



# The Impact of Community Caregivers in Côte d'Ivoire

Improving Health and Social Outcomes through Community Caregivers in Côte d'Ivoire

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## Abstract

**Objective:** The study examined the impact of community caregivers on children orphaned or made vulnerable by HIV/AIDS in Côte d'Ivoire.

**Design:** The study used a quasi-experimental design to compare an intervention group of 512 households who received community caregiver support to a control group of 212 households not in the program.

**Methods:** Participants were selected from 5 regions in the country. Quantitative analysis of survey data investigated access to health care and social support for children. Qualitative analysis of data collected through structured interviews with NGO key informants and focus groups with community caregivers was used to investigate factors that enhance or impede caregivers' work in the field.

**Results:** On average, those who received support had received 2 years of support. The majority (86%) of the households interviewed indicated a high level of satisfaction with the support they received. About half had received 2 clinical services and over two-thirds (68%) had received 5 to 8 services out of the 10 available. Those who received caregiver support were more likely to receive better health care and social service than those without. They were also more likely to be connected to the community through social support groups.

**Conclusions:** Households that received community caregiver support received better care and had better clinical and social outcomes than those not being supported by a community caregiver. Programs should consider using community caregivers to support adherence to treatment, improve psychosocial wellbeing of caregivers and children, and increase overall access to needed services.

**Keywords:** HIV, AIDS, Côte d'Ivoire, community caregivers, community based care, local NGO



# Improving Health and Social Outcomes through Community Caregivers in Côte d'Ivoire

## Introduction

Côte d'Ivoire has one of the highest adult rates of HIV prevalence in West Africa, estimated at 3.7% [1]. HIV-related orphans and vulnerable children are estimated to number 410,000, of which 61,000 are living with HIV [2]. The pressures that HIV puts on families and communities have often resulted in the disruption of the family structure and difficulties in accessing essential services, such as health care, education, and adequate shelter and nutrition [3-6].

### *Programs in Côte d'Ivoire*

In Côte d'Ivoire, community-based organizations are pioneering solutions to support children left vulnerable by the HIV epidemic. Much of the support is provided by an invisible workforce, known as the '*conseillers communautaires*' or community caregivers [7, 8]. Community caregivers are usually members of the community in which they 'work' [9-11] to offer care and support through home visits. They assess the families' needs, refer them to appropriate services, and provide emotional, psychosocial, and practical support [12, 13]. However, this is a largely unrecognized, unregulated work force. There are no legal texts to frame the actions of community caregivers and no national guidelines or standards governing their role. They are not remunerated or officially recognized by the state, despite the fact that the Ministry of Solidarity, Family, Women, and Children (MSFFE) relies on the data they produce. PEPFAR, by allowing its partners to provide training and regular stipends for community caregivers, has made huge investments in this cadre of workers in the community-based response to HIV[8].

Since September 2008, USAID/West Africa, through PEPFAR, has funded Save the Children to build the capacities of local NGOs and government entities to provide care and support for orphans and vulnerable children in 8 regions of Cote d'Ivoire [8]. One of the specific objectives of this program is to strengthen the capacity of families, communities, and local partners to provide quality care and support for orphans and children made vulnerable by HIV/AIDS. To this end, Save the Children has worked with 13 local NGO partners who provide care and support to vulnerable children and their families, in accordance with the national strategic plan[2]. During the fiscal year 2011-2012, these NGO partners recruited and trained nearly 400 community caregivers who provided direct care and support to nearly 20,000 vulnerable children and their families[14, 15]. Save the Children believes that community caregivers have played an important part in reaching this many people. However, they have no empirical evidence of the impact they have had on the health and social outcomes for children affected by HIV or of the importance of their role in the social welfare system in Côte d'Ivoire [8].

This study sought to understand how community caregivers impact access to health care and



social services for these children and families. It compared the services provided by Save the Children's program to other programs that do not use community caregivers in their model of service delivery. The study investigated a range of activities carried out by caregivers and evaluated the impact of their efforts on clinical and social outcomes; it also investigated the support for and barriers that community caregivers must overcome to provide support to this vulnerable population.

## Methods

### *Study Design*

This study used a mixed-methods approach to evaluate the impact of community caregivers on children orphaned by or made vulnerable by HIV/AIDS in Côte d'Ivoire [16-18]. The study included quantitative analysis of survey data complemented by qualitative research at the household, caregiver, and NGO level. This mixed-methods approach permitted a more rigorous analysis of the impact of community caregivers on this vulnerable population, while understanding further elements that might impact the sustainability of this workforce.

The study used a quasi-experimental design to compare data from 512 orphans and vulnerable children who received community caregiver support (the intervention group) to 212 orphans and vulnerable children who were not receiving any community caregiver support (the control group). Participants were selected from 5 of 8 regions in which Save the Children works in Côte d'Ivoire: Lagune (Abidjan), Indenié-Djuablin (Abengourou), Guémon (Duékoué), Tonkpi (Danané) and Kabadougou (Odienné). These regions were selected based on the number of caregivers in the Save the Children program and the number of vulnerable children in these regions. The selected control group was supported by NGOs with similar demographic attributes but not using community caregivers in their program.

### *Selection*

The participants for the intervention group were selected using data provided by Save the Children offices in Côte d'Ivoire. The data was used to match community caregivers to the households. Caregivers were randomly selected and stratified by region, cities, suburbs, or villages. The study selected 74 community caregivers who worked with 13 NGOs in the Save the Children program.

Children enrolled in the Save the Children program were HIV+, lived in a household with someone identified as HIV+, or engaged in risky behavior that increased their chances of HIV infection (e.g. commercial sex work, injecting drugs). Proof of HIV status had to be provided before enrollment.



The control group included vulnerable children who lived in the same program areas as the intervention group, were in the same age range as the intervention group (approximately 1-20 years in age), were known by the caregivers, and were not receiving direct support from Save the Children’s program.

For both the intervention and control group, the vulnerable households were first selected and then a child was identified for review. If there were more than one child in the household, only one was selected to be in the study. For children who were unable to talk, their parents or guardians were questioned instead. There were difficulties identifying participants for the control group in Abidjan and Kabadougou, where there is a large transient population, so those areas were excluded from the control group. This challenge resulted in approximately one participant in the control for every two in the intervention group.

*Ethical Consideration*

The research study followed the standard child safeguarding protocol set by Save the Children. All research investigators, supervisors, and field interviewers reviewed and signed the Child Safeguarding Policy and required agreement framework that protects the confidentiality of the research participants. Participation in the study was voluntary and informed consent was provided. The consent form was also read and explained in the local language. Data was placed in secure and locked location at the Save the Children office. All identifiable information was removed and only summary and aggregate data have been analyzed, presented, or shared.

**Table 1: Distribution by Region and Gender**

	Intervention		Control	
	Male (%)	Female (%)	Male (%)	Female (%)
<b>Abidjan</b>	29 (6%)	47 (9%)	-	-
<b>Indenie-Djuablin</b>	48 (9%)	55 (10%)	31 (15%)	38 (18)
<b>Guemon</b>	61 (12%)	72 (14%)	42 (20%)	33 (16)
<b>Kabadougou</b>	42 (8%)	59 (12%)	-	-
<b>Tonkpi</b>	47 (9%)	50 (10%)	33(16%)	33 (16)
<b>TOTAL</b>	227 (45%)	283 (56%)	106 (50%)	104 (50%)
Goodness of fit $\chi^2$	0.65		0.41	

### *Data Collection*

Questionnaires were designed to capture seven indicators of social support (food and nutrition, health care, education and apprenticeships, psychosocial support, legal and child protection, shelter and care, and household economic strengthening) and two clinical indicators (HIV testing and adherence to HIV treatment.). The questionnaire also asked for the level of satisfaction with the community caregiver support (intervention group) or the desire for a community caregiver (the control group). The questionnaire was designed so that it could be completed within an hour.

Structured interviews were used for the eight NGO key informants. The 74 community caregivers participated in focus group discussions. Personal interviews and focus groups took a little longer, depending on the field dynamics and the desire to capture key information. The interviews and focus group discussions were conducted in French and in the local language by trained interviewers led by the local researcher. The interviews were taped, and then summarized in English, based on notes and review of the audiotapes.

### *Data Analysis*

Epi Data version 9.0 was used for data entry, and analysis was completed using SPSS version 19.0. Univariate and bivariate analysis were carried out on the social and clinical indicators. Summary statistic and odds ratios (OR) were used to compare the impact of the intervention with the control group.

Qualitative analysis of transcripts of the interviews and focus groups was completed to gain an understanding of the community caregivers' work in Côte d'Ivoire. The study employed interpretive phenomenology to analyze the interviews and focus groups [19, 20]. This approach offered the best method to describe the meanings and culturally situated social experiences of the participants. The local research team reviewed the interviews and focus groups, and generated an interpretive summary. The lead researcher also reviewed the transcripts to ensure there was consensus in the summary.

## **Results**

The average age of children in the study was 10.8 years (SD=4.3) for the intervention group and 10.2 years (SD=4.2) for the control group. On average, children who received community caregiver support had received two years of support.

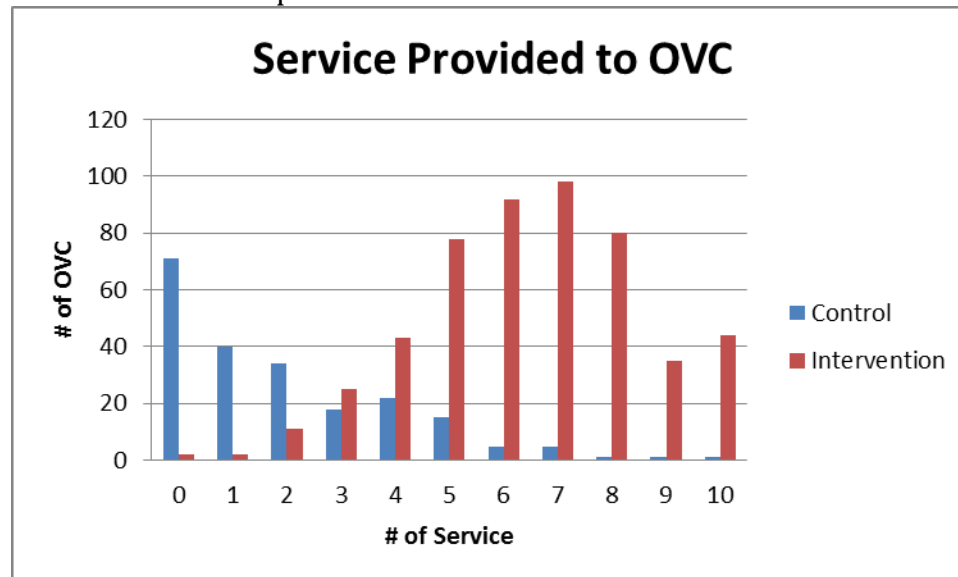


**Table 2:** Descriptive OVC Information for the Intervention and Control Groups

	<b>Intervention</b>	<b>Control</b>
	N = 512	N = 212
<b>Mean Age (years)</b>	10.8 ( <i>SD</i> =4.3)	10.3 ( <i>SD</i> =4.2)
<i>Range</i>	0.6 to 19 years	1 to 24 years
<b>Average Time with CC</b>	2 years	-
<b>Gender</b>		
<i>Male</i>	227 (45%)	106 (50.5%)
<i>Female</i>	283 (55%)	104 (49.5%)

The majority of the community caregivers supported households interviewed indicated a high level of satisfaction with the support they received. The household level of satisfaction ranged from 56% to 99% for the different services the household received. About half received two clinical services and over two-thirds (68%) received five to eight services of the ten available. Those who received caregiver support were about 12 (average) times more likely to receive care and services than those who had no community caregiver (Table 3). They were also more likely to be connected to the community through social support groups. Children supported by a community caregiver had higher rates of access to services (both social and clinical) than those in the control group. Almost all the children in the intervention group received some support to access services, but about 30% of the control group that were registered with a local NGO did not receive any services (Figure 1).

**Figure 1:** Number of services provided to OVC





The most common services accessed by households who had caregiver support were psychosocial support (93%), health care (86%), and nutrition and food (85%), followed by child protection (70%) and education (68%). Fewer than 40% reported accessing resources for household economic strengthening or care and shelter. Fewer than half of those who did not receive community caregiver support accessed any of these forms of support (range 2% - 35%). Fewer than half (46%) accessed HIV testing, compared to nearly three-fourths of those who had received caregiver support (74%).

**Table 3:** Descriptive Statistics of the Impact CC have on OVC compared to the Control Group

	Intervention		Control		
<b>SOCIAL OUTCOMES</b>	<b>Yes (%)</b>	<b>No (%)</b>	<b>Yes (%)</b>	<b>No (%)</b>	<b>OR (95% CI)</b>
<b>Nutrition and food***</b>	432 (85)	75 (15)	36 (17)	171 (83)	27.4 (17.7, 42.3)
Improved nutritional Status***	386 (83)	79 (17)	26 (14)	155 (86)	29 (18.4, 48.8)
<b>Health care***</b>	431 (85)	73 (15)	73 (35)	133 (65)	10.4 (7.2, 15.2)
Accessing health care education & advice***	417 (83)	84 (17)	126 (61)	82 (39)	3.3 (2.3, 4.8)
Registered & Going to health center***	290 (67)	141 (33)	58 (33)	125 (68)	4.3 (3.1, 6.4)
Having regular medical check-up***	94 (32)	196 (68)	19 (14)	114 (86)	2.8 (1.6, 4.8)
<b>Education and apprenticeship***</b>	344 (68)	160 (32)	52 (25)	154 (75)	6.4 (4.4, 9.2)
Accessing vocational training / apprenticeship ***	68 (20)	279 (80)	9 (5)	163 (95)	4.3 (2.1, 8.9)
Attend School*	354 (70)	151 (30)	128 (62)	78 (38)	1.4 (1.0, 2.0)
<b>Psychosocial support***</b>	475 (93)	35 (7)	46 (22)	161 (78)	47.5 (29.6, 76.4)
Receiving psychosocial support – involved in a support group***	275 (56)	216 (44)	14 (7)	178 (93)	15.9 (9.0, 28.2)
<b>Legal and child protection***</b>	353 (70)	152 (30)	21 (10)	184 (90)	20.4 (12.5, 33.2)
Receiving legal support***	288 (58)	210 (42)	17 (8)	190 (92)	15.3 (9.1, 26.0)
<b>Care and shelter***</b>	180 (37)	310 (63)	9 (4)	196 (96)	12.7 (6.4, 25.4)
Accessed the Shelter***	136 (28)	357 (72)	10 (7)	196 (95)	7.5 (3.8, 14.5)
<b>Household eco. Strengthening***</b>	164 (34)	324 (66)	5 (2)	201 (98)	20.5 (8.3, 50.7)
Microcredit association***	80 (18)	355 (82)	13 (7)	167 (93)	2.9 (1.6, 5.4)
Hold a bank account**	42 (10)	375(90)	7 (4)	189 (96)	3.0 (1.3, 6.8)
	Intervention		Control		
<b>CLINICAL OUTCOMES</b>	<b>Yes (%)</b>	<b>No (%)</b>	<b>Yes (%)</b>	<b>No (%)</b>	<b>OR (95% CI)</b>
Have been tested for HIV***	372 (74)	134 (26)	98 (46)	114 (54)	3.2 (2.3, 4.5)
Adherence to treatment <sup>1</sup> ***	111 (57)	84 (43)	25 (13)	175 (88)	9.3 (5.6, 15.3)

†Note: \*\*\* $p < 0.001$ , \*\* $p < 0.01$ , \* $p < 0.05$

<sup>1</sup>For retention in services and adherence to treatment, not all participants provided a consistent response

We endeavored to understand the activities in which the caregivers engaged and the impact of their support on the children and families they served. We compared access to services for those in the intervention group with those in the control group. We used relative risk and odds ratios to analyze the impact (Table 3).

**Nutritional status:** The program provided emergency food kits to children on a temporary basis and helped them with some nutrition-related activities, such as providing nutritional advice. Nutrition-related activities included food/hygiene education, buying food items, and cooking with and for some children. Nearly all (93%) reported that they had received some nutrition-related support from the caregivers. Over half (51%) acknowledged that caregivers brought them food at one time, while over a third (35%) reported that caregivers bought food often. Caregivers cooked with or for less than one-fifth (16%) of the children.

We reviewed weight information in the medical records from the time the children entered the program through August 2013. Based on this data, children in the intervention group were 29 times (OR=29, 95% CI = 7.2 – 48.8) more likely to have improved nutritional status compared to the control group.

**Table 4:** Distribution of Healthcare Education

Frequency	Intervention	Controls
Never	4%	66%
Often	33%	27%
Very often	64%	5%
<b>TOTAL</b>	<b>487</b>	<b>204</b>

**Health:** Those in the intervention group had proportionally higher access to health care and higher health education than those in the control group. The frequency of health education, including HIV prevention information, ranged from never to very often (Table 4). Nearly two-thirds of those in the intervention group (64%) reported receiving health advice or education very often, while nearly two-thirds of those in the control group (66%) reported *never* receiving any health advice or education. Of those receiving health advice and education, five out of six (83%) received healthcare counseling related to HIV infection and HIV testing. Those in the intervention group were over three times (OR=3.3, 95% CI = 3.3 – 4.8) more likely to receive health care when needed compared to those in the control group (Table 3). They were also three times more likely to be tested for HIV than those in the control group. Only 11% of the total reported that they had tested positive. Of course, the percentage could be higher, since many were not ready to disclose their status.

**Adherence to treatment:** Since the program served children that were HIV+, at risk of HIV

infection, or had family members who were infected, the program had a higher number of HIV+ children that needed treatment. Consistent ARV treatment for HIV+ children would improve their quality of life and lower treatment costs for the community and country. About one-fifth (21.6%) of those in the intervention group were under ARV treatment, compared to 12% of those in the control group. Treatment duration varied from one week to eight years. The majority (62%) said that the caregiver's support for their adherence to treatment was good; a third (33%) rated it as excellent; and only 5% said it was not good.

**Education and apprenticeship:** The percentage in the intervention group attending school was slightly higher (70%) than in the control group (62%). The difference between the two groups was more pronounced when we examined the number of children accessing vocational training or apprenticeships (20% to 5%). Although those accessing vocational training in both groups were in the minority, those in the intervention group were four times more likely to receive vocational training than those in the control group.

**Psychosocial support:** Psychosocial support included not only frequent visits of the community caregiver, but also membership in psychosocial support groups. Almost all in the intervention group reported that their caregiver provided psychosocial support (93%); most (89%) reported that their caregiver encouraged them to be part of a psychosocial support group. They were more likely to be involved in a support group than those in the control group (56% compared to 7%). The caregiver also counseled them on possible HIV infection transmission routes (89%), HIV treatment (47%), STI infection (55%), and personal hygiene practices (86%).

**Legal and child protection:** Nearly three-fourths (70%) of those in the intervention group accessed the legal services provided by the program, compared to 11% in the control group (OR=20.4, 95% CI = 12.5 – 33.2) (Table 3). Of those who accessed the legal services, about 82% of those in the intervention group and 77% in the control reported facing legal problems or issues. Problems included fighting, disagreements with adults, child abuse, refusing to go to school, and accessing a birth certificate. Most (96%) acknowledged that the caregivers were part of the process of resolving their problems.

**Economic strengthening:** About one third (34%) of those in the intervention group reported that they benefitted from economic strengthening activities. Over half (53%) recognized that the caregivers contributed to changes in their economic status. Those in the intervention group were nearly three times more likely to become members of a micro-credit association (OR=2.9, 95% CI = 1.6 – 5.4) than those in the control group. They were also three times more likely to open a bank account.



**Table 5: OVC Level of Satisfaction of CC**

	Not satisfied	Satisfied
<b>Nutrition and food</b>	5%	95%
<b>Healthcare</b>	2%	98%
<b>Education and apprenticeship.</b>	12%	88%
<b>Psychosocial support</b>	1%	99%
<b>Legal and child protection</b>	5%	95%
<b>Care and shelter</b>	44%	56%
<b>Household economic strengthening</b>	27%	73%

**Levels of satisfaction.** The level of satisfaction with the caregivers' actions and support was generally high. The satisfaction level ranged from 56% for care and shelter services to 99% for psychosocial support (Table 5). The average satisfaction rate for all the services provided by the program was about 86%. Almost all (96%) of those in the control group reported that they wanted to be supported by someone like a community caregiver. They saw community caregiver support as an opportunity to get better care and support.

**Support for Community Caregivers.** The key informant interviews with NGO staff revealed a lack of consistency in the supervision provided to the community caregivers across all organizations. Larger and better-organized NGOs had more robust human resource structures in place that provided greater oversight for the caregivers and tracking of assignments in the NGO zone of intervention. In addition, the larger organizations were able to provide services on site and used the caregivers for support on the children they served. For example, some organizations had their own healthcare center. Organizations with limited financial and human resources were less able to support caregivers in their activities.

Focus group interviews with community caregivers also revealed that many lack official recognition and clear terms of service. They also lack a consistent and secure income to ensure their own economic stability. Some of caregivers were HIV+. Many were not able to access healthcare and medication support for themselves.

## Conclusion

This study documents the impact that community caregivers have in Côte d'Ivoire. We found that it made a significant difference in the children's lives and a positive impact on their well-being. The results consistently showed that those with a community caregiver received better



care at a higher rate than those who did not. The program increased access to support and improved the efficacy of the services by increasing their utilization and reach. The difference in services was large and significant. The widest difference between groups was in accessing psychosocial support.

The community caregivers themselves provided psychosocial counseling as well as counseling in personal hygiene practices, nutritional information, health-seeking behavior, adherence to treatment, and HIV and STI infection information. This support may have had a big impact on the children and their families, contributing to the increased likelihood of accessing the social services supported by the Save the Children program. The presence of the caregiver in the children's lives may have provided them with the stability they needed to seek other forms of support.

While the community caregivers provide an invaluable source of support to the children and their families, our research also revealed a number of problems that need to be addressed to continue and extend the program. At the individual and family level, one of the barriers to joining the program is the issue of privacy, rooted in the fear of stigma and of exposure of issues that are confidential to the family. Better communication and greater assurances of confidentiality may help to address these concerns. However, some of these fears are deeply embedded in the cultural stigma associated with HIV that no organization or program can eradicate single-handedly.

The status of community caregivers needs to be formalized and their work recognized as para-professionals. At the organizational level, host NGOs need to provide more supervision of the community caregivers and linkages to service providers. They need broader sources of support, such as the government social welfare system, to receive the necessary supportive supervision and to help them better carry out their role in supporting children and families. Remuneration for community caregivers in Côte d'Ivoire also needs to improve. The allowance provided currently does not take into account the cost of living in the country. Support for this cadre should include health care support. They need to have access to some of the same services provided to the vulnerable children and their households. Lack of a clear plan for providing these services or remuneration for the services they provide could impact the long-term effectiveness of the caregivers. Programs will need to pay more attention to addressing these needs and consider ways in which they can participate in some of the microfinance program activities such as Village Savings and Loans Associations (VSLAs) to improve their own household economy[15].

There was a strong association between the work of the community caregivers and improvements in clinical outcomes. This suggests that they have the potential to improve care and adherence to treatment and could help reduce the costs of patient follow-up and promote increased use of social, educational, nutritional, and clinical services.





The study found a majority of those surveyed were satisfied with caregivers' work and almost all who were in the control group wanted support from a community caregiver. This demonstrated that there are compelling reasons why this cadre should be supported formally by the social welfare system and continue addressing social and healthcare issues within these communities.



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