

# Saving the sick and improving the socio-economic conditions of people living with HIV in Ethiopia through traditional burial groups

Francis Ogojo Okello,<sup>1\*</sup> Francesca Stuer,<sup>2</sup> Altaye Kidane<sup>1</sup> and Medhanit Wube<sup>1</sup>

<sup>1</sup>Global Program Management, Family Health International (FHI) 360/Ethiopia, Addis Ababa, Ethiopia, <sup>2</sup>Currently independent consultant based in Addis Ababa, Ethiopia; at the time of the study was at FHI 360/Ethiopia

\*Corresponding author. FHI 360/Ethiopia, 175 Djibouti Road, Bole Kifle Ketema, Kebele 05, P.O. Box 121789, Addis Ababa, Ethiopia. Tel: +251-11-663 9879 (direct); +251-11-663 9880 (pbx); +251 922 778 366 (cell). Fax: +251 663 9883. E-mail: fokello@fhi360.org.

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Poverty and limited availability of health facilities are major barriers to health care in resource-poor countries. For people living with HIV (PLHIV), these factors are compounded by social stigma and decreased mobility, making delivery of public health services a greater challenge. In 2003, the international development organization FHI (formerly known as Family Health International and now known as FHI 360) collaborated with the Ethiopian government, local non-governmental organizations and traditional burial societies (*Idirs*) to implement community and home-based care interventions for PLHIV in Addis Ababa and 13 other major cities. Programme activities included capacity building, care and support, stigma reduction, resource mobilization, support of orphans and vulnerable children, and income generation through community savings and loans groups. Programme results from 2003 to 2010 were evaluated using a quasi-experimental design with an intervention group (PLHIV who received community and home-based care programme services) and a control group (PLHIV who did not receive programme interventions). Propensity score matching was used to select matched intervention and control pairs for analysis. McNemar and Wilcoxon signed-ranks tests were used to determine outcomes and impact. Findings from routine monitoring data and a population survey showed that individuals who received the integrated community and home-based care services from *Idirs* reported significantly more savings, better social relations, more independence and better environments for PLHIV. Programme clients were also shown to have known their HIV status longer than the control respondents. However, a higher percentage of control respondents reported not having had an opportunistic infection in the past 6 months. We conclude that volunteer-based community organizations can be empowered to deliver and sustain health interventions for PLHIV. We also conclude that targeting the multiple needs of PLHIV enables holistic improvements in the quality of life and socio-economic conditions of PLHIV.

**Keywords** People living with HIV, community and home-based care, *Idirs*, integrated programme, intervention, control

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## KEY MESSAGES

- Donor and government interventions for people living with HIV have mostly been vertical. The use and evaluation of traditional community groups in HIV programming is uncommon.
- We measured the impact of an integrated programme that worked with traditional burial groups, or *Idirs*, to address the multiple needs of people living with HIV. While *Idirs* traditionally support community members during bereavement, this programme engaged them to provide additional physical, psychological and socio-economic services for the living.
- Results showed that the programme significantly improved clients' physical conditions, psychological conditions, level of dependency, social relations and household savings.

## Introduction

Poverty and limited availability of health facilities are major barriers to health care in resource-poor countries. For people living with HIV (PLHIV), economic and geographic factors are compounded by social stigma and decreased mobility, making delivery of public health services an even greater challenge. In most developing countries, community-based organizations (CBOs) play a major role in the delivery of care and support to PLHIV. A key outcome of CBO involvement in HIV interventions has been the facilitation of community-level access to services, particularly in areas where public systems are either inadequate or absent. Partnerships with CBOs provide governments and donors a less costly means of delivering support to underserved populations. The success of most CBOs stems from their understanding of, respect for and connections with their communities.

Despite these benefits, a major challenge to providing CBO support of PLHIV has been limited resources and technical and managerial capacities on the part of the CBOs. The multiple needs of PLHIV, exacerbated by extreme poverty, have also contributed. Also, most community-level interventions target only health-related and psychosocial needs of PLHIV and their households. Although these efforts tend to produce some immediate benefits for clients, the benefits are often lost over time, as other important client needs come to the fore. Although vertical programmes that address only health and psychosocial needs allow for more focused use of resources and implementation of activities, vertical programmes are less sustainable (beyond donor funding) than integrated programmes (Glaser 1981; Goodman and Steckler 1989; Bossert 1990; Lafond 1995; Mona and Lee 1998). Addressing basic needs, strengthening socio-economic status, and reducing stigma in co-ordination with health and psychosocial interventions would likely achieve far greater and more sustainable impact.

In 2002, the Ethiopia office of FHI (an international development organization formerly known as Family Health International and now known as FHI 360) and its partners conducted a baseline assessment to identify the coverage and quality of HIV/AIDS care services for PLHIV in key urban and peri-urban areas of Ethiopia where HIV prevalence was high and where poverty and stigmatization were widespread. At the individual level, the assessment showed dire living conditions for PLHIV. Many lived in extreme poverty (often in unhygienic conditions), experienced social isolation due to stigma and discrimination, and were generally in very poor health. At the structural level, the assessment showed that some

community-level services for PLHIV existed, but on a very limited scale.

Results of the assessment also showed that *Idirs* were a widely available social network, and that their leaders were highly respected in almost all communities. *Idirs* are traditional burial groups common to most communities in Ethiopia and many other African countries. Although their function has traditionally been to provide money for burials and to socially support the families of the deceased, the assessment showed that the viability of *Idirs* was being threatened by high rates of mortality among PLHIV.

The assessment further showed *Idirs* to be particularly well positioned to implement interventions to reduce stigma, to mobilize communities to change attitudes toward PLHIV, and to promote volunteerism and the mobilization of resources to respond to HIV in their communities. Because the multiple interdependent needs of PLHIV pose a challenge to programmes with vertical strategies targeting health and psychosocial needs alone, and because of the widespread respect for *Idirs* as a social group, the assessment suggested *Idirs* could make ideal community-level partners for delivering community home-based care (CHBC) services.

Based in part on these results, in 2003 FHI in partnership with the government of Ethiopia, local non-governmental organizations (NGOs), and *Idirs* launched an integrated CHBC programme to address the multiple needs of PLHIV. The design of the programme relied on elements of social cognitive theory, as applied to the World Health Organization (WHO) framework for CHBC (WHO 2002). The programme, which was scheduled to end in September 2011, focused on (1) building sustainable capacity of *Idirs* in management, leadership, behaviour change communication, supervision, local resource mobilization, and the monitoring and reporting of programme results; (2) training community volunteers identified by the *Idirs* in care and support, counselling, stigma reduction, and support for orphans and vulnerable children; (3) training households of PLHIV and orphans and vulnerable children in alternate income generation, community self-help, and savings and loans groups; and (4) mobilizing communities to provide PLHIV with shelter, clothing and other basic needs. In addition, community volunteers and nurse supervisors were trained on providing nursing care, creating linkages with other sources of care and support, and implementing referrals to services not provided by the CHBC programme.

In the present study, we evaluated the outcomes and impact of this unique integrated CHBC programme on a variety of environmental, personal and behavioural factors related to the multiple inter-related needs of PLHIV. Although the contribution

of CBOs in expanding access to HIV services has been well documented, our study is among the first to measure the results of the engagement of burial groups for delivering critical care and support for PLHIV. Results should help generate lessons for improving programme implementation and identifying new strategies for empowering indigenous organizations to contribute to community-level development initiatives.

## Methods

### Study design

This study was conducted from May 2010 through July 2010. A population survey and secondary data analysis methods were used. We contracted independent consultants to collect and enter the survey data, but data analysis was conducted internally. The secondary data came from routine programme monitoring data collected by FHI and its partner organizations between 2003 and 2010.

The cognitive theory was the main premise behind the design of this study. Specifically, we adapted the three elements of the cognitive theory—environmental, personal and behavioural (Bandura 1989)—and applied them to the design of this study. The cognitive theory factors were applied to the study design as follows. (During data analysis, which we describe in detail later, we grouped variables differently to measure the impact of the programme on clients' quality of life.)

#### *Environmental factors*

We measured how the CHBC programme positively influenced the community response to HIV. Key environmental factors investigated from secondary data included the extent of community-level capacity building, community volunteerism to support PLHIV, local resource mobilization, involvement in community savings and self-help groups, and linkages to other services within the community. The survey was used to measure the perception of stigma toward PLHIV at the community level, the extent of direct service delivery to PLHIV, access to information about HIV and participation in leisure or recreational activities.

#### *Personal factors*

We investigated the effect of the programme on individual PLHIV. Specifically, the survey was used to evaluate the impact of the programme on health, quality of life and psychosocial conditions, independence and physical condition, perception of economic conditions and expectations for social life.

#### *Behavioural factors*

The survey was also used to evaluate clients' perceptions of changes in the personal and environmental factors that directly affect their access to services and support. These included attitudes and behaviours of community members and institutional personnel (e.g. health care workers, community group leaders) toward PLHIV (stigmatization), individual behaviours that aim to improve personal health, participation in household economic strengthening activities, and changes in social relations.

### Study population

The study population was composed of PLHIV in 13 urban and peri-urban communities in four regions of Ethiopia: Amhara;

Oromia; Southern Nations, Nationalities and People's Region (SNNPR); and the capital city Addis Ababa. The survey samples were drawn from PLHIV registers, but secondary data analysis was conducted only on data for PLHIV who had received the CHBC programme interventions.

An intervention survey sample was randomly selected from the master register of PLHIV enrolled in the FHI-supported CHBC programme (which included 19 500 PLHIV from all programme sites). The registers were maintained by the supported *Idirs*. Individuals were included in the intervention sample only if they had been receiving CHBC services for at least 1 year. A control sample was randomly drawn from the list of 30 512 PLHIV registered at health facilities where they received care. The control sample was selected from within the catchment areas of hospitals and health centres located in the same towns as the intervention group, but in neighbourhoods where the CHBC programme was not implemented.

Before the survey was conducted, the control respondents were screened to ensure that they were not enrolled in any of the services supported under the CHBC programme. However, the respondents in both groups had access to facility-based care and support provided by the government health centres. These services included HIV counselling and testing, general health counselling, antiretroviral therapy (ART), and diagnosis and treatment of opportunistic infections.

### Calculation of survey sample size

We designed the study to have adequate power to compare the outcomes and impact of the intervention and control groups, in which each test was conducted at the two-sided 0.05 significance level without adjustments for multiple comparisons. For binary outcomes, making the most conservative assumption that 50% of the control group would have the outcomes, we calculated that enrolling 2500 participants (with approximately half in the intervention group and half in the control group) would provide at least 80% power to detect a difference of 5.5% between groups. We added 10% to this sample size to cater for possible non-response and matching failures, making the total targeted sample size 2750 PLHIV.

We generally expected to achieve better power with propensity score matching, as the analysis would only be undertaken with paired intervention–control cases. Continuous outcomes commonly require smaller sample sizes, so this sample size provided sufficient power to detect meaningful differences for those outcomes as well.

### Propensity score matching

Propensity score matching was used to match the intervention respondents with the control respondents based on a computed score of common covariates considered to have a confounding effect on the outcomes (Rosenbaum and Rubin 1983). For studies in which recipients and non-recipients of interventions are not randomly assigned, this approach has been used to effectively measure the causal effects of interventions (Orley 1978; LaLonde 1986; Heckman et al. 1998; Dehejia and Wahba 1999; Hill and Reiter 2006).

The propensity score, which was estimated using logistic regression, was constructed based on seven covariates: age, sex, geographic location (region), employment, highest education

level, marital status and household size. Matched pairs of intervention and control respondents were created using one-to-one nearest neighbour matching without replacement. Programme interventions were accessed directly by individuals in the intervention group, but control respondents may have indirectly received programme information, especially regarding strategic behavioural communication interventions. We reduced this possible bias by including the geographic location covariate in the computation of the propensity score.

### Procedures for data analysis

Data were analysed to measure outcomes and impact of the CHBC programme. We used binary variables from the survey to analyse outcomes related to: (1) disclosure of HIV status, (2) current use of antiretroviral drugs, (3) length of time on ART, (4) self-reported non-infection with an opportunistic disease, and (5) household savings. To compare the outcomes between the matched individuals, we used McNemar's tests for binary variables.

In addition, outcomes related to capacity building, participation in community savings and self-help groups, service delivery, change in health status (from being bed-ridden to being physically mobile), and mortality were analysed from secondary data. These data were contained in membership and service delivery registers and capacity building reports. Routine monitoring data were only analysed for intervention clients, as we did not have access to similar data on control clients. These data were collected routinely by FHI and the supported *Idirs* during implementation of programme activities.

Data on ART adherence were analysed from clients' registers. Measurement of adherence was based on the national ART guideline, which defines good adherence as having taken 95% of prescribed doses (Ethiopia Federal Ministry of Health 2007). Regimen adherence was self-reported by clients during home care visits and validated by community volunteers through pill counts. The main limitation to the use of secondary data in this paper was that we could not compare the outcomes between the intervention and control groups, as we did not have similar data for the control group.

To determine impact, we first adapted the guidelines for the WHO Quality of Life measurement tool (WHO 2005) to compute selected domains as dependent variables. We then compared the matched individuals on the impact domains using the Wilcoxon signed-rank test to determine if there were any significant differences between them.

Domain scores were calculated from the responses of survey participants who were asked to rate their perceptions of the level of improvement in these domains on a five-point scale in which '1' represented no improvement at all and '5' represented extreme improvement. The domain scores were divided by the total number of facets in each domain and then multiplied by four to standardize the maximum score for each domain at 20. The programme impacts on the intervention PLHIV were analysed based on the following five domains:

*Domain 1: Physical condition* was computed from the variables that measured the levels to which the respondent experienced (1) pain and discomfort, (2) energy and (3) sleep and rest.

*Domain 2: Psychological condition* was computed from variables that measured the levels of (1) positive feelings, (2) negative feelings (re-recorded inversely), (3) self-esteem and (4) acceptance of body image.

*Domain 3: Independence* was computed from variables that measured the levels of (1) ability to perform daily activities, (2) mobility and (3) dependence on medications to function.

*Domain 4: Social relationships* was computed from variables that measured the levels of change in (1) satisfaction with personal relationships, (2) dependence on others for basic needs, and (3) perception of change in attitudes of the community toward PLHIV.

*Domain 5: PLHIV environment* was computed from variables that measured the levels of improvement in (1) the physical and social environment (living place and feeling of personal safety), (2) financial resources, (3) access to health care, (4) transportation and (5) participation in leisure/recreation.

Additionally, we computed the overall quality-of-life measure, which was the mean score from all domains. We used this variable to measure the impact of the programme on the overall quality of life of PLHIV.

## Results

An original sample size of 2667 PLHIV was achieved: 1195 in the intervention group and 1482 in the control group. Following the propensity score matching, 111 participants from the intervention group and 398 from the control group were excluded from analysis because their propensity scores did not match. Thus, 1084 intervention-control matched pairs were included in the final analyses, resulting in a total sample of 2168 PLHIV. Table 1 shows the distribution of the study sample by key demographic characteristics.

### Programme outcomes based on data from capacity-building interventions and clients' registers

Overall, 208 *Idirs* in the programme areas had received technical support to improve their management practices and to build their capacity to deliver care and support to PLHIV. As a result, all supported *Idirs* improved their organizational capacity to the level that enabled them to transition from informal groups to legally registered community-based care and support organizations for PLHIV. To improve their capacity for co-ordination, networking and advocacy, the registered *Idirs* were provided with technical support to form coalitions. In total, 47 *Idir* groups joined together to form four coalitions.

The *Idirs* and their communities demonstrated a strong commitment to supporting the interventions implemented under the FHI-supported CBHC programme. In 2009 the programme-supported *Idirs* raised 1 260 980 Birr (equivalent to US\$109 650) in cash and kind donations from community sources. Mobilized resources were used to support PLHIV, their households and the operations of the *Idirs*. The CBHC programme also supported the formation of 48 community savings and self-help groups of enrolled PLHIV, with a total membership of 10 287 PLHIV. Between October 2009 and September 2010, these groups saved a total of 376 108 Birr (US\$32 705) in cash.

**Table 1** Distribution of the intervention and control samples by demographic characteristics

		Control		Intervention		Total	
		<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Region	SNNPR	104	9.6	165	15.2	269	12.4
	Oromia	292	26.9	184	17.0	476	22.0
	Amhara	200	18.5	215	19.8	415	19.1
	Addis Ababa	488	45.0	520	48.0	1008	46.5
	<b>Total</b>	<b>1084</b>	<b>100.0</b>	<b>1084</b>	<b>100.0</b>	<b>2168</b>	<b>100.0</b>
Age (years)	18–24	75	6.9	65	6.0	140	6.5
	25–29	239	22.0	238	22.0	477	22.0
	30–34	250	23.1	244	22.5	494	22.8
	35–39	219	20.2	242	22.3	461	21.3
	40–44	116	10.7	107	9.9	223	10.3
	45–49	75	6.9	78	7.2	153	7.1
	50+	99	9.1	101	9.3	200	9.2
	Don't know	11	1.0	9	0.8	20	0.9
	<b>Total</b>	<b>1084</b>	<b>100.0</b>	<b>1084</b>	<b>100.0</b>	<b>2168</b>	<b>100.0</b>
Sex	Male	261	24.1	202	18.6	463	21.4
	Female	823	75.9	882	81.4	1705	78.6
	<b>Total</b>	<b>1084</b>	<b>100.0</b>	<b>1084</b>	<b>100.0</b>	<b>2168</b>	<b>100.0</b>
Marital status	Currently married/in union	438	40.4	407	37.5	845	39.0
	Never married	89	8.2	77	7.1	166	7.7
	Divorced/separated	237	21.9	205	18.9	442	20.4
	Widowed	320	29.5	395	36.4	715	33.0
	<b>Total</b>	<b>1084</b>	<b>100.0</b>	<b>1084</b>	<b>100.0</b>	<b>2168</b>	<b>100.0</b>
Highest level of education	Never attended school	231	21.3	285	26.3	516	23.8
	Adult education	59	5.4	69	6.4	128	5.9
	Primary education (grade 1–4)	158	14.6	193	17.8	351	16.2
	Primary education (grade 5–8)	398	36.7	392	36.2	790	36.4
	Secondary education (grade 9–10)	164	15.1	107	9.9	271	12.5
	Preparatory (grade 11–12)	66	6.1	38	3.5	104	4.8
	Technical/vocational certificate	6	0.6	0	0.0	6	0.3
	University/college diploma	2	0.2	0	0.0	2	0.1
<b>Total</b>	<b>1084</b>	<b>100.0</b>	<b>1084</b>	<b>100.0</b>	<b>2168</b>	<b>100.0</b>	
Main employment	Regular salaried job	92	8.5	72	6.6	164	7.6
	Casual employment	408	37.6	394	36.3	802	37.0
	No employment	255	23.5	244	22.5	499	23.0
	Retirement income	13	1.2	6	0.6	19	0.9
	Retired with no income	3	0.3	5	0.5	8	0.4
	Self employed	300	27.7	350	32.3	650	30.0
	Other	9	0.8	10	0.9	19	0.9
	No response	4	0.4	3	0.3	7	0.3
	<b>Total</b>	<b>1084</b>	<b>100.0</b>	<b>1084</b>	<b>100.0</b>	<b>2168</b>	<b>100.0</b>
Household size	1–2	229	21.1	187	17.3	416	19.2
	3–4	370	34.1	336	31.0	706	32.6
	5–6	256	23.6	293	27.0	549	25.3
	7+	229	21.1	268	24.7	497	22.9
	<b>Total</b>	<b>1084</b>	<b>100.0</b>	<b>1084</b>	<b>100.0</b>	<b>2168</b>	<b>100.0</b>

Results from the analysis of data from clients' registers showed that the CHBC programme served 20 387 PLHIV between its inception in 2003 and September 2010. Services provided included nursing, referral and follow-up clinical services, psychosocial support, nutritional support and economic strengthening. Cumulatively, 11 409 PLHIV were put on ART through referrals over 6 years of programme implementation. In 2009, 99% of programme clients reported good adherence to their ART regimens. The annual mortality rate among current programme clients declined from 10% in 2005 to 0.7% in December 2009.

### Programme outcomes based on survey data

Table 2 presents survey results related to the period since HIV diagnosis, current use of ART, length of time on ART and perception of improvement in household savings.

Nearly 69% of the individuals in the intervention group, compared with 58% in the control group, had been diagnosed with HIV more than 3 years ago. The difference between intervention and control respondents on the length of time since HIV diagnosis was statistically significant ( $P = 0.000$ ).

A higher percentage of individuals in the control group (95%) than in the intervention group (91%) were currently receiving ART. This difference was statistically significant ( $P = 0.001$ ). Conversely, a higher percentage of individuals in the intervention group than in the control group had been receiving ART for more than 2 years (56.5% vs 46.2%;  $P = 0.000$ ). In terms of opportunistic infections, those in the control group were more likely than those in the intervention group to report not having

an opportunistic infection in the past 6 months (53.8% vs 45.5%;  $P = 0.000$ ).

Survey findings confirmed the routine monitoring data on savings under the community savings and self-help groups. A statistically larger portion of individuals in the intervention group (36.9%) than in the control group (20.7%) reported an improvement in their household savings ( $P = 0.000$ ).

### Core programme impact

Table 3 presents the impact of the programme on physical, psychological, independence, social relations and environmental quality-of-life domains. The results showed a statistically significant difference ( $P = 0.000$ ) between the median composite quality-of-life score for PLHIV who received the interventions (11.87) and those in the control group (11.47). When the domains were analysed separately, we found that individuals in the intervention group reported more improvements in (1) independence ( $P = 0.025$ ), (2) social relations ( $P = 0.000$ ), and (3) the environment for PLHIV ( $P = 0.029$ ) when compared with those in the control group.

## Discussion and implications

Transformational development focuses on enhancing the capacities of individuals to improve the quality of life of individuals and communities. Sachs (2005) observes that transformational development also aims to support long-term economic change by helping a country achieve structural transformations that should allow it ultimately to escape

**Table 2** Distribution of the intervention and control samples by programme outcomes

		Control		Intervention		P-value
		n	%	n	%	
Disclosed their HIV status to someone else other than a health provider	No	42	3.9	20	1.8	0.011
	Yes	1042	96.1	1064	98.2	
	<b>Total</b>	<b>1084</b>	<b>100.0</b>	<b>1084</b>	<b>100.0</b>	
Period since HIV diagnosis	≤1 year	79	7.3	15	1.4	0.000
	>1 to 2 years	139	12.8	94	8.7	
	>2 to 3 years	235	21.7	232	21.4	
	>3 years	631	58.2	743	68.5	
	<b>Total</b>	<b>1084</b>	<b>100.0</b>	<b>1084</b>	<b>100.0</b>	
Currently taking ART	No	58	5.4	99	9.1	0.001
	Yes	1026	94.6	985	90.9	
	<b>Total</b>	<b>1084</b>	<b>100.0</b>	<b>1084</b>	<b>100.0</b>	
Length of time on ART	≤2 years	524	51.1	375	34.6	0.000
	>2 years	501	48.9	610	56.4	
	<b>Total</b>	<b>1026</b>	<b>100.0</b>	<b>985</b>	<b>100.0</b>	
Reported having had an opportunistic infection in the past 6 months	No opportunistic infection	501	53.8	591	45.5	0.000
	Had an opportunistic infection	583	46.2	493	54.5	
	<b>Total</b>	<b>1084</b>	<b>100.0</b>	<b>1084</b>	<b>100.0</b>	
Reported improved savings	Improved	860	20.7	684	36.9	0.000
	Not improved	224	79.3	400	63.1	
	<b>Total</b>	<b>1084</b>	<b>100.0</b>	<b>1084</b>	<b>100.0</b>	

**Table 3** Median scores of intervention and control samples on levels of improvement on impact domains

	Control	Intervention	P-value	95% CI Interval—Control		95% CI Interval—Intervention	
	Median	Median		Lower limit	Upper limit	Lower limit	Upper limit
Physical conditions	12.89	13.11	0.792	12.782	12.996	12.96	13.26
Psychological condition	11.27	11.33	0.797	11.111	11.422	11.19	11.47
Independence	8.44	8.89	0.025	8.113	8.776	8.60	9.18
Social relations	13.33	14.67	0.000	13.122	13.545	14.53	14.80
PLHIV environment	11.00	11.33	0.029	10.768	11.232	11.11	11.55
Overall quality of life score	11.47	11.87	0.000	11.397	11.554	11.78	11.96

dependence on outside aid. Several publications have described local capacity building and local ownership as central features of this process (Sachs 2005; US Agency for International Development 2006; US Overseas Cooperative Development Council 2007; Veillette 2007). In the context of developing countries, it is difficult to expect positive transformational development without the involvement of CBOs, because of their influence and proximity to the beneficiaries of development interventions. For this reason, strengthening the capacity of CBOs to play a frontline role in implementing interventions in health, economic and social development is a prerequisite for transformational development. The focus on CBOs in HIV programming has increased in recent years with the realization of the devastating effects that HIV can have on local communities, especially where public resources are limited. Yet, the results of programmes working with CBOs have been mixed, depending on the approaches and interventions undertaken.

To our knowledge, the FHI-supported community programme is probably the first programme that has worked with traditional burial societies (*Idirs*) to deliver CHBC services in poverty-stricken settings and has had its impact rigorously measured. Results from this evaluation mainly show that the process we used to empower *Idirs* to go beyond their traditional burial role and become development partners delivering services to PLHIV was successful. Our results suggest that, with proper training and supervision, individuals with basic or even no schooling can effectively support the efforts of governments and donors to care for PLHIV. In particular, our study has illustrated and explained the ability of the *Idirs* to contribute to improving the quality of lives of PLHIV in Ethiopia.

The process of selecting a CBO with which to collaborate was an important factor in the success of the CHBC programme. At the start of the programme in 2003, FHI worked with local NGOs, PLHIV and government partners to conduct an assessment and to explore how to engage CBOs in home-based care for PLHIV. The intent was to identify a model through which many CBOs could be engaged to respond to the overwhelming need for care and support at the community level. The Addis Ababa City Government and the Health Bureau assisted in calling *Idirs* to action for home-based care. The *Idirs* were chosen because they were present in nearly all communities and, even though they were an informal group, they were more organized and had larger membership than many other groups operating at the community level.

Bevan and Pankhurst (1996) have described the widespread availability of *Idirs* in rural Ethiopian communities, where they

have played key roles in the economy and in provision of social support. In their study, Bevan and Pankhurst observed that the *Idirs* not only supported community members in bereavement but also were a source of social economic support (through savings schemes). *Idirs* have also been documented to play a significant role (though largely informal) in conflict resolution. In land-related conflicts, resolutions of *Idirs* are not often contested in court by the affected parties, as the opinions of *Idirs* are highly respected (Mahiteme 2009).

With the first group of 20 *Idirs* who were engaged at the start of the CHBC programme, we explored and defined the operational modalities for *Idir* engagement in the delivery of home-based care. During this process, some initial *Idirs* disengaged because they were not able to take on the required responsibilities, which were far greater than their traditional burial-support role. However, the engagement of new *Idirs* in Addis Ababa and other cities was facilitated by clarification about what exactly *Idirs* should take on in home-based care, and by the capacity-building approaches that had been developed to help *Idirs* effectively deliver home-based care.

Despite how well-suited the *Idirs* were for the CHBC programme, the strategy of working with them also posed some challenges. A core vulnerability of *Idirs* was their voluntary nature. CHBC programming involved day-to-day management of service delivery functions. To expect an *Idir's* CHBC Committee, composed of volunteers, to take on this responsibility is risky. In order to strengthen their systems and structures to effectively manage service delivery functions, and also to eventually take on a contract management role, it was important that *Idirs* engaged in CHBC formalize their structure. This involved registration as a legal entity and recruitment of a minimum number of professional staff to ensure operational functions and capacity transfer within the organization. Additionally, building the *Idirs'* capacity for delivering home-based care and support for PLHIV was difficult because most of the *Idirs* had either basic or no school-based education. Thus, educating them about HIV and about caring for PLHIV was a lengthy process. Stigma and lack of compensation for volunteers were also major hindrances to mobilizing the *Idirs* and volunteers. The *Idirs* also lacked offices, as most of their activities for supporting burial needs did not require them. Overall, most of these challenges were addressed through continuous training, strategic behaviour change communication, direct mobilization of volunteers by the *Idirs* themselves, and the addition of supervisors who were nurses to work with the volunteers. Furthermore, the local government authorities in most of the programme sites donated office space for the *Idirs* involved in the CHBC programme. Ultimately, this

improved their organizational and service-delivery capacity to the level necessary for the success of the CHBC programme interventions.

A key impact of the CHBC programme has been its contribution to strengthening adherence to ART, which likely contributed to reductions in the mortality rate of the intervention group over time. Our analysis of routine monitoring data showed 99% self-reported adherence to ART among CHBC clients, verified through pill counts by community volunteers. A meta-analysis of studies measuring ART adherence in sub-Saharan Africa, published in 2006, showed 77% adherence (Mills *et al.* 2006). Even if factors beyond community support can be associated with the high adherence levels in our study, our results suggest that community-level mechanisms for clients' follow-up and monitoring are important components of adherence support for PLHIV. Similarly, the reduction in the annual mortality rate of CHBC clients (from 10% in 2005 to less than 1% in 2009) suggests that the CHBC intervention improved the management of health conditions among PLHIV. However, we cannot entirely attribute our adherence and mortality results to the CHBC intervention because we lacked comparative data for the control group.

Interestingly, our findings also showed that a significantly higher proportion of the control respondents than the intervention respondents were currently on ART. While this result calls for further investigation, it is possible that the point of selection into the survey influenced this result. The control sample was selected from health facility registers, while the intervention sample was selected from the membership records of the *Idirs*. It was impossible to sample the control group from the community, as there was no common register for these individuals except at the health facilities.

In the CHBC programme, the activities of the communities themselves may have had the greatest impact, with the programme providing organizational and technical support for capacity building, leadership and community mobilization. Where stigma is rampant, services are limited and PLHIV are extremely poor, it is all too common for PLHIV to lose hope about improving their lives. Through significant improvements in the overall quality of life of its clients, the programme helped PLHIV overcome their despair. Communities were able and willing to come together to support PLHIV, including volunteering and mobilizing local resources. With effective mobilization and technical assistance, and despite extreme poverty, the clients of the CHBC programme were also able to undertake self-help initiatives, as indicated by the savings and loans groups that were formed. As a result, when compared with PLHIV who did not have direct access to the CHBC programme, those who received the programme interventions reported more improved social relations, levels of independence, and physical and social environments for PLHIV.

These findings highlight an important element that government policy makers, donors and organizations implementing CHBC programmes need to take into account: the targeting of multiple but interrelated needs of PLHIV to achieve more sustainable results. It is difficult for a single programme to meet all the needs of PLHIV, but a substantial number of needs could be addressed by establishing effective linkages between community-level programmes.

Another interesting finding is that a higher proportion of individuals in the intervention group than in the control group had been diagnosed with HIV more than 3 years ago. Considering the widespread stigma and discrimination surrounding HIV prior to the CHBC programme, this finding suggests that the programme's beneficiaries were among the earliest to test for HIV and the programme interventions successfully mitigated stigma, created a positive community response toward PLHIV, and provided support to PLHIV and their households. During the intervention, volunteers and the nurses supervising them enrolled all individuals who were bedridden into the programme. The enrolment process included counselling on HIV. Those who were willing to test for HIV were linked to health centres, where they were further counselled and tested for HIV.

Although selection bias was one of the weaknesses of our study (as it is for any non-randomized study), the use of propensity score matching helped increase the comparability of the different study participants and the validity of the results. Development programmes that are not based on research are often faced with the challenges of (1) balancing resources among activities that directly deliver the desired services within donor-specified time frames (which are often short), and (2) conducting rigorous impact evaluations. In the FHI-supported CHBC programme, the need for allocating resources for an impact evaluation came much later in the implementation time frame, which is why a baseline survey had not been conducted. This limited our choice of evaluation methodologies, for which propensity score matching was the most suitable. Considering that the programme delivered services directly to individuals enrolled in the programme (except for strategic behavioural change interventions, which could have been accessed indirectly by the control group), we do not expect much contamination of the data. But irrespective of this argument, we recognize an important limitation to this study arising from the fact that a baseline had not been conducted, which would have allowed for a more meaningful determination of study populations and comparison of the outcomes between the study samples.

Despite the limitations of this study, our findings provide compelling evidence of the effectiveness of an *Idir*-based CBO to deliver PLHIV services in its communities. The findings also make a case for the effectiveness of integrated programmes in improving the lives of PLHIV in a more sustainable manner.

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## Conflict of interest

None declared.

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