculty at National University of Rwanda School of Public Health and the Biomedical Institutional Review Board at Tulane University.

6. MAIN RESULT SUMMARY

As detailed in the manuscripts found in Appendices A-C, the majority (66%) of the 247 clients who reported themselves to be taking ARVs at the time of the survey were female. They ranged in age from 18 to 75, with an average age of 40 years. Slightly more than half (54%) were married formally or informally (that is, legally or cohabitating), 32% were widowed, 10% were divorced or separated, and 4% were single. Respondents averaged 2.2 assets per household. The most common assets were a radio (67%), bicycle (35%), or telephone/mobile phone (33%). Food insecurity was high among respondents. More than one-half (57%) of respondents met the criteria for moderate or severe food insecurity. Stigma and marginalization were generally low among clients in the sample, but clients averaged a score of 15.00 on the scale measuring depressive symptoms. Slightly less than one-half (45%) self-reported as being HIV asymptomatic, 28% reported being HIV symptomatic, and 27% reported suffering from AIDS-related illness at the time of the survey.

Two survey items were used to assess program exposure. Most respondents (79%) indicated that they had a Linkages focal point. Similarly, 79% indicated that they had a community volunteer who met with them to discuss their HIV. However, only 64% of clients indicated that they had both a focal point and a community volunteer. About 14% said they had a focal point but did not have a community volunteer, and 15% had a community volunteer but did not have a focal point. There were 7% who indicated that they had neither.

Self-reported ARV medication adherence was very high among respondents (Appendix A). Most respondents were taking a triple combination of Stavudine, Nevirapine, and Lamivudine requiring one pill taken two times per day. The vast majority of respondents reported complete adherence during the four days prior to the survey, and most respondents reported never skipping their medication at any time. Among those who indicated that they sometimes miss their medication, the most common causes included being busy with other things, forgetting, and having a change in daily routine. In the multivariate analysis, respondents who had a Linkages focal point were 3.6 times more likely than those without a focal point to never skip medication (p=0.002), but having a community volunteer was not significantly related to medication adherence. Although not statistically significant, food insecurity was a borderline predictor of medication adherence (p=0.084). Adherence to medication was predictive of health outcomes. After controlling for initial CD4 count and length of time on ARVs, those who were always adherent had a statistically higher current CD4 count than did those who sometimes missed medication.

Client need for support services was high (Appendix B). The overall number of referrals was low relative to need such that, with the exception of health insurance, most support service needs were not being met. Multivariate analyses suggested that exposure to program personnel was associated with increased likelihood of referrals and reduced unmet need. Respondents who had a focal point were more likely to have been referred for nutritional support (p=.012), counseling (p=.003), and health insurance (p=.009). They were also more likely to have lower unmet need for counseling (p=.005) and for health insurance (p=.011). Though the other analyses exploring the relationship between having a focal point or community volunteer and referrals and unmet need were not statistically significant, most were in the anticipated direction.

Review of the service inventory data suggested a weak network of support service providers in the district. Most service providers were associations for PLHIV or health facilities. Nearly all service providers had wait lists at the time of the service inventory, indicating that low referrals and high unmet need was a function of the capacity of the network and not entirely related to program limitations. The qualitative data substantiated these findings. Community volunteers and focal points indicated that, given the narrow provider network, community volunteers triaged cases to determine which clients had the greatest need and brought those cases to the attention of focal points that made referrals as possible.

Psychosocial wellbeing was varied (Appendix C). Internalized HIV-related stigma levels were low, and levels of marginalization were moderate. However, depressive symptoms were pervasive. None of the psychosocial outcomes statistically differed based on whether clients had a Linkages focal point or community volunteer. In contrast, food insecurity and HIV symptom status were significantly associated with all three outcomes. Those with more food insecurity or symptoms of HIV had statistically higher levels of stigma, marginalization, and depression. The qualitative data revealed that focal points and community volunteers underestimated the prevalence of depressive symptoms among clients, although Linkages personnel acknowledged that depression may exist due to poverty and disease symptomology. The qualitative data further suggested that program personnel may not have possessed the skills to identify or address depression.

7. CONCLUSIONS AND RECOMMENDATIONS

This study was completed to determine outcomes related to participation in a Linkages HIV case management program in 12 sectors of Nyagatare District in rural Rwanda. In particular, this research sought to establish the relationship between exposure to Linkages focal points ("case managers") and community volunteers and levels of ARV medication adherence, unmet need for support services, and psychosocial wellbeing. Results were drawn from primary data collected in a quantitative survey of clients and secondary analysis of data from medical chart extraction, a service inventory, and qualitative data collected from program clients, community volunteers, and focal points. The data are suggestive that exposure to program personnel, particularly Linkages focal points, was associated with client medication adherence and unmet need for support services but was not related to psychosocial wellbeing.

The findings regarding medication adherence concur with other research on the high levels of adherence achieved in Rwanda and the importance of consistent adherence in achieving beneficial health outcomes. Although the study design limited the ability to establish a causal relationship between program exposure and adherence, the results are suggestive of a relationship. As such, program personnel should continue to promote ARV adherence among clients and help clients to address the most common reasons for missed medication.

Support service needs were very high among program clients, but few of those needs were being met. The service inventory illuminated the limited capacity to respond to the tremendous client need for ancillary services. The vast majority of providers had wait lists for their services. However, multivariate analyses suggested that exposure to program personnel was associated with increased likelihood of referrals and reduced unmet need. These findings suggested that program personnel were making referrals when possible. The qualitative data further suggested that program personnel were aware of the limitations of the current provider network and triaged cases based on perceived level of need, with community volunteers referring clients to focal points, who in turn made referrals for services. The ability of program personnel to further reduce unmet need requires efforts to bolster the capacity of existing support service providers and to fill gaps in the network.

These data point to the emergence of psychosocial wellbeing, especially depression, as an important consideration for programs for PLHIV in Rwanda. Depressive symptoms were highly prevalent among program clients. Exposure to program personnel was not related to levels of depressive symptoms, perhaps because personnel were not equipped to screen for or to address depression, as was indicated by information provided by program personnel regarding their training in this domain. In fact, the qualitative data indicated that program personnel did not perceive depression to be a major problem among clients. If the program seeks to address depression among clients, additional training will be necessary. Because the primary emphasis for program personnel was resource management and not counseling, it may be most effective to equip program personnel with the skills to screen for depression and to utilize clinically trained mental health professionals for treatment. Rwanda's current human resource deficit will necessitate an investment in workforce development. Further, given the high prevalence of depression among respondents, individual-level interventions may not be efficient or practical. Group interpersonal psychotherapy could be used in conjunction with the existing associations for PLHIV.

Alternatively, internalized HIV-related stigma was generally low among respondents and marginalization was somewhat moderate. There were no obvious program effects related to these outcomes. It is possible that community or national efforts have contributed to lowered levels of stigma or that the program's efforts to address stigma have occurred primarily among new clients as they seek to accept their HIV status, of which there were none in the present sample. The study findings pertaining to marginalization conceivably point to the isolation felt by impoverished PLHIV and to the social division that continues to exist in post-genocide Rwanda. In either case, the data suggest the need for sustained sensitization and relationship-building.

Together, the findings of the three papers challenge the efficacy of lay health workers at the community level. There was no significant relationship between having a community volunteer and any of the outcomes of interest. On the other hand, having a focal point was significantly related to medication adherence, increased referrals, and reduced unmet need for support services.

In an earlier assessment of case management in Rwanda, Thurman et al. (in press) found that focal points were extended to capacity, necessitating reliance on community volunteers. The Linkages model's tiered approach to case management was designed to serve heavy PLHIV caseloads in a setting with severe human resource constraints, by having community volunteers interact frequently with clients to assess their needs and to relay information to Linkages focal points. That process may be occurring, but the data suggest that the Linkages focal points are the key to program outcomes. The lack of outcomes associated with community volunteers may be due to their limited authority, training deficiencies, or the lack of clearly defined roles and responsibilities. The lack of findings also may be attributed to the limited research design, one that may not have assessed outcomes that could have been affected by the community volunteers. Additional research is necessary to determine the utility of community volunteers in this model.

Another important finding from this research was the severity of food insecurity among program clients and its relationship to the outcomes assessed. More than one-half of study participants reported occurrences that demonstrated moderate or severe food insecurity during the four weeks prior to the survey. Most survey respondents indicated that they needed food assistance during the four weeks prior to the survey, but this need was largely unmet. Food insecurity was a significant predictor of stigma, marginalization, and depression, and it was a borderline predictor of medication adherence. To improve client wellbeing, comprehensive care and support programs for PLHIV in Rwanda should include a component to adequately address issues related to food security and nutrition.

To this author's knowledge, this research appears to be the first quantitative study exploring HIV case management outcomes in a developing country context. Given the substantial limitations of the research design, additional research is necessary to confirm whether HIV case management programs improve client outcomes. A longitudinal study of clients and a true comparison group that achieves adequate sample sizes is recommended. Additional qualitative work may be appropriate to explore the different roles of focal points and community volunteers, to help determine whether both are necessary to achieve beneficial outcomes among clients. In the interim, there is insufficient evidence to scale-up the model in Rwanda.

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APPENDIX A. IMPROVING MEDICATION ADHERENCE AMONG PLHIV IN RWANDA THROUGH THE USE OF A LINKAGES MODEL

Background

With a 3% national prevalence, the burden of HIV in Rwanda is relatively low in comparison to other countries in sub-Saharan Africa (Institut National de la Statistique du Rwanda & ORC Macro, 2005). As part of its strategic response to the control of HIV, the Rwandan Government has devoted substantial resources to care and support of people living with HIV and AIDS (PLHIV). National strategy recommends antiretrovirals (ARVs) for those with CD4+ counts lower than 350, and these drugs are subsidized for those meeting income requirements and other criteria (Republic of Rwanda, 2003; Rwanda Ministry of Health, 2003). In 2007, an estimated 66% of adults with advanced infection were receiving ARVs as recommended (Republic of Rwanda, 2008).

An extensive evidence base supports that ARVs are highly efficacious at reducing opportunistic infections and postponing death. However, ARVs require an exceptionally high adherence rate to effectively suppress viral load (Paterson et al., 2000). Thus considerable effort has been taken to monitor adherence, to understand the correlates of adherence, and to identify interventions that promote ARV adherence.

Numerous factors are believed to affect HIV medication adherence. Garcia, Schooley, and Badaro (2003) suggest a trilogy of information, behavioral skills, and motivation is the key to medication adherence. Life circumstances such as forgetting, being away from home, being busy, lack of food with which to take medicine, and changes in routines are cited as common reasons for disruption of medication schedules (Amberbir, Woldemichael, Getachew, Girma, & Deribe, 2008; Chesney et al., 2000; Hardon et al., 2006; Jean-Baptiste, 2008; Reynolds et al., 2004). Other correlates of adherence include reduced unmet need for support services, quality of the patient-physician relationship, mental health status, and social support (Amberbir et al., 2008; Chesney et al., 2000b; Diabeté, Alary, & Koffi, 2007; Gordillo, del Amo, Soriano, & Gonzalez-Lahoz, 1999; Hardon et al., 2006; Kumarasamy et al., 2005; Reif, Whetten, Lowe, & Ostermann, 2006; Safren et al., 2001; Schneider, Kaplan, Greenfield, Li, & Wilson, 2004).

Indeed, many interventions have attempted to provide various levels of social support to boost medication adherence. For example, Reynolds et al. (2008) describe an intervention that provides telephone calls tailored to the individual to provide information and solve problems that threaten adherence. Mukherjee, Ivers, Leandre, Farmer, and Behforouz.(2006) detail a multifaceted program to decrease barriers to medication access and to promote adherence, including the use of community health workers to provide psychosocial support to patients and to directly observe their therapy. Furthermore, a qualitative study among patients and providers in South Africa identified social support as a key to medication adherence, with the authors concluding that a "treatment supporter" could be an effective intervention strategy (Nachega et al., 2006).

In light of results of this research, a "Linkages" case management model has been in place in Nyagatare District, Rwanda since 2006 for PLHIV. The Linkages model has three levels of activity, two of which provide direct social support to clients: (1) "case managers" or Linkages "focal points" located within health centers to identify clients' needs and link them with appropriate support service providers; (2) community volunteers, who make home visits to PLHIV to monitor wellbeing and medication adherence, discuss stigma and psychosocial wellbeing, and encourage membership in an association for PLHIV; and (3) Linkages committees at the sector and district levels coordinate and implement HIV care and support activities.[1] Anecdotal evidence from a qualitative assessment of the model suggests that it has facilitated improved medication adherence among clients (Thurman et al., in press).

This paper examines the results of a quantitative study of the Linkages model, with particular focus on whether exposure to program personnel was associated with medication adherence. This research also assessed the common reasons for adherence failure among the study population and the extent to which medication adherence was predictive of improved health status. To the author's knowledge, this is the first quantitative evaluation of case management in Africa.

Methods

Study Procedures

A cross-sectional household survey was conducted in June 2009 with Linkages model clients living in 12 of the 14 sectors in Nyagatare District, in northeast Rwanda. The sample was drawn among 626 clients over age 18 whose case management intake form indicated they were taking ARVs. Among the 400 sampled clients, interviews were completed with 275. Of these, only 247 reported that they were currently taking ARVs. The survey was double translated into the local language, Kinyarwanda, and discrepancies in the double translations were rectified by a third party who was fluent in

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[1] In Rwanda, the national policy for prevention and treatment of HIV and AIDS is set at the national level, while the implementation of the policy, including support and coordination activities for PLHIV, has been decentralized to lower administrative units. Rwanda is divided into the following governmental administrative units, listed in descending order: province, district, sector, cell, and village.

both languages. Interviewers received extensive training, including use of the survey and consent procedures. Interviews lasted about 1 hour, and all data were double-entered into Epi-Info.

Following completion of the quantitative survey, medical records were abstracted for 85 respondents for whom the research team was able to obtain access.[2] Using a standardized data abstraction form, the team collected data including ARV regimen, date of ARV initiation, CD4 count prior to ARV initiation and date of that CD4 count, and most recent CD4 count and data of that CD4 count. These records were linked to the survey data.

Ethical Procedures

The full research protocol and questionnaires underwent ethical approval by Tulane University in the United States and faculty from the National University of Rwanda, School of Public Health, and the evaluation was authorized by the Rwandan Ministry of Health. All potential respondents were informed at the outset that their participation was voluntary and would not affect their eligibility to receive services at present or in the future. Due to low levels of literacy in the settings where the study was conducted, interviewers read the consent forms aloud to each participant and requested verbal consent of the participant to conduct the interview and extract their medical records. The interviewer then signed and dated the consent form as a witness to the given

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[2] The research team was unable to obtain medical records from all consenting study participants because several health facilities in Nyagatare District declined to participate in the study.

consent and noted whether permission had been granted. Respondents were not provided payments or incentives for participation.

Survey Measures

Socio-demographics: Socio-demographic measures included gender, marital status, and ownership of assets derived from items in the Rwanda Demographic and Heath Survey (Institut National de la Statistique du Rwanda & ORC Macro, 2005). Marital status provides one measure of possible social support, which has been shown to be associated with increased medication adherence. The asset count serves as a measure of socio-economic status. Those with lower socio-economic status may have lower medication adherence due to inability to pay for medication. The asset scale was constructed by giving 1 point for possession of each of the following eleven assets: bicycle, motorcycle or scooter, car or truck, electricity, radio, television, telephone or mobile phone, refrigerator, piped water, non-earth flooring, and charcoal fuel for cooking.

Food Security: Because many ARVs must be taken with food and a common side effect of ARVs is the experience of hunger, low food security is hypothesized to reduce medication adherence. To measure food security, a modified version of the Household Food Insecurity Access Scale (HFIAS) (Coates, Swindale, & Bilinsky, 2006) was utilized, after consultation with staff from Food and Nutrition Technical Assistance project. The modified scale recently has been cross-culturally validated, and has demonstrated internal and external validity. Three items were used from the original HFIAS: In the last four weeks, how often (1) was there ever no food at all in your household because there were no resources, (2) did you or any household member go to sleep at night hungry because there was not enough food, and (3) did you or any household member ever go a whole day and night without eating anything at all because there was not enough food. Respondents rated the frequency of these occurrences on a three-point scale of Never, Sometimes, and Often. Cumulative scores were generated (range=0-6), and higher scores indicated more food insecurity (Cronbach's alpha = .88).

Psychosocial Wellbeing: Psychosocial wellbeing was measured using three constructs: stigma, marginalization, and depression. Internalized HIV-related stigma was measured using a 12-item index (Visser, Kershaw, Makin, & Forsyth, 2008). Responses were scored on a four-point scale containing strongly agree, agree, disagree, and strongly disagree. Cumulative scores were generated (range=0-12), with higher scores indicating more stigma (Cronbach's alpha=.62).

Marginalization was measured using 6 items developed by Thurman et al. (2006). Responses were scored on a four-point scale containing strongly agree, agree, disagree, and strongly disagree. Mean scores were generated (range=1-4), with higher scores indicating higher marginalization (Cronbach's alpha=.87).

Depression was measured using the 10-item Center for Epidemiological Studies Depression scale (Andresen, Malmgren, Carter, & Patrick, 1994). Cumulative scores were calculated (range=0-30), with higher scores indicating higher depressive symptoms (Cronbach's alpha=.83).

Medication adherence: Self-reported medication adherence was measured using the AIDS Clinical Trials Group (ACTG) adherence questionnaire (Chesney et al., 2000). Clients reported their ARVs, the number of doses prescribed per day, and pills per dose. Then, they were asked to report how many doses they missed for each medication over each of the previous four days. If a portion of a dose was missed, it was counted as a missed dose. Percent adherence was calculated as the number of doses actually taken divided by the number of doses each client should have taken over the four days. Additionally, clients answered other items from the ACTG adherence questionnaire, including identifying the last time any medication was missed and rating the frequency that various circumstances caused them to miss their medication.

Program participation: Several self-generated items measured program exposure. Respondents were asked whether they had a Linkages focal point and whether they had a community volunteer.

Analysis

Using an item on the ACTG adherence questionnaire that inquired about the last time medication was missed, a dichotomous medication adherence variable was created: sometimes miss medication versus never miss medication. Logistic regression was conducted to determine the extent to which exposure to focal points and community volunteers was associated with never missing ARV medication. The multivariate model contained items with $p<.05$ at the bivariate level but also was built based on the face validity of control variables—that is, it included control variables shown important in other studies of adherence. Odds ratios, 95% confidence intervals, and significance levels are presented. Although the results are not presented herein, forward stepwise modeling was used to establish that multicollinearity was not affecting the results of the multivariate analysis. Further, other relevant descriptive statistics are reported, including reasons for missing HIV medication.

Ordinary Least Squares regression was used to determine the relationship between adherence and health outcomes, as measured by current CD4 count. Prior to constructing the multivariate model, bivariate analysis was conducted to determine the relationship between current CD4 and client characteristics, including gender, age, marital status, number of assets, household food insecurity, and levels of depressive symptoms, stigma, and marginalization. None of these characteristics were statistically significant predictors of current CD4 count, so they were excluded from the multivariate model (see Appendix F). The model controlled for whether the individual reported being always adherent, initial CD4 count, days between initial CD4 count and inception of ARVs, and days between ARV initiation and current CD4 count. Coefficients and significance levels are presented.

Results

Among the 247 clients who reported themselves to be taking ARVs at the time of the survey, 66% were female (Table 1). They ranged in age from 18 to 75, with an average age of 40.2 years. Slightly more than half (54%) were married formally or informally (i.e., common-law marriages), and the remaining were widowed, divorced, or single. On average, respondents had 2.2 assets, with the most common assets being a radio (67%), bicycle (35%), or telephone/mobile phone (33%) (data not shown). Food insecurity was high among respondents. The average food insecurity scale score was 2.0, and more than one-half met the criteria for moderate or severe food insecurity (data not shown). Stigma and marginalization were generally low among clients in the sample, but clients averaged a score of 15.0 on the scale measuring depressive symptoms.

Two items were used to assess program exposure. Most (64%) had both a focal point and community volunteer, about 30% though some had one or the other and 7% reported having neither (data not shown). As seen in Table 1, there were no significant differences in background characteristics by exposure program category.

The majority of respondents had been prescribed a triple combination of Stavudine, Nevirapine, and Lamivudine requiring one pill taken two times per day. In the four days prior to the survey, only 10 individuals (4.0% of the respondents) reported missing one or more doses of medication (data not shown). When asked about medication adherence more generally, in terms of the last time they had missed a dose, most respondents (82%) reported never missing medications (Figure 1). Among the 45 individuals who reported sometimes missing medication, the most common reasons for missed medication included being busy with other things, forgetting, and change in daily routine (Table 2).

At the bivariate level, never missing medication was significantly associated with higher depressive symptoms, higher marginalization, and having a focal point, but no other factors were statistically related to adherence (Table 3). In the logistic multivariate regression, having a focal point increased the likelihood of never skipping medication by 3.6 times (p=.002) (Table 4). Depressive symptoms and marginalization were no longer associated with higher medication adherence, however. There was no independent statistically significant relationship between having a community volunteer and medication adherence. Though no other factors were significantly associated with medication adherence, level of food insecurity was a borderline predictor (p=.084).

Ordinary Least Squares regression was used to determine the relationship between current CD4 count and medication adherence (never skipping medication versus sometimes skipping medication). Never skipping medication was predictive of a higher current CD4 count (p=0.015), as were initial CD4 count and days between ARV initiation (p<.001_and current CD4 count (p=.003) (Table 5). Individuals who reported never skipping medication had a CD4 count that was 122 points higher, on average, than those who sometimes skip medication, even after controlling for initial CD4 count and length of time on ARVs.

Discussion

This study examined whether exposure to Linkages focal points ("case managers") and community volunteers was associated with ARV adherence among a sample of PLHIV in rural Rwanda and, in turn, whether adherence was predictive of better health outcomes. Self-reported medication adherence was obtained using items from the ACTG adherence questionnaire, and those data were merged to patient clinical data.

Clients reported high adherence in the four days prior to the study, and fewer than 20% reported ever skipping medication. Rates of adherence were slightly higher than found previously in other general studies of medication adherence rates in Rwanda. Jean-Baptiste (2008) found 92% of PLHIV visiting four clinics in Rwanda had been 95%-100% adherent to their ARVs over the previous four days.

This analysis uncovered inconsistent findings regarding the potential efficacy of the program. Having a focal point was statistically related to medication adherence.

Clients with a focal point were more than 3.5 times more likely to never skip ARV medication. However, there was no statistical relationship between having a community volunteer and medication adherence.

For this program, the different roles of the focal point and community volunteer in support of medication adherence are not well understood. Focal points do discuss adherence with clients, but their interaction tends to be more limited. There is anecdotal evidence to suggest that clients often have monthly impromptu meetings with focal points when they fill their ARV prescriptions at the health facility. This perhaps explains the link between focal points and adherence. Conversely, the apparent absence of a statistical relationship between having a community volunteer and medication adherence was surprising considering that community volunteers are the program's frontline personnel, who have the most interaction with clients. It may be that community volunteers truly do not affect medication adherence among clients. It also is possible that low sample sizes limited power in this latter analysis, and further research is recommended.

Food insecurity was not a statistically significant predictor of adherence in this analysis, likely due to sample size limitations, but the relationship between food availability and adherence trended in the anticipated direction--greater food insecurity reduced the likelihood of always being adherent. In fact, among the 10 individuals who reported missing medication in the four days prior to the survey, 8 were living in households with moderate or severe food insecurity. These findings regarding the relationship between food scarcity and medication adherence corroborate that of a previous assessment of the case management model in Rwanda in which clients indicated that insufficient food presented a challenge to medication adherence (Thurman et al., in press). Though not all ARVs require food for ingestion, a common side-effect of ARVs is an increased appetite, and malnourished PLHIV more frequently experience some of the other side effects of ARVs, such as vomiting and dizziness (Chen et al., 2003). Given this relationship, multi-sectorial initiatives that combine food and livelihood activities into HIV and AIDS programs are increasingly common (Byron, Gillespie, & Nangami, 2006), and the findings of the current study reinforce the need for such integrated programming.

Other common predictors of medication adherence were not statistically related to adherence in this study. Stigma, marginalization, and depression were not statistically predictive of adherence. The lack of significant findings may have been due to sample size limitations or because these factors are not related to adherence in this population, and further research is warranted.

Among those who did report sometimes missing medication, the most common reasons for missed medication parallel those found in the literature—being busy with other things, forgetting, and change in daily routine (Chesney, 2000; Chesney, Morin, & Sherr, 2000; Chesney et al., 2000; Reynolds et al., 2004; Amberbir et al., 2008; Jean-Baptiste, 2008; Hardon et al., 2006). Some low-cost tools utilized in developed countries may be easily adapted to the Rwandan context to support clients who have trouble maintaining their medication schedule. For example, weekly pill organizers are easily portable, and could help clients who must be away from their home at the time of dosage. Another potential tool is mobile phone reminder. Not all program clients have a mobile phone, but for the approximately one-third that do, mobile phone reminders (via alarm or text message) might be implemented at relatively low cost.

Results from the analysis of the relationship between adherence and CD4 count reaffirm the importance of medication adherence in achieving improved client health. Individuals who reported always being adherent had significantly higher CD4 counts at follow-up compared to those who were not always adherent, even after controlling for length of time on ARVs and data of ARV initiation. Though a causal relationship cannot be established between program exposure and health outcomes, these findings support the theory that exposure to program personnel promotes adherence, which in turn improves health status.

The results of this analysis should be considered cautiously in light of the limitations of the research design. The post-test only design lacking a true comparison group prevents both an understanding of longitudinal trends, as well as outcomes in the total absence of the program, thus limiting the ability to establish causality. At best, the data provide suggestive evidence of program outcomes.

Though extreme care was taken with the design of the survey and with field team training, information bias still may be present in these data. In particular, the adherence classification was dependent on client self-reports. Some respondents may have overstated their level of adherence due to social desirability bias, in which case the current study would be overestimating the proportion that are always adherent. Certainly, pill counting and electronic monitoring of pill bottles tend to yield the most accurate measures of adherence, though the considerable time and financial resources required by these methods tend to be limiting. Patient self-reports tend to be less reliable, and often overstated, relative to the aforementioned methods due both to recall and social desirability (Simoni et al., 2006). However, others have found that patient self-reports of adherence are correlated with viral load and CD4 count (Duong et al., 2001; Simoni et al., 2006).

Conclusions

This study sought to determine whether exposure to Linkages case management personnel was associated with higher medication adherence among a sample of PLHIV in Rwanda. Though medication adherence was high overall, having a Linkages focal point was statistically predictive of always adhering to ARVs. There was no apparent relationship between adherence and having a community volunteer, but this may have been due to sample size limitations. Although the results are not confirmatory, given research design limitations, they are suggestive that social supports may improve medication adherence in a developing country setting. In turn, adherence generates improved health outcomes. Further research is necessary to understand the role of focal points and community volunteers in promoting adherence and to confirm whether program exposure does in fact lead to adherence.

Table 1. Characteristics of the sample

	Total sample (n=247)	**Have a focal point and community volunteer (n=159)**	**Have a focal point only (n=35)**	**Have a community volunteer only (n=36)**	**Have neither (n=17)**
Gender %					
Male	34.4	37.7	31.4	30.6	17.7
Female	65.6	62.3	68.6	69.4	82.4
Relationship Status %					
Married (legal or common law)	54.2	53.5	45.7	61.1	64.7
Unmarried (widowed, divorced, single)	45.8	46.5	54.3	38.9	35.3
HIV symptom status %					
HIV-asymptomatic	45.3	46.5	40.0	47.2	41.2
HIV-symptomatic	27.5	28.3	28.6	27.8	17.7
AIDS related illness	27.1	25.2	31.3	25.0	41.2
Age (mean)	40.2	40.7	40.3	38.1	40.1
Number of assets (mean)	2.2	2.1	2.5	1.9	2.5
Food insecurity scale score (mean)	2.0	2.0	1.8	2.2	1.2
Stigma scale score (mean)	3.4	3.4	3.1	3.5	2.9
Marginalization scale score (mean)	2.6	2.5	2.6	2.6	2.5
Depressive symptom scale score (mean)	15.0	15.2	15.5	14.2	14.0

*p<.05

** p<.01

Figure 1
ART Adherence

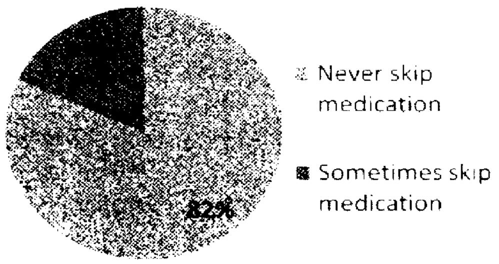

Table 2. Reasons for sometimes missing medication, n=45

	% Often/Sometimes	% Rarely/Never
Were busy with other things	22	78
Simply forgot	20	80
Change in daily routine	20	80
Were away from home	16	84
Problems taking pills at specified times	16	84
Felt good	11	89
Wanted to avoid side effects	4	96
Felt drug was harmful/toxic	4	96
Fell asleep/slept through dose time	4	96
Felt sick/ill	4	96
Ran out of pills	4	96
Felt depressed/overwhelmed	2	98
Had too many pills to take	2	98
Did not want others to notice	2	98

Table 3. Unadjusted Factors Associated with Medication Adherence

	Never Miss Medication (n=202)	Sometimes Miss Medication (n=45)
Male %	33.7	37.8
Married %	54.5	53.3
Asymptomatic HIV %	43.6	53.3
Age (mean)	40.5	39.1
Number of assets (mean)	2.2	1.9
Food insecurity scale score (mean)	1.9	2.3
Stigma scale score (mean)	3.4	3.0
Marginalization scale score (mean)*	2.6	2.4
Depressive symptoms scale score (mean)**	15.5	12.6
Has a focal point % **	82.2	62.2
Has a community volunteer %	78.7	80.0

*p<.05

** p<.01

Table 4. Predictors of never skipping ARV medication (n=247)

	Odds Ratio	95% Confidence Interval
Male	.50	0.18-1.35
Married	1.42	0.60-3.34
Symptomatic HIV	1.13	0.46-2.75
AIDS-related illness	1.77	0.66-4.74
Age	1.04	0.99-1.09
Number of assets	1.08	0.82-1.43
Food Insecurity score	.81	0.65-1.03
Stigma scale score	1.08	0.87-1.34
Marginalization score	1.31	0.65-2.65
Depressive symptoms scale score	1.05	0.99-1.12
Has a focal point	3.57**	1.61-7.90
Has a community volunteer	.90	0.35-2.32

*p<.05

** p<.01

Table 5. Predictors of current CD4 count (n=85)

	Coefficient	p-value
Always adherent*	122.28	0.015
Initial CD4 count**	0.95	0.000
Days between initial CD4 count and ARV inception	0.14	0.296
Days between ARV inception and current CD4 count**	0.16	0.003
Constant	56.32	

*p<.05

** p<.01

APPENDIX B. ADDRESSING SUPPORT SERVICE NEEDS AMONG PLHIV IN RWANDA THROUGH A LINKAGES MODEL

Background

The case management approach has been effective for managing the complicated needs of those with chronic illnesses in resource-rich countries. In the last twenty years, case management has been widely used to manage the complex support service and health needs of people living with HIV and AIDS (PLHIV) as well. Case management is associated with increased access to and retention in HIV primary care (Cunningham, Wong, & Hays, 2008; Gardner et al., 2005; Huba, Melchior, & Panter, 2000; Sherer et al., 2002;), increased uptake of needed community-based support services (London, Leblanc, & Anshensel, 1998), and reduced unmet need for supportive services such as counseling, health insurance, and income assistance (Katz et al., 2001). In fact, Orwin, Sonnefeld, Garrison-Mogren, & Smith (1994) suggest that intermittent contact between a case manager and client is more effective at connecting clients to support services than the client could accomplish alone. Nevertheless, effective linking of clients to needed support services requires accurate assessments of client needs, routine and adequate follow-up, as well as the availability of services (Murphy, Tobias, Rajabiun, & Abuchar, 2003).

To address the myriad needs of PLHIV in a developing country context, the President's Emergency Plan for AIDS Relief (PEPFAR) recommends the establishment of country-level networks of domestic and international organizations aligned to coordinate care, offer support services, and facilitate referrals for PLHIV (Office of the U.S. Global AIDS Coordinator, 2006). Additionally, the Institute of Medicine (2007) calls for strong referral mechanisms and interdisciplinary networks providing community-based care and support.

In Rwanda, where 3% of the population is living with HIV and AIDS (Institut National de la Statistique du Rwanda & ORC Macro, 2005), numerous variations on "case management" have been implemented to link PLHIV to community and facility-based resources. One of these initiatives, the Linkages case management model for PLHIV in Nyagatare District, employs "Linkages focal points" within health centers to identify clients' needs and link them with appropriate support service providers and to monitor their clinical and psychosocial wellbeing and coordinate medical care. Additionally, focal points supervise community volunteers, who make home visits to PLHIV to continually assess their need for support services, to monitor their medication adherence, and to attend to issues related to psychosocial wellbeing, such as depression and stigma.

The literature lacks concrete evidence of the efficacy of HIV case management to reduce unmet need for support services in developing countries and of the aspects of programming that are the more important determinants of reduced unmet need. As part of a larger evaluation of the Linkages case management model, this analysis was undertaken to determine the extent to which the Linkages model is meeting the traditional case management role of brokering support services for clients. In particular, the analysis explores to what extent exposure to Linkages program personnel is related to referrals for support services and unmet need for support services. Additionally, this analysis considers how the availability of services and the referral process itself mitigate the effectiveness of the Linkages model.

Methods

Quantitative Survey

In June 2009, a household survey was completed among 275 of 400 randomly selected clients of the Linkages case management model in Nyagatare District, Rwanda. Eligible participants were PLHIV age 18 and over, who had program intake forms indicating they were receiving antiretroviral therapy. Interviews were conducted in Kinyarwanda and lasted approximately one hour. Among those who completed the survey, only 247 indicated that they were currently taking antiretrovirals; the analysis is limited to these individuals.

The survey inquired about basic demographics, including gender, age and socio-economic status. One measure of socio-economic status was an asset index constructed using four items from the Rwanda Demographic and Health Survey (Institut National de la Statistique du Rwanda & ORC Macro, 2005). The asset index quantified the number of assets owned by giving one point for each of the following eleven assets: bicycle, motorcycle or scooter, car or truck, electricity, radio, television, telephone or mobile phone, refrigerator, piped water, non-earth flooring, and charcoal fuel for cooking. Another measure of socio-economic status, food insecurity, was measured using three items from the Household Food Insecurity Access Scale (Coates, Swindale, & Bilinsky, 2006). Cumulative scale scores were calculated, and a higher scale score indicates more food insecurity. Client health status was measured using a single categorical variable in which participants self rated their symptoms as HIV+ asymptomatic, HIV+ symptomatic, or AIDS related illness. Depression, which may be associated with lack of service uptake, was measured by the Centers for Epidemiological Studies Depression brief scale

(Andresen, Malmgren, Carter, & Patrick, 1994), on which higher scores, on a scale from 0-30, indicate higher depressive symptoms. Several self-generated items measured program participation, including whether respondents had a community volunteer and whether they had a Linkages focal point ("case manager").

The survey asked about recent need for 10 support services: nutritional support, home-based health care, assistance around the home (e.g., cooking or cleaning), counseling, legal advice, financial assistance, school fee assistance, school material assistance, housing assistance, and health insurance ("*mutuelle*"). Clients were asked whether they needed each of these services in the previous four weeks, with the exception of school fee assistance, school material assistance, and health insurance, which were asked of the current calendar year because they have an annual uptake pattern. Those who indicated a recent need were asked whether (1) they had been referred to a service provider and (2) they had received the service. Unmet need was determined if there was a need but the service was not received.

Service Mapping

In October 2009, CARE International in Rwanda facilitated a service inventory in Nyagatare District to determine the availability of the 10 aforementioned support services. Three regional meetings were convened in which representatives from direct service providers attended, including international and local NGOs and district government agencies. Approximately 70 attendees completed questionnaires regarding their organization's provision of support services, eligibility criteria, geographic coverage, and the presence of a wait list.

Qualitative Data Collection

Also in October 2009, CARE International in Rwanda collected qualitative data among community volunteers and focal points to understand the referral process for support services and strengths and weaknesses of the referral mechanism. Two focus groups were held among randomly selected community volunteers in Gatunda and Rukomo sectors of Nyagatare District. Additionally, in-depth interviews were conducted with two Linkages focal points working in health facilities in the same two sectors. Focus groups and interviews were conducted in Kinyarwanda by a member of the CARE staff, who was not affiliated with the Linkages program, using semi-structured protocols and were timed to last approximately 1.5 hours. Audio recordings were transcribed and translated into English.

Ethical Review

The full research protocol and questionnaires received ethical approval from Tulane University in the United States and faculty from the National University of Rwanda, School of Public Health, and the evaluation was authorized by the Rwandan Ministry of Health. All potential respondents were informed that their participation was voluntary and that they were free to terminate participation at any time or to decline to answer any question. Due to low literacy levels in Rwanda, verbal consent was obtained from participants, and the interviewer signed and dated the consent form to document that consent procedures had been followed. No payments or incentives were given to participants.

Analysis

The analysis examined process and outcome measures associated with program exposure. Referral to support services, a process measure, was defined as a case in which an individual reported a need for a service and indicated that they had been referred to a provider. Unmet need, an outcome measure, was defined as a case in which an individual reported a need for a service but had not been referred or had not received the service. Sector-level data from the service inventory on availability and geographic coverage of each individual support service were compared to sector-level data on unmet needs to quantify the proportion of cases with each unmet need that should theoretically have met needs based on service availability.

Multivariate analysis, using logistic regression, was used to determine whether Linkages program exposure was associated with the likelihood that clients were referred to an individual support service. Logistic regression also was conducted to assess whether Linkages program exposure was associated with unmet need for each individual support service. The Anderson Behavioral Model of health services was utilized as the conceptual framework for the multivariate analysis. The model theorizes that uptake of health services is driven by three coalescing forces: (1) predisposing factors at the individual level, such as socio-demographic characteristics, social supports, and health beliefs; (2) enabling factors, which promote or inhibit uptake, such as the availability of and access to services; and (3) actual needs for health services, which are dependent on the medical condition (Anderson, 1995; Anderson & Newman, 1973). Thus, the models contain the following: predisposing factors (gender, age, food insecurity score, asset index, depressive symptoms), enabling factors (has a focal point, has a community volunteer), and actual needs (sum of supportive services needed, HIV symptom status). Odds ratios and 95% confidence intervals are presented.

The qualitative data were reviewed for themes, which were then triangulated between respondent types. In particular, the qualitative data was reviewed to understand strengths and weaknesses in the referral process. Quotes are provided to illustrate themes.

Results

Among the 247 quantitative survey respondents on antiretroviral therapy, most (66%) were female, and the average age was 40.3 years (Table 1). The survey inquired about ownership of 11 assets, but they had 2.2 assets in their household, on average. Most were classified as having moderate food insecurity at the household level (average scale score = 2.0). Slightly less than half (45%) reported themselves to be asymptomatic of HIV, 28% were HIV symptomatic, and 27% had AIDS-related illness. The mean depressive symptoms score was 15.0. A score of 10 or above meets the criteria for depression. Although most (64%) reported having a focal point and community volunteer, about 14% had only a focal point and 15% had only a community volunteer. Approximately 7% reported having neither a focal point nor a community volunteer.

On average, respondents indicated that they needed 6.1 services in the weeks and months before the survey, with a range of 1 to 10 (data not shown). That is to say, all respondents had had at least one service need, and some respondents reported needing all 10 of the support services about which were inquired. The most common needs were financial assistance (97%), health insurance (92%), and school material assistance (73%)

(Table 2). The least common needs were home-based health care and legal assistance, which nevertheless were reported as needs by approximately one-third of the sample.

With the exception of health insurance, clients reported being referred to few needed support services (Table 2). Only 6% of clients who needed financial assistance reported being referred to a provider of financial assistance, and 7% of clients who needed housing assistance were referred to a provider. However, the vast majority (93%) of clients needing health insurance were referred to an organization that could provide assistance.

Among those who were referred to a provider, the majority reported receiving the service that they needed (Table 2). As seen in the column reporting the percent of unmet need as a proportion of referred clients, all individuals who reported being referred for home-based healthcare, help around the home, school fee assistance, and school material assistance said that they had received those services (i.e., the percent of unmet need as a proportion of referred is equal to zero). Small proportions of those being referred for other services indicated that they had not received the services. For example, 3 (9%) of the 34 individuals referred for counseling indicated that their need had not been met. Only 2 (1%) of the 210 individuals referred to a provider of health insurance indicated that they did not obtain health insurance.

Unmet need for support services was high. On average, respondents had 4.4 unmet needs, with a range of 0 to 9 (data not shown). The services with the highest ratio of unmet needs to needs were housing assistance and financial assistance, with about 95% of respondents who needed those services reporting that they had not received the services (Table 2). Whereas 92% of respondents indicated that they had needed health insurance in the previous year, only 8% of those indicated that they had not received health insurance.

Table 3 shows the unadjusted proportion of referrals for each support service by program exposure category. In the bivariate analysis, clients with a focal point were significantly more likely to have been referred for nutritional support, counseling, and health insurance. Clients with a community volunteer were significantly more likely to have been referred for nutritional support and school material assistance.

After adjusting for potential confounders, respondents who had a focal point were more likely to have been referred for nutritional support (p=.012), counseling (p=.003), and health insurance (p=.009) (Table 4). Similarly, individuals who had a focal point were more likely to have been referred for the other seven support services; however, the associations were not statistically significant. Having a community volunteer was not associated significantly with referrals for any support service. For most services the direction of the relationship was as hypothesized—having a community volunteer increased the likelihood of referral. Indeed, for counseling (p=.083) and school material assistance (p=.055), the relationship was nearly significant. However, those with a community volunteer trended toward a reduced likelihood of referrals for assistance around the home and health insurance.

Table 5 shows the unadjusted proportion of unmet need for each support service by program exposure category. In the bivariate analysis, clients with a focal point were had significantly lower levels of unmet need for counseling and health insurance. Those with a community volunteer had significantly lower levels of unmet need for school material assistance.

In the multivariate analysis of unmet need, exposure to program personnel was related to the level of unmet need for two social services (Table 6). Having a focal point was associated with reduced unmet need for counseling (p=.005) and for health insurance (p=.011). For all other services, those with a focal point had lower unmet need or the same unmet need as those without a focal point, although the results were not statistically significant. Those with a community volunteer tended to have lower unmet need for support services than those without, although none of the results were statistically significant. For two services (assistance around the home and health insurance), having a community volunteer was associated with slightly higher levels of unmet need.

The service inventory data were used to quantify the number of cases of unmet need for each service that could theoretically be met based on availability of the service. Generally, the health facilities, sector social affairs offices, and associations for PLHIV were the only providers of support services for PLHIV in any given sector. Most sectors had at least one provider per support service, though some sectors did not provide for all ten of the services. For seven of the services, no unmet needs could have been met at the time of the survey, due to lack of service availability or the presence of wait lists (Table 7). However, there was availability of home-based health care, help around the home, and counseling that theoretically could have met the need of some respondents living in certain geographic locations.

The qualitative data provided insight to several aspects of the referral process. In general, when asked about referrals for services, the focal points and community volunteers discussed referrals for clinical services, such as CD4 counts, ARVs, and prevention of maternal to child transmission. They rarely mentioned referrals for supportive services.

The focal points and community volunteers provided information that helped to clarify the delineation in responsibilities when responding to the needs of clients. They suggested that the responsibility of community volunteers is to visit clients to identify their needs and to advocate on their behalf for necessary services. The community volunteers bring cases of need to the attention of focal points. In most cases, it is the focal points who officially make referrals for services.

> "Generally we mainly offer advocacy for those services that we cannot afford to give." Community volunteer
>
> "You go straight to the case manager and tell him what is the problem." Community volunteer
>
> "Usually there is a monthly meeting with the volunteers. All the clients problems that we become aware of are from the volunteers who tell us." Focal point
>
> "So every client that does get a transfer, we give the information to his volunteer so that he knows and can follow the client's situation." Focal point

The focus groups and in-depth interviews also made clear that the need for services must be balanced against the availability of services in the community. Program personnel triage cases to determine who has priority to limited services.

> "Again it depends on what kind of service is available and who needs it. For example, we know our clients and how much they suffer, so it's easy for us to determine who comes first." Community volunteer

The qualitative data revealed inconsistencies between sectors in the way the referral process is tracked. In one sector the focal point and community volunteers reported using a form to document that a referral has been made. When the client pursues the referral, the provider completes a portion of the form to document that the service has been received. This form is then to be returned to the focal point or community volunteer, so that they can track client receipt of services.

> "There is an official form that we have to fill and follow it." Community volunteer
>
> "The transfer paper has another part that must be filled by the doctor who will work on him, and the client must bring back that piece of paper." Focal point

In the other sector, the focal point and community volunteers indicated that there is no official documentation to track referrals. Community volunteers communicate the needs of clients to the focal point, who helps put the client into contact with a provider. Follow-up about receipt of service requires direct communication with the provider or the client.

> "No, we don't have those kind of papers. What happens is you go straight to the case manager and tell him what is the problem." Community volunteer
>
> "You have to follow it up until you know [whether the client received the service]." Community volunteer

Discussion

This research examined the extent to which exposure to Linkages focal points (case managers) and community volunteers was associated with referrals and unmet need for ten ancillary social services among a sample of PLHIV clients in rural Rwanda. Among respondents, needs for ancillary services were high. Although the number of referrals was generally low and the number of unmet needs was high, the data suggest a relationship between program exposure and both referrals and unmet need.

Exposure to program personnel, particularly focal points, was associated with significantly higher likelihood of referral for nutritional support, counseling, and health insurance. The relationship between having a focal point and referrals for the other 7 support services was not statistically significant, likely due to inadequate sample sizes. However, the relationships were in the anticipated direction. Although the relationship between having a community volunteer and referrals for each of the 10 support services was not statistically significant, most of the relationships were in the anticipated direction.

Similarly, having a focal point was strongly related to reduced unmet need for counseling and health insurance. Having a community volunteer was not statistically related to unmet need for any service. Still, for most of the support services, the relationship between unmet need and program exposure was in the anticipated direction.

Several published quantitative studies of HIV case management have found that it increases uptake of needed support services (London, LeBlanc, & Aneshensel, 1998) and reduces unmet need for support services (Katz et al., 2001). Those studies were completed in developed countries with comparatively robust support networks for PLHIV. However, this study found that most service providers in the study site were at their capacity for the number of clients they could assist, which may account for the low overall number of referrals relative to reported need. Indeed, the inventory of support services revealed only a few instances in which need could have been met theoretically, based on availability of services. The low number of referrals also is consistent with an earlier assessment of HIV case management in Rwanda (Thurman, Haas, & Dushimimana, 2006). In that assessment, the researchers hypothesized that the low number of referrals may have been due to a limited network of support services. The noticeable absence of references to supportive services in the current study's qualitative discussions with focal points and community volunteers helps to substantiate that idea. In a developing country context, the ability of case management programs to reduce unmet need for PLHIV requires efforts to bolster the capacity of existing support service providers and to fill gaps in the network so that case managers can make referrals.

For the Linkages program, an additional area for improvement is the referral process itself. Others have reported that service brokerage by a case manager does not necessarily equate to service uptake by clients (Lehrman, Gentry, Yurchak, & Freedman, 2001). In this study, some referred clients did not receive the service they needed. It is possible that those individuals did not meet eligibility criteria for receipt of the service or that they were placed on a wait list. Another explanation is that the clients did not follow-up on the referral. The qualitative data revealed inconsistencies in the way the Linkages program tracks referrals. Without adequate documentation, program personnel have no simple way of ensuring that clients attain the services for which they have been referred. The implementation and consistent use of two-way referral forms, documenting both referral and service provision, is an efficient way to monitor service uptake that should be incorporated into any case management program.

This case management program is unique to other case management programs studied in the published literature because it takes a tiered approach to case management—two individuals working at different levels to assess need and make referrals. This approach was designed to address the need for more frequent contact with numerous clients in an atmosphere with few trained case managers. However, for all of the referral and unmet need outcomes analyzed, the magnitude of the relationship between exposure to program personnel and outcomes was greater for the focal point than for the community volunteer. This finding corresponds with remarks in the qualitative data suggesting that the focal point is the ultimate gatekeeper for referrals. Although community volunteers have more contact with clients, their role is to monitor client wellbeing and communicate need to the focal points. The determination of whose case is brought to the attention of focal points or whose case is advocated is subjectively made by community volunteers based on the level of need. If community volunteers are conducting the triage and focal points refer based on these recommendations, then the strength of the relationship between outcomes and focal points is logical. The data further suggest that if a case makes its way to referral, it is likely to result in attained services. However, the subjective referral process used in this program is open to scrutiny and may result in client perceptions of inequitable distribution of resources.

To some extent, these findings challenge the theory that a tiered approach to case management in a developing country is an efficacious model. The data indicate that focal points contribute to referrals and uptake of necessary services among PLHIV, but did not find a significant relationship between community volunteers and referrals and unmet need for support services. It may be that community volunteers lack the authority to make official referrals for services, thus restricting them to be conduits of information passed to focal points. However, this finding should not diminish the potential value of the community volunteers. Thurman et al. (in press) reported in an assessment of an earlier case management model in Rwanda that focal points were extended to capacity by the volume of clients and needed the assistance of community volunteers to meet their case loads. The results of the current study may suggest that by granting community volunteers some authority to make official referrals, unmet need for support services could be further reduced. However, as previously described, the ability to make referrals is deeply limited by the weak service infrastructure in the district.

Several limitations should be considered when interpreting the results of this study. Foremost are limitations in the quantitative survey study design. Because the quantitative survey used a cross-sectional approach, outcomes cannot be definitively attributed to exposure to Linkages personnel. The interpretation of outcomes also is hindered by the lack of a true comparison group devoid of program exposure.

Second, due to the questionnaire structure for unmet need, the quantitative data may be overestimating the extent of unmet need. All clients were asked whether they needed each of 10 different services. Those who said that they had a need were asked whether they were referred to a provider. Only those who said that they were referred to a provider were asked whether they had received the necessary service. As previously described, unmet need was characterized as those who said (a) they were not referred or (b) they were referred but did not receive the service. Thus, it is possible that some individuals actively sought services on their own (that is, were not referred) and received the service. However, given the response patterns on the survey, as evidenced particularly for the questions pertaining to need for health insurance, it is unlikely that the data greatly exaggerates the level of unmet need in the community. Most individuals in this context must be referred to a provider in order to obtain services, especially in light of the limited provider infrastructure.

Other misclassification may have occurred on the quantitative survey. For example, some questions may have been prone to recall problems, such as those pertaining to reported need for services in the last month. Additionally, some individuals may have intentionally over or under stated their situation.

Finally, though multiple attempts were made to fill gaps that existed in the service inventory data, the database contained holes. The effect of these gaps on the interpretation of findings is difficult to ascertain. The availability of services in Nyagatare District may be understated due to the absence of certain providers from the meetings in which these data were collected or due to incorrect reporting of program coverage. Alternatively, the calculation of theoretical cases for which needs should be met based on service availability did not account for eligibility criteria, such as income or association membership, which could result in an overestimation of these theoretical cases.

Future research should include studies using a longitudinal design with a true comparison group and adequate sample size. Further, given that the tiered case management approach is unique in the literature, research should explore the efficacy of the tiered approach relative to traditional case management in developing countries that have high client burdens and low human resource capacities. It would be especially helpful to parse out the unique contributions of the focal point relative to the community volunteer and the efficacy of a tiered system, while considering the defined roles of program personnel.

Conclusion

Scant quantitative research has explored interventions to reduce unmet need for support services among PLHIV, and this study appears to be the first quantitative outcomes research of this kind in a developing country. This study sought to determine the outcomes associated with exposure to a Linkages case management program for PLHIV in Rwanda and found some significant associations between exposure to program personnel and both referrals and unmet needs for 10 supportive services. Having a Linkages focal point ("case manager") was significantly related to increased referrals for nutritional assistance, counseling, and health insurance and decreased unmet need for counseling and health insurance. Having a community volunteer was not significantly related to any of the outcomes assessed. For most outcomes, the direction of the relationship was as anticipated, though the magnitude of association tended to be larger for the association with focal points, matching data suggesting that referrals tend to be made by focal points after cases are submitted to them by community volunteers . Overall, there were high levels of unmet support service need among program clients, which was likely due to limited capacity among a small network of service providers rather than program failures. Case management for PLHIV is a promising practice in the developing world, but to maximize outcomes it requires a robust support service infrastructure to support the demand.

Table 1. Demographic characteristics (n=247)

	Mean	SD
Age	40.3	8.4
Food Insecurity scale score	2.0	1.9
Number of assets	2.2	1.5
Depressive symptoms	15.0	7.0
	%	
Male	34.4	
Symptom status		
Asymptomatic	45.3	
Symptomatic	27.5	
AIDS-related illness	27.1	
Have a focal point and community volunteer	64.4	
Have a focal point only	14.2	
Have a community volunteer only	14.6	
Have neither a focal point nor a community volunteer	6.9	

Table 2. Proportion of Clients with Need, Referrals, and Unmet Need for Support Services

	% Need	% Referred as a Proportion of Need	% Unmet Need as a Proportion of Referred	% Unmet Need as a Proportion of Need
Nutritional assistance	70.0 (n=173)	31.8	16.4	74.0
Home-based health care	33.2 (n=82)	15.9	0	84.2
Help around home	45.8 (n=112)	17.9	0	82.1
Counseling	45.8 (n=113)	30.1	8.8	72.6
Legal assistance	30.3 (n=75)	20.0	20.0	84.0
Financial assistance	97.2 (n=240)	6.3	26.7	95.4
Housing assistance	64.0 (n=158)	7.0	36.4	95.6
School fee assistance	63.2 (n=156)	14.1	0	85.9
School material assistance	72.5 (n=179)	25.7	0	74.3
Health insurance	91.5 (n=226)	92.9	1.0	7.5

Table 3. Unadjusted Proportion of Referrals for Support Services, by Exposure to Program Personnel

	N	Focal Point		Community Volunteer	
		% Yes	% No	% Yes	% No
Nutritional Support	171	36.6*	16.7	35.5*	17.1
Home based health care	81	16.9	11.8	19.4	5.0
Assistance around home	112	20.7	8.0	17.1	20.8
Counseling	113	38.6**	6.7	34.1	16.0
Legal assistance	75	22.8	11.1	21.4	15.8
Financial assistance	238	7.4	2.0	7.3	2.0
School fee assistance	155	16.4	5.9	16.0	8.1
School material assistance	178	28.4	15.8	29.1*	13.2
Housing assistance	127	8.1	2.9	7.1	6.5
Health insurance	225	95.0*	85.1	92.7	93.6

*p<.05

**p<.01

Table 4. Adjusted Association between Case Management Personnel and Referrals for Support Services

	N	Has a focal point	Has a community volunteer
		Odds Ratio (95% CI)	Odds Ratio (95% CI)
Nutritional Support	171	3.64 (1.33-10.00)*	2.32 (.79-6.82)
Home based health care	81	3.54 (.39-31.66)	2.86 (.21-38.61)
Assistance around home	112	3.49 (.65-18.77)	0.68 (.19-2.45)
Counseling	113	11.76 (2.36-58.74)**	3.25 (.86-12.36)
Legal assistance	75	2.04 (.26-15.84)	1.26 (.20- 7.92)
Financial assistance	238	4.99 (.58-42.86)	4.12 (.49-34.76)
School fee assistance	155	3.49 (.69-17.55)	2.14 (.54-8.56)
School material assistance	178	2.28 (.83-6.28)	2.86 (.98-8.35)
Housing assistance	127	3.73 (.42-33.56)	1.39 (.24-8.03)
Health insurance	225	5.01 (1.51-16.64)**	0.92 (.21-4.14)

Note: Multivariable logistic regression analysis adjusted for gender, age, food insecurity score, asset index score, depressive symptom score, sum of supportive services needed, and HIV symptom status.

*p<.05

**p<.01

Table 5. Unadjusted Proportion of Unmet Need for Support Services, by Exposure to Program Personnel

	N	Focal Point		Community Volunteer	
		% Yes	% No	% Yes	% No
Nutritional Support	171	71.0	83.3	71.0	85.7
Home based health care	81	83.1	88.2	80.7	95.0
Assistance around home	112	79.3	92.0	82.9	79.2
Counseling	113	65.1**	93.3	69.3	84.0
Legal assistance	75	82.5	89.0	82.1	89.5
Financial assistance	238	94.7	98.0	94.8	98.0
School fee assistance	155	83.6	94.1	84.0	91.9
School material assistance	178	71.6	84.2	70.9*	86.8
Housing assistance	127	95.2	97.1	94.5	100.0
Health insurance	225	5.6*	14.9	7.8	6.4

*p<.05

**p<.01

Table 6. Adjusted association between Case Management Personnel and Unmet Need for Support Services

	N	Has a focal point	Has a community volunteer
		Odds Ratio (95% CI)	Odds Ratio (95% CI)
Nutritional Support	171	0.46 (.17-1.26)	0.49 (.15-1.53)
Home based health care	81	0.28 (.03-2.53)	0.35 (.03-4.71)
Assistance around home	112	0.29 (.05-1.54)	1.48 (.41-5.35)
Counseling	113	0.10 (.02-.50)**	0.37 (.10-1.40)
Legal assistance	75	1.01 (.14-7.41)	0.61 (.08-4.33)
Financial assistance	238	0.29 (.03-2.62)	0.34 (.04-2.98)
School fee assistance	155	0.29 (.06-1.44)	0.47 (.12-1.87)
School material assistance	178	0.44 (.16-1.21)	0.35 (.12-1.02)
Housing assistance	127	0.68 (.07-6.73)	[a]
Health insurance	225	0.22 (.07-.71)*	1.11 (.25-4.87)

Note: Multivariable logistic regression analysis adjusted for gender, age, food insecurity score, number of assets, depressive symptom score, sum of supportive services needed, and HIV symptom status. Food insecurity score was excluded as a covariate in the analysis of unmet need for nutritional assistance because of potential endogeneity of that variable's relationship with unmet need for nutritional assistance. Depressive symptom score was excluded as a covariate in the analysis of unmet need for counseling because of potential endogeneity of that variable's relationship with unmet need for counseling.

[a] The community volunteer variable predicts success perfectly and was dropped from the model. All individuals without a community volunteer had unmet need for housing assistance.

*p<.05

**p<.01

Table 7. Comparison of Cases of Unmet Need and Cases of Theoretical Met Need. Based on Service Availability

	Cases of Unmet Need	Cases of Theoretical Need Met
Nutritional assistance	128	0
Home-based health care	69	13
Help around home	92	17
Counseling	82	11
Legal assistance	63	0
Financial assistance	229	0
Housing assistance	151	0
School fee assistance	134	0
School material assistance	133	0
Health insurance	17	0

APPENDIX C. PSYCHOSOCIAL WELLBEING AMONG PLHIV CLIENTS OF A LINKAGES MODEL IN RWANDA

Background

Though physical health tends to be the initial focus of care and support for people living with HIV and AIDS (PLHIV), the needs of PLHIV are more extensive. Psychosocial issues are common. Indeed, the published literature is replete with evidence of the high prevalence of stigma, marginalization, and depression among PLHIV and efforts to address these psychosocial issues.

Stigma and marginalization frequently are reported among PLHIV due to misperceptions about disease transmission, the severity and perceived fatality of the disease, as well as the ostensible association between immoral behaviors and HIV (Baingana, Thomas, & Comblain, 2005; Herek, 1999; Maman et al., 2009). For example, in a recent study, Visser, Kershaw, Makin, and Forsyth (2008) found a moderate level of HIV-related stigma among a sample of HIV-positive women in South Africa. Further, the level of perceived blame and judgment reported by these women was significantly higher than the level of interpersonal distancing they attributed to HIV. Among a separate sample of PLHIV in the United States, Lee, Kochman, and Sikkema (2002) found that most felt some degree of internalized stigma related to their condition. Similarly, moderate levels of marginalization have been reported among adults and children made vulnerable by HIV (Thurman et al., 2009).

The literature provides ample evidence of the pervasiveness of depression among PLHIV (Collins, Holman, Freeman, & Patel, 2006). Warren & Stern (1995) found that PLHIV were two times more likely to suffer from depression than those in the general population. Yet, though the prevalence is high, studies among PLHIV of varying backgrounds have identified depression at varying levels. Research by Esposito, Steel, Gioi, Huyen, and Tarantola (2009) found a 19% prevalence of depression among a sample of PLHIV in Vietnam. Among different subsets of PLHIV in the US, Kilbourne et al. (2002) found 46% prevalence of depression, while Yi et al. (2006) reported that over one-half suffered from significant depressive symptoms.

Addressing psychosocial issues in PLHIV is an important aspect of their care. Severe psychosocial issues are associated with increased problems related to HIV care (Fremont et al., 2007), and stigma and depression have been shown to be significant predictors of medication adherence failure (Gordillo, del Amo, Soriano, & Gonzalez-Lahoz, 1999; Nachega et al., 2006; Reynolds et al., 2004). Thus, psychosocial wellbeing is a consideration for many comprehensive care and support programs. Given that psychosocial wellbeing depends both on individual "psychological factors and the social context in which they occur" (Baingana, Thomas, & Comblain, 2005, p3), addressing psychosocial issues requires attention at individual- and societal-levels.

One of the major challenges, however, to improving psychosocial wellbeing among PLHIV is determining the level and type of support needed (Baingana, Thomas, & Comblain, 2005). Medications and group psychotherapy have demonstrated success in addressing depressive symptoms among PLHIV in developed countries (Zisook et al., 1998). In sub-Saharan Africa, community responses to HIV and AIDS include social support groups or associations that can provide psychological support and income generating activities to address the poverty-related aspects of depression (Mutangadura, Mukurazita, & Jackson, 1999). Case management also is a promising practice for improving psychosocial wellbeing among PLHIV, as it facilitates referrals for counseling and allows the establishment of a direct supportive relationship between case manager and client. In fact, in a study of PLHIV in Toronto who were randomized to receive case management versus self-directed care, clients with the highest levels of depression benefited most from case management (Husbands et al., 2007).

In Rwanda, the 1994 genocide and the HIV epidemic have created a complicated combination of psychosocial issues, ranging from profound grief to guilt. The current mental health system lacks the resources to respond to these needs and, thus, alternative approaches have been attempted. Since 2006, CARE International in Rwanda has supported a Linkages case management model for PLHIV in Nyagatare District. The model utilizes "Linkages focal points" located at district health facilities, whose responsibility is to refer clients for ancillary services, as needed. Another core component of the model is the use of community volunteers, many who themselves are living with HIV, to make home visits to clients to monitor medication adherence and to address client psychosocial needs through dialogue and active listening.

Little is known about the ability of this model to address the psychosocial needs of clients. Thus, the current evaluation was undertaken to determine outcomes related to having a focal point and/or a community volunteer. Specifically, the research sought to discern the extent to which exposure to various components of the case management model was associated with reduced stigma, marginalization, and depressive symptoms.

Methods

Study Procedures

As part of a larger study, a quantitative survey was conducted in June 2009 among randomly selected Linkages clients living in 12 of the 14 sectors in Nyagatare District, Rwanda. In total, 400 potential participants were selected among 626 clients age 18 and above whose case management intake form indicated that they were taking antiretrovirals (ARVs) for their HIV. Out of this target group, 275 surveys were completed, but only 247 individuals reported that they were currently taking ARVs. Survey items were selected based on the intended outcomes of the program, as well as correlates indicated in the published literature. The survey was double translated into Kinyarwanda and rectified by a third party. Then it was pretested among a small group of Linkages clients and several items were revised based on feedback from the pre-test. Interviews were conducted by trained interviewers at the homes of participants and were timed to last approximately 1 hour.

In October 2009, CARE International in Rwanda collected qualitative data to facilitate the development of program documentation and to explore in-depth trends from the quantitative survey, such as the causes of psychosocial distress among people living with HIV in Rwanda, efforts to mitigate this distress, and the training and capacity of program personnel to address psychosocial needs among clients. Two focus groups were held with clients who had participated in the quantitative survey and were living in Gatunda and Rukomo sectors in Nyagatare District. Clients were purposefully selected based on gender, level of unmet need for support services, and level of psychosocial wellbeing. Further, two focus groups were held with randomly selected community volunteers working in the same sectors as the clients lived. Finally, in-depth interviews were conducted with two Linkages focal points in the same sectors. Focus groups and in-depth interviews were conducted in Kinyarwanda by trained facilitators using semi-structured protocols, and audio-recordings of the focus groups and interviews were transcribed and translated into English for thematic analysis.

Ethical Procedures

The full research protocol underwent human subjects review by Tulane University in the United States and by faculty from the National University of Rwanda, School of Public Health. Further, the evaluation was authorized by the Rwandan Ministry of Health. The evaluation adhered to standard consent procedures, including (1) voluntary participation, (2) full disclosure of the study purpose, potential benefits, and potential harms, and (3) the right to discontinue participation at any time. Verbal consent was obtained from respondents due to low levels of literacy in Rwanda, and the interviewer signed and dated the consent form to document informed consent. No payments or incentives were offered for participation in the evaluation.

Quantitative Measures

Socio-demographics: Measures included age, gender, marital status, and ownership of assets derived from items in the Rwanda Demographic and Heath Survey (Institut National de la Statistique du Rwanda & ORC Macro, 2005). To construct the asset scale, individuals were given 1 point for each of the following eleven assets: bicycle, motorcycle or scooter, car or truck, electricity, radio, television, telephone or mobile phone, refrigerator, piped water, non-earth flooring, and charcoal fuel for cooking. The potential score range was from 0-11.

HIV Symptom Status: A single item asked the respondent to indicate whether he or she was HIV+ asymptomatic, HIV+ symptomatic, or had AIDS related illness.

Food Security: A short version of the Household Food Insecurity Access Scale (HFIAS) (Coates, Swindale, & Bilinsky, 2006) was utilized (Cronbach's alpha = .88) to measure food insecurity. Respondents rated the frequency of three occurrences indicating food insecurity over the last four weeks on a three-point scale of Never, Sometimes, and Often. Cumulative scores were generated (range = 0-6), with higher scores representing more food insecurity.

Program participation: Program participation was measured using two categorical variables inquiring about whether the respondent (1) had a community volunteer, and (2) had a focal point.

Stigma: Twelve items measured HIV-associated internalized stigma related to blame and judgment and interpersonal distancing (Visser et al., 2008). One item was modified to adjust for circumstances in Rwanda: an item assessing whether other people would refuse to drink from a "water fountain" was modified to say from a "cup" because water fountains are not present in Rwanda. Responses were scored on a four point scale containing strongly agree, agree, disagree, and strongly disagree. Cumulative scores were generated. The potential score range was from 0-12, with higher scores indicating higher internalized stigma (Cronbach's alpha=.62).

Marginalization: Marginalization was measured using 6 items related to general perceptions of community marginalization (Thurman et al., 2006). Responses were scored on a four point scale with options of strongly agree, agree, disagree, and strongly disagree. Mean scores were generated, with a potential range of 1-4, and higher scores indicated higher marginalization (Cronbach's alpha=.87).

Depressive symptoms: Depressive symptoms were measured using the 10-item Center for Epidemiologic Studies Depression (CES-D) scale, derived from the widely-used CES-D 20 (Andresen, Malmgren, Carter, & Patrick, 1994; Radloff, 1977). Respondents rated the frequency of depressive symptoms over the last week on a four-point scale of Never, Sometimes, Often, and Always. A scale score ranging from 0-30 was calculated based on the responses, with higher scores indicating more depressive symptoms (Cronbach's alpha=.83). A score of 10 or greater was categorized as significant elevation of depressive symptoms.

Analysis

The quantitative analysis was limited to the 247 individuals who reported they were currently taking antiretrovirals. Because each scale had an alpha value greater than 0.6, stigma, marginalization, and depressive symptoms were analyzed as scales. Ordinary Least Squares regression was conducted to assess factors associated with each of the three outcome variables independently. The multivariate models included items with $p<.05$ at the bivariate level but also were built based on the face validity of control variables. Marital status was dichotomized, with the reference group comprised of those who were married (officially or common law) and the other group comprised of those who were single, divorced/separated, or widowed. HIV symptom status was used as a categorical variable with HIV-asymptomatic as the reference category. Age, number of assets, and food insecurity scale score were utilized as continuous variables.

The focus group and in-depth interview data were analyzed thematically. In particular, the qualitative data was reviewed to understand reasons for psychosocial distress in the community and programmatic responses to address this distress.

Results

Table 1 presents the demographic characteristics of the quantitative survey sample. Most participants (66%) were female. The mean age of the sample was 40.3 years, with a range of 18-75. Over half were married, nearly one-third were widowed, and the remaining proportion was divorced/separated or single. On average, they possessed 2.2 assets, with a range of 0-7. The most common assets were a radio (67%), bicycle (35%), and telephone/mobile phone (33%) (data not shown). The mean food insecurity scale score was 2.0. Fewer than half (45%) self-reported as being HIV-asymptomatic, 28% reported being HIV-symptomatic, and 27% reported suffering from AIDS-related illness at the time of the survey.

Most reported having a focal point (79%) and community volunteer (79%) (data not shown). Nearly two-thirds (64%) reported having both a focal point and community volunteer (Table 1). There were 14% who said they had a focal point but did not have a community volunteer, and 15% said they had a community volunteer but no focal point. And, 7% reported that they did not have either.

In general, internalized HIV-related stigma was low among respondents. The mean stigma score was 3.3 (SD = 2.2, range = 0-11) (data not shown). However, the responses to several items were notable. More than half of respondents (66%) strongly agreed or agreed that they would understand if people rejected their friendship because they are HIV+ (Table 2). Nearly one-third (31%) strongly agreed or agreed that their neighbors would not like them living next door if they knew they had HIV. Further, 43% strongly agreed or agreed that they think less of themselves because they have HIV and 34% strongly agreed or agreed that getting HIV is a punishment for bad behavior.

At the bivariate level, stigma level was significantly associated with gender, food insecurity scale score, HIV symptomology, and number of assets (Table 3). In the multivariate analysis, higher stigma levels were associated with being male ($p=.002$; $\beta = 1.11$), being HIV-symptomatic ($p=.003$; $\beta = 1.00$), and having a higher food insecurity scale score ($p=.001$; $\beta = .27$) (Table 4). In the multivariate analysis, number of assets was not significantly related to stigma. Neither having a focal point nor having a community volunteer was associated with stigma levels.

The mean marginalization score was 2.6 (SD = .7, range = 1-4) (data not shown). Most respondents strongly agreed or agreed that people in the community would rather hurt than help them (65%) and that people make fun of their situation (64%) (Table 5). About one-third (36%) strongly agreed or agreed that they feel isolated from others in the community. On the one marginalization item specific to HIV, 43% strongly agreed or agreed that the community rejects families affected by HIV and AIDS.

At the bivariate level, marginalization level was significantly associated with age, food insecurity scale score, HIV symptomology, and number of assets (Table 6). In the multivariate analysis, marginalization levels significantly differed on several characteristics (Table 7). Marginalization scores were higher for those who were HIV symptomatic ($p=.009$; $\beta = .26$) or who had AIDS-related illness ($p=.001$; $\beta = .34$), relative to those who were asymptomatic. Marginalization scores increased as food insecurity scale score increased ($p=.030$; $\beta = .05$). However, age and number of assets were not related to marginalization in the multivariate analysis. Having a focal point or community volunteer also was not associated with significantly different marginalization levels.

Depressive symptoms were high for the sample overall. The mean depressive symptom score was 15.0 (SD = 7.0, range = 0-29) (data not shown). Table 8 presents the results on the individual scale items. Most (77%) respondents indicated that in the week prior to the study they often or always felt that everything they did was an effort, and 65% said they often or always felt depressed. Only 19% often or always felt hopeful about the future. A score of 10 or greater on the CES-D brief inventory is considered clinically significant levels of depression. Most respondents (75%) met this criterion for depression.

At the bivariate level, levels of depressive symptoms were significantly associated with gender, age, food insecurity scale score, HIV symptomology, relationship status, and number of assets (Table 9). Multivariate analysis revealed that higher levels of depressive symptoms were associated with having AIDS-related illness ($p=.004$; $\beta = 2.84$), younger age ($p=.047$; $\beta = -.10$), and higher food insecurity scale score ($p<.001$; $\beta = 1.65$) (Table 10). Though not statistically significant ($p=.050$), males had lower levels of depressive symptoms ($\beta = -2.02$). In the multivariate analysis, number of assets was not related significantly to depressive symptoms score, and no program effects were observed.

Given the high levels of depression uncovered in the quantitative data, in the focus groups with community volunteers and the in-depth interviews with focal points, participants were asked to discuss the prevalence of, and reasons for, depression among clients. Both community volunteers and focal points perceived that depression was not a substantial issue among clients.

> "I don't think there are any sad feelings with our clients" Community volunteer

> "That's no longer a big problem nowadays as the volunteers keep doing their jobs and offering a lot of advice." Focal point

Indeed, they generally perceived depression levels had reduced among clients over time, particularly with exposure to the program. Community volunteers asserted that because all clients were receiving ART and accessing medical services when needed, their clients' depression levels were lower than prior to being in the program. Further community volunteers and focal points believed that client depression related to knowing their HIV-status had largely been addressed. However, program personnel acknowledged that if depression remained, it was due to the experience of poverty or the advanced disease symptoms of clients.

> "...so you find that those that still have problems are those we haven't identified yet or haven't been able to reach. The problems among those we have visited seem to be in other areas. The problem of sadness due to living with HIV-AIDS has reduced." Community volunteer

> "The main problem is when a patient is really sick and he does not have proper food and his life is misery." Community volunteer

When asked more directly about how the program has diminished depression among clients, community volunteers indicated that they provide comfort to clients by talking and listening. Indeed, program personnel generally had little training in counseling of clients. Focal points and community volunteers had participated in a three-day training on active listening and client counseling, offered by a Rwandan association of trauma counselors. Most program personnel respondents did not comment on the adequacy of the training, though one of the focal points indicated that the training was not long enough in duration and that more training was necessary.

To address the psychosocial needs of clients, program personnel also urged clients to join associations for PLHIV, which serve as support networks that also provide opportunities for income generation and advocacy. In fact, 98% of quantitative survey respondents belonged to a PLHIV association (data not shown). Clients substantiated the role of community volunteers and membership in PLHIV associations in improving psychosocial wellbeing.

> "What we do is comfort them and let them know life goes on. When they understand that it's not the end and that life goes on, then they follow up their health. We also convince them to join associations, then they realize they are not alone and not the only ones and the desperation starts to reduce." Community volunteer

> "They visited and it really helped me a lot, because I felt like I was being taken care of and that life goes on." Client

> "It is good to be in a group and meet with each other. It reduces the desperate feelings that a person always has." Client

Discussion

This study examined the extent to which exposure to Linkages focal points ("case managers") and community volunteers was associated with reduced stigma, marginalization, and depression among a sample of PLHIV clients in rural Rwanda. Substantial empirical evidence indicates that social relationships impact health (House, Landis, Umberson, 1988), such that the provision of social support is a common tactic to address the psychosocial needs of PLHIV.

Numerous international studies confirm that HIV-related stigma remains highly prevalent despite efforts to curtail it. However, clients in this sample had relatively low levels of stigma, especially compared to a study using the same scale among pregnant women living with HIV in South Africa (Visser et al., 2008). In the current study, several characteristics were related to stigma levels. Men had higher internalized stigma than women, which is consistent with a recent study in South Africa (Simbayi et al., 2007). Whereas a study among youth living with HIV found perceived stigma was associated with HIV symptoms and AIDS related illness (Swendeman, Rotherman-Borus, Comulada, Weiss, & Ramos, 2006), the relationship between HIV-related stigma and disease symptoms was inconsistent in the current study. Being HIV symptomatic was associated with higher stigma but having AIDS-related illness not significantly related to stigma levels.

Further, there was an association between level of food insecurity and HIV-related stigma, a relationship not well explored in the literature. Studies have found a link between HIV-related stigma and poverty. For example, Bond (2006) found that HIV-related stigma in Zambia was a result of the difficulty managing HIV in the context of extreme poverty, especially in light of the heavy economic burden that poor PLHIV place on their families and communities. The burden engenders negative attitudes and resentment for the added strain placed on the household or community, and these feelings may transform into stigma and discrimination. The literature also indicates that food production tends to decline as HIV disease progresses (Jayne, Villarreal, Pingali & Hemrich, 2006), further promoting economic decline. In the Rwandan context, a high premium is placed on one's ability to provide for his or her family, and the internalized stigma among PLHIV clients in this sample who had high levels of household food insecurity may be related to this perceived failure.

There were no obvious program effects on levels of internalized stigma among PLHIV clients. However, at the urging of the program, nearly all respondents were members of PLHIV associations—a public disclosure of their HIV status. This membership may account for the low overall levels of internalized stigma, though further studies are needed to confirm this relationship. It also may be that national efforts by the Rwandan government to address HIV-related stigma have contributed to lower stigma overall.

The data revealed moderate levels of marginalization among respondents. Similar to the findings for stigma, the degree of food insecurity and disease progression were found to be associated with marginalization levels. However, the items measuring marginalization were less explicitly related to HIV-status than the stigma scale used in this study. Thus, while HIV symptomology did account for differences in marginalization, the prevalence of marginalization may be more related to unmeasured characteristics, including societal mistrust related to the Rwandan genocide, and perhaps was less readily affected by a case management program designed to address issues associated with HIV. Indeed, program exposure was not a significant predictor of marginalization. Conversely, the provision of services to specific subsets of vulnerable populations may actually accentuate marginalization, as has occurred elsewhere (Thurman et al., 2008).

Perhaps the most striking finding was the extremely high prevalence of depression within the sample. Few studies have measured the level of depression in post-genocide Rwanda. A 2005 study among women who survived the Rwandan genocide found that those with HIV had significantly more depressive symptoms than those without HIV, with 82% of women with HIV meeting the criterion for clinically significant levels of depressive symptoms (Cohen et al., 2009). In a random sample of adults living in rural Rwanda, Bolton, Neugebauer, and Ndogoni (2002) found a 15% prevalence of depression. Boris, Thurman, Snider, Spencer, and Brown. (2008) found 53% of a sample of child heads of household met the criteria for depression. Our literature review found that the highest estimates of the prevalence of depressive symptoms among PLHIV in other countries have approximated 50% (Kilbourne et al., 2002; Yi et al., 2006). This study found that 75% of participants met the criteria for depression. Interestingly, program personnel did not perceive depression to be a major issue among program clients.

Consistent with other studies among PLHIV, age, food insecurity, and disease symptomology were significantly associated with level of depressive symptoms (Kelly et al., 1993; Mavandadi, Zanjani, Ten Have, & Oslin, 2009; Wu et al, 2008). The qualitative data corroborated that these variables contribute to depression in this population. Although a clear relationship between gender and depression in the general population is well established in the literature (Weissman & Klerman, 1985), these quantitative data found gender was a borderline predictor of depressive symptoms, with women experiencing more symptoms than men. Having a Linkages focal point or community volunteer was not associated with level of depressive symptoms, which is perhaps not surprising given the burden of the problem in this setting.

These findings highlight the need for better screening for depression among PLHIV in Rwanda and interventions that specifically target depression among that portion of the population. The data suggest the program personnel may not possess adequate training to identify and respond to depression among clients. Screening easily could be done by either community volunteers or focal points using several tools that already are available in Kinyarwanda.

Individual-level interventions would not be efficient or practical in this context, given the pervasiveness of the depression and Rwanda's human resource deficiencies. In other developing countries with high HIV prevalence, group interpersonal psychotherapy (GIP) has been effective in reducing depressive symptoms (Bolton et al., 2003). It may be possible to capitalize on the existing associations for PLHIV, to which most program clients are members, as a conduit through which GIP could be offered. GIP also may be useful for addressing internalized stigma and marginalization in this population. Such therapy might extend beyond PLHIV, incorporating other members of the community to address the underlying dynamics that promote stigma and marginalization in Rwanda. These findings also suggest that long-term investments in the production of trained social workers and clinical psychologists are warranted, given the current deficit in such personnel and the magnitude of the problem.

Several design issues limit the interpretation of results. The absence of baseline measurement and a comparison group totally devoid of program exposure restricts the internal validity of this evaluation and the ability to attribute outcomes to program exposure. Moreover, flaws in the sampling frame, including the inclusion of individuals who had died or moved out of the district and the possible exclusion of some enrolled clients due to incomplete program records, limit the generalizability of these findings.

Additionally, though the survey and field team training were designed to minimize information bias, some misclassification of respondents may have occurred due to recall issues, social desirability bias, or the survey items themselves. For example, self-reported disease status was open to some degree of interpretation among clients and is a less accurate measure of disease progression than the more commonly used CD4 count or viral load. Likewise, there may have been misclassifications due to an inability to correctly classify respondents using western psychosocial concepts. To minimize the latter, the evaluation employed scales that had been utilized in other non-western settings including Rwanda and translations were scrutinized for accuracy. Nevertheless, none of the psychosocial scales have been validated in Rwanda, and others have voiced that depression in particular may be a difficult concept to measure in Rwanda (Bolton, 2001; Cohen et al., 2009). Nonetheless, previous evaluations of the psychometric properties of the full CES-D have found it to have high internal and external validity, and it has been used with success in international settings, including Rwanda (Boris et al., 2006).

Additional research is recommended, in light of the research findings and the limitations of the design. Foremost, there is a need for more quantitative studies assessing the psychosocial impact of case management for PLHIV using longitudinal research designs that employ a comparison group and achieve adequate power. Such research would require the use of measures that have been validated in the local setting. These results also point to a need for more work to assess the prevalence of depression in Rwanda and to evaluate interventions designed to address depression in low-resource, high-prevalence settings.

Conclusion

A study to assess the outcomes associated with exposure to a Linkages case management program for PLHIV in Rwanda found internalized HIV-related stigma levels were low and levels of marginalization were moderate. Depression was pervasive. Food security and HIV symptom status were significantly associated with all three outcomes. However, none of the psychosocial outcomes differed based on whether clients had a Linkages focal point (case manager) or community volunteer. Program personnel underestimated the extent of the problem of depression among clients and may not possess the skills to address the issue. Given the limitations of the study design, further research is necessary to discern whether and how the program model is addressing the needs of clients. In the meantime, given the high prevalence of depression among clients, interpersonal group therapy using the existing community structures available for PLHIV is one approach that could be used to ameliorate depression in this context.

Table 1. Demographic characteristics by exposure category (n=247)

Age, mean (SD)	40.3 (8.4)
Food Insecurity scale score, mean (SD)	2.0 (1.9)
Number of assets, mean (SD)	2.2 (1.5)
Gender %	
Male	34.4
Female	65.6
Relationship status %	
Married (official & common law)	54.2
Widowed	32.4
Separated/Divorced	9.7
Single	3.6
Symptom status %	
Asymptomatic	45.3
Symptomatic	27.5
AIDS-related illness	27.1
Program exposure %	
Have a focal point and community volunteer	64.4
Have a focal point only	14.2
Have a community volunteer only	14.6
Have neither	6.9

Table 2. Frequency of internalized HIV-related stigma (n=247)

	% Strongly Agree/Agree
Interpersonal Distancing	
You would understand if people rejected your friendship because you are HIV+.	66
Your neighbours would not like you living next door if they knew you had HIV.	31
When people know you have HIV you feel uncomfortable around them.	28
Most employers would not employ you because you are HIV+.	22
If you were in public or private transport and someone knew you had HIV they would not sit next to you.	17
If you drank from a cup and people knew you had HIV they would not drink from the same cup.	17
Blame and Judgement	
You think less of yourself because you have HIV.	43
Getting HIV is a punishment for bad behavior	34
You must have done something wrong to deserve getting HIV.	30
You feel that it is your fault that you got HIV.	25
You feel ashamed that you have HIV.	17
People are right to be afraid of you because you have HIV.	5

Table 3. Mean stigma scale score by demographic and program exposure characteristics (n=247)

	Stigma Scale Score
Gender**	
Male	3.84
Female	3.09
Relationship status	
Married (official & common law)	3.47
Not married (widowed, divorced, single)	3.20
Symptom status*	
Asymptomatic	2.99
Symptomatic	4.02
AIDS-related illness	3.29
Age	
≤40 years	3.27
>40 years	3.44
Number of assets**	
0	3.88
1	3.90
2	3.34
3 or more	2.77
Food Insecurity scale score**	
1-2	2.65
3-4	3.81
5-6	4.11
Has a focal point	
Yes	3.37
No	3.28
Has a community volunteer	
Yes	3.43
No	3.06

*p<.05 **p<.01

Table 4. Factors associated with stigma in the multivariate analysis (n=247)

Stigma	β	p-value	SE
Male	1.11	.002	.348
Married	-.16	.617	.310
HIV symptomatic	1.00	.003	.330
AIDS-related illness	.32	.342	.331
Age	-.02	.237	.018
Food Insecurity scale score	.27	.001	.081
Assets	-.11	.278	.100
Have a case manager	-.07	.843	.334
Have a community volunteer	.13	.697	.335
Constant	3.20		

Table 5. Frequency of marginalization (n=247)

	% Strongly Agree/Agree
People in this community would rather hurt you than help you.	65
People make fun of your situation.	64
People speak badly about you or your family.	47
The community rejects families affected by HIV and AIDS.	43
You feel no one cares about you.	41
You feel isolated from others in the community.	36

Table 6. Mean marginalization scale score by demographic and program exposure characteristics (n=247)

	Marginalization scale score
Gender*	
Male	2.45
Female	2.61
Relationship status	
Married (official & common law)	2.55
Not married (widowed, divorced, single)	2.57
Symptom status**	
Asymptomatic	2.38
Symptomatic	2.67
AIDS-related illness	2.74
Age*	
≤40 years	2.63
>40 years	2.48
Number of assets	
0	2.70
1	2.65
2	2.57
3 or more	2.44
Food Insecurity scale score**	
1-2	2.42
3-4	2.62
5-6	2.80
Has a focal point	
Yes	2.55
No	2.59
Has a community volunteer	
Yes	2.55
No	2.59

*p<.05 **p<.01

Table 7. Factors associated with marginalization in the multivariate analysis (n=247)

Marginalization	β	p-value	SE
Male	-.05	.612	.104
Married	.04	.628	.093
HIV symptomatic	.26	.009	.098
AIDS-related illness	.34	.001	.099
Age	-.01	.067	.005
Food Insecurity scale score	.05	.030	.024
Assets	-.03	.276	.030
Have a case manager	.00	.987	.100
Have a community volunteer	-.04	.657	.100
Constant	2.78		

Table 8. Frequency of depressive symptoms (n=247)

	% Often/Always
You felt that everything you did was an effort.	77
You felt depressed.	65
You could not "get going."	58
You had trouble keeping your mind on what you were doing.	57
You were bothered by things that usually don't bother you.	56
You felt lonely.	56
You felt fearful.	51
Your sleep was restless.	50
You were happy.	49
You felt hopeful about the future.	19

Table 9. Mean depressive symptoms scale score by demographic and program exposure characteristics (n=247)

	Depressive Symptoms scale score
Gender**	
Male	12.74
Female	16.21
Relationship status*	
Married (official & common law)	14.20
Not married (widowed, divorced, single)	15.95
Symptom status*	
Asymptomatic	13.88
Symptomatic	14.98
AIDS-related illness	16.91
Age**	
≤40 years	16.23
>40 years	13.54
Number of assets*	
0	16.15
1	16.03
2	15.34
3 or more	13.60
Food Insecurity scale score**	
1-2	11.90
3-4	16.65
5-6	19.49
Has a focal point	
Yes	15.24
No	14.13
Has a community volunteer	
Yes	15.01
No	14.98

$^{*}p<.05$ $^{**}p<.01$

Table 10. Factors associated with depressive symptoms in the multivariate analysis (n=247)

Depression	B	p-value	SE
Male	-2.02	.050	1.02
Married	-.67	.466	.913
HIV symptomatic	.80	.411	.971
AIDS-related illness	2.84	.004	.972
Age	-.10	.047	.052
Food Insecurity scale score	1.65	<.001	.240
Assets	.49	.101	.296
Have a case manager	1.38	.162	.983
Have a community volunteer	-.40	.694	1.00
Constant	14.2		

APPENDIX D. ADULT WELLBEING SURVEY: NYAGATARE DISTRICT

TO BE COMPLETED BY INTERVIEWER

INTERVIEWER ID # [____________]

DATE [___][___]/[___][___]/___][___]___][___]
Day Month Year

SUBJECT ID# [____________]

START TIME [___][___]:[___][___]

AKAGALI |____________________|

UMURENGE [____________]

RESULT CODES (Circle one):

Interview Complete..1

Refused...2

Language Issue...3

Partial Interview..4 ⇒ Rescheduled (circle one): Yes No

Why stopped ______________ When: [___][___]/[___][___]
Month Day

Other..88

*Specify*________________

Module A: Demographics

Q#	Question	Responses	
A1	RECORD SEX OF THE RESPONDENT	Male................................1 Female.............................0	
A2	How old are you?	__________Years	
A3	What is your current marital status? **READ ALL**	MARRIED LEGALLY...............1 MARRIED ILLEGALLY (e.g., polygamy)..2 DIVORCED/SEPARATED...... 3 WIDOWED...........................4 SINGLE................................5	
A4	How many children under the age of 18 live in your household?	__________Children	
A5	Have you ever attended school?	Yes.........................1 No..........................0	**0⇒B1**
A6	What is the highest level of school you have completed? **READ ALL**	DIDN'T COMPLETE PRIMARY..........1 COMPLETED PRIMARY...................2 DIDN'T COMPLETE SECONDARY....3 COMPLETED SECONDARY............4 PROFESSIONAL STUDIES..............5	

Module B: Economic Status

B1	MAIN MATERIAL OF THE FLOOR RECORD OBSERVATION ***IF OTHER, PLEASE SPECIFY*** ______________________________	Earth/sand..............................1 Dung.....................................2 Wood planks............................3 Palm, bamboo..........................4 Parquet or polished wood...........5 Vinyl or asphalt strips.................6 Ceramic tiles............................7 Cement...................................8 Carpet....................................9 Other (specify)........................88	

B2	Does your household have: ***READ ALL, RECORD A RESPONSE FOR EACH ITEM***	**Yes No** a. BICYCLE..........1 0 b. MOTORCYCLE/ MOTOR SCOOTER..........1 0 c. CAR/TRUCK..........1 0 d. ELECTICITY.......... .1 0 e. RADIO..........1 0 f. TELEVISION..........1 0 g. TELEPHONE/ MOBILE PHONE..........1 0 h. REFRIGERATOR..........1 0	
B3	What type of fuel does your household mainly use for cooking? **READ ALL** ***IF OTHER, PLEASE SPECIFY*** ____________________	ELECTRICITY..........1 LPG/NATURAL GAS..........2 BIOGAS..........3 KEROSENE..........4 COAL, LIGNITE..........5 CHARCOAL..........6 FIREWOOD, STRAW..........7 DUNG..........8 OTHER (specify)..........88	

B4	What is the main source of drinking water for members of your household? (i.e. during the current time of year) *DO NOT READ RESPONSES* *IF OTHER, PLEASE SPECIFY* __________________________	Piped into dwelling........................1 Piped into yard/plot.......................2 Public tap....................................3 Open borehole in compound/plot......4 Open public borehole.....................5 Covered borehole in compound/plot...6 Covered public borehole..................7 Spring ....8 River/stream.................................9 Pond/lake..................................10 Dam..11 Rainwater..................................12 Tanker truck...............................13 Bottled water...............................14 Other (*specify*)............................88	

Module C: Food Security

Now I would like to ask you some questions about food used in your household, and the ways in which you are managing your needs for food. Please respond according to your situation <u>in the past 4 weeks.</u>

C1.	In the last 4 weeks, how often was there ever no food at all in your household because there were no resources? READ ALL	NEVER ....1 SOMETIMES ....2 OFTEN 3	
C2.	In the last 4 weeks, how often did you or any household member go to sleep at night hungry because there was not enough food? READ ALL	NEVER ....1 SOMETIMES ....2 OFTEN 3	
C3.	In the last 4 weeks, how often did you or any household member ever go a whole day and night without eating anything at all because there was not enough food? READ ALL	NEVER ....1 SOMETIMES ....2 OFTEN 3	

Module D: Social Service Needs

I now am going to ask about types of social services that you may have needed during the last 4 weeks.

D1.	During the last 4 weeks, have you needed nutritional support services?	Yes....1 No....0	**0⇒D4**
D2.	Were you linked to nutritional support services?	Yes....1 No....0	**0⇒D4**
D3.	Did you receive some nutritional support?	Yes....1 No....0	
D4.	During the last 4 weeks, have you needed home-based health care?	Yes....1 No....0	**0⇒D7**
D5.	Were you linked to home based health care services?	Yes....1 No....0	**0⇒D7**
D6.	Did you receive some home based health care?	Yes....1 No....0	
D7.	During the last 4 weeks, have you needed health with tasks around your home, like cooking or cleaning?	Yes....1 No....0	**0⇒D10**
D8.	Were you linked to someone who could help with these tasks?	Yes....1 No....0	**0⇒D10**
D9.	Did you receive help with these tasks?	Yes....1 No....0	
D10.	During the last 4 weeks, have you needed counseling?	Yes....1 No....0	**0⇒D13**
D11.	Were you linked to counseling services?	Yes....1 No....0	**0⇒D14**
D12.	Did you receive some counseling services?	Yes....1 No....0	
D13.	During the last 4 weeks, have you needed legal advice?	Yes....1 No....0	**0⇒D15**

D14.	Were you linked to legal assistance?	Yes.....1 No.....0	**0⇒D15**
D15.	Did you receive some legal assistance?	Yes.....1 No.....0	
D16.	During the last four weeks, have you needed financial assistance to support yourself or your family?	Yes.....1 No.....0	**0⇒D19**
D17.	Were you linked to financial assistance?	Yes.....1 No.....0	**0⇒D19**
D18.	Did you receive some financial assistance?	Yes.....1 No.....0	
D19.	During the current school year, have you needed help paying for school fees?	Yes.....1 No.....0	**0⇒D22**
D20.	Were you linked to school fee assistance?	Yes.....1 No.....0	**0⇒D22**
D21.	Did you receive some school fee assistance?	Yes.....1 No.....0	
D22.	During the current school year, have you needed help paying for school materials?	Yes.....1 No.....0	**0⇒D25**
D23.	Were you linked to school material assistance?	Yes.....1 No.....0	**0⇒D25**
D24.	Did you receive some school material assistance?	Yes.....1 No.....0	
D25.	During the current year, have you needed housing assistance?	Yes.....1 No.....0	**0⇒D28**
D26.	Were you linked to housing assistance?	Yes.....1 No.....0	**0⇒D28**

D27.	Did you receive some housing assistance?	Yes……1 No……0	
D28.	During the current year, have you needed help getting community health insurance [mutuelle]?	Yes……1 No……0	**0⇒E1**
D29.	Were you linked to a place that could help you get community health insurance?	Yes……1 No……0	**0⇒E1**
D30.	Did you get some help getting community health insurance?	Yes……1 No……0	
	Module E: Health and Wellbeing		
	I now want to ask you some questions about your health and general wellbeing. *I want to remind you that everything you say is confidential and will not be told to anyone else. Please remember that your honest answers are very important.*		
E1	In general, how is your health? **READ ALL**	VERY GOOD……1 GOOD……2 NEITHER GOOD NOR POOR……3 POOR……4 VERY POOR……5	
	The next questions ask about how much you have experienced certain things in the <u>last two weeks.</u>		
E2	To what extent did you feel that physical pain prevented you from doing what you needed to do? **READ ALL**	NOT AT ALL……1 A LITTLE……2 A MODERATE AMOUNT……3 VERY MUCH……4 AN EXTREME AMOUNT……5	
E3	Did you have enough energy for everyday life? **READ ALL**	NOT AT ALL……1 A LITTLE……2 MODERATELY……3 MOSTLY……4 COMPLETELY……5	
E4	How satisfied were you with your sleep? **READ ALL**	VERY SATISFIED……1 SATISIFED……2 NEITHER SATISFIED NOR DISSATISFIED……3 DISSATISFIED……4 VERY DISSATISFIED……5	
	For this study, your case manager has shared with us some information about your health status. I would like to now ask you a few questions about your HIV disease.		

Remember, everything you say is confidential and will not be told to anyone else.			
E5	What is your HIV serostatus? **READ ALL**	HIV+ ASYMPTOMATIC.................1 HIV+ SYMPTOMATIC..................2 AIDS (AIDS RELATED ILLNESS)......3 Don't Know................................98	
E6	In the last two weeks, how much were you bothered by any physical problems related to your HIV infection? **READ ALL**	NOT AT ALL........................1 A LITTLE.............................2 A MODERATE AMOUNT.........3 VERY MUCH........................4 AN EXTREME AMOUNT..........5	
E7	How long ago do you think you were infected with HIV? **READ ALL**	LESS THAN 1 YEAR.....................1 BETWEEN 1 AND 5 YEARS AGO.....2 MORE THAN 5 BUT LESS THAN 10 YEARS AGO...........................3 MORE THAN 10 YEARS AGO..........4 Don't Know...............................98	
INTERVIEWER: CHECK A3, PAGE 2. ***WHAT IS YOUR CURRENT MARITAL STATUS?*** ***IF THE RESPONDENT IS NOT MARRIED (3,4,5), SKIP TO F1*** ***IF RESPONDENT IS MARRIED (1,2), CONTINUE TO E8***			
E8	Has your spouse or partner had a positive HIV test?	Yes..................................1 No....................................0 Don't know..........................98	
Module F: Medication Adherence			
The next questions ask about the HIV medications that you have been prescribed.			
F1	Which health facility do you go to in order to get your HIV medications? *IF OTHER, PLEASE SPECIFY* ____________________________ ___	Nyagatare hospital.........................1 Rurenge health center......................2 Rukomo health center......................3 Nyagahita health center...................4 Nyarurema health center..................5 Karangazi health center...................6 Ntoma health center........................7 Matimba health center.....................8 Other (specify).............................88	
F2	Is this the nearest health facility to where you live?	Yes..1 No...0	

F	**Can you tell me the names of each of the HIV medications you are currently taking and the frequency and doses of each? It may be helpful if you get the medications and we talk about each one.**

	DRUG NAME	# TIMES A DAY (DOSES PER DAY)	# PILLS EACH TIME (PILLS PER DOSE)
F3			
F4			
F5			
F6			
F7			
F8			

The next questions are about the ARV medications that you may have missed taking over last four days. Most people taking ARVs have many pills to take at different times during the day. We need to understand how people with HIV are really doing with their pills. Please tell us what you are actually doing. Don't worry about telling us that you don't take all your pills. We need to know what is really happening, not what you think we "want to hear." And, remember, everything you say is confidential and will not be told to anyone else.

If you only took a portion of a dose, please report the dose as being missing.

How many doses did you MISS....?

	DRUG NAME	Step 2 Yesterday	Step 3 Day before yesterday (2 days ago)	Step 4 3 days ago	Step 5 4 days ago
F9					
F10					
F11					
F12					
F13					
F14					

F15	During the past 4 days, on how many days have you missed taking all of your doses?	None....1 One day....2 Two days....3 Three days....4 Four days....5	

F16	Most anti-HIV medications need to be taken on a schedule, such as "2 times a day" or "every 8 hours." How closely did you follow your specific schedule over the last four days? **READ ALL**	NEVER................................1 SOME OF THE TIME.............2 ABOUT HALF OF THE TIME....3 MOST OF THE TIME...............4 ALL OF THE TIME..................5	
F17	Do any of your anti-HIV medications have special instructions, such as "take with food" or "on an empty stomach" or "with plenty of fluids?"	Yes..................................1 No.....................................0	**0⇒F18**
F18	How often did you follow those special instructions over the last four days? **READ ALL**	NEVER...............................1 SOME OF THE TIME............2 ABOUT HALF OF THE TIME.....3 MOST OF THE TIME...............4 ALL OF THE TIME..................5	
F19	When was the last time you missed any of your medications? **READ ALL**	WITHIN THE PAST WEEK.......1 1-2 WEEKS AGO...................2 2-4 WEEKS AGO...................3 1-3 MONTHS AGO.................4 MORE THAN 3 MONTHS AGO....................................5 NEVER SKIP MEDICATIONS....6	**6⇒F34**

People may miss taking their medications for various reasons. I am going to read a list of possible reasons why you may miss taking your medications during, and I want you to tell me how often they occur. The response options are "Never," "Rarely," "Sometimes," "Often." How often have you missed taking your medications because you:					
		Never	**Rarely**	**Sometimes**	**Often**
F20	Were away from home	1	2	3	4
F21	Were busy with other things	1	2	3	4
F22	Simply forgot	1	2	3	4
F23	Had too many pills to take	1	2	3	4
F24	Wanted to avoid side effects	1	2	3	4
F25	Did not want others to notice you taking medication	1	2	3	4
F26	Had a change in daily routine	1	2	3	4
F27	Felt like the drug was toxic/harmful	1	2	3	4

F28	Fell asleep/slept through dose time	1	2	3	4
F29	Felt sick or ill	1	2	3	4
F30	Felt depressed or overwhelmed	1	2	3	4
F31	Had problems taking pills at specified times (with meals, on an empty stomach, etc.)	1	2	3	4
F32	Ran out of pills	1	2	3	4
F33	Felt good	1	2	3	4

Module G: Psychosocial Wellbeing

Thank you for all of your answers so far. Now, again I am going to read you a list of statements. This time, I wish to know "how often" you have or have not felt a certain way <u>during this past week</u>. You will tell me whether you have "Never," "Sometimes" "Often" or "Always" felt this way during the past week.

	DEPRESSION	**Never**	**Sometimes**	**Often**	**Always**
G1	You were bothered by things that usually don't bother you.	1	2	3	4
G2	You had trouble keeping your mind on what you were doing.	1	2	3	4
G3	You felt depressed.	1	2	3	4
G4	You felt that everything you did was an effort.	1	2	3	4
G5	You felt hopeful about the future.	1	2	3	4
G6	You felt fearful.	1	2	3	4
G7	Your sleep was restless.	1	2	3	4
G8	You were happy.	1	2	3	4
G9	You felt lonely.	1	2	3	4

G10	You could not “get going.”	1	2	3	4

Now I am going to read some statements and I would like you to tell me whether you “Strongly Agree,” “Agree,” “Disagree,” or “Strongly Disagree.”

	Stigma	**Strongly Agree**	**Agree**	**Disagree**	**Strongly Disagree**
G11	Getting HIV is a punishment for bad behavior.	1	2	3	4
G12	If you were in public or private transport and someone knew you had HIV they would not sit next to you.	1	2	3	4
G13	You think less of yourself because you have HIV.	1	2	3	4
G14	Your neighbours would not like you living next door if they knew you had HIV.	1	2	3	4
G15	You would understand if people rejected your friendship because you are HIV+.	1	2	3	4
G16	People are right to be afraid of you because you have HIV.	1	2	3	4
G17	You feel that it is your fault that you got HIV.	1	2	3	4
G18	Most employers would not employ you because you are HIV+.	1	2	3	4
G19	You must have done something wrong to deserve getting HIV.	1	2	3	4

G20	You feel ashamed that you have HIV.	1	2	3	4
G21	When people know you have HIV you feel uncomfortable around them.	1	2	3	4
G22	If you drank from a tap and people knew you had HIV they would not drink from the same tap.	1	2	3	4
	MARGINALIZATION	**Strongly Agree**	**Agree**	**Disagree**	**Strongly Disagree**
G23	People speak badly about you or your family.	1	2	3	4
G24	People make fun of your situation.	1	2	3	4
G25	People in this community would rather hurt you than help you.	1	2	3	4
G26	You feel isolated from others in the community.	1	2	3	4
G27	You feel no one cares about you.	1	2	3	4
G28	The community rejects families affected by HIV and AIDS.	1	2	3	4
G29	Your friends and family help you remember to take your medication	1	2	3	4
G30	The distance that you must travel to the clinic makes it difficult to get your anti-HIV medication.	1	2	3	4

Module H: Program Exposure			
Now I would like to ask you some questions about your experiences with particular services and programs offered in your community. These questions are not meant to determine your eligibility or need for services. The information you provide will be helpful to service organizations in your community, however neither your name nor the name of your family will be shared with service organizations in connection with your answers. Any information that you share with me will not affect your eligibility for services.			
H1	Do you belong to an association for people living with HIV and AIDS?	Yes....................1 No......................0	
H2	Are you a Linkages program community volunteer?	Yes....................1 No......................0	
H3	Do you have a community volunteer who visits you in your home to give you advice to live positively with HIV/AIDS?	Yes......................1 No.......................0	**0⇒H17**
Now I'm going to ask you about the community volunteer who visits you in your home. Your answers will help us learn how to improve the services that community volunteers provide. Your answers will be kept confidential and will not be shared with your community volunteer.			

H4	What gender is your community volunteer?	Male....................1 Female...............0	
H5	When was the last time you met with your community volunteer to discuss your wellbeing? **READ ALL**	Within the last week...........1 Within the last 2 weeks.....2 Within the last 3 weeks.....3 Within the last 4 weeks................4 More than 4 weeks ago................5	**5⇒H8**
H6	Within the last month, how many times have you met with your volunteer (umukorerabushake) to discuss your wellbeing? SPECIFY ____________________	Not at all..................................1 1 time..2 2 times.....................................3 3 times.....................................4 4 times..5 Other (specify)...............................88	
H7	During the last month,what have you talked about with the community volunteer? **DO NOT READ RESPONSES** **CIRCLE ALL** ***PROMPT: ANYTHING ELSE?*** ***IF OTHER, PLEASE SPECIFY*** ____________________	Medication adherence...........A Family/friend relationships.....B Stigma...............................C Needed social services..........D Health issues.......................E Psychological issues (depression, grief, etc.)..........................F Other (specify)....................O	

H8	How satisfied are you with the things the Community Volunteer does for you and your household? *READ ALL*	VERY UNSATISFIED................1 UNSATISFIED.........................2 SATISFIED............................3 VERY SATISFIED....................4			
I am going to read some statements about the community volunteer, and please tell me if you strongly agree, agree, disagree or strongly disagree with the statement.					
		Strongly Agree	**Agree**	**Disagree**	**Strongly Disagree**
H9	The volunteer gives you good advice	1	2	3	4
H10	The volunteer understands your feelings	1	2	3	4
H11	Your volunteer visits only when you have a problem	1	2	3	4
H12	When the volunteer visits, you have enough time to talk about everything that you want to talk about	1	2	3	4
H13	You trust the volunteer	1	2	3	4
H14	The volunteer visits you enough	1	2	3	4
H15	The volunteer has helped you to accept your HIV status.	1	2	3	4
H16	The volunteer advocates for your wellbeing.	1	2	3	4

Now, I want to ask you a few questions about your interaction with your Case Manager. Your answers will not be shared with the case manager, so please answer openly and honestly.

H17	Since January 1, 2009, how many times have you met with your case manager (umuganga w'umujyanama) to discuss your wellbeing? SPECIFY ____________________	Not at all..........................1 1 Time..............................2 2 Times..............................3 3 Times.................................4 4 Times................................5 Other (specify).......................88	
H18	When was the last time you met with your case manager to discuss your wellbeing? **READ ALL**	WITHIN THE LAST MONTH........1 WITHIN THE LAST 3 MONTHS....2 WITHIN THE LAST 6 MONTHS.....3 WITHIN THE LAST YEAR...........4	
H19	How satisfied are you with the things the Case Manager does for you and your household? ***READ ALL***	VERY UNSATISFIED...............1 UNSATISFIED........................2 SATISFIED............................3 VERY SATISFIED....................4	

I am going to read some statements about your case manager, and please tell me if you strongly agree, agree, disagree or strongly disagree with the statement.

		Strongly Agree	**Agree**	**Disagree**	**Strongly Disagree**
H20	The case manager gives you good advice	1	2	3	4
H21	The case manager understands your feelings	1	2	3	4
H22	Your case manager sees you only when you have a problem	1	2	3	4

H23	When you are with the case manager, you have enough time to talk about everything that you want to talk about	1	2	3	4
H24	You trust the case manager	1	2	3	4
H25	The case manager sees you enough	1	2	3	4
H26	The case manager has helped you to accept your HIV status.	1	2	3	4
H27	The case manager advocates for your wellbeing.	1	2	3	4

Closing Statement: I want to thank you for answering these questions today. I appreciate the time you have taken to talk with me. Some of the questions I asked today may have been difficult for you to answer, but it is by hearing from adults in this community that we can begin to better understand the situation of adults and their families. You have helped us a lot by sharing your time and your experiences today.

INTERVIEWER COMMENTS:

APPENDIX E. CLINICAL DATA EXTRACTION FORM

EXTRACTOR ID #	[__________]	**DATE**	[__][__]/[__][__]/[__][__]__][__] Day Month Year
SUBJECT ID#	[__________]	**FACILITY**	[__________]

DATE DU PREMIER TEST VIH POSITIF	[__][__]/[__][__]/[__][__]__][__] Day Month Year	
DATE DEBUT ARV	[__][__]/[__][__]/[__][__]__][__] Day Month Year	
REGIME INITIAL	______________________________	
INITIAL CD4 COUNT	____________	[__][__]/[__][__]/[__][__]__][__] Day Month Year
CD4 COUNTS **(START WITH MOST RECENT AND WORK BACKWARDS)**		
DATE	**COUNT**	
[__][__]/[__][__]/[__][__]__][__] Day Month Year	MOST RECENT ____________	

[___][___]/[___][___]/[___][___]___][___] Day Month Year	2nd MOST RECENT ____________
[___][___]/[___][___]/[___][___]___][___] Day Month Year	3rd MOST RECENT ____________
[___][___]/[___][___]/[___][___]___][___] Day Month Year	4th MOST RECENT ____________
[___][___]/[___][___]/[___][___]___][___] Day Month Year	5th MOST RECENT ____________
[___][___]/[___][___]/[___][___]___][___] Day Month Year	6th MOST RECENT ____________
[___][___]/[___][___]/[___][___]___][___] Day Month Year	7th MOST RECENT ____________

BACTRIM PRESCRIPTION INFORMATION

HAVE A BACTRIM/SAPSONE PRESCRIPTION?

Yes……………1

No……………0

DEBUT PRESCRIPTION [___][___]/[___][___]/[___][___]___][___]
Day Month Year

TB TEST RESULT (+/-)	**DATE**
MOST RECENT ______________	[___][___]/[___][___]/[___][___]___][___] Day Month Year
2nd MOST RECENT______________	[___][___]/[___][___]/[___][___]___][___] Day Month Year
3rd MOST RECENT ____________	[___][___]/[___][___]/[___][___]___][___] Day Month Year

PATIENT WEIGHT (kg)	**DATE**
INITIAL ___________	[___][___]/[___][___]/[___][___]___][___] Day Month Year

MOST RECENT ____________	[__][__]/[__][__]/[__][__]__][__] Day Month Year
2nd MOST RECENT ____________	[__][__]/[__][__]/[__][__]__][__] Day Month Year
3rd MOST RECENT ____________	[__][__]/[__][__]/[__][__]__][__] Day Month Year
4th MOST RECENT ____________	[__][__]/[__][__]/[__][__]__][__] Day Month Year
5th MOST RECENT ____________	[__][__]/[__][__]/[__][__]__][__] Day Month Year
PATIENT HEIGHT (cm) ____________	

APPENDIX F. BIVARIATE ANALYSIS OF CURRENT CD4 COUNT

	CD4 Count
Gender	
Male	485.2
Female	501.3
Relationship status	
Married	469.5
Unmarried	523.5
Symptom status	
HIV-asymptomatic	472.2
HIV-symptomatic	565.4
AIDS-related illness	455.9
Age	
≤40 years	497.4
>40 years	481.7
Number of assets	
0	450.5
1	509.9
2	469.5
3 or more	495.6
Food Insecurity scale score	
1-2	518.8
3-4	457.3
5-6	531.9

*p<.05

**p<.01