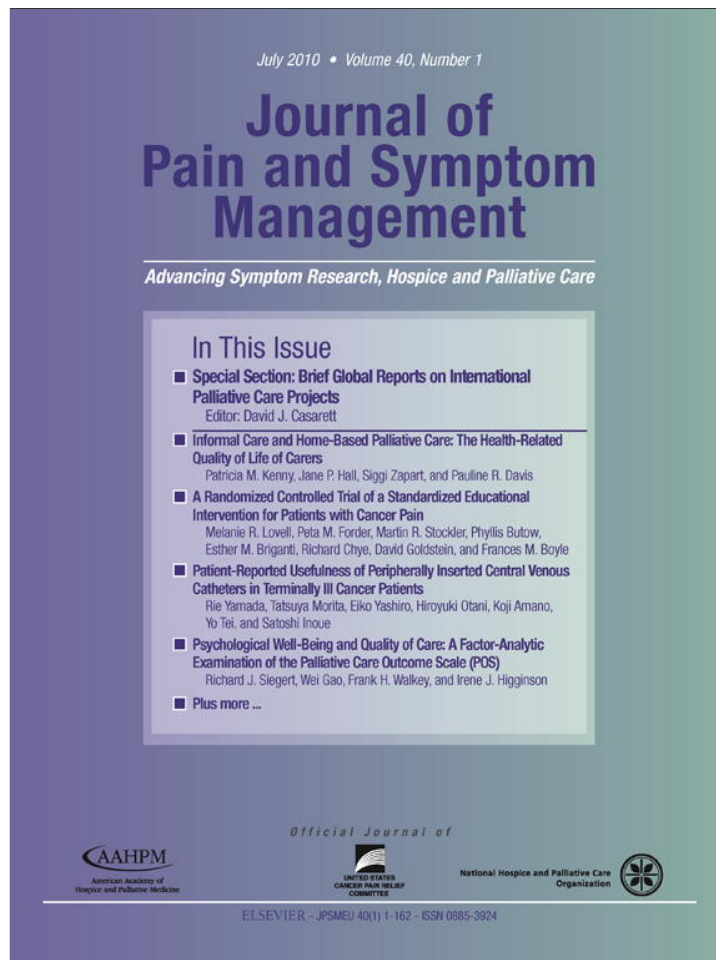


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**Special Article**

## Expanding the Reach of Palliative Care to Community-Based Home Care Programs

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**Abstract**

*This article describes a pilot project, run over a two-year period in the Eastern Cape province of South Africa. It was aimed at assessing the impact of a model of introducing a palliative care component and professional supervision of community caregivers on the quality of care given to people living with HIV/AIDS and their families. The use of the African Palliative Care Association African Palliative Outcome Scale as an assessment tool is outlined, and the challenges and outcomes encountered by the various role players are listed. The overall conclusion is that this model is a cost-effective way of increasing access to palliative care in resource poor settings. J Pain Symptom Manage 2010;40:3–5. © 2010 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

**Key Words**

*Palliative care, professional supervision, community caregivers, expanding reach, assessment*

### **Introduction to the Setting and Problem**

The aim of this two-year project, funded by the Elton John AIDS Foundation, was to pilot and assess the impact of a model of professional supervision of community caregivers on the quality of care given to people living with HIV/AIDS (PLHA) and their families. According to statistics published in 2008, 5.6 million people in South Africa are HIV+, with a prevalence rate of 20% for adults between the ages of 20 and 64 and an estimated

350,000 only AIDS-related deaths.<sup>1</sup> Hospice Palliative Care Association of South Africa (HPCA) member hospices collectively cared for 47,904 HIV-infected people during 2008, the vast majority of all whom were unable to contribute to the cost of their care. It is unrealistic to expect hospices to provide the services that are needed as they simply do not have the required resources. Numerous home care programs have been established, most of which are run by community-based organizations (CBOs) without access to professional input, and provide supportive care.

In the Eastern Cape of South Africa, the site of the pilot, a total of 730,000 people were estimated to be HIV+, and there were 44,000 AIDS-related deaths during 2008. While 111,000 people needed treatment and 49,000 accessed antiretroviral therapy (ART),<sup>1</sup> for those on ART, it is only part of the total care needed. In cases of treatment failure, “palliative care is the main treatment option.”<sup>2</sup>

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### Description of the Intervention

This project was coordinated by the HPCA and was based at St. Bernard's Hospice in East London, which seconded an experienced, palliative care-trained professional nurse (PN) proficient in the local languages and able to provide training to the community caregivers for the project duration. The four CBOs run multiple HIV/AIDS-related programs that promote awareness and prevention, provide childcare, prevent domestic violence, and support community gardens and feeding schemes. All are in informal settlement areas, within 30 km of the hospice.

Criteria for selection included registration as a legal entity and an existing group of caregivers with basic home-based care training. The CBOs selected a group of 30 caregivers who would focus on working with the PN to provide palliative care to homebound patients. The level of care provided by the CBOs was assessed using the African Palliative Care Association African Palliative Outcome Scale (APCA POS) (copy available at [www.jpsmjournal.com](http://www.jpsmjournal.com)), which measures outcomes of the care given to patients and families.

Caregiver competencies were measured using a tool developed for this purpose, and this information guided the development of a five-day palliative care training program. Documents such as a patient record form, monthly data capturing forms, in-service training register, a supervision roster, claim forms, and timesheets were compiled to collect accurate data. The PN spent a full day each week with caregivers in each area, conducting first assessments, drawing up care plans, visiting patients, discussing problems, and monitoring record keeping. Caregivers were provided with cell phones so that they could liaise with the PN for advice and support between visits. Each month, an average of 194 people received care from supervised community caregivers, and there were approximately 135 people on ART and 270 on tuberculosis (TB) treatment.

Financial statements were reviewed at monthly HPCA management meetings. Toward the end of the project, caregiver competencies were reassessed (Fig. 1). An independent PN assessed patient and family

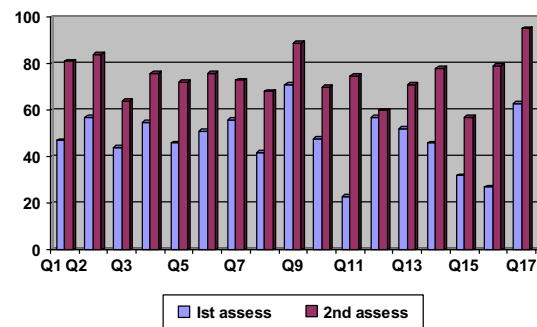


Fig. 1. Comparison of caregiver scores between first and second assessments. Q1: Information regarding patient and family; Q2: Physical care; Q3: Patient assessment; Q4: Teaching family; Q5: Infection control; Q6: Communication; Q7: Assess patient's feelings; Q8: Assess risk of suicide; Q9: Action to take; Q10: Dealing with patient's anger; Q11: Dealing with unrealistic expectations; Q12: Communication with family; Q13: Bereavement; Q14: Grants; Q15: Planning for the future; Q16: Record keeping; and Q17 Overall impression.

perceptions of care using the APCA POS with a sample of 24 patients with advanced disease. The summarized results are depicted in Fig. 2.

### Experience with Implementation

Good care is dependent on good management and, although this was not part of the original project planning, workshops on organizational capacity building were included.

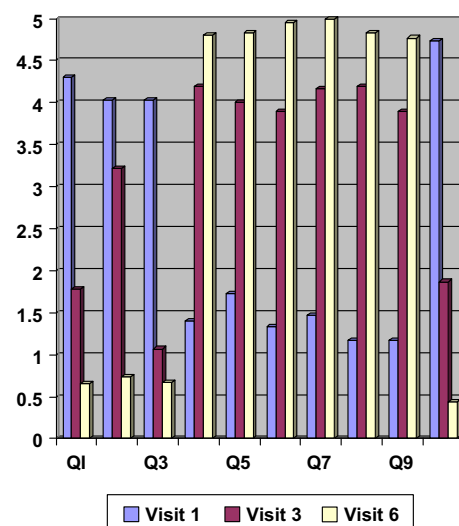


Fig. 2. Average APCA POS scores on Visits 1, 3, and 6. Q1: Pain; Q2: Symptoms; Q3: Patient worry; Q4: Sharing/disclosure; Q5: Quality of life; Q6: Peace; Q7: Planning for future; Q8: Information for family; Q9: Family confidence; and Q10: Family worry.

In particular, information regarding the effective use of financial and human resources is of pivotal importance in making decisions regarding further implementation of the model. None of the caregivers received any form of remuneration from the CBOs and after the training, a few obtained jobs. To ensure that the remaining caregivers were retained, HPCA sourced funding to pay stipends. Although there were signed agreements with each of the CBOs, these did not establish sufficiently clear boundaries at the outset, resulting in some unrealistic expectations. For instance, the PN received many unnecessary phone calls, sometimes unrelated to patient care. To use the scarce resource of professional supervision even more optimally in the future, it is planned to train a core of senior caregivers drawn from the larger group. These caregivers will be empowered to conduct initial screening and deal with straightforward problems so that the input from the PN is reserved for those instances where professional intervention is most needed.

The PN felt that she was isolated from the rest of the hospice care team and that it was difficult to ensure continuity of care when she was on leave. For future programs, a team rather than an individual approach is recommended. The fact that sufficient time needs to be allowed for building up trusting working relationships between organizations was another important lesson.

### ***Impact and Outcomes***

This pilot project demonstrated that it is possible to successfully expand the reach of professional palliative care supervision beyond traditional hospice boundaries. This is in line with HPCA's development strategy of strengthening the health system at the subdistrict level in terms of palliative care by establishing strategic partnerships and contributes to HPCA's vision of *Quality Palliative Care for All*.

The APCA POS proved to be a relevant assessment tool. The assessment of community caregiver competencies showed an average improvement of 28.5%. Caregivers also reported increased confidence in caring for people with advanced disease.

CBOs indicated that, as a result of improved levels of care, their credibility in the community was enhanced and that their overall

management skills and ability to control finances had grown appreciably. There was a marked increase in the quantity and quality of networking partnerships established with both the formal and informal sectors. The strong networking relationships established with the local TB hospital and ART site meant that people were able to start HIV treatment without delay, treatment support was made available, and treatment adherence strongly promoted. One program reported that the maternity department at the local hospital referred HIV+ mothers and babies to them for follow-up and home care. CBOs reported that they encourage PLHA who have divulged their status to motivate others to follow their example and break the cycle of silence and fear that still surrounds this illness.

St. Bernard's Hospice indicated that the project had not interfered with their service delivery and instead had encouraged a wider strategic vision regarding their role in the promotion of palliative care within their health district. The supervising PN reported that her involvement in the program had contributed to professional development, increased self-confidence, and awakened interest in mentoring.

In addition to making a significant contribution in terms of improving the quality of life of individuals with a life-threatening illness, palliative care enhances both the prevention and treatment of HIV.<sup>3</sup> This pilot showed that grafting a palliative care component onto existing home care programs is an effective way of providing many more people living with advanced illness with access to an improved quality of life.

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