

Integrated Community Palliative Care: Impact of a Project in South Africa

PROJECT OVERVIEW

Integrated community palliative care (ICPC) is a family-centered approach to palliative care that systematically addresses the holistic social, physical, spiritual, and emotional needs of patients with chronic illnesses such as HIV and AIDS by linking formal public health systems with community-level services. Through trainings and capacity building, FHI 360 and sub-partners used this integrated approach to improve the provision of palliative care services for people living with HIV in two regions of South Africa.



Background

Despite major achievements by the Government of South Africa, an estimated one million people living with HIV are still in need of antiretroviral therapy and an additional three million are in need of care and support.¹ The impact of HIV and AIDS in South Africa has led to many innovative responses to meeting the treatment, care, and support needs of adults and children who are infected with HIV. Among these is the development of community-based models of palliative care.

People living with HIV face substantial side effects, morbidities, opportunistic infections, psychosocial issues, and health complexities associated with aging and pain management. Comprehensive palliative care has been shown to be associated with better patient outcomes and improved adherence to antiretroviral drugs.² Recognizing the need for increased access to comprehensive health care services in underserved areas, South Africa's National Department of Health identified community-based palliative care as an important component of a primary health response.

In 2006, FHI 360 conducted a situation analysis to identify gaps in the delivery of palliative care services in South Africa. The analysis found limited knowledge about palliative care, limited access to palliative care, and weak referral systems. It also found that clinics were under-resourced (e.g., had limited amounts of drugs, wheelchairs, and other equipment) and that the level of stigma and discrimination within the community was high.

Based on these findings, FHI 360 with support from the U.S. Agency for International Development (USAID) developed an integrated community palliative care (ICPC) model to meet the needs of different local contexts. ICPC is a family-centered approach to palliative care that systematically addresses the holistic social, physical, spiritual, and emotional needs of patients with chronic illnesses such as HIV and AIDS by linking formal public health systems with community-level services.

In 2006, through the Contraception Research Utilization Technologies project, FHI 360 identified regional sub-partners in three provinces: Northern Cape (e.g., Nightingale Hospice and South African Red Cross Society); Limpopo (e.g., Evelyn Lekganyane and Makhuduthamaga (MK) Umbrella); Gauteng (e.g., Wits Health Consortium/Charlotte Maxeke Hospital Palliative Care Team (CMHPCT)) to pilot the ICPC model and provided technical assistance to address specific needs during the project's development and implementation.

Under the Preventive Technologies Agreement (PTA) the ICPC project was implemented from August 2009 to August 2014 with two main partners: MK Umbrella and Wits Health Consortium/Charlotte Maxeke Hospital Palliative Care Team. Three partners were not included under the PTA project due to several challenges including geographical coverage and proximity to health facilities, which made it impossible for the project team to link project activities with facilities.

Sub-partners

FHI 360 worked in collaboration with Provincial Departments of Health to strengthen ICPC services at Makhuduthamaga (MK) Umbrella in Sekhukhune District (Limpopo Province) and the Wits Health Consortium/CMHPCT

in Johannesburg (Gauteng Province). These two sub-partners worked directly with government health facilities and community-based organizations (CBOs) while FHI 360 provided comprehensive technical assistance; capacity building opportunities; and training on palliative care fundamentals, quality improvement (QI), and monitoring, evaluation, and reporting processes. FHI 360 customized the trainings based on the unique needs of the two regions.

The Sekhukhune District was selected as a focus area for the ICPC project because it is predominantly rural and underserved and because of FHI 360's ongoing relationship with MK Umbrella and its four affiliated CBOs. Sekhukhune District has a population of 1.2 million people with an estimated HIV prevalence of 20.4 percent.³

The Charlotte Maxeke Hospital Palliative Care Team (CMHPCT) is a non-governmental organization affiliated with the Wits Health Consortium, selected as a focus organization for the ICPC pilot because of its prior work in providing hospital-based palliative care for people living with HIV. Initially, only the hospital and HIV out-patient departments provided palliative care services. Over time, the provision of services has expanded to gynecological wards, cancer and surgical wards, community clinics, and households.

Training and Capacity Building

PALLIATIVE CARE FUNDAMENTALS

FHI 360 developed a training manual and conducted five-day trainings on palliative care fundamentals for multi-disciplinary teams of health care providers including doctors, nurses, social workers, and community health workers (CHWs). Topics included basic information on HIV and AIDS; supervision and stress management; healthy living; basic nursing skills; social, emotional, and spiritual support; and advocacy for palliative care, family planning, and monitoring and evaluation.

Over the five years of project implementation, FHI 360 trained 2,973 health workers at the Wits Health Consortium site alone. FHI 360 also trained 18 trainers of trainers (TOTs) on facilitation skills. In turn, these trainers trained 30 CHWs on palliative care. Following the training, FHI 360 provided technical assistance to the CHWs through field-based mentoring, coaching, and case review.

QUALITY IMPROVEMENT

FHI 360 conducted a three-day QI training in Pretoria in July 2013. The training included information on developing models and flow charts for QI systems, presenting plan-do-study-act cycles, analyzing current programs for cause and effect, identifying and testing ideas for QI efforts, identifying QI teams, and developing QI assessment tools. Following the training, FHI 360 provided technical support to district-level QI teams that were implementing plan-do-study-act cycles.

MONITORING, EVALUATION, AND REPORTING

FHI 360 provided customized trainings for sub-partners during the project to develop and improve their skills and knowledge in monitoring, evaluation, and reporting. The

trainings covered monitoring, evaluation, and reporting concepts and systems; data collection and management; and data handling and completeness.

FHI 360 also conducted routine data quality assessments (RDQAs) to identify strengths and weaknesses in monitoring and evaluation systems and to develop action plans. The initial RDQA conducted in 2012 identified the need for QI and validation procedures for the sub-partners' ICPC data. It also revealed weaknesses in data collection tools, missing data, and inaccurate data collation.

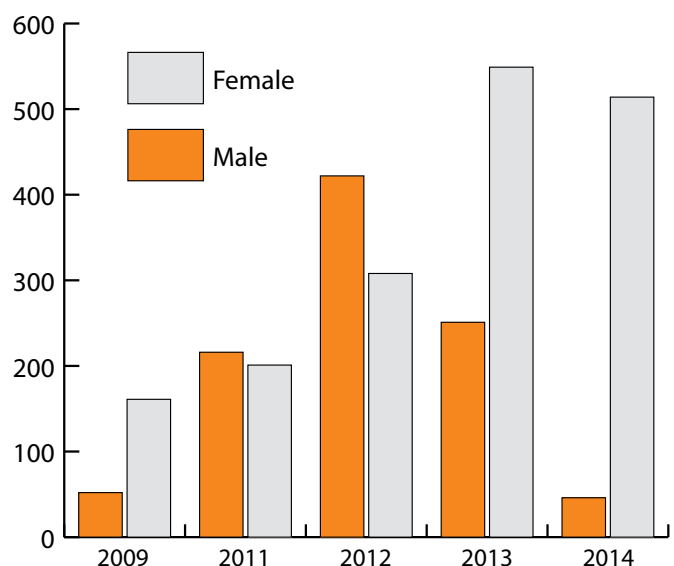
Based on the findings from the initial RDQA, FHI 360 provided onsite mentoring to CHWs and CBO coordinators on the importance of and process for recording home-based services for long-term monitoring. FHI 360 mentored CBO coordinators on how to conduct spot checks, collate data, and verify data before submitting reports to the district level. A follow-up RDQA conducted in October 2013 indicated substantial improvement in the quality and completeness of data submitted by the CBOs.

Results of the Project

INCREASE IN SERVICE PROVISION

Service provision expanded to encompass the physical, social, emotional, and spiritual needs of clients with HIV. In addition to receiving clinical services, patients received support from CHWs including bathing and feeding; distribution of family planning and information, education, and communication materials; toiletries, hygiene products, food parcels, and condoms; support for medication adherence for tuberculosis (DOTS support) and HIV treatment; facilitation of monthly support group meetings with other HIV-positive clients; and health education. CHWs also provided grief and bereavement support to affected family members. On average, each CHW saw 15 to 20 clients per month. They also identified clients in the community who were critically ill and referred them to clinics for follow-up.

Number of HIV-positive clients who received palliative care services in Sekhukhune District, 2009–2014



STRENGTHENING OF NETWORKS AND REFERRAL SYSTEMS

The ICPC project improved access to and use of HIV and AIDS, tuberculosis, and other health services in the communities. It also strengthened networks and referral systems between hospitals and community structures. Collaborative capacity building among clinics and home-based care organizations improved referral linkages, the integration of formal and informal health care providers, patients' access to needed services, and experiences of stigma and discrimination.

During the implementation of the project, community-level care for patients improved, with services transitioning from primarily hospice care to more home-based care in Gauteng Province. The rising number of patients receiving services outside of a facility demonstrated the importance of home-based care for achieving the region's primary health care goals.

Challenges

INADEQUATE ORGANIZATIONAL CAPACITY

District-level CBOs faced various organizational and resource challenges because of structural barriers associated with rural Sekhukhune District. CBOs lacked strong governance structures and leadership to oversee their organizational strategic direction. They were unable to secure diverse or stable financial support and partnerships to adequately address their goals. Similarly, CBOs lacked qualified personnel, leading to inefficient and ineffective operations and management. Lack of access to basic equipment and tools such as computers, Internet connectivity, and printers also hindered CBOs' ability to compete for funding opportunities.

As a result of MK's supervisory approach, the bulk of customized trainings with CBOs took place toward the end of the project (2013–2014). The delayed promotion of organizational sustainability potentially compromised MK's mentoring and coaching efforts with individual CBOs.

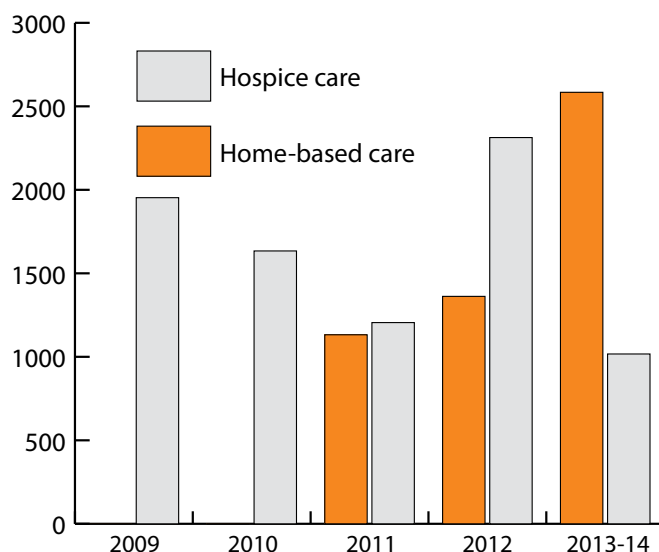
INADEQUATE INCENTIVES FOR COMMUNITY WORKERS

Inconsistent staffing and high turnover rates affected the number of community-level providers who were trained and able to provide both quality and comprehensive palliative care services. Most CHWs were volunteers and lacked the incentives, recognition, or rewards (financial or otherwise) to motivate them to become long-term caregivers. Retention rates were often low because many CHWs found gainful employment or migrated out of the districts. Among the few CHWs who were paid, many failed to receive their stipends in a timely and consistent manner. Although financial support is ideal for all CHWs, the inequitable distribution of stipends dissuaded unpaid volunteers from remaining in their roles for the long-term.

DIFFICULT TERRAIN AND POVERTY

Given the vast terrain and widespread poverty in Sekhukhune District, CHWs often had to walk long distances to conduct home visits or obtain transportation to the clinic. Furthermore, limited

Number of HIV-positive individuals who received hospice care and home-based care through the Wits Health Consortium, 2009–2014



financial and human resources made it difficult to supervise many CHWs working in diverse geographical areas.

SHORTAGES OF SUPPLIES

CBOs often reported inconsistent supplies of drugs and home-based care kits. These supply issues negatively affected the quality of care that was provided. They also left CHWs unsure of how to support their communities, as they didn't have the necessary tools.

LACK OF COMPREHENSIVE APPROACH BY PROVIDERS

Within the hospitals, staff members tended to focus on diagnostic and biomedical services rather than appreciating patients' broader psychosocial needs. Furthermore, sub-partners viewed monitoring and evaluation as necessary only for reporting to their donors, rather than as a means of continuously improving the project; this resulted in the underuse of findings for improving the project and designing future interventions.

Recommendations

FHI 360's technical assistance resulted in a "cascading model" wherein the MK Umbrella transitioned from a recipient of capacity building to a recognized provider. This allowed MK to continue promoting and supporting its local CBOs. The cascading approach to technical assistance and capacity building can be an effective means of strengthening project sustainability and expanding coverage. However, to minimize dependency, lead-role sub-partners should be trained to supervise CBOs in capacity building and to guide them in developing a sustainability strategy both early on and on an ongoing basis.

Collaborative capacity building among clinics and home-based care organizations improved referral linkages, the integration of formal and informal providers, patients' access to needed services, and experiences of stigma



About FHI 360: FHI 360 is a nonprofit human development organization dedicated to improving lives in lasting ways by advancing integrated, locally driven solutions. Our staff includes experts in health, education, nutrition, environment, economic development, civil society, gender, youth, research and technology — creating a unique mix of capabilities to address today's interrelated development challenges. FHI 360 serves more than 60 countries, all 50 U.S. states and all U.S. territories.

FHI 360/HEADQUARTERS

359 Blackwell Street
Suite 200
Durham, NC 27701 USA
T 1.919.544.7040
F 1.919.544.7261

FHI 360/SOUTHERN AFRICA REGIONAL OFFICE

Building 3, Hatfield Square, 4th Floor
1115 Burnett Street
Hatfield, South Africa 0083
T + 27-12-762-4000
F + 27-12-762-4001

www.FHI360.org

and discrimination. In addition, transferring basic palliative care skills to a patient's primary caregiver was an essential layer of training and capacity building that created a sustainable integrated continuum of care.

The competence of multi-disciplinary teams across all levels of the health system is vital to ensure both integrated services and comprehensive palliative care. In this framework, palliative care includes not only crisis and diagnostic investigations but also anticipatory treatment and attention to patients' broad psychosocial needs.

To improve health outcomes, strong referral systems need to be developed among hospitals, clinics, and communities. The established network and linkages with Wits Health Consortium/CMHPCT and hospices provided an enabling environment for uninterrupted holistic care. Furthermore, as part of the re-engineered primary health care strategy, these linkages created proactive follow-up mechanisms with patients and their families to ensure health promotion and access to preventive services.

Training for health professionals at all levels should include education on palliative care to improve knowledge and alleviate resistance to change. The role of CHWs in providing palliative care services throughout the community is indispensable, demonstrated in the number of clients reached through their services. Future efforts should target professional development opportunities for CHWs, as they are both eager for the professional opportunity and invested in the health outcomes of the communities they serve. Building the capacity of CHWs is vital for ensuring the quality of palliative care data, reporting data collected during home visits, and reducing incompleteness and inaccuracies. Ongoing training is also needed among this cadre of health workers to account for the arrival of new CHWs entering the system.

Conclusion

Palliative care is increasingly recognized as an integral component of comprehensive quality care for patients and their support systems, regardless of prognosis. Nurses, district health officials, CHWs, and other formal and informal health care providers must continue to play a key role in making this evidence-based paradigm a reality across a range of care settings.

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ACKNOWLEDGMENTS

This work is made possible by the generous support of the American people through the U.S. Agency for International Development (USAID). Financial assistance was provided by USAID to FHI 360 under the terms of the Preventive Technologies Agreement No. GHO A 00 09 00016-00. The contents do not necessarily reflect the views of USAID or the United States Government.