CARE Rwanda's Case Management Program

Evaluation Report
July 17, 2006

National University of Rwanda
School of Public Health

Prepared by:
Tonya R Thurman, PhD
Laura J Haas, PhD
Abel Dushimimana, PhD

Acknowledgements

This evaluation was conducted by a team from the National University of Rwanda, School of Public Health (NUR/SPH). This activity was made possible through the financial support of CARE Rwanda who provided funding for the evaluation of the Case Management program. The principal actors for this research activity are Abel Dushimimana, PhD, Project Coordinator; Laura J. Haas, PhD, Co-Coordinator; and Tonya R. Thurman, PhD, Technical Consultant. All contributed significantly to the development of the research protocol, survey instruments, technical support, and final report preparation. This evaluation and subsequent report would not have been possible without the dedicated participation and invaluable support from numerous individuals.

Fieldwork was accomplished by the NUR/SPH team lead by Prof. Dushimimana, in collaboration with a number of faculty members. Mr. Isaac Ntahobakulira, PhD candidate and Assistant Lecturer, facilitated all focus group discussions and was supported by Drs. Ina Kalisa and Sabrine Furere, Assistant Lecturers, who transcribed focus groups notes. Ms. Laetitia Nyirazinyoye and Mr. Manassé Nzayirambaho, PhD candidates and Assistant Lecturers, conducted the in-depth interviews and supervised transcription of same. Ms. Nyirazinyoye also provided translation support of the in-depth interviews as did Ms. Solange Zwadi for all of the focus group data. Mr. Pallotti Rusanga and Mr. Nusabyimana Molachie transcribed all in-depth interviews. Dr. Laurent Musango, PhD, Director of the NUR/SPH, provided invaluable input to the finalization of the evaluation report. Finally, additional gratitude is given to the entire NUR/SPH administrative team for their ongoing support and assistance.

Special thanks also go to Katherine McDonald, MPH candidate, Tulane University, for her efforts in tracking down appropriate literature and drafting the original literature review; great appreciation goes to Manuela Villar, MPH candidate, Tulane University, who spent many long hours and many late nights analyzing and organizing the quantitative data and whose assistance was invaluable in the numerous revisions of this report.

The research team would also like to thank its colleagues at CARE Rwanda for their continued engagement and high-level participation throughout this activity, namely, Delphine Pinault, HIV/AIDS & OVC Program Manager and Antoine Bigirimana, HIV/AIDS Deputy Program Manager, who consistently took time away from their busy schedules to respond to our many questions and needs. In addition, we are greatly appreciative of the input and commentary of Dr. Gaspard Hakizimana, HIV/AIDS Program Medical Coordinator as well as that of the project managers: Innocent Mbabariye, Butare; Théonaste Mbuyu, Gisenyi; Frederic Nzamurambaho, Cyangugu; and Elie Nduwayesu, Gitarama who also provided invaluable coordination and support to our research team in the field.

This evaluation report would be less than it is without the participation of all those who responded to our questions and openly shared their perceptions and attitudes. We hope that in some small way, this evaluation report may somehow contribute to improving the lives of PLWHA in Rwanda and assist those working so hard to make this improvement a reality.

Table of Contents

LIST OF TABLES

ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ARV	Anti-retroviral Therapy
CM	Case Management
FOSA	Formation Sanitaire (health facility)
GOR	Government of Rwanda
HIV	Human Immunodeficiency Virus
IGAs	Income-Generating Activities
MOH	Ministry of Health
MOU	Memorandum of Understanding
NGO	Non-governmental Organization
OVC	Orphans and Vulnerable Children
PLWHAs	People Living With HIV/AIDS
PMTCT	Prevention of Mother To Child Transmission
STD	Sexually Transmitted Disease
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	Voluntary Counseling and Testing

EXECUTIVE SUMMARY

CARE International has implemented the Case Management (CM) model in Rwanda since September 2004 to respond to the critical need of linking community and facility-based services for people living with HIV/AIDS (PLWHAs). The CM model aims to holistically address the complex and numerous needs of PLWHA with a specific focus on enhancing anti-retroviral (ARV) treatment and adherence. This evaluation was conducted in June 2006 and incorporates both quantitative and qualitative methods from multiple sources. Data from all seven former provinces where the CM program is operational was collected and in-depth information from three randomly selected sites was gathered. This report presents the results of this evaluation, discussing the viability of the CM model in the Rwandan context and analyzing CARE's capacity to incorporate lessons learned into ongoing program activity.

Though Rwanda's HIV prevalence, estimated to be 3.1% among 15-49 year-olds (UNAIDS, 2005), it is not as high as many other African nations; however the economic and human costs associated with the HIV/AIDS crisis have been devastating. The needs of PLWHA and often their families have been identified in four interrelated domains: medical needs, psychological needs, socioeconomic needs, and human rights and legal needs. Little is known about the applicability and effectiveness of the CM approach within a resource constrained environment, but research from the United States suggests that CM may be a particularly effective strategy for supporting PLWHA and evidence suggests CM may also increase adherence to HIV care regimens.

CARE's adaptation of the CM model is in alignment with recommended strategies concerning the care and support of PLWHA. The CM program in Rwanda has successfully established linkages between facility-based and community-based service providers for PLWHA. Case managers monitor, strengthen and facilitate client interaction with HIV/AIDS care and support providers. While CARE's CM program bears limitations in terms of the range of services or lack thereof for PLWHA in Rwanda, this approach has generated a functioning method for connecting clients with different service providers across the continuum of HIV/AIDS care and support. As a result, the coordination and comprehensiveness of care for PLWHA are enhanced.

Overall, clients and health providers alike reported increased FOSA involvement in the care of PLWHA. In addition, health providers acknowledge an improvement in the general health of clients as a result of the psychological and other types of support case managers provide. The successful integration of case managers into health facility operations has filled a gap in client support that was not adequately addressed prior to their arrival. However, the range of helping roles adopted by the case manager has important implications for training. Case managers, health providers and CARE staff emphasized the need for additional skills among case managers.

Anecdotal evidence from this study suggests that CARE's CM program is positively impacting ARV adherence with the home visits highlighted as a

particularly important factor in improving adherence. Respondents repeatedly cited positive psychosocial benefits of the program including increased social support and a heightened sense of hope concerning their future. This program was credited with reducing stigma and discrimination within the household as well as encouraging PLWHA to seek out services and support without being ashamed of their sero-status.

In spite of case managers' efforts to increase PLWHA access to resources and services via referral networks, demand far outweighs supply. The poor economic situation of clients was identified as a primary need among PLWHA and the need for food was continually highlighted. The referral networks often facilitate client involvement with associations, providing further social support sources, but limited economic assistance. However, it is hard to determine how clients' economic and living conditions may have varied or improved, even slightly, overtime as documented information on procurement or uptake of services and resources among clients is sorely lacking. Case managers' ability to both support and track clients may be impacted by the high number of clients under their care.

In some instances, referral networks for PLWHA have been strengthened due to the advocacy of the case manager and community volunteer. However, referral partners were generally limited in number and were typically community-based associations, whose means to deliver financial or material support is often limited in scope. In addition to increased networking among service providers, a need for case managers to network amongst themselves was also identified; case managers reported a desire to communicate with one another to gather lessons learned and effective problem-solving techniques. In addition, motivation of community volunteers also remains a pressing concern as these individuals are also poor and in need of basic support.

Program modifications have been made in view of identified problems or concerns to improve program implementation. However, CARE's capacity to incorporate lessons learned into program activities is hindered by insufficient program monitoring. Although the pilot model has demonstrated achievements, the structure of the program must remain open to modifications to ensure the commitment of all of those involved.

Recommendations are implicit throughout this report as study participants offer suggestions and results are discussed, however, the evaluation team's principal recommendations based on findings of this investigation include: 1) Establish mechanisms for ongoing client and program monitoring; 2) Facilitate better support for Case Managers; 3) Enhance stakeholders' participation and leadership in program operations; 4) Strengthen and expand referral networks; 5) Economically empower volunteers; 6) Promote community awareness and involvement in program activities; and 7) Gather further information to assess program impacts and costs

CARE's efforts have demonstrated some key successes in the integration and utilization of case managers within Rwanda's health care system to positively impact PLWHA and close the gap in linkages among care and support services. Although this evaluation does not provide conclusive data as to measurable impact of the CM program on clients' health outcomes and well-being, it does

provide evidence of positive changes in the lives of clients. It further attempts to add to the knowledge base concerning program strategies for the care and support of PLWHA within Rwanda and recognizes its own limitations in terms of generalizability to other contexts within Africa.

INTRODUCTION

1. Purpose

CARE International has implemented the Case Management (CM) model in Rwanda since September 2004 to respond to the critical need of linking community and facility-based services for people living with HIV/AIDS (PLWHAs). The CM model aims to holistically address the complex and numerous needs of PLWHA with a specific focus on enhancing anti-retroviral (ARV) treatment and adherence. In June 2006, the National University of Rwanda's School of Public Health was contracted by CARE Rwanda to evaluate this initiative, measuring both process and impact of the program. This report presents the results of this evaluation, discussing the viability of the CM model in the Rwandan context and analysis of CARE's capacity to incorporate lessons learned into ongoing program activity. The seven main objectives of the evaluation were organized into three main areas: *Implementation*, *Outcomes*, and *Prospects & Opportunities*. Specific objectives of this evaluation are as follows:

Implementation

1. Assess the implementation of the CM model in the Rwandan context through a review of the gaps between theory and practice.

2. Assess the level of integration of the CM model within the existing health care system, specifically within the programs of VCT/PMTCT/ARV at the FOSA (formation sanitaire = health facility) level.

Outcomes

3. Assess if the CM model has increased access to services, specifically increased access and adherence to ARVs.

4. Determine client perspectives as to how the CM model has impacted their lives, both positively and negatively, in terms of access to services, stigma and discrimination, and relevance to their needs.

5. Determine partner perceptions, both positive and negative, of the CM model, including awareness and attitudes towards the CM program and perceived client benefits.

Prospects & Opportunities

6. Consider the potential to extend the CM model to the care and support of other diseases within the Rwandan health care system.

7. Analyze lessons learned and feedback mechanisms for program modification.

2. HIV in Rwanda

Though Rwanda's HIV prevalence, estimated to be 3.1% among 15-49 year-olds (UNAIDS, 2005), is not as high as many other African nations, the economic and human costs associated with the HIV/AIDS crisis has been devastating. Over 190,000 Rwandans are believed to be infected, of which 91,000 are women and 27,000 are children (UNAIDS, 2005). In 2005, 21,000 Rwandans were estimated to have died from AIDS and 210,000 youth under age 18 had lost one or more parent to the disease (UNAIDS, 2005). By 2010, the percentage of orphans in Rwanda is expected to grow from 13% to 20%-- with 83% of these cases due to AIDS (UNAIDS et al., 2004). HIV/AIDS also disproportionately burdens urban residents. Preliminary results from the recent DHS survey (2005) found that while only 2.2% of rural adults were HIV infected, rates in urban areas were as high as 7.3% overall and 8.6% among urban women.

The needs of PLWHA and often their families have been identified in four interrelated domains: medical needs, such as treatment information and treatment; psychological needs, such as emotional support; socioeconomic needs, such as helping hands and orphans support; and human rights and legal needs, such as access to care and protection against violence and discrimination (FHI, 2001). In Rwanda, Koegh et al (1994) found that the reported services most needed among forty-seven HIV-positive women in Kigali included housing, employment and money. Women also expressed concern about meeting their needs for food and childcare in the event they became ill. As HIV progresses, productivity declines and income losses are aggravated by the increasing out-of-pocket expenses for medical care. Moreover, the high morbidity and mortality among HIV-infected adults creates the need for systems of care and support for orphans and vulnerable children.

International efforts are improving access to anti-retroviral drugs and enhancing the life expectancy and quality of life among PLWHA. The first ARV site was introduced in Rwanda in 1999 and, since that time, treatment availability has expanded to 103 sites (Kayirangwa et al. 2006). However, access to ARV does not secure adherence to ARV regimens. Fischer et al.'s (2006) research among 233 patients in Kigali receiving ARV therapy found that over half of patients had experienced at least one treatment interruption. Reasons for lack of adherence included drug shortage, drug intolerance, financial accessibility, and doubts about treatment efficacy. Yet, Demeester et al's (2005) research illustrates how access to support services can positively influence patient adherence. Their study among 95 hospital patients in Kigali found that 85% of patients had efavirenz drug blood levels at the therapeutic range. They concluded that patient counseling and family support mitigated the challenges of poverty, adverse effects of medicines and the advanced clinical stage of participants in this group. It is clear that in Rwanda, as elsewhere in Africa, there is a need to develop comprehensive systems of HIV care and support to both promote ARV adherence and address the myriad challenges facing PLWHA and their families.

3. Case Management Programming

Case managers have been a part of the health and social sector of the United States since the early 1900s. With the appearance of HIV/AIDS, however, there was renewed emphasis on the CM approach (CDC, 1997). The long-term needs of the HIV client made hospital-based care too costly and placed infeasible demands on the formal health institution. CM provides the alternative of relying on community resources to build comprehensive systems of health care delivery (CDC, 1997). Ideally, the range of professional prevention, care and support services that PLWHA and their families need can be delivered in a coordinated manner through the establishment and support of linkages between community and facility-based services.

The National Center for HIV, STD and TB Prevention and the Center for Disease Control (1997) endorse the following definition of CM:

> The provision for some greater continuity of care through the periodic contact between case managers and the client that provides greater (or longer) coordination and brokerage of services than the client could expect to obtain on their own (Orwin, et al., 1994, p 154).

To provide further clarity on CM programming, researchers (Brennan, et al, 1993; CDC 1997; Intagliata et al., 1982; Rothman, 1992; Piette et al., 1990) have identified six key responsibilities of a Case manager:

1. Client identification, outreach and engagement;
2. Medical and psychosocial assessment of need;
3. Development of a service plan or care plan;
4. Implementation of the care plan by linking with service delivery systems;
5. Monitoring of service delivery and reassessment of needs; and
6. Advocacy on behalf of the client (including creating and obtaining, or brokering needed client resources).

There are considerable variations in the actual services brokered by case managers. For instance, some case managers offer only in-office support, whereas others provide in-home services themselves or utilize community volunteers for this purpose. Additionally, case managers may concentrate on either providing direct resources or on linking clients with community resources, and services received are also context dependent. “Care provided varies from agency to agency, from helper to helper, and from client to client,” (Woodside et al., 2003). While these variations add complexity in the design and evaluation of CM programs (CDC, 1997), they address the reality that what might work in one community may be inappropriate in a different setting and among different target groups (Rothman, 1992). As such, programs are typically established by agencies to meet the specific needs and resources of their community (CDC, 1997).

Notwithstanding program variations, research from the United States suggests that CM may be particularly effective strategy for supporting PLWHA. London et

al's (1998) findings among a panel survey of 642 HIV positive individuals suggests that CM can be a successful mechanism for integrating formal services into informal care. In particular, study participants with a case manager were more likely to utilize community-based services than participants without a case manager. Similarly, Katz et al's (2001) baseline and follow-up interviews of a national probability sample of 2,437 HIV positive individuals receiving medical care found a positive association between having a case manager and decreased unmet need for services. The specific needs of patients were identified at baseline and individuals with a case manager had a decreased unmet need for income assistance, health insurance, home health care and emotional counseling at follow-up.

Evidence suggests CM may also increase adherence to HIV care regimens. Katz et al's (2001) study found an association between having a case manager and a higher use of medications among patients receiving HIV treatment Magnus et al (2001) also reported increased retention in care and higher medication adherence among a cohort of HIV positive women with a case manager. More recently, Sherer's (2002) retrospective analysis of clinical datasets on 2,647 patients at an inner city public hospital found that patients who needed and received CM were more likely to receive regular HIV primary care in years one and two than patients who needed and did not receive CM (Sherer, et al., 2002). In fact, Sherer suggests that support service assessment and provision can significantly improve retention in HIV primary care by as much as 15–18% as well as make a substantial contribution to the improvement of patient adherence and HIV clinical outcomes.

The success of CM programs, however, may be mediated by a variety of factors. For instance, research illustrates that client characteristics such as level of disability, health status, gender and age (London et al, 1998); and program structure factors such as client load, skills and enthusiasm of case managers, as well as the availability of services (CDC, 1997) influence program effectiveness. Despite these limitations, CM remains a standard practice for assisting HIV positive individuals within the United States.

Little is known about the applicability and effectiveness of the CM approach within a resource constrained environment. In fact, our review was unable to identify additional instances where the CM model has been applied in a developing country. The prevailing thought on care and support programs for PLWHA in the developing world recognizes the importance of linking clients to essential services through a referral system; though general consensus is lacking on the best way to achieve this aim (Abedayo et al, 2003; Gilborn et al., 2001; Kithata et al, 2002). Research from Africa concludes that many opportunities have been missed to encourage PLWHA to enter the care continuum and to strengthen care services (Osborne, 1996). In short, there remains a need to "look for cost-effective and sustainable options that link the effectiveness of care systems to the availability of resources" (Gilborn, et al; 2001). CM may be a promising approach within developing countries that face an ever-growing HIV epidemic as well as increased access to ARVs. Much can be learned from CARE-Rwanda's innovative program strategy.

4. Overview of CARE Rwanda's CM Program

CM is a PLWHA care and support program implemented by CARE Rwanda. This program was developed in order to fulfill identified needs among PLWHA as well as support Rwanda's National Strategic Plan in the fight against HIV/AIDS. Specifically, the CM program contributes directly to the national plan Axis III to improve care and treatment for PLWHA; the CM program also supports Axis IV to mitigate the negative socio-economic conditions affected by HIV/AIDS by linking PLWHA to income-generating activities (IGAs) and other economic-strengthening activities. The specific objectives of the CM program are as follows:

- To ensure that PLWHA clients with complex needs receive timely coordinated services, with the ultimate objective to strengthen their ability to function independently as long as possible (through increased access and adherence to ARV and increased access to other HIV-AIDS related services);

- To strengthen linkages and collaboration between facility-based service providers and community-services;

- To adapt the CM model (originally from resource-rich countries) to the Rwandan context and integrate/institutionalize it within Rwanda's minimum package of services for PLWHAs.

CARE Rwanda employs a number of strategies to meet the above objectives. PLWHA (clients) are assigned a case manager that identifies clients' needs and links them with appropriate service providers. It is the case manager's job to coordinate, monitor, evaluate, and advocate for a package of multiple services on behalf of their clients. Specifically, case managers facilitate access and adherence to ARV treatment and link PLWHAs and the OVCs under their care to community-based care and support services. Additionally, case managers train and supervise community volunteers who provide home-based care to clients. Community volunteers concentrate on promoting ARV adherence and monitoring possible side effects of treatment. Finally, case managers work towards strengthening and developing institutional and organizational capacity to care for PLWHAs and OVCs through advocacy efforts and establishing effective linkages for HIV detection, treatment and support.

Case managers operate within district hospitals or health centers and identify clients through facility-based VCT/PMTCT/ARV programs, PLWHA associations and community volunteers. After having identified a potential client, case managers assess the client's and his/her family's needs as well as their socio-economic situation and support network. Based on the assessment, an individual plan to access the various necessary services is developed, implemented and regularly evaluated and adjusted by and with the client. Case managers identify available services for PLWHAs in their catchment area and advocate for the creation of services currently not available. In collaboration with the local health facilities, case managers provide comprehensive training and regular supervision to home-based care community volunteers. Case managers are like a spin in the web, responsible for contacting other service providers identified as part of the

plan and for coordinating the services to ensure they are delivered in a timely, client-friendly and cost-effective manner.

Services received vary by client but have included: home-based care; training in ARV compliance, opportunistic infections, TB and HIV management; transportation and hospital fees to access ARV and CD4 tests; health services for pregnant and lactating women; transport for OVC and other family members to access VCT; counselling sessions for PLWHA and OVCs; legal assistance; and provision of basic needs such as food, hygienic kits, treated mosquito nets, school fees, uniforms and clothing.

The CM model was first implemented in September 2004 in the former provinces of Butare and Cyangugu. Program roll-out involved the development of training curricula and monitoring tools, training sessions among case managers and supervisory CARE staff and mapping of HIV/AIDS care and support service providers. In April and May of 2005, the program was expanded to three additional former provinces: Gisenyi, Kibuye, and Umutara. The last two former provinces, Gikongoro and Gitarama were added in August and September of 2005. Since its inception, 149 case managers and 1,013 community volunteers have been recruited and trained.

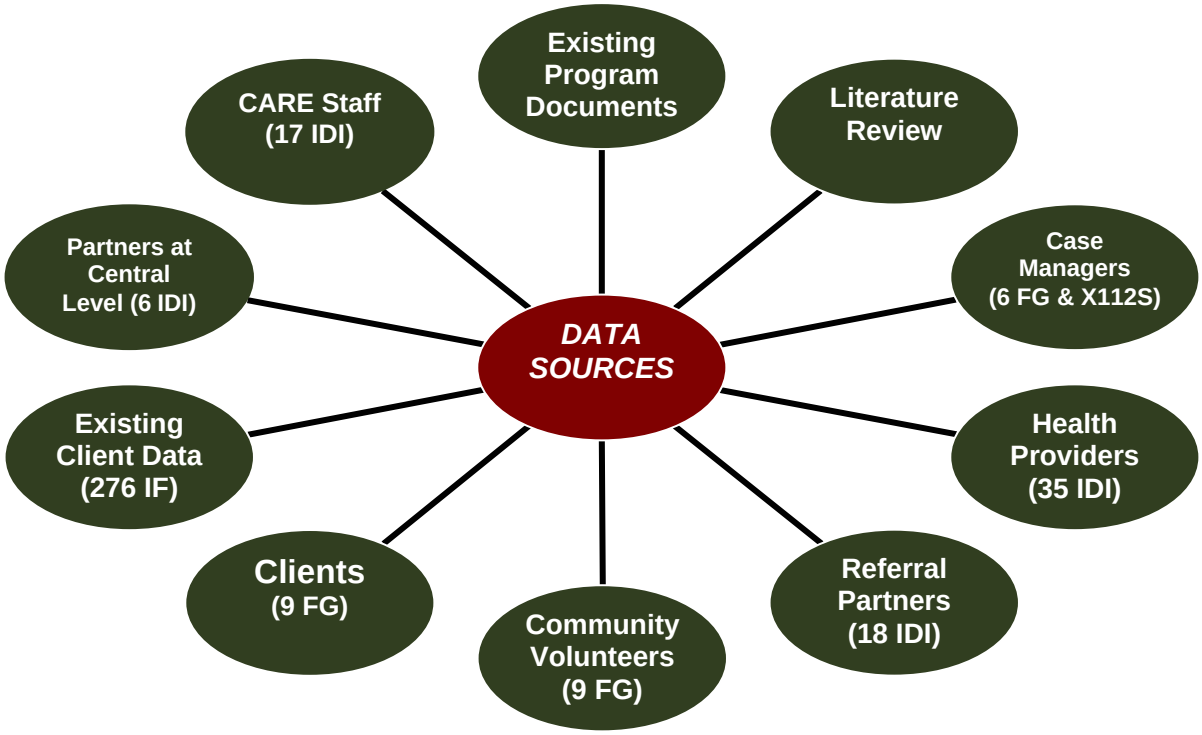
This research was undertaken to explore the impact of CARE Rwanda's CM program and to provide further information that will assist them to more effectively support PLWHA.

METHODS

1. Data collection

This evaluation was conducted in June 2006 and incorporates both quantitative and qualitative methods from multiple sources. Data from all seven former provinces where the CM program is operational was collected and in-depth information from three randomly selected sites was gathered. Information from all implementation sites was captured via anonymous self-report questionnaires among case managers in all sites as well as review of existing program documents, such as monthly reports and past evaluation reports. In-depth information was obtained from selected sites in the former provinces of Cyangugu, Gisenyi, and Gitarama. These three sites were randomly selected from a total of seven possible sites via the division of sites into three strata based on their degree of program implementation: initial phase, mid-term phase, and end phase. One site from each strata was randomly selected to participate in comprehensive research activities, such as focus groups or in-depth interviews among key actors in these sites. Figure 1 provides an overview of the data sources and methods employed for this evaluation.

Figure 1: Overview of Data Collection Methods and Sources



Legend. FG = Focus Groups; IDI = In-depth interviews; S = Surveys; IF = Intake forms completed by Case Managers in conjunction with clients

As described above, data was collected from case managers, clients, community volunteers, representatives from referral agencies and health providers. The following outlines the number of methods employed, participant selection and information acquired from each source. With exception of the self-report questionnaire, all data was collected from the selected sites of Cyangugu, Gisenyi, and Gitarama. Methods employed were divided evenly among sites. For example, of the six focus groups conducted with case managers, two occurred in each of the three sites. The methods below were complemented by review of existing program documentation and relevant literature. Analyses involved a triangulation of all data sources to provide a comprehensive assessment of the CM program.

- **Self-report questionnaire among 112 case managers**. Case managers in all seven sites were asked to complete an anonymous self-report survey that included questions about awareness and relationship with FOSA programs and referral agencies, perceived program impact and application of lessons learned. While the goal was to collect 150 which would include all case managers, only 112 were received.

- **Analysis of 276 client intake forms.** The intake and monitoring forms used by case managers to assess and track client needs were quantitatively analyzed. These forms provided information on client profiles, number and type of referrals, as well as adequacy of form completion/ease and utility of forms. Intake forms from each of the 604 clients were expected but unfortunately some case managers reported discontinuing the use of the form since the beginning of the program. It is hence important to note that the forms analyzed cannot be considered representative of all clients in these sites

- **Six focus groups among case managers**. Focus Groups discussions facilitated information gathering concerning case manager's awareness and relationship with FOSA programs and referral agencies, perceived program impact and application of lessons learned. A total of 54 case managers participated in these focus groups, averaging 9 informants per group and consisting of 83% of all case managers in these sites. All the case managers from both Gisenyi (15) and Gitarama (17) sites as well as 20 out of a total of 32 case managers from Cyangugu were randomly selected to participate. Case managers ranged in age from 21 to 53.

- **Nine focus groups among clients.** Focus group discussions concentrated on revealing program impacts on self-reported adherence to ART, perceived stigma and utilization of referral and health services. Their attitudes towards the program generally as well as the relevance of activities in addressing their needs were also discussed. Clients were randomly selected at each site from a complete list of clients and sent an invitation to participate in the focus groups; 83% of selected clients participated. A total of 75 clients participated in these groups, averaging 8 per group. Discussions included clients ranging in age from 17 to 65 of both genders.

- **Nine focus groups among community volunteers**. Focus group discussions occurred among volunteers providing home-based care to clients

with support from case managers. These discussions concentrated on volunteer perceptions of the impact of the program on clients' lives, awareness and relationship of volunteers and clients with referral agencies and case managers, as well as logistical, training and support needs met and desired from case managers.. Volunteers were randomly selected at each site from a complete list of 90 total volunteers and sent an invitation to participate in the focus groups; 60% of all selected volunteers participated. A total of 54 volunteers participated, averaging 6 per group. Participating volunteers ranged in age between 22 and 63.

- **In-depth interviews among 35 health providers.** FOSA directors provided information as to the integration of the CM model into health service facilities and perceived impact of the program on clients, including client adherence to ART. In addition, they offered their opinion as to the feasibility and utility of extending the program model within Rwanda and applying it to other chronic conditions. A total of 35 Health Providers participated from a total of 45 selected participants (15 from each site).

- **Six in-depth interviews with partners at the central level.** Interviews occurred with a representative of each of the 6 partners (ministry of health, CNLS, TRAC, MAP, CDC, RRP+). These discussions revealed the level of recognition and appreciation of CM program activities at a central level, their attitudes regarding program impact and their opinion as to the feasibility and utility of extending the program model within Rwanda and applying it to other chronic conditions.

- **Eighteen in-depth interviews with referral partners.** Representatives from agencies where case managers referred clients participated in interviews to acquire information on their awareness and attitude towards the CM program., current referral mechanisms, client utilization of referral services and perceived program impact and suggestions. 21 referral partners were selected but only a total of 18 participated with 6 from each site.

- **Seventeen in-depth interviews with program staff at CARE.** Five interviews occurred with staff at the central level and 12 occurred with staff at the peripheral level. Interviewees from the peripheral level came from each of the 3 sites. Questions posed primarily sought to identify specific implementation issues regarding the management and support of case managers. Additionally respondents provided their perceptions on how best to improve the CM program and its potential for expansion.

Quantitative data, including client intake forms and case manager surveys, were entered into Epi-info and analyzed using SPSS 13.0. All focus groups and in-depth interviews were transcribed verbatim in the language they occurred (Kinyarwanda or French). All transcriptions were then translated into English for analysis. Each interview and focus group was attended by three members of the field team: the facilitator who led the interview/focus groups, and two assistants who took field notes. The facilitator and assistant jointly transcribed the text following each discussion/interview.

2. Limitations

This research includes some important limitations the reader should bear in mind when interpreting these results. First, this study is limited to only three of the seven sites where the CM program is implemented and results can therefore not be generalized to all program sites. However, the fact that the sites and informants were randomly selected offers some degree of confidence that results may be similar across sites. Secondly, evidence of program impact is discerned anecdotally rather than relying on biological markers such as clinical assessments of treatment adherence or CD4 counts, or baseline and follow-up analysis of the program's ability to address unmet client needs. However, the inclusion of multiple perspectives concerning program impact strengthens the validity of these findings.

Finally, while not a limitation of the current methods employed, it is important to note that this study was unable to address all of the objectives desired by CARE Rwanda due to the retrospective design and time constraints of this evaluation. Specifically, CARE was interested in assessing the measurable impact of case managers on unmet needs for care and support services among PLWHA and particularly ARV treatment and adherence; and assessing the cost savings associated with case managers in the avoidance of costly hospital stays and other clinical services.

These additional objectives would be better served by a prospective, case-comparison study that could demonstrate measurable differences between clients served by case managers and those not served by case managers. These differences could then be "costed" in order to determine the value-added of the CM approach. A costing analysis could be conducted on all factors contributing to the placement and maintenance of a case manager in the field as well. Critical to this study would be matching individuals (clients) and FOSA with similar characteristics and services, and following clients' paths through the health care system, monitoring their access and adherence to ARVs as well as their access and utilization of other support and care services.

RESULTS

1. *Program Operations*

1.1 *Client intake and assessment*

Case managers complete an intake and assessment form, ideally, on each client to gather demographic information and an overview of client needs. Analysis of the available sample of intake forms offers valuable insight as to client characteristics. Clients range in age from 6 to 65 with a mean age of 37 and most (70%) are age 30 and above. Most (88%) clients rely on farming as their primary income source. About half (45%) have never attended school and 36% indicate an inability to read, write and count. The majority (61%) of clients are single but a large percentage (38%) are widows. Most clients also have a significant care-giving burden with nearly one half (47%) having three or more children residing in their household. In addition, 29% of clients reported that someone else living in the household was also HIV positive.

Table 1: Description of clients

	Percentage (%)
Age *(n=233)*	
0-19	5.2
20-29	15.5
30-39	35.6
40+	43.8
Mean (range: 6-65) 37.3	
Marital status *(n=256)*	
Separated	0.4
Single	61.3
Widow/widower	38.3
Number of children living with client *(n=227)*	
0	6.2
1-2	47.1
3-4	26.4
5-6	16.7
7+	3.5
Mean (range: 0-8) 2.67	
Someone else in the household is HIV+ *(n=196)*	28.6
Occupation: Farming *(n=215)*	87.9
Has ever attended school *(n=183)*	54.6
Can read, write and count *(n=179)*	63.7
Owns home *(n=240)*	57.5

Table 2: Identified client needs

	Percentage (%)
Economic Situation	
Earnings are insufficient to cover everyday needs *(n=221)*	93.7
Sole financial contributor to household income *(n=207)*	82.6
Is a member of a savings or credit association *(n=172)*	33.7
Has legal case pending *(n=141)*	34.0
Family needs	
Difficulties providing education to children *(n=174)*	68.4
Difficulties providing health services to children *(n=179)*	63.1
Difficulties ensuring proper nutrition for their children *(n=176)*	77.3
All members of the family have sufficient clothing *(n=158)*	18.4
Living conditions	
House is in poor condition *(n=202)*	67.8
Has access to transportation *(n=155)*	18.7
Health	
Has insurance or mutuelle de santé *(n=213)*	70.0
Has had at least one or more probable TB symptoms[†] *(n=147)*	55.8
Insecticide treated net at home *(n=142)*	52.8
Lives far from a health center/hospital *(n=170)*	29.4
Psychosocial	
Recent change in mood *(n=215)*	56.3
Feels rejected by friends and relatives *(n=227)*	38.8
Lifestyle	
Has recently drank alcohol *(n=162)*	20.4
Has a sexual partner *(n=161)*	31.1
Has more than one sexual partner *(n=141)*	14.9

The holistic needs of clients are seen in Table 2. Client needs include those related to their economic situation, living conditions, physical health and psychosocial well-being. Clients also reported concerns about meeting the needs of their children. The majority of clients had difficulties providing for their children's educational, nutritional and health service needs. These challenges may be in part due to the fact that 82% of clients are the sole contributor to their household income. Overall, 94% reported a lack of sufficient earnings to cover everyday needs. Their poverty is further reflected by the reported poor housing and insufficient clothing among the majority of respondents.

Many clients reported access to existing support services, as 34% were a member of a credit savings and loans group and 70% indicated having health insurance. On the other hand, 29% reported living far from a health center or hospital and only about one half (52%) reported possessing an insecticide treated net. Psychosocial issues, including mood fluctuation and stigma, are also a concern to many respondents. Finally, the general health and well-being of clients may be further compromised by their lifestyle, as for instance, 20% reported drinking

alcohol recently. Moreover, the sexual activity of clients may present the need for educational intervention so as to avoid further transmission of the disease.

The information provided in the intake forms may be useful to case managers in discerning client needs and directing them to referral sources. However, our data entry team noted a great deal of missing information (as can be seen in the varying samples sizes recorded in Tables 1 and 2) and that as many as 27 forms were missing pages. This suggests that intake forms may not be used consistently or appropriately by case managers. In fact, 27% of case managers reported that the monitoring tools were not easy to use. Previous assessment of the CM program also concluded that case managers perceived the client intake and assessment tool as being "too long" and time consuming to complete considering the number of new clients under their care, resulting in delays in the development of individualized plans (Bedoya-Hanson, 2006).

1.1. Support of Case Managers

Case managers and health providers alike commented on the inadequacy of resources—human, financial, material and educational—necessary to meet the demands of the case manager's job and ensure their commitment and satisfaction. At times, the program was scaled-up to additional former provinces absent of key elements such as standardized procedures and methods for case manager training and supervision and program data collection and monitoring systems (Bedoya-Hanson, 2006). Overall, 79% of case managers surveyed felt they had insufficient resources to carry out their duties. In particular, case managers' heavy client and volunteer allocation combined with insufficient means of transport poses challenges to program implementation. This finding was identified and documented during the initial phase of implementation in the former provinces of Butare and Cyangugu but has yet to be fully addressed (Bedoya-Hanson, 2006). As seen in Table 3, case managers reported an average of 63 clients under their care, with nearly 38% responsible for more than 50 clients. Responsibility for volunteers was less, with the majority (70%) supervising 10 or less volunteers; however, 9% supervised more than 20 volunteers. Health providers and case managers felt the client load should be reduced. Moreover, they noted how home-visits and frequent communication with PLWHA associations necessary to complete the job is hindered by a lack of operational resources, such as transport, per diem for field days and private work space. In fact, only 30% of case managers reported having a private office to facilitate personal conversations with clients and many desired a motorcycle and/or higher travel allowance. Most commonly, informants commented on the inability of case managers to sufficiently visit clients.

> "There is serious problem of case manager transportation. It is very difficult and painful for the case manager to arrive to PLWHA households. Sometimes the case manager just visits a few while there are many persons that need to be visited or s/he arrives very late at their home and this affects their ability to do their job," Health provider

"I propose that they raise the number of case managers so that we can work better. For example, I work in two health centers and it is difficult for me to reach PLWHA in the area of one of the health centers," Case manager

Table 3: Clients and community volunteers supervised by case managers

	Percentage (%)
Number of clients (n=98)	
0-10	33.7
11-50	29.6
51-100	19.4
101-298	17.3
Mean (range: 3-298) 63	
Number of community volunteers supervised (n=107)	
0-10	70.1
11-20	20.6
21+	9.3
Mean (range: 2-60) 10.4	

The responsibilities of case managers are met with what is considered substandard salaries as well as irregular pay distribution from CARE (which at times required FOSA to pay and be reimbursed). FOSA staff felt the salaries of case mangers should be increased to a more equitable level with other clinic employees. Although case manager salaries were determined utilizing GOR matrices for nurses at the appropriately equivalent pay scale, CARE suggests that primes paid by FOSA or donor-supported FOSA aggravate differences in pay received. CARE provides funds for case manager salaries directly to the FOSA for distribution. CARE staff also commented on pay irregularity, but indicates that the only delay in payment of case manager salaries was during the period of January to March 2006. This delay was due to the GOR's administrative and territorial reform in which former health districts were dissolved and incorporated into new administrative districts. This action required that CARE identify new partners and develop new MOUs to be signed by the FOSAs and the newly created districts. However, this delay has clearly left an impression on FOSA staff and case managers.

In addition, case managers and health providers indicated that vacation rights were not honored due to a lack of staff coverage to fill their duties. The need for other trained staff to fill-in was emphasized. CARE staff and case mangers further conveyed how case mangers' short-term contract with FOSA did not provide "stability." These issues may affect job satisfaction and commitment. In fact, CARE staff claim that the CM program has been plagued by a high turnover of case managers and that CARE has difficulty in retaining case managers.

> "Our contracts represent many disadvantages to us [case managers]—limited time, no rights to a leave, carrier plan, or social security—this makes some of them go to look elsewhere," Case manager

It is notable that this finding is in contradiction to the agreed upon MOU between CARE, FOSA, and the district. The MOU clearly states that the contract between the FOSA and case managers should conform to the labor laws in force in Rwanda. In fact, as stated in the MOU, the FOSA is responsible for assuring payment of various taxes and social obligations such as social security, again conforming to the laws of Rwanda, although case managers clearly felt they were at a disadvantage contractually. This further suggests the need for monitoring mechanisms for ensuring that contract terms are met.

Case managers desired opportunities to acquire feedback and network amongst each other. Only 53% of case managers indicated they received feedback on the reports they prepared. CARE's ability to provide supervision and direct feedback has been comprised by major budget cuts resulting in a staff reduction of approximately 50%, greatly diminishing the manpower available to adequately supervise and monitor case managers as remaining staff are now responsible for multiple programs. This inability to adequately supervise case managers is an admitted deficiency also noted in CARE program documentation. Case managers also indicated a desire to exchange lessons with other case managers "in order to improve the care and support to PLWHA." About 22% reported they were unaware of the challenges facing other case managers.

Additional training was also suggested as a needed way to enhance their skills. Not all case managers received the same amount of training and in fact, the end phase group was employed to their post without completing a significant portion of their training, resulting in a "lack of a common knowledge base" among case mangers. As seen in Table 4, case managers reported general satisfaction with training on the self-administered questionnaire. The majority (95%) were at least somewhat satisfied with the pre-service training received from CARE which included additional content of VCT after CARE realized the difficulties of communication between VCT counselors and case managers. About 91% of case managers reported receiving additional in-service training from CARE and among those, an equally high proportion was at least somewhat satisfied. However, qualitative data highlights case managers' desire for further training and even some CARE staff indicated that training could be more practical than theoretical. Health providers also emphasized the importance of additional skills for case managers.

> "Case managers should be trained much more because PLWHA have different diseases as side effects," Health provider.

Table 4: Case managers' satisfaction with training

	Very Satisfied	Satisfied	Somewhat Satisfied	Not at all Satisfied
Pre-service training provided by CARE.*(n=112)*	6.3%	49.1%	37.5%	7.1%
In-service training provided by CARE. *(n=104)*	12.5%	57.7%	25.0%	4.8%

2. Factors influencing service delivery

2.1. Integration within health facilities

Case managers have been effectively integrated into the FOSA team. All of the health providers interviewed expressed that case managers were considered normal FOSA staff and treated "just like everyone else." Case managers share this sentiment, as 93% of the Case managers surveyed reported feeling like a member of the FOSA team. Case managers are subjected to the same rules and regulations as other FOSA staff. Case manager's interaction with other FOSA staff ranges from twice a week to daily, and FOSA staff remains aware of the case managers' schedule and activities. Case managers participate in the regularly scheduled staff meetings, where they discuss their work and problems facing particular clients. Health providers work collaboratively with case managers to address client needs.

> "The case manager is integrated into the personnel. They present us their report and we take advantage of this opportunity to try and resolve the problems they have been unable to resolve themselves. When we meet each other, we discuss the general problems and particularly those of the PLWHAs," Health provider

> "We see each other every day and he gives me a daily report on his home visits. We discuss the follow-up of the PLWHA and he presents their problems, then we try to resolve them in the best way possible," Health provider

The integration of CM has taken time and CARE helped to support this process by sensitizing FOSA staff to the role of case managers and addressing their initial concerns. The GOR's recent administrative and territorial reform which required CARE to renegotiate its MOUs with different partners, bringing into the fold FOSA and newly formed districts afforded CARE the opportunity to better inform FOSAs about the CM program and more fully integrate the program. This process has resulted in greater ownership of the CM program by FOSA.

> "At the beginning, the health center personnel didn't understand the role of case managers but now, after they were informed about it, they consider us like one of them," Case manager

> "At first he had his own programs which we didn't intervene, and we treated him as CARE employee. But now, it is ok, we work together without any problem," Health provider

> "At first they behaved as if they were supposed to get orders only from CARE and not the hospital. CARE would call them without informing us. Later we discussed this with them and CARE, and now things are fine," Health provider

As evidenced from the findings above, case managers are well integrated into the FOSA: however, not all central level partners were aware of CARE's recent success in overcoming initial challenges with integration. Generally though, central level partners consistently expressed appreciation for the program and acknowledged its pertinence for PLWHA. These partners also stated repeatedly that the CM program "responds well to national policy."

> "When it was introduced, the CM program was not well explained to the FOSA and this was an important obstacle to its integration. With the recruitment of the case managers, the FOSA were happy to see their problem of personnel shortages alleviated," Central level partner

> "The program is pertinent because it responds to real needs," Central level partner

Regardless of the support that case managers receive from CARE, FOSA has taken ownership of the CM program. In fact, 83% of the case managers surveyed felt that FOSA considered CM as one of its own programs. In many cases, the program has been adjusted to respond to the wider needs of FOSA, given the qualifications of the case managers. In the CM program, case managers are comprised of two distinct groups: nurses and social workers. In fact, 82% of the case managers are nurses and this group was sometimes felt to be more "useful" to the FOSA since they could more easily support other clinical services, and expand their role. Many case managers spend two to three days in the field conducting home visits or meeting with PLWHA associations and the rest of the week supporting other FOSA activities. These activities often include providing support to VCT, PMTCT, and ARV services and there are instances where case managers support prenatal consultations and family planning activities. Occasionally, case managers combine their field visits to include follow-up of vaccination coverage.

> "We have two kinds of case managers: the nurses and the social workers. The two have the same mandate. However, the nurse understands better the CM...case manager model...but s/he is used for other FOSA activities because they [FOSA staff] do not understand perfectly the approach. The social worker possesses good communication but has a harder time integrating into the FOSA," CARE staff.

The multi-tasking of case managers appears to be a concern to CARE staff. However, health providers appreciate the opportunities that case managers provide to follow-up on patient needs and support FOSA activities. Moreover, health providers praise the role of case managers as an integral part of the FOSA system and see the value of activities for the care and support of PLWHA.

> "Before this program of CM, we were not capable of doing the following: taking care of nutritional needs of bedridden PLWHAs, taking care of the medical needs of PLWHAs, working with the PLWHA associations. Actually, all this is now possible thanks to this program," Health provider

FOSA staff is committed to the program. They expressed an interest in becoming more involved in the CM activities and being apprised of program operations. In particular, they want information on the selection criteria for food assistance and health insurance provided to clients and would like the opportunity to contribute to this process. They would also like to be informed of the food distribution dates and program budget. Additionally, many FOSA heads expressed interest in receiving additional case manager training for other members of health facility staff.

Table 5: Case Managers' attitudes concerning their integration within FOSA

	Percentage (%)
Percentage of case managers that believe,	
FOSA considers the Case Management Model as one of its own programs/services. *(n=108)*	83.3
Case managers are considered members of the FOSA team. *(n=112)*	92.9
Percentage of case managers that,	
Meet regularly with the staff of the VCT program. *(n=110)*	78.2
Meet regularly with the staff of the PMTCT program. *(n=106)*	74.5
Meet regularly with the staff of the ARV program. *(n=96)*	56.3

* Note: not all facilities supported an ARV program

2.2. Referral Networks

Case managers rely on a short list of referral partners to direct clients in need. CARE has previously documented the difficulties encountered when attempting to establish comprehensive referral lists, either from headquarters or the provincial level (Bedoya-Hanson, 2006). Only 72% of surveyed case managers even had a list of services and, among them, nearly a quarter (22%) did not have a description of the services these agencies provided. Moreover, the majority had

a list of five or less care and support providers. Referral agencies included mostly small scale community associations and groups focusing on support of PLWHA. Support services ranged from legal and administrative services to assistance in joining community health insurance programs (mutuelles) to income generating activities, school fees, and food distribution. Referral networks have not extended to include a large number of faith-based nor international organizations. CARE staff indicated that working with faith-based organizations was challenging because churches prefer to provide support to only those who share their denominations. However, advocacy on behalf of clients increases the support available to clients. Referral networks may extend beyond those cited specifically by case managers as referral partners may also have their own set of partners to link clients.

> "The questions of PLWHAs that we cannot solve are the questions relative to medicines and food assistance. For these problems, we also advocate towards other partners such as the NGO ICYUZUZO," Referral partner

> "We speak for them to the local authorities so that when they organize community work, they help repair the roof of a PLWHA who can't do it himself," Case manager

Though each case manager typically has access to only a small number of referral partners, this small ratio may facilitate regular communication and positive relationships between them. Case managers and partners indicate close relationships with one another. Referral partners also expressed appreciation for the program and feel it accentuates and strengthens their work in the community.

> "The case manager is always aware of what we do with regards to the PLWHAs. Each time that we do something for the PLWHA associations, we inform them and they do the same. For example when there is a PLWHA who dies, we work with the case manager for their burial." Referral partner

> "Before this program, we did not have the time to follow the PLWHAs very closely. We held meetings with them and that was 2-3 times per month without otherwise seeing them. However with the case managers, the problem is resolved because they have the time to visit them at home." Referral partner

Available data sources offer inconsistent information as to the actual number of referrals made to clients by case managers. As can be seen in Table 6, 76% of case managers indicate that they made referrals to address food and nutritional needs of clients; however, only 4 referrals of this nature were recorded on the client intake forms. Similarly, whereas nearly 70% indicated that referrals were made for medical services, only 14 were documented. As discussed in section 3.1.1, these discrepancies are likely due to incomplete use of the intake forms as well as an insufficient tracking of client referrals and uptake of services.

The information available from the case manager survey and intake forms may also be indicative of the limited referral options. Referral to specific agencies may be so common and second hand that case managers do not feel it is necessary to document it. On the other hand, case manager survey results may highlight the unavailability of referral sources. For instance, whereas economic constraints were identified as a primary need among 94% of clients (see Table 2), only 34% of case managers reported they referred clients for these services. This finding is surprising given that CARE is a major provider of economic security services to PLWHA. CARE suggests that case managers may not be documenting referrals to CARE, but only to "other" referral partners, thereby greatly reducing the number of documented referrals. The uptake of referrals by clients is also unknown; however, the potential impact of these services is discussed in section 3.3.

Table 6: Reported and recorded referrals made for clients

Referrals reported by case manager in the survey *(n=112)*	Percentage (%)
Medical assistance for PLWHA & families	69.6
Home care	58.9
Psychosocial support	74.1
Food and nutritional assistance	75.9
Financial assistance	33.9
Educational assistance	55.4
Legal assistance	44.6
Referrals documented by case managers in available intake forms *(n=276)*	**Number**
Health Services	
Health insurance	13
Psychosocial and mental health	15
Treatment adherence	11
Substance abuse	2
TB diagnosis	4
Reproductive health	2
Risk reduction	5
Basic Needs	
Income/ Financial Aid	17
Housing	9
Food and Nutrition	8
Transport	5
Clothing	6
Education	
School fees for children	2
Informal and formal education	4
Vocational training for client	7
Other	
Legal assistance	2
Communication	2
Spiritual support	3

2.3. Volunteer support and motivation

Community volunteers are an integral part of the CM system. Their work is valued by clients and case managers, and to a lesser degree (due primarily to limited contact), health providers. As seen in Table 7, 92% of case managers feel the work of volunteers is indispensable to the program. One case manager described how "volunteers are the eyes of the case manager in the community." Referral partners also mentioned the imperativeness of volunteer activities, indicating how volunteers informed them of sick or highly isolated volunteers in need of intervention. Health providers commented that volunteers are used as "messengers" to communicate information or suggestions to patients.

Table 7: Case Managers attitudes concerning community volunteers

	Percentage
Case managers	% Agree
Community volunteers conduct their work appropriately. *(n=110)*	88.2
Community volunteers are indispensable to the success of the CM. *(n=106)*	92.5
Community volunteers are accepted by the PLWHAs. *(n=110)*	95.5
Prefer PLWHA volunteers *(n=96)*	84.4

Volunteer home visits and activities vary based on their determination of client needs. Volunteers reported that their home visits to clients may entail a variety of support activities: assistance with daily chores, information sharing, bathing the client, monitoring ARV use, and advising clients and case managers as to when medical attention is required. They also tackle issues of stigma and discrimination through discussions with client family members as well as information-education activities within the community.

Volunteers are motivated primarily from the sense of pride in their work, the application of new skills they learn in trainings, and the positive changes they see resulting from their activities.

> "It's a pleasure to see someone you encouraged about going get tested bring you his results," Community volunteer

> "I have become a person people trust and love, I am proud," Community volunteer

The majority (84%) of case managers felt HIV positive individuals were the most motivated volunteers. Many volunteers agreed, but expressed that it is not imperative that they are HIV positive, only that they are committed to their work in their community. To identify effective volunteers and weed out those who may have corrupt motives, CARE helped to establish a nominating system. The case manager facilitates discussions among association members as to who is and

who is not performing as expected, in turn, members nominate successful volunteers; the volunteers and case managers feel this is a vital process that has improved the quality of work. In fact, 88% of case managers feel that volunteers conduct their work appropriately. However, a couple of clients mentioned unseemly behavior among volunteers, such as a breach in confidentiality and requests for handouts to ensure services; suggesting the need for additional monitoring and reporting systems. Moreover, many respondents noted volunteers' financial and physical restrictions hinder their effectiveness.

> "The volunteers are poor and sometimes use the kits themselves at home. For example, [they personally use] the soap that they are suppose to utilize on the bedridden patients," CARE Staff

> "We don't have means for ourselves so we can't help PLWHA," Community volunteer

Volunteers also spoke of the need for provisions to aid in their work and reward them for their efforts. In particular, there is a desire for additional home-based care kits to distribute to clients as well as for their own use. Volunteers also commented on their limited means to assist clients. Volunteers mentioned the challenges of visiting clients "empty-handed" and would like to have something they can provide clients on their visits, such as sugar or flour. Moreover, they felt their lack of transportation means hindered their ability to visit clients as needed. Correspondingly, clients noted that those who lived far away were infrequently visited, if at all. Of note is that some volunteers have been provided with bicycles to facilitate home visits; though not all volunteers have received this advantage, as it was not considered practical for those in living in areas with a mountainous landscape. This may explain volunteers' desire for per diem to facilitate regular visits. In addition, volunteers noted the need for emergency funds to transport clients to the hospital when required.

Volunteers expressed interests in efforts that would increase their own capacity to assist clients. Many expressed a desire for additional trainings as well as support for income-generating activities that would in turn allow them to provide support to PLWHA.

> "We would like that volunteers be financially supported and helped with income-generating so that we can help PLWHA ourselves when they need it," Community volunteer

Although CARE provides transport reimbursement to volunteers at the quarterly meeting, the limited ability of case managers to also deliver incentives may impede upon their ability to manage and work effectively with volunteers.

> "Volunteers ask money for transportation to come to the monthly meeting or when they have to bring us reports because they are used to receive that money for quarterly meetings with CARE," Case manager

> "We don't work well with the volunteers because we have nothing to give them when they come for the meetings," Health Provider

However, case managers and health providers felt that volunteers were entitled to incentives and other empowerment opportunities as recognition of their work. CARE has attempted to address this concern by encouraging community volunteer participation in its savings and loan activities conducted in collaboration with PLWHA associations.

2.4. Community involvement

Case managers, CARE staff and health providers all reported that case managers had established relationships with politico-administrative local authorities. Case managers hold meetings with authorities, provide reports at district and sector levels, inform them of food distributions and engage them in facilitating community meetings. Almost all (92%) of case managers surveyed felt authorities were necessary to the success of the program. As many as 69% felt local political authorities currently played a concrete role in the CM program. However, case managers noted that their relationships and collaboration could be improved and some desired more government involvement in their activities.

> "There is a need to improve the coordination at the administrative district level in collaboration with the case manager so that the aid gets to those who need it," Case manager

Volunteers also expressed a desire to work more closely with local authorities and acquire their support. They requested that local authorities be informed of their work and participate in organizing community events for the volunteers' HIV/AIDS information education activities.

There also appears to be a need for greater involvement of the general community. Volunteers felt the public held misconceptions about their work, were suspicious of their motives and activities, and believed they were paid program staff. To address this issue, volunteers suggested that their role be explained to the community through information sessions and development and distribution of brochures. Case managers also recognized the need for community awareness activities concerning not only the role of volunteers, but the CM program in general.

> "There should be a promotion of the importance of the CM program so that it is known to the public," Case manager

3. Program Outcomes

3.1. ARV access and adherence

Health providers and case managers reported a noticeable increase in the utilization and adherence of ARV medicines among clients. They attribute this change to the attention and follow-up of case managers and volunteers. Case managers facilitate ARV access where possible, with an average of 52% of their

clients on ARVs[1]. Case managers and community volunteers provide encouragement and advice in regards to adherence and pay attention to clients' reactions to the medicine. This responsibility was also noted and appreciated by central level partners. Case managers persuade clients to visit health facilities when higher level medical intervention from side effects is required and remind clients of when they need to re-supply their medications. Health providers recognize the value of the home visits made by case managers and volunteers as do central level partners.

> "The ARV adherence is much improved because the community volunteers give advice to the PLWHAs and they follow them closely to ensure that they are taking their medication," Health provider

> "ARV adherence is much improved because before no one was following them (the PLWHA) at home. Actually, the case manager goes all the way to the home of the PLWHA to see how they take their ARVs," Health provider

> "It is interesting to have an effective system of follow-up that guarantees [ARV] treatment compliance so as to avoid resistance," Central level partner

The presence of the case manager at the facility also seems to contribute to increased adherence. Referral partners and case managers noted how clients feel comfortable visiting the clinic when they have a relationship with a case manager. Clients feel more welcomed at the facility and more comfortable discussing ARVs with health providers. In turn, a health provider commented that they too have better follow-up and relations with PLWHA.

> "Before this program, the PLWHAs would abandon the ARVs while taking them, but actually they come to claim re-supplies. They are no longer afraid of bringing up this subject with the health personnel," Health provider

> "There was a very large change. Before this program, our relationship with the PLWHA was limited to testing for the disease, there was no other follow-up. We didn't even know if the seropositives had finally taken their dosage of ARV," Health provider

Clients appreciate access to ARVs and reported an improvement in their health, many commenting specifically on significant weight gain. However, actual patient records concerning adherence were not reviewed. Moreover, patients also mentioned factors which could negatively affect adherence. They reported bothersome side effects such as dizziness and abdominal pain. Other potential barriers reported included the overwhelming cost of transport to access drugs

[1] Percent of clients on ARV was calculated as number of clients on ARVs divided by total number of clients for each case manager. Discrepancies occurred in 7 responses and 11 others did not respond both questions.

and the reported increase in appetite resulting from ARV use coupled with insufficient food.

> "We think these medications are too strong for us since we don't have enough proper nutrition," Client

> "We live far away from FOSA where we have our blood tests and take ARVs," Client

Case managers further recognize the myriad obstacles to ARV maintenance.

> "They have a difficult treatment that they have to follow their lifelong so when the patient starts feeling better he has the tendency of not following it as he should," Case manager

In spite of these challenges, 93% of case managers felt the program increased ARV adherence and health providers also indicated similar changes.

> "This program has really changed the ways of the clients in taking the ARVs, because the number has increased and the number of those abandoning the ARVs has decreased," Health provider

3.2. Stigma

The CM program has reduced stigma surrounding HIV/AIDS. Clients and referral partners commented on how counseling conducted by volunteers and case managers has helped them to reconcile with their families and gain acceptance from the general community.

> "Visits and the attention from case managers and community volunteers on our regard have made people who stigmatized us understand that, despite our HIV+ status, we still have value," Client

> "Case manager teaches the family not to discriminate against them [PLWHA], thus bringing them together," Referral partner

In addition, health providers have also altered their own attitudes and treatment of HIV positive patients. Clients and case managers mention increased involvement of medical staff in the lives of their patients, even attending the funerals. There is improved respect and rapport between clients and health providers.

> "I learned that we must love the PLWHAs until their death, avoid stigma, and give them value as a human being," Health provider

> "At first the PLWHA would not like to disclose that they take ARV, but now they take it as a normal thing," Health provider

The increased acceptance of HIV positive individuals has had wider community level impacts. All types of informants described a heightened degree of community openness concerning HIV. They reported that people are more likely to disclose their status, seek services for HIV positive individuals and, in particular, access voluntary counseling and testing.

> "With the help of the case manager, I was able to convince my husband to do the test," Client

> "In a general manner, there are more and more people who come to have themselves tested voluntarily, without fear or shame of the result of their test. Additionally, the PLWHAs make themselves known more thanks to this program and no longer have shame of their serological status. For example, they accept to go into the different associations; this was not possible before the CM program," Health provider

3.3. Psychosocial Support

Clients expressed appreciation for the emotional and social support they receive from case managers and volunteers. They sit and listen to clients, serve as a trusted confident and help them accept their disease. Clients indicated how the counseling and home visits have helped them maintain an optimistic perspective.

> "They gave us taste for life again; they took us from death and brought us back to life," Client

> "The psychological support I received helped me regain hope in life and fight because I was overwhelmed by the problems I was facing," Client

The isolation of PLWHA is also lessened through program activities. As discussed above in the context of stigma, the work of case managers and volunteers increases the social support that clients receive from their families, health workers and the general community. The association membership encouraged by case managers also provides support. Clients benefit from the camaraderie, sharing of problems and joint resolution of issues. Moreover, association members help one another in times of need.

> "Because of their [case manager's] advices, we have joined associations of PLWHA; now we are not alone anymore," Client

> "When we are too weak to cultivate our land, other [association] members help us," Client

Health providers recognize the difference this is making in the lives of clients and see this as a vital service. They commented that clients often wanted to talk to medical staff about these issues and they did not have the time to address this need. However, they appreciated the opportunity to refer clients to case

managers and receive a summary of the clients' situation. Moreover, they felt the acceptance gained by PLWHA facilitated a better relationship between them.

> "This program has been very useful to the PLWHAs because it take a lot of counseling for a PLWHA to accept his/her status, his/her illness. Thanks to the work of the case manager, the PLWHAs now know that life continues in spite of their illness. They are composed and calm, which was not the case before, as they were aggressive," Health provider

3.4. Unmet needs

Food assistance and support for children now and in the event of their death were the most common unmet needs mentioned by clients. They also commented on a desire for basic essentials such as soap and body cream. In addition, the challenge of transport to medical facilities was cited as an impediment to receiving needed care. Health providers, case managers, referral partners and volunteers reiterated these needs, especially the inadequacy of food provisions. While health providers acknowledge the value of the program, they also felt that case managers and volunteers should be equipped with resources to regularly distribute to clients.

> "The PLWHA also need material support; things like something to eat, soap etc. The case manager should be given something to support the client," Health provider

> "The case manager has a big problem of going in remote villages to visit people without any material support to give to them or a transport mean to bring them to the hospital if needed," Health provider

Case managers try to advocate for additional services for clients, however, the financial and material needs of clients outweigh the resources available. Limited resources accessed are often designated to those considered the most in need by case managers and/or association leaders; however, all clients felt they needed them, as discussed under section 3.2.3 in the context of volunteer support and motivation, volunteers also conveyed the need for provisions to distribute to needy clients, means to transport ill patients, and access to support that would increase their own capacity to support clients and themselves. Similarly, clients were also interested in ways to become more self-sufficient, rather than rely on hand-outs.

> "We always need assistance from other people and we are tired of it," Client

Some clients reported benefiting financially through involvement with the referred associations as well as through the provision of services these groups and case managers facilitate. Associations encourage small income-generating projects, such as livestock and group savings and loans. In addition, the services

procured, such as health insurance and educational assistance for their children, reduce their burden of expenses.

> "Giving access to "mutuelles" and finding us aid, the program was able to reduce our poverty," Client

> "It has improved their socio-economic life because they no longer sell their possessions to pay health care or drugs or transportation," Referral partner

While there were reports suggesting economic benefits for clients, this domain is the least affected by the CM program. Though appreciative of the services provided, most clients desired additional support to improve their economic situation and desired access to the food, education and health insurance they were aware some clients received. Moreover, referral partners noted problems with loan default and limited means to support micro-finance projects. However, this finding is contrary to that of CARE's experience where reimbursement rates were over 90% in its savings and loan program.

Finally, the support of their children is a particular concern to clients. In addition to medical assistance and school related expenses for children, case managers noted that clients "were preoccupied by the care of their children after they died."

4. Program Expansion and Sustainability

4.1. Opportunities for expansion

Informants conveyed strong support for incorporating case managers into all FOSAs across the country. CARE staff indicated how other FOSA are approaching them to request case managers. Almost all (94%) case managers surveyed felt the program should be expanded. Health providers were very supportive of program expansion, though they reiterated the need for additional case managers and the resolution of administrative issues. Referral partners also highlighted the need to expand the program's capacity to address material and financial needs of PLWHA. Central level partners supported program expansion as well but consistently mentioned the resource burden of implementing the CM program. However, it should be noted that in spite of this concern, central level partners admitted that they did not have sufficient details regarding program costs. CARE recently conducted a rapid analysis of case manager costs inclusive of salary, operations (transport and communication), supervision and ongoing training, regular meetings, and documentation of monitoring and evaluation reports. The annual cost to maintain a case manager in the field comes to $6,000 US per year or $500 US per month. Overall, health providers, referral partners and central level partners endorsed expansion, citing program achievements and the important needs it addressed.

> "I support the idea of expanding the program in all of the country. In effect, AIDS constitutes a very important problem. It would be a good thing to put a case manager in each of the FOSA because we

are overwhelmed by the work and we don't have the time to take care of the PLWHAs in all the ways they need," Health provider

"I would recommend that this program be implemented in all the country because everywhere one finds PLHWA. They need someone who listens to them and who takes care of them in a particular way. This system provides timely information on PLWHA and that permits rapid intervention," Referral partner

"I recommend it because AIDS exists in all of the country and this program has a lot of advantages: it diminishes the transmission of the disease, there is a good follow-up of the PLWHA, the problems are known in a timely fashion and are resolved in a timely fashion. This program also increases the chance of survival of the PLWHA," Health provider

"The CM program is a good approach to be expanded throughout the rest of the country," Central level partner.

Health providers were also asked whether they felt the CM model could be applied to other chronic conditions. Most felt the program would be valuable for addressing other diseases and mentioned the benefits for patients suffering from diabetes, tuberculosis, malnutrition, asthma, heart disease, cancer and malaria.

"Asthmatics, for example, most of the times tend to stop taking their drugs. If they had a case manager to visit and counsel them they would be encouraged to use health care facilities and to respect their treatments correctly so that they stay alive longer," Health provider

"The chronically ill would have someone who follows them day to day and this time we would know the patient's evolution, because usually these types of ill people come to us late when the situation is serious. However, it will be necessary to increase the number of case managers because only one person cannot do this work," Health provider

Though most health providers endorsed wider application of the CM approach, a few were reluctant. For instance, one informant indicated that health educators already existed to address many of these other conditions. Another informant mentioned how the program should be strengthened within the HIV/AIDS context before extending it to other diseases. Even those who were supportive of extending the model indicated that additional case managers would be needed in each FOSA to address the increase in client load and that case managers would require specialized training.

"It would depend on the case managers competences, because some of them studied social sciences and do not have knowledge about those diseases to know whether or not the client has such signs or what services or drugs he needs," Health provider

4.2. Prospects for sustainability

Referral partners, clients and CARE staff suggest how the initiative has evolved to be viewed as a standard service, rather than a "program." For example, several clients and referral partners mentioned they were unaware of a CM program per say, but knew of case managers within FOSA who take care of PLWHA. Interestingly, health providers suggested a reduction in case manager and FOSA meetings with CARE, perhaps suggesting a desire to work more independently. Health providers have come to recognize the value of the services a case manager provides and have come to depend upon them.

> "Even if the PLWHAs have a FOSA near them, that would serve for nothing if there isn't someone who will take care of them specifically," Health provider

> "In the absence of the case manager, the follow-up of the PLHWA would become very difficult," Health provider

Health providers want case managers to remain part of the FOSA team. Several case managers suggested that the GOR take over the program to ensure its continuance. While the value of CARE's financial support was mentioned, health providers are so dependent upon this service that some are willing to invest their own resources to maintain it.

> "One can say equally that the case manager contract with CARE will soon be completed although they must tell us soon so that we can begin the first steps to have them hired on as civil servants," Health provider

> "We have learned that the program is very helpful for the health clinic as well as it is for the clients. It is so wonderful that even if they say that it is over, we would keep it on the health clinics behalf," Health provider

As demonstrated elsewhere in this report, clients, volunteers and referral partners also highly value the service. They too express commitment to the program and are hopeful of its continuation.

> "There should be a way of assuring that the program stays a long time," Community volunteer

DISCUSSION

The discussion section identifies and provides in-depth consideration of key findings from the evaluation. The italicized sub-headings highlight the general themes emerging from the results; more specific findings are integrated into each sub-section as appropriate.

The subsequent discussion should be reviewed with the CM program's stated objectives in mind:

- To ensure that PLWHA clients with complex needs receive timely coordinated services, with the ultimate objective to strengthen their ability to function independently as long as possible (through increased access and adherence to ARV and increased access to other HIV-AIDS related services);

- To strengthen linkages and collaboration between facility-based service providers and community-services; and

- To adapt the CM model (originally from resource-rich countries) to the Rwandan context and integrate/institutionalize it within Rwanda's minimum package of services for PLWHAs.

Overall, the CM program achieved its program objectives, although areas for improvement remain. There is evidence that the program has increased clients' adherence to ARVs as well as enhanced their overall psychosocial well-being. The program has facilitated complementary services for PLWHA; however, many unmet needs remain among clients due primarily to a lack of existing services, high demand, and/or weak referral systems. Despite these limitations, the CM program has effectively strengthened linkages and collaboration between facility-based service providers and community services. The approach has been well integrated into Rwanda's health services and adapted to respond to the wider needs of FOSA. The findings also highlight the opportunities for the CM model to become part of the country's minimum package of services for PLWHAs, though additional efforts are required to ensure achievement of this aim. The program has demonstrated successes in terms of its outlined objectives, however, the findings also point to program features that could be improved. Strengths and limitations of the CM program identified in this evaluation are discussed throughout the subsequent sections.

Linkages established between HIV/AIDS care and support providers

The CM program has successfully established linkages between facility-based and community-based service providers for PLWHA. Case managers monitor, strengthen and facilitate client interaction with HIV/AIDS care and support providers. The chain of service providers includes case managers, health providers, referral partners and community volunteers. Client needs are

identified and addressed through a complex interplay of communication and advocacy amongst these providers. For instance, case managers' presence within health facilities increases and enhances patients' interactions with medical staff and ensures health providers are regularly updated on patients' situation. Health providers frequently interact with case managers, and at times, they also depend upon volunteers to transmit advice to clients. Volunteers, referral partners and case managers all maintain close relationships with one another and independently or jointly, provide support to clients. However, case managers remain the integral link in this process, mediating to ensure attention to client needs and procurement of available support.

CARE's adaptation of the case management model is in alignment with recommended strategies concerning the care and support of PLWHA. The model of "Comprehensive Care Across a Continuum" promoted by the World Health Organization recognizes that PLWHA require psychological, social, legal and clinical support and services (Gilborn, et al., 2002). Achieving this idealized package of services for PLWHA requires involvement of providers with various specialties. Professionals in the humanitarian field emphasize the importance of a referral system for linking PLWHA with needed services and resources; however, there is no general consensus on the best way to achieve this aim (Abedayo, 2003; Gilborn et al., 2002; Kithata et al., 2002). Moreover, most recent studies of referral in Africa conclude that 'the referral system was poor' or 'inadequate' or 'non-functioning' (Blas and Limbambala, 2001b). While CARE's CM program bears limitations in terms of the range of services or lack thereof facilitated for PLWHA in Rwanda, this approach has generated a functioning method for connecting clients with different service providers across the continuum of HIV/AIDS care and support. As a result, the coordination and comprehensiveness of care for PLWHA are enhanced.

Case managers help FOSA to better serve patients

Research has demonstrated the importance of patient-doctor relationships in ensuring adequate care (Inui, 1998; Kaplan, 1998; Mechanic, 1992). Health providers commented on improved interactions with patients. Case managers have aided medical staff to become more empathetic and aware of each client's situation and the plights of PLWHA more generally. In turn, patients more openly disclose personal information and "embarrassing diseases." Moreover, they generally feel more comfortable visiting the clinic when needed. The case manager and the home visits also provide improved follow-up and further information necessary for ensuring comprehensive patient care. Overall, clients and health providers alike reported increased FOSA involvement in the care of PLWHA. In addition, health providers acknowledge the improved general health of clients as a result of the psychological and other types of support case managers provide. Health providers overwhelming expressed appreciation of the CM program and the efforts of the case manager. The successful integration of case managers into health facility operations has filled a gap in client support that was not adequately addressed prior to their arrival.

It appears that in addition to filling a service gap of coordinating and interacting with PLWHA, case managers fill a human resource need among FOSA for more

qualified health personnel. The fact that 82% are nurses may facilitate additional benefit to FOSA operations beyond typical case manager duties. It is perhaps their wide-ranging utility within the FOSA which adds to their appreciation and effective integration. However, the authors of this evaluation do not suggest that case managers with nursing backgrounds are preferred over case managers with social work backgrounds, as each has its advantages. Those with nursing backgrounds may be integrated more easily into daily FOSA operations. Those with social work backgrounds may be better equipped to respond to the needs of other program stakeholders, such as community volunteers and referral partners. The results do not offer clear indications as to whether one profile better serves PLWHA, however, it is clear that case managers are generally highly regarded by FOSA and other program participants.

Case manager roles are influenced by the objectives of the CM program, resources allocated to case management, and the availability of community resources. No models of case management are universally accepted, and no case management model is appropriate in all settings with all populations (Rothman, 1992). However, the range of helping roles adopted by the case manager has important implications for training. Case managers, health providers and CARE staff emphasized the need for additional skills among case managers. Trainings may need to be adjusted in accordance with the activities a case manager is expected to perform within a particular FOSA. In short, if case managers maintain multiple roles, they must have broader skills and more training since the complexity and range of their tasks has increased (CDC, 1997). Case manager training should not be limited to pre-service only, but also include continuing education to maintain cutting edge skills and competencies.

Results were somewhat supportive as to the possibility of applying the case manager approach to other chronic diseases. However, endorsements of this idea were conditional on an increase in the number of available case managers so as not to dilute their focus from HIV/AIDS. Further investigation as to the needs of other chronically ill clients; the roles and responsibilities of case managers vis-à-vis other chronic disease; the extent of referral networks to address these needs; and the utility and feasibility of applying the CM program to other chronic disease should be undertaken prior to any extension of the current CM program.

The importance of HIV/AIDS as a critical health challenge to the country was repeatedly cited as a primary reason to expand the program to other FOSA sites. Health providers also emphasized the programs ability to combat their feelings of being “overwhelmed” by the myriad challenges of supporting PLWHA. In fact, CARE staff indicated that requests have been received from other FOSA to equip them with a case manager. Support for expansion suggests that case managers are satisfying an actual need in the Rwandan health system. However, administrative and support issues affecting implementation should be addressed before any geographic expansion of the program is initiated. These issues are discussed more thoroughly throughout this discussion and include: case manager contract duration, salary harmonization, and high turnover; case manager training, both pre-service and continuing education; additional support for case managers such as transport, supervision, networking and feedback opportunities; motivation of volunteers; strengthening of referral networks; and improved client and program monitoring.

Program improves clients' ARV treatment outcomes and psychosocial well-being

Anecdotal evidence from this study suggests that CARE's CM program is positively impacting ARV adherence. This finding is supported by other studies in Western settings that have found similar outcomes among case management clients (Katz, 2001, Magnus 2001, Sherer, 2002). The home visits were noted as a particularly important factor in improving adherence by a range of informants. Visits from both volunteers and case managers offer the opportunity to monitor and discuss clients' use of medications and possible side effects. The reduction in stigma resulting from the visits as well as the CM program more generally also encourages ARVs usage.. Correspondingly, Katabira (1991) found that home-visit programs increased adherence to ARV regimes in resource poor settings. Within Rwanda, the improved relationships with health providers resulting from the CM program also positively contribute to adherence,

Respondents repeatedly cited positive psychosocial benefits of the program including increased social support and a heightened sense of hope concerning their future. This program was credited with reducing stigma and discrimination within the household as well as encouraging PLWHA to seek out services and support without being ashamed of their sero-status. Case managers and volunteers also provide emotional support through informal counseling. PLWHA gained advocates and confidants with whom they could share their problems and concerns, whereas previous to the case manager intervention, other health personnel were often too busy to address these needs. By facilitating client involvement with associations and other referral partners, clients obtain further social support sources.

Client needs outweigh available resources

In spite of case managers' efforts to increase PLWHA access to resources and services via referral networks, demand far outweighs supply. The poor economic situation of clients was identified as a primary need among PLWHA, as indicated by both the intake forms and focus groups. Volunteers, referral partners and health providers also reiterated the challenging financial situation and harsh living conditions facing clients. Informants highlight clients' inability to obtain basic essentials. In particular, food assistance was consistently cited as inadequate; a key resource to ARV adherence considering how the medicine may induce an increase in appetite and food intake may mitigate potential side effects. Many informants commented that volunteers and case managers should be empowered to provide some needed essentials directly to clients. In fact, in low-resource settings it has been documented that case managers often become providers of direct services rather than solely link clients with services (CDC, 1997).

While distribution of resources may be feasible and appropriate in some settings, within Rwanda, this may pose challenges. Placing case managers in a position of resource distribution or rationing could be detrimental to the program and compromise the perceived neutrality of case managers if selection criteria is not transparent and resources are limited, as was evidenced in this evaluation by

informants' inquiries concerning food distribution. In particular, the limited distribution of resources raised questions among respondents as to the selection criteria of beneficiaries as well as their consistent application throughout the CM program. A lack of transparency and consistency could easily create problems of jealousy and mistrust in the community and greatly reduce the legitimacy of the program and its ability to be an effective means of increasing care and support services for PLWHA in Rwanda. When resources are distributed, clear explanation as to their allocation is important. However, in light of the present limited resources case managers can directly access, perhaps it is most appropriate if they concentrate on the provision of counseling services and/or health services related to HIV, as appropriate, and facilitate access to additional resources through referral partners.

Documented information on procurement or uptake of services and resources among clients is lacking. Overall, there is a scarcity of data currently collected by CARE and case managers in regards to program operations and client assessment. As such, it is hard to determine how clients' economic and living conditions may have varied or improved, even slightly, overtime. Client monitoring and evaluation are essential parts of case management, "because services are needed on a continuous and indeterminate basis" (Rothman, 1992, p. 22-23). The maintenance of client intake forms was sometimes abandoned by case managers, suggesting that these forms need to be revisited in a participatory manner by CARE and its case managers to increase their utility and make them more user-friendly. However, incomplete client tracking may also be in part due to the high client load of case managers.

Case managers themselves are a vital resource and their ability to support clients may be impacted by the number of clients under their care. A common request was to increase the number of case managers per FOSA as "only one person cannot do this work." Case managers were found to support an average of 63 clients, in addition to supervision of volunteers. Yet, a CDC (1997) analysis of the literature suggests that ideal case loads should range from 10 to 35 clients, depending on client needs and the role and expectations of case managers. Extension beyond this ideal number is not uncommon, as HIV case managers in the US were found to support a median of 50 clients (CDC, 1997). However, case managers in the US typically don't supervise volunteers, possess transportation means and may also have more general access to resources needed to support clients. Rubin (1992) suggests that caseloads should be small when there are difficult environmental factors such as poverty. The high case loads may also lead to burn-out and perhaps contribute to the high turnover among case mangers reported by CARE.

The resource constrained environment in which this program operates poses a number of challenges. Motivation of community volunteers remains a pressing concern as these individuals are also poor and in need of basic support. Case managers further face their own resource challenges in terms of substandard salary in relation to other FOSA staff, perhaps caused by inequities or nonpayment of primes among case managers. An actual comparison of FOSA staff and case manager salaries was not conducted although both groups reported issues related to case managers' inequitable salary. Obviously, these

motivational issues as well as the idea of increased direct service provision to clients invite questions regarding cost and feasibility for program sustainability.

Limited networking hinders program effectiveness

"One of the inherent weaknesses of case management is that it is dependent on the availability and accessibility of other medical, social, and psychological resources. Many case management systems have been established without the benefit of a network of community support programs," (Rubin, 1992). Without referral sources, a skilled case manager can assist a client personally, for example, by providing emotional support. However, the limited number of referral partners remains a challenge in addressing the myriad needs of PLWHA.

In some instances, referral networks for case management clients have been strengthened due to the advocacy of the case manager and community volunteer. However, regular referral partners were limited in number, with most case managers having access to five or less providers. (Although CARE staff suggested that case managers may not be including CARE, a common referral partner, as part of this list). Moreover, referral partners were typically community-based associations, whose means to deliver financial or material support is often limited in scope. Referral partners also conceded that they were unable to meet all needs, either due to the volume of PLWHA need and/or inability to supply the type of service demanded. Though the linkage with CARE is advantageous on multiple levels, one agency is also incapable of addressing the wide array of client needs.

Sowell found that "professional turf guarding" rendered most CM models ineffective (1994) and this phenomenon may also affect services in Rwanda. While FOSA team members recognize case managers as staff, general perceptions of the approach as a CARE program may hinder effective collaboration with other large international organizations. In addition, inaccurate perceptions of case managers as solely operating in support of CARE programs rather than as agents well integrated into the GOR health system may exist. The narrow target groups of other initiatives also seem to hinder collaboration. Some referral partners were less likely to participate in the CM program and were only interested in servicing their specific target PLWHA populations. The tendency of faith-based organizations to restrict their services to only those PLWHA within their denominations also emerged from the data.

In addition to increased networking among service providers, a need for case managers to network amongst themselves was also identified. Case managers reported a desire to communicate with one another to gather lessons learned and effective problem-solving techniques. Increased collaboration among them may also serve to resolve the staff shortage problem, as one may be able to temporarily cover for another when ill or on vacation. Finally, they can share strategies and resources for more effectively engaging the community in program operations. Jointly, they may be better equipped to tackle community misconceptions concerning the program and garner additional support. Clients'

access to available resources may further be improved as case managers share their lists of referral partners with one another.

Lessons Learned

There are several instances where CARE has successfully applied lessons learned to improve program operations, some of which have been illustrated by this evaluation. However, review of existing program documentation and discussion with informants also highlights that CARE has previously identified and been made aware of some of the issues described throughout this report and has yet to modify the program to respond to these problems or concerns.

CARE has been responsive to issues concerning case manager integration within VCT programs and the FOSA more generally as well as taken actions in regards to appropriate volunteer selection. Mechanisms for identifying and weeding out inappropriate volunteers have been employed and informants recognized and appreciated these measures. CARE has also found ways to improve case managers' relationships with key stakeholders. For instance, in the initial implementation phase of the CM program, CARE staff realized the challenges existing between VCT programs and the case manager, primarily due to fear of "breaching confidentiality" on the part of the VCT counselor by sharing information with the case manager. In response, VCT content was incorporated into pre-service training for the case managers. While this strategy was advantageous, it is noteworthy to highlight that not all case managers benefited from this training. As has been mentioned previously in this report, case managers placed in the field during the end phase of implementation did not receive the required pre-service training. Another example of program responsiveness is in relation to the integration of case managers into their FOSA site. Initially, this integration was problematic, as some case managers were operating independently and answering directly to CARE rather than the FOSA head. CARE has addressed this problem and the success of this integration was repeatedly mentioned by respondents. This program modification resulted both from CARE's recognition of the problem as well as governmental reform which provided CARE the opportunity to identify new partners and engage FOSA contractually.

Other remaining issues seem to be fairly well recognized by CARE and its partners, but have yet to be resolved. For instance, the weaknesses within the existing referral network and client assessment tools have also been noted previously (Bedoya-Hanson, 2006). Additional outstanding issues include those of case manager salaries being too low and late; case manager contracts being of too short duration and causing "instability" and possibly contributing to a high turnover rate; inadequate supervision and feedback for case managers; and transport allowance being insufficient or lacking for home visits. Issues of motivation and transport for community volunteers have also been raised previously.

While many of these issues may be related to limited resources, their importance is repeatedly emphasized by key stakeholders and some compromise or at least

acknowledgement of these challenges would be advantageous. The continued neglect of these problems over time could potentially negate any positive program impact on clients as well as reduce morale and performance among both case managers and community volunteers alike. Moreover, failure to respond to previously and presently identified issues could hinder health providers and referral partners' endorsement of program expansion and sustainability. Though the pilot model has demonstrated achievements, the structure of the program must remain open to modifications to ensure the commitment of all of those involved.

CARE's capacity to incorporate lessons learned into program activities is hindered by insufficient program monitoring. Lack of documentation of referrals, ongoing assessment of the clients' situation and other indicators reflecting program activities makes it difficult to discern the program's progress, achievements and areas in need of improvement. The overall lack of program indicators and the insufficient tracking of client circumstances and utilization of available services greatly reduced the CM program's capacity to document its successes as well as lessons learned. As this initiative was began as a pilot program, mechanisms for program monitoring as well as opportunities to critically review these indicators and modify the program accordingly overtime would have been particularly advantageous.

Conclusion

CARE's efforts have demonstrated some key successes in the integration and utilization of case managers within Rwanda's health care system to positively impact PLWHA and close the gap in linkages among care and support services.

In spite of the need for specific improvements to the program, key stakeholders support the expansion of the case manager program throughout the Rwanda health system. Health providers overwhelmingly support the continuation of this program and many recommended that it be adopted by the Ministry of Health (MOH) and that case managers be hired as GOR civil servants. Again, this support demonstrates the utility of the program within the existing health system and suggests a value added to current HIV/AIDS care and support services. However, this transfer of the program from an NGO-supported activity to one that is fully assumed by the MOH obviously has significant cost implications which should be addressed before such a transition can be implemented and sustainability assured.

Although this evaluation does not provide conclusive data as to measurable impact of the CM program on clients' health outcomes and well-being, it does provide evidence of positive changes in the lives of clients. It further attempts to add to the knowledge base concerning program strategies for the care and support of PLWHA within Rwanda and recognizes its own limitations in terms of generalizability to other contexts within Africa. The authors hope that this evaluation will provide a useful contribution to the continuing dialogue on case management and how best to address the myriad of needs among PLWHA in a resource constrained environment, and specifically in the context of Rwanda.

RECOMMENDATIONS

Recommendations are implicit throughout this report as study participants offer their suggestions and results are discussed, however, the following highlights the evaluation team's principal recommendations based on findings of this investigation.

Establish mechanisms for ongoing client and program monitoring

Defining and regularly tracking monitoring and evaluation indicators would improve understanding of program impact and help to generate ongoing lessons for best practice. Better documentation of referrals and adoption of standard methods for assessing clients' situation initially and overtime would further help to reveal met and unmet client needs. Revision of the present client intake, assessment and tracking systems and the establishment of indicators for program monitoring appears necessary. Developing and improving these mechanisms is best achieved in a participatory manner including CARE, case managers and perhaps other FOSA staff.

Facilitate better support for Case Managers

To effectively fulfill their duties, case managers require basic support. Training, feedback and networking opportunities among other case managers would enhance their capacity, provide needed staff coverage and improve job performance. Regular support and facilitation of information-sharing among case managers may require additional staff resources. One consideration is to promote existing case managers into that role; advancement opportunities also aid in staff retention. Similarly, outstanding issues concerning salary, transport, and length of contract are important to address to retain talented individuals. Finally, the responsibilities of case managers need to be critically reviewed in a collaborative fashion to establish standards for client and volunteer loads.

Enhance stakeholders' participation and leadership in program operations

CARE can work towards transferring program leadership and responsibility of the program to key stakeholders. Capitalizing upon the interest expressed by FOSA staff to assume more responsibility of the program may be particularly advantageous. Involving representatives of relevant government ministries in the program's direction would also help to achieve integration of CM within health systems at a national level. In addition, regular meetings among a Working Group consisting of key stakeholders may generate participatory problem-

solving and program improvement. A more active role among stakeholders in program activities would enhance the likelihood of sustainability of the CM model as a standard service for PLWHA in Rwanda.

Strengthen and expand referral networks

Efforts to create a more comprehensive system of referral partners could more sufficiently attend to client needs. Linking clients to the range of services offered by CARE, such as the Nkundabana Initiative for Psychosocial Support and Group Savings and Loans, could address some of the economic and childcare concerns of clients. While CARE can and does provide some services to case manager clients, one agency is unable to adequately address the myriad challenges facing PLWHA. Holistic care for PLWHA and enhancement of their capacity to meet their own needs may be achieved via participation in services and projects offered through other agencies. Though the CM program attempts to meet this aim, the program would be more successful if the number of available referral partners was increased. Networking and relationship building with a range of international organizations, faith-based organizations s and local NGOs is necessary. A period of information-gathering to collect a list of potential referral partners within each community where case managers operate would be required and perhaps specific staff identified to attend to this issue. Regular communication between case managers and these partners would sustain the linkage and ensure an updated and applicable referral system.

Economically empower volunteers

Key considerations in the success and sustainability of the home visit aspects of the project are the motivation, retention and sense of accomplishment among volunteers. Income-generating projects among volunteers would be valuable motivators, mitigate their own financial hardships and enable them to independently attend to client needs. In particular, the PLWHA associations in which many volunteers are members could be strengthened; addressing both the economic needs of volunteers as well as PLWHA more broadly. In regions where volunteers have demonstrated organization and commitment, an emergency fund could be established. This fund could be used by volunteers to address urgent client situations, such as transport to hospitals and needed material support. Use of the fund could be monitored collectively by volunteer groups and/or associations to ensure appropriate application and members could be responsible for replenishing the money, perhaps through participation in group savings and loans and other income-generating activities. At times, CARE could also consider providing small resources for volunteers to both distribute to clients and use themselves as well as means to facilitate transportation for client visits. While such capacity building and resource distribution efforts bear cost implications, the integral nature of volunteers to program activities is also a strong consideration. It is important to be sensitive to the personal, family and financial demands in the lives of volunteers and maintain realistic expectations of them in this capacity.

Promote community awareness and involvement in program activities

Methods to engage and inform the general community about the program and the role of volunteers would be advantageous. Community awareness activities could resolve misconceptions concerning the program and contribute to a reduction in stigma surrounding HIV/AIDS. In addition, these activities may result in more referral opportunities, volunteer recruitment and community initiatives to support PLWHA. Promotional materials, community information sessions and even dissemination of the evaluation results could achieve this aim. In addition, local authorities could be tasked with specific responsibilities related to the program such as facilitating information sessions, suggesting suitable volunteers, identifying potential clients and general program endorsement.

Gather further information to assess program impacts and costs

Findings illustrate that the Case Management program addresses important needs surrounding HIV/AIDS care and support, including issues facing health providers and referral partners as well as PLWHA. Evidence suggests it is a promising strategy for increasing ARV adherence, improving psychosocial well-being and linking PLWHA to essential services. Assuming identified programmatic issues are addressed, this program seems to merit further investigation into the quantifiable impacts and cost assessment of program operations.

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PROGRAM DOCUMENTS REVIEWED

1. Bedoya-Hanson, Sandra. FIELD REPORT : Case Management Program : "Experiences From The Field," January 18, 2006 (File: Case Management...First Draft)

2. The Case Management Model, A Pilot Model For Linking Community And Facility Based Services To PLWHAS In Rwanda

3. Care Rwanda (ppt File)

4. CASE MANAGER PROFILE

5. Case Manager's Specific Responsibilities: (File: Job Description Rwanda)

6. CORE Initiative Grants Semester Performance: Monitoring Report July-December/2005, Date Submitted: January 13th, 2005

7. Manuel de Case Management par Care International au Rwanda (Premier Draft), Mars 2005

8. Memorandum Of Understanding (File : Tripartite Mou 13/2/06)

9. Scope Of Work, Review/Evaluation And Documentation Of Care Rwanda's 'Case Management Model'

MONITORING & EVALUATION TOOLS REVIEWED

1. APIE: Assessment, Planning, Implementation (Intervention) & Evaluation
2. Case Mangement Monthly Log Of Activities
3. Fiche Journaliere des Activités
4. Lettre de Reference- Annexe III
5. Profiling des Besoins Biopsychosociaux Des PVVS- Annexe II
6. Rapport Mensuel des Activités de Case Management
7. Record Of Encounter
8. Verification d'adhesion aux Services de Soins de Santé Primaires - Annexe IV
9. Uruhushya Rwo Gukorana Na Porogaramu Ya Case Management
10. Bedoya-Hanson, Sandra FIELD REPORT : Case Management Program : "Experiences From The Field," January 18, 2006 (File: Case Management...First Draft)
11. The Case Management Model, A Pilot Model For Linking Community And Facility Based Services To PLWHAS In Rwanda
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DATA COLLECTION INSTRUMENTS & TOOLS

1. APIE: Assessment, Planning, Implementation (Intervention) & Evaluation
2. Case Mangement Monthly Log Of Activities
3. Fiche Journaliere des Activités
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