## **Brief Report**

# A Hospital-Based Palliative Care Service for Patients With Advanced Organ Failure in Sub-Saharan Africa Reduces Admissions and Increases Home Death Rates

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#### Abstract

**Context.** Despite emerging data of cost savings under palliative care in various regions, no such data have been generated in response to the high burden of terminal illness in Africa.

**Objectives.** This evaluation of a novel hospital-based palliative care service for patients with advanced organ failure in urban South Africa aimed to determine whether the service reduces admissions and increases home death rates compared with the same fixed time period of standard hospital care.

**Methods.** Data on admissions and place of death were extracted from routine hospital activity records for a fixed period before death, using standard patient daily expense rates. Data from the first 56 consecutive deaths under the new service (intervention group) were compared with 48 consecutive deaths among patients immediately before the new service (historical controls).

**Results.** Among the intervention and control patients, 40 of 56 (71.4%) and 47 of 48 (97.9%), respectively, had at least one admission (P < 0.001). The mean number of admissions for the intervention and control groups was 1.39 and 1.98, respectively (P < 0.001). The mean total number of days spent admitted for intervention and control groups was 4.52 and 9.3 days, respectively (P < 0.001). For the intervention and control patients, a total of 253 and 447 admission days were recorded, respectively, with formal costs of \$587 and \$1209, respectively. For the intervention and control groups, home death was achieved by 33 of 56 (58.9%) and nine of 48 (18.8%), respectively ( $P \le 0.001$ ).

**Conclusion.** These data demonstrate that an outpatient hospital-based service reduced admissions and improved the rate of home deaths and offers a feasible

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#### Key Words

Palliative care, organ failure, terminal care, evaluation, admissions, place of death, costs, Africa, hospital

#### Introduction

The majority of deaths annually occur in lowand middle-income countries. 1,2 High mortality rates because of HIV/AIDS are well documented in sub-Saharan Africa.<sup>3</sup> However, increasing mortality associated with noncommunicable diseases has brought a new challenge to the region. Two-thirds of global deaths each year are attributable to noncommunicable diseases, and four-fifths of these deaths occur in low- and middle-income countries.4 National South African mortality statistics for 2009 attribute deaths from diseases of the circulatory and the respiratory systems to be 14.7% and 13.1% of all deaths, respectively.<sup>5</sup> Statistics from the Western Cape Province attribute 31.2% (n = 12,392) of deaths in 2009 to cardiovascular and respiratory disorders and diabetes.<sup>6</sup>

The World Health Organization describes palliative care as an essential component of a public health system for those affected by life-limiting disease. <sup>1,7</sup> Palliative care services in South Africa have been well established over the past decade. Currently, about 60 organizations linked to a national nongovernmental association provide a range of services to patients and their families. Traditionally, services have focused mainly on addressing the end-of-life care needs of patients affected by cancer and HIV/AIDS. To date, there has been no dedicated palliative care program in public hospitals to address the growing end-of-life care needs of patients suffering from advanced organ failure.

The course of malignant disease can often be predicted and timely referral made for palliative care. However, in all regions of the world, patients with chronic diseases such as heart failure or chronic obstructive pulmonary disease pose great prognostic uncertainty for the attending health professional.<sup>16</sup> The classic trajectory of slow decline over years with scattered episodes of deterioration and improvement caused by acute exacerbations makes it difficult to predict death and initiate timely palliative management.<sup>17</sup> The lack of advanced directives and good education for patients with organ failure causes them become part of a "revolving door" cycle, with recurrent acute hospital admissions and frequent emergency unit visits. Patients often die suddenly with little warning, away from home and their loved ones, and the process of dying causes great psychological distress for the patient and their family.

The impact of the lack of palliative care services for this patient group not only has negative consequences on the quality of care the patient receives but also on the strained South African health care system. Frequent and prolonged hospital visits place an increased demand on scarce resources and are a major cost driver. Providing appropriate and timely end-of-life care can account for significant cost savings. Internationally, the benefits of palliative care programs in containing costs have been demonstrated. 18-22 A single African evaluation of costs to deliver palliative care from a hospital-based service found home outreach palliative care consultations to be less costly than hospital-based appointments.<sup>23</sup> Although a high proportion of hospital inpatients in Africa have life-limiting disease and, therefore, would benefit from palliative care,<sup>24</sup> hospital-based models are rare.

Given the situation of scarce resources, and the burden of patients affected with advanced organ failure, a public hospital in Cape Town developed a novel outpatient-based palliative care service that aims to improve quality of patient care, save hospital costs by reducing admissions, and allow for home death. This study aimed to conduct an evaluation of a novel hospital-based palliative care service for patients with advanced organ failure, in terms of admissions, place of death, and formal costs over a fixed period of time until death.

#### Methods

### Study Design

This study used existing routine data to compare patients recruited into the novel intervention to a historical control group of patients before the service introduction (i.e., comparison to best previously available care).

#### Setting

The service is delivered in a public district hospital in Cape Town, South Africa. It currently provides coverage for around 600,000 uninsured people. The hospital has 158 beds, and of these, 56 are medical.

#### The Intervention

The objectives of the novel palliative care service (known as "Abundant Life") are to control physical and psychological symptoms, reduce the number of admissions and enhance continuity of care, reduce costs, provide education and support to the family, and promote achievement of home death. The service comprises a weekly outpatient group clinic and a multidisciplinary clinical team.

The outpatient group clinic is attended by both patients and their families, and the group is facilitated to enable family groups to interact and provide support to each other. Three sessions are structured as follows: In Week 1, the physician, offers explanation of the disease, palliative care, and symptom management. Each family is given a disease-specific information pamphlet, with contact numbers for further queries. Following group discussion, patients and their families are organized into groups by diagnosis. Week 2 provides physiotherapy and occupational therapy training, aiming to enhance patient autonomy in the home, and alleviating the stress of the family caregivers. The third session provides social work guidance on welfare benefits and pensions and offers spiritual counseling. Following each weekly session, patients can be assessed by the clinical team, and a psychologist is available for counseling.

The clinic is run on a multidisciplinary team model. The nurse project coordinator counsels

and educates patients and families about the disease and prognosis, particularly focusing on assisting them to understand information given to them by their medical consultant. The coordinator also provides practical advice to the family to help them prepare for the death of their loved one, and simple advice on food preparation and nutrition, coping with patient breathlessness, fluid restriction where appropriate, and assisting the patient and caregiver to share their emotional concerns with each other. The coordinator is also available by phone and in person during office hours. Weekly telephone calls are made to patients to identify those who require follow-up visits. The team physician reviews patient files to make recommendations regarding medical management, attends clinic, and manages end-stage patients. Because of the poor socioeconomic status of the majority of the patient population, a social worker manages social and emotional problems and coordinates care within available resources, with an emphasis on expediting discharge. Physiotherapy assists with chest problems, mobilization, and family training to improve the symptoms at home. The occupational therapist assesses the functionality of patients and provides them with aids for patient independence. Work assessments also are conducted for patients, and recommendations are made to employers. A dietician is available for nutritional advice.

#### Admission Criteria

The admission criteria for entry into the program are shown in Table 1.

#### Sampling

All consecutive patients who had received the palliative care intervention during its first year of delivery and were deceased (n=56) were compared with a control group of consecutive patients (n=48) who had died at the time of the introduction of the new service but met the intervention inclusion criteria in Table 1. The control group consisted of consecutive most recent deaths. The study was conducted in 2011, 12 months after the introduction of the new service. Data were extracted for a period of 2.5 months for both groups, as this was the average length of time under the novel palliative care service.

# Table 1 Admission Criteria

- 1. Advanced Neurological Illness
  - Evidence of advanced motor neuron disease, multiple sclerosis, etc.
    - i. Immobile
    - ii. Requiring assistance with all daily living activities
    - iii. Declining nutritional status
    - iv. Dyspnea
    - v. Medical complications, e.g., pneumonia, sepsis, etc.
  - Shortened prognosis as recognized by a primary care provider
- 2. Pulmonary Disease: COPD, ILD
  - a. Evidence of advanced illness
    - i. Dyspnea at rest
    - ii. Recurrent pulmonary infections
    - iii. Declining functional status
- 3. Cardiac Disease: CCF
  - a. Evidence of advanced illness
    - i. Discomfort with minimal physical activity
    - ii. Symptomatic despite maximal medical management
- 4. End-Stage Hepatic Disease
  - a. Evidence of advanced illness
    - i. Dyspnea at rest
    - ii. Discomfort with physical activity
    - iii. Abdominal ascites irreversible
- 5. End-Stage Renal Disease: CRF, CKD
  - a. Stage 5 Chronic Kidney Disease (GFR <15)
  - b. Evidence of advanced illness
    - i. Not appropriate candidate for dialysis or transplant
    - ii. Confusion and uremic states (pericarditis, gastritis, anasarca)

This provides a fixed, directly comparable time period to extract data for the control group. Sample size calculations were conducted for each of the endpoints. For admissions, to detect a reduction from 98% to 75% in the proportion of patients with at least one admission, with 90% power at a 5% significance level, 90 patients were required. For number of days spent admitted, for a 50% reduction (from a mean of 9.31 days to 4.5 days), with 90% power at a 5% significance level, 98 patients were required. For proportion of home deaths, to increase from 20% to 50%, with 90% power at a 5% significance level, 90 patients were required in total.

#### Data Collection

The following variables were extracted from routine patient records for the period: age, gender, primary terminal diagnosis, number of hospital admissions, length per stay in days, and place of death (home vs. institution). Hospital admission costs were determined by use of standard economic costing represented by the South African patient daily expense method calculation of R1039 (South African

Rand; \$130) per patient per bed day. This includes direct and indirect costs.

#### Statistical Analysis

The demographic characteristics of the two groups were presented using descriptive statistics and compared using parametric and non-parametric tests as appropriate. The comorbidities of the intervention and control groups were tabulated.

#### Ethics

The study was approved by the Hospice Palliative Care Association of South Africa Ethics Committee (reference 04/12).

#### Results

#### Sample Characteristics

The mean age of the intervention patients was 65.3 years (median = 65, SD = 13.4, interquartile range = 22.8, 54–76.8) and of control patients was 68.7 years (median = 71, SD = 11.0, interquartile range = 17.7, 58.3–76.0) (t = 1.38, P = 0.170). Among intervention patients, the majority were male (n = 32; 57.1%), and among the control patients, the majority were female (n = 31; 64.6%) ( $x^2 = 4.90$ ; P = 0.027).

The primary progressive diagnoses are shown in Table 2. It is notable that 34 of the 56 intervention patients and 27 of the 48 control patients had a comorbid diagnosis of diabetes, and eight of the 56 intervention patients and 17 of the 48 control patients had a comorbid diagnosis of hypertension. As there was a difference in the proportion of men and women between the two groups, we controlled for gender in the analysis of the place of death outcome by using the Mantel-Haenszel test for place of death and analysis of covariance (ANCOVA) for the continuous outcome variables (mean number of admissions, total number of days admitted, and mean length of admissions).

#### Admissions

The proportion of patients in the control group with at least one admission (n=47 of 48, 97.9%) was higher than in the intervention arm (n=40 of 56, 71.4%) (Fisher's exact test, P<0.001). Controlling for gender, the

Table 2
Patient Primary Progressive Diagnoses

Primary Progressive Diagnosis	Intervention Group $(n = 56)$	Control Group $(n = 48)$
Cardiovascular disease	4	1
Cardiac failure	10	20
Respiratory disease	9	3
Renal failure	10	5
Cardiac failure and respiratory disease	8	10
Cardiac failure and renal failure and respiratory disease	2	1
Renal failure and cardiac failure	9	6
Renal failure and cardiovascular disease	3	1
Cancer	1	
Cancer and cardiovascular disease		1

contingency table of admission by group showed a significant difference in place of death for the intervention and control groups (Mantel-Haenszel  $\chi^2=13.724, P<0.001$ ). The Breslow-Day test for homogeneity of odds according to gender showed no significant difference ( $\chi^2=0.635; P=0.426$ ).

The mean number of admissions for the control group was 1.98 and was lower for the intervention group (1.39, Mann Whitney  $U=798.00,\,P<0.001$ ). Controlling for gender, in a two-way univariate ANCOVA, with gender added to group as a fixed factor, gender was not significant (F = 0.027, P=0.871), but group was significant (F = 8.5, P=0.004). The model was significant (F = 3.47, P=0.019).

The mean total number of days spent admitted was 9.3 days for the control group and was lower at 4.52 days for the intervention group (4.0 days, Mann Whitney U=707.00, P<0.001). Controlling for gender in a two-way univariate ANCOVA, gender was not significant (F = 0.087, P=0.768) but group allocation remained significant (F = 14.7, P<0.001). The corrected model was significant (F = 6.4, P=0.001).

For each admission, the mean length of days per admission was 4.7 days for the control group and was lower, that is, 3.5 days, for the intervention group (Mann Whitney U=814, P=0.001). Controlling for gender in a two-way univariate ANCOVA, gender was not significant (F = 179.3, P<0.001) but group allocation remained significant (F = 8.5, P=0.004). The corrected model was significant (F = 8.5, P=0.004).

#### Costs

For the 56 intervention group patients, a total of 253 admission days were recorded at a mean

of 4.52 days per patient, for a formal cost of R4696 per patient. For the 48 control patients, a total of 447 admission days were recorded, resulting in a formal cost of R9673 per patient.

The admission bed day formal costs per patient over the study period were, therefore, a mean of R4977 lower per patient for the intervention patients compared with the controls.

#### Place of Death

For the intervention group, 33 of 56 (58.9%) patients achieved a home death, and for the historical controls, nine of 48 (18.8%) patients died at home (Fisher's exact test  $P \leq 0.001$ ). Controlling for gender in the contingency table (place of death by group controlling for gender), there was no difference in the odds of dying at home according to gender (Breslow-Day test, P = 0.426).

#### **Discussion**

In the context of limited resources and a high prevalence of progressive disease, sub-Saharan Africa requires cost-effective palliative and end-of-life care for its population. This is the first study from the region to report a novel service for patients with advanced organ failure, or to describe outcomes in terms of admissions and place of death. Compared with prior best available care, the new service achieved greater rates of home death, fewer admissions, and fewer total days spent in admissions for this population with high rates of comorbidity.

There are a number of further considerations and limitations to our data. First, although the comparison found lower admission formal costs, further study would need to take account of service costs (including

clinical time and administration) and informal costs of care. Additional costs include the salary of a palliative care-trained nurse, educating the staff with inservice training for all medical doctors, and, when necessary, medical consultant-led ward rounds. With respect to costs, as the evaluation was conducted from service launch, we would anticipate a learning effect (i.e., an improvement in service performance), and the number of patients being referred to the novel service has since increased greatly. The learning effect and enhanced economies of scale may contribute to improved cost savings. The comorbid nature of this population makes it difficult to determine whether the patient profile was different under the new service compared with patients who died before its introduction, that is, whether the service potentially took more or less complex cases than those identified as controls. The common problem of late referral to palliative care also may have introduced bias; therefore, we compared a fixed time period (i.e., 2.5 months under care before death). There also may be a seasonal effect on death that we have not been able to control for, and we cannot compare the performance status of the two groups, survival or time since diagnosis. Our comparison is of admissions, place of death, and formal costs over a fixed period of time. We are not aware of any concurrent palliative care service developments in the locality during the period of study.

The model takes the standard palliative care approach, that is, patient- and family-based multidimensional care addressing physical, psychological, social, and spiritual problems and delivers a model that is appropriate to sub-Saharan African settings. Community and family participation are strongly evident in African societies in comparison with individualistic societies. The weekly family sessions are well attended and may be an active ingredient in successful home death and lower admissions. Further prospective process and outcome research is needed to determine whether patient self-report outcomes are enhanced under this intervention, and to identify the informal support needs of family caregivers. Data also are needed to understand the relative costs of advanced HIV standard and palliative care, where cost drivers

such as lab services and antiretroviral treatment are relevant. Further study also is required in other sub-Saharan African countries with different health systems.

The study design may have led to a referral bias in that once the service was initiated it may have received referrals from clinicians for those patients with worst health status and who had the most complex problems to manage. Such a bias may cause an underestimation of the intervention effect on outcomes. Conversely, an overestimation may have been caused by those with greatest interest in receiving the novel intervention electing to enroll.

This novel study provides first data from sub-Saharan Africa on hospital admissions and place of death under palliative care and also the first to describe and evaluate a palliative care service for patients suffering from advanced organ failure. Our findings add to the growing body of evidence that palliative care can reduce costs at the end of life and offer important data to guide provision of appropriate care in resource poor settings with high burden of disease.

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