

Challenges in the provision of palliative care at resource-limited South African hospice settings

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Abstract

Palliative care and pain management is one of the most important challenges faced by resource-limited settings in Africa. In South Africa, the need for palliative care has increased with the growing Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) pandemic. A quantitative and descriptive study was conducted at five resource-limited hospice settings for the purpose of investigating the provision of palliative care and pain management, from the perspectives and experience of patients, family carers and palliative care workers. The validated African Palliative Care Association African Palliative Outcome Scale (APCA African POS) was used in structured interviews with 50 patients and 41 family carers, to measure pain experienced and quality of care received. Structured interviews were also conducted with 12 palliative care workers to identify challenges experienced by the hospice in the provision of palliative care and effective pain management. When using the APCA African POS to measure pain, 82% of the patients suffered moderate to very severe pain indicating that pain management was neither adequate nor appropriate. Family carers being worried about the patient correlated with the level of pain experienced by patients. Key challenges to effective provision of palliative care included lack of access to appropriate analgesics, adequately trained health professionals in effective pain management and palliative care and limited human and physical resources. Recommendations offered to overcome these challenges are essential and require action by the management of these facilities.

Keywords: APCA African POS, palliative care, resource-limited, hospice.

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Introduction

Resource-limited settings in Africa face challenges of access to palliative care and pain management. Several African countries have limited access to pain

medication, poor health care infrastructure, lack of health care workers who are properly trained in palliative care and lack of national policies for pain and symptom management (Consultation on Pain and Palliative Care in Resource-Limited Settings, 2009). Furthermore, factors such as poorly functioning medicine supply systems, unnecessarily restrictive legislation and fear amongst health care workers for legal sanctions of opioids have also been identified as barriers to effective palliative care and pain treatment (Human Rights Watch, 2011).

In South Africa, the need for palliative care has increased with the growing Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) pandemic (Gwyther, 2006). The availability and accessibility of well-resourced palliative care hospice settings are also limited. According to a review by Clark, Wright, Hunt and Lynch (2007), 37 of the 76 hospice and palliative care organisations in South Africa, make provision for in-patient hospice services. It is estimated that the vast majority of HIV positive patients (96%) and more than 70% of cancer patients in South Africa experience moderate to severe pain during the course of their disease, because they do not have access to affordable and effective pain medication (Stassen, 2012).

The African Palliative Care Association African Palliative Outcome Scale (APCA African POS) is a multidimensional scale that has been validated in five palliative care sites - four in South Africa and one in Uganda. These sites were based in rural, peri-rural and urban areas and included homecare, day care and inpatient facilities. Evidence indicated that the APCA African POS has good psychometric properties, is well comprehended and is quick to use, which makes it ideal for use amongst African patients and families affected by life-threatening diseases. Since the validation of the APCA African POS as a quality improvement tool, it has been used by hospices in South Africa and established to be valuable in terms of identifying areas requiring quality improvement activities (Harding, Selman, Agupio, Dina et al., 2010).

Taylor, Gostin and Pagonis (2008) highlighted that appropriate pain treatment and access to pain medication are both essential in palliative care and should be prioritised as a public health matter, from a national and global perspective. They emphasised the fact that if this is not done, an escalating proportion of the world's population will continue to live with pain and furthermore die in pain, which is not necessary. The aim of this study was to investigate the provision of palliative care and pain management, from the perspective and experience of patients, family carers and palliative care workers, at under-resourced South African hospice settings.

Methodology

In the context of this study, a palliative care worker refers to both nurses and registered nurses or medical practitioner providing care to the patient at the hospice setting during the time of the study.

Study design and study sites

A cross-sectional descriptive study was conducted at five resource-limited hospice settings in the vicinity of the University of Limpopo (Medunsa Campus), South Africa. All the hospices were located within the different communities, where they are easily accessible. At the time of the study, the capacity to accommodate patients at the hospices ranged from 10 to 28 beds. Details about the study sites are provided in Table 1.

Table 1: Study sites in the vicinity of Medunsa Campus, University of Limpopo

Hospice	Province	Type of area	Bed capacity	Number of palliative care workers
Hospice A	North West	Rural	10	3
Hospice B	Gauteng	Peri-urban	12	2
Hospice C	Gauteng	Peri-urban	10	2
Hospice D	North West	Rural	28	3
Hospice E	Gauteng	Peri-urban	10	2

Study population and sample

The study population included all patients receiving palliative care at the five hospices, each patient's family carer and the palliative care workers at the hospices. Exclusion criteria were participants not willing to participate and provide informed consent and participants who had been interviewed on a previous visit during the study period. The final sample included 50 patients (≥ 18 years of age) admitted at the hospice, 41 family carers and 12 palliative care workers involved in patient care at the hospice. Fewer family carers (41) than patients (50) were interviewed because nine patients had passed away, by the time of the family carer interview. The deceased patients' family carers were therefore not included in the study.

Data collection process and instruments

Data collection took place over a period of eight months (October 2012 to July 2013) in two to three cycles, i.e. each hospice was visited twice to thrice during the study period. Patients and family carers were interviewed individually, with a structured questionnaire to determine the quality of care received and the pain experienced by the patient. All the interviews were conducted privately, face-to-face and by the same field worker.

Responses were recorded by the field worker on an individual questionnaire for each participant. The questionnaire included demographic information in addition to the validated APCA African POS (Harding et al., 2010), and was available in English and Setswana, the most common languages spoken in the area. The APCA African POS consists of ten questions of which the first seven are directed to patients while the last three questions are meant for family care givers. Responses to all questions are scored using a 6-point Likert scale ranging from 0-5, with numerical and descriptive labels available (Collins & Harding, 2007). For example, if the question is to determine whether the patient has been feeling worried over the past three days, the scale would be as follows: 0 = Not worried at all; 1 = Worried occasionally; 2 = Worried some of the time; 3 = Worried a lot of the time; 4 = Worried most of the time; 5 = Worried all the time.

Patients' records were reviewed to identify and record patients' pain medication, which was prescribed for each individual patient by the medical practitioner or registered nurse at the hospital or clinic, and subsequently brought to the hospice by the patient on admission. A palliative care worker questionnaire was designed based on practice experience, discussion with experts and consideration of the literature (Elcigil, Maltepe, Eşrefgil & Mutafoğlu, 2011). Questions addressed issues related to pain treatment, management of medicines and palliative care worker experience in terms of the provision of palliative care.

Reliability and validity

The APCA African POS, which was used in the patient and family carer interviews, was validated in African settings and therefore served as a reliable tool to use for this study (Harding *et al.*, 2010). A pilot study was conducted prior to the commencement of the actual study, to verify the data collection procedures and ensure the reliability and validity of the data collection instruments. All the interviews were done by the same field worker, who was trained in interview techniques and the administration of the APCA African POS, to ensure reliable data collection.

Ethical considerations

Ethical clearance for the study was granted by the University of Limpopo (Medunsa Campus) Research and Ethics Committee (Clearance number: MREC/H/106/2012:PG) prior to the commencement of the study. Permission to conduct the study at the different hospices was obtained from the respective hospice managers. Participation in the study was voluntary and participants had the right to withdraw from the study at any time without explanation.

Participants provided written informed consent, and all information remained anonymous and confidential.

Data analysis

Data were analysed using IBM Statistical Package for the Social Sciences (SPSS®) V21.0. Descriptive statistics were used to summarise demographic data. Patients' and family carers' responses to the questions on the APCA African POS were calculated by frequencies and percentages for each point on the scale. A mean score with standard deviation for all respondents was then calculated for each of the questions. Certain scores on the APCA African POS were reversed for analysis and comparison purposes, which means that the lower the score, the better the outcome against the question asked and the higher the score, the more severe the outcome. Patient and family carer responses were compared using Spearman's correlation, with $p \leq 0.05$ regarded as statistically significant. Responses to the palliative care worker questionnaire were grouped and categorised to aid analysis.

Results

Socio-demographic and disease characteristics

The socio-demographic and disease characteristics of the patients and family carers are summarised in Table 2, which indicates that just more than half of the patients were female (52%; $n=50$). Slightly more males (51%; $n=41$) than females were responsible for taking care of their family members.

Table 2: Socio-demographic and disease characteristics

Characteristics		Patients ($n=50$)		Family carers ($n=41$)	
		Frequency	%	Frequency	%
Gender	Male	24	48	21	51
	Female	26	52	20	49
Age categories (years)	18-30	2	4	4	10
	31-45	9	18	11	27
	45-60	23	46	17	41
	>60	16	32	9	22
Employment status	Employed	8	16	24	59
	Unemployed	40	80	14	34
	Self-employed	2	4	3	7
Patient diagnosis	HIV with/without TB	29	58	NA	NA
	Cancer	5	10	NA	NA
	Other	15	30	NA	NA
	Not specified	1	2	NA	NA

Characteristics		Patients (n=50)		Family carers (n=41)	
		Frequency	%	Frequency	%
Relationship with patient	Spouse	NA	NA	4	10
	Child	NA	NA	2	5
	Brother, sister, in-laws	NA	NA	24	59
	Friend	NA	NA	1	2

NA: Not applicable.

Care provided to patients and family carers

The APCA African POS was used to assess the quality of care provided to patients, considering the needs of the patients and their family carers. Table 3 shows the percentages for the scores on a 6-point Likert scale for each item on the APCA African POS.

Table 3: Percentages for each item on the APCA African POS for patients and family carers

Respondents	APCA African POS items	APCA African POS scale*					
		Positive ←→ Negative					
		0	1	2	3	4	5
		Percentages (%)					
Patients (n=50)	Pain rate (from 0 = no pain to 5 = worst/overwhelming pain) during the last 3 days	6	6	6	38	30	14
	Feelings being affected by any other symptoms in the last 3 days	16	8	4	28	26	18
	Feeling worried about illness in the past 3 days	8	10	14	32	22	14
	Being able to share feelings with family and friends over the past 3 days	56	8	12	16	2	6
	Felt that life is worthwhile over the past 3 days	48	18	14	8	6	6
	Felt at peace over the past 3 days	18	6	28	28	12	8
	Had enough help and advice for family to plan for the future	56	6	16	10	2	10
Family carers (n=41)	Information given to family members	81	17	0	2	0	0
	Confidence in caring for the patient	0	0	12	37	32	19
	Family been feeling worried about the client over the last 3 days	7	15	22	41	5	10

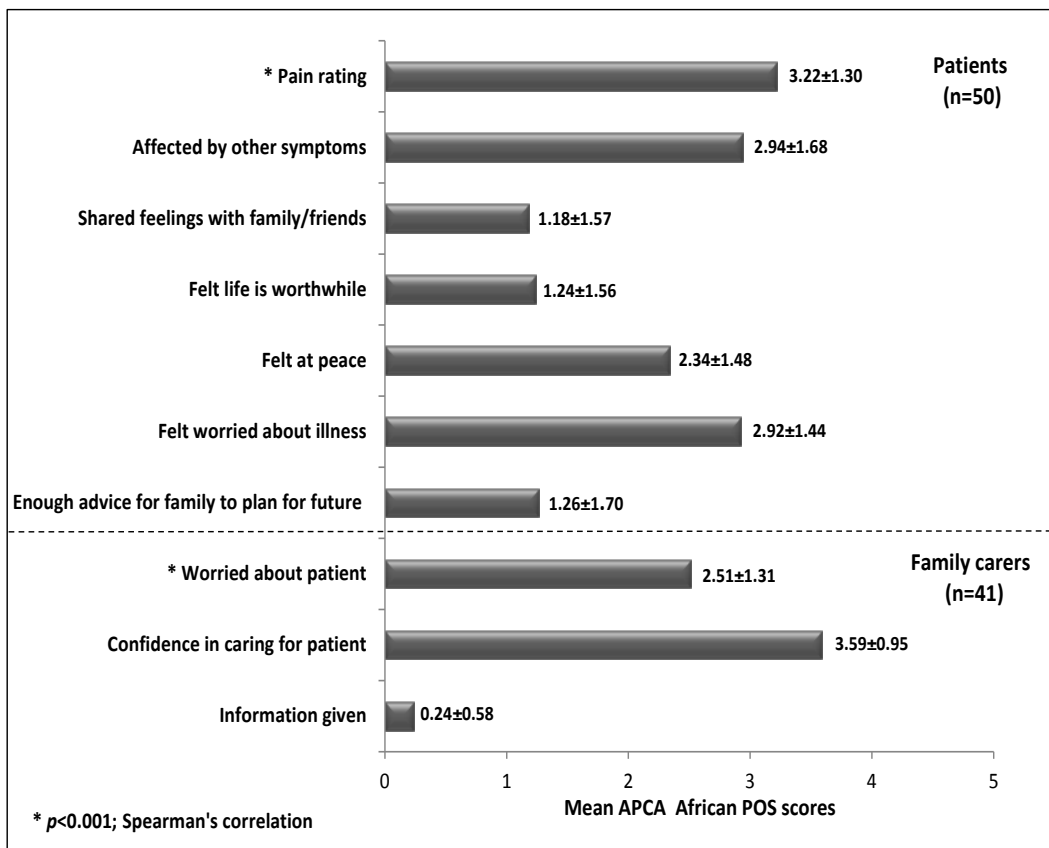
*Lower APCA POS score: better / positive outcome; Higher APCA POS score: more severe / negative outcome

From the APCA African POS scores, it was evident that the majority (82%; 41; n=50) of patients experienced moderate to very severe pain (pain rate: 3-5). Only

three patients (6%; 3; n=50) indicated that they were not experiencing any pain; two of these patients were primarily diagnosed with HIV (with one of the two patients suffering from concomitant tuberculosis) and the third patient was diagnosed with epilepsy. A review of patients' records indicated that 50% (25; n=50) of all patients were not on any form of analgesic treatment. The majority of the patients who were on an analgesic (20; 80%; n=25) were on a non-opioid analgesic (aspirin, ibuprofen or paracetamol).

Only five patients (20%; n=25) were on a weak opioid (codeine phosphate or hydrocodone), while none of the patients were on a strong opioid.

Mean scores and standard deviations for each item on the APCA African POS are depicted in Figure 1.



Note: Lower APCA POS score: better / positive outcome; Higher APCA POS score: more severe / negative outcome

Figure 1: Mean APCA African POS scores for patients (n=50) and family carers (n=41)

Mean scores on the APCA African POS indicated that many of the patients suffered severe pain (3.22±1.3). They have been affected by severe symptoms which interfered with their daily activities (2.94±1.68) which may include coughing, constipation, dyspnoea, etc. It was evident that patients have been worried about their illness a lot of the time (2.92±1.44). On the other hand, patients reported that they have often been able to share their feelings with family and friends (1.18±1.57) and they have had sufficient help and advice to plan for the future (1.26±1.70). Overall patients indicated that they felt that life was worthwhile ‘some of the time’ to ‘most of the time’ (1.24±1.56).

The majority (81%; n=41) of the family carers indicated that they were given as much information as they needed about the type of care provided to the patient at the hospice.

Confidence amongst the family carers, in their own ability to care for the patient themselves, was not very positive (3.59±0.95). When the responses of the family carers were compared with those of the patients, the results showed that there was a positive correlation between the patients’ level of pain experienced and the family carers being worried about the patient (Spearman’s correlation; $p < 0.001$). None of the other correlations were significant.

Availability of resources for care and pain management

Table 4 provides a summary of the resources available at each of the hospices in terms of human resources, palliative care training, pain medication and pain management guidelines. The qualifications of the nurses at the hospices (n=11) included auxiliary nurses (3), enrolled nurses (2) and professional nurses (6). Only one of the five hospices offered formal training to their palliative care workers. However, nurses at all of the hospices received some form of in-house palliative care training. Only one hospice had a visiting doctor.

Table 4: Resources for care and pain management at the hospices according to palliative care workers interviewed (n=12)

Indicators	Hospice				
	A	B	C	D	E
Number of palliative care workers interviewed	3	3	2	2	2
All nurses received in-house palliative care training	Yes	Yes	Yes	Yes	Yes
All nurses received formal palliative care training	No	Yes	No	No	No
Visiting doctor	No	Yes	No	No	No
Availability of pain medication (non- and weak opioids)	No	Yes	No	No	No
Availability of strong opioids (Schedule 5 & 6 pain medication)	No	No	No	No	No
Medicines elevated from the floor	Yes	Yes	Yes	Yes	Yes

Indicators	Hospice				
	A	B	C	D	E
Medicines kept in a locked cupboard	No	Yes	No	No	No
Temperature in medicine room monitored	No	No	No	No	No
Availability of pain management guidelines	Yes	Yes	No	Yes	No
Adequate knowledge to assess pain	Yes	Yes	Yes	Yes	Yes
Adequately trained on pain management	No	No	No	No	No

Only one of the five hospices kept pain medication in stock, which ranged from non-opioids to weak opioids. None of the hospices kept strong opioids, which are classified as Schedule 5 and Schedule 6 analgesics. The following reasons were provided for not keeping analgesics in stock at the facilities:

Patients bring their own medication when admitted

- Patients are administered the medication prescribed for them by the hospital or clinic, which is often not appropriate
- No medical practitioner available to prescribe scheduled pain medication
- No pharmacist at the hospice to manage Schedule 5 and 6 medicines
- Insufficient space and infrastructure to keep medication in bulk
- Insufficient funds to procure medicines

At all five hospices, the medicines which patients brought with them to the hospice on admission, were kept in separate containers in a medicine trolley. Administration of medication was done by the registered nurses in all of the hospices. Four hospices had no policy for administering pain medication when needed by the patient.

Discussion

This study highlights the challenges experienced in rendering palliative care in resource limited settings. From the results it was apparent that service provision at the five hospice-settings was not limited to patients with life threatening conditions only. The diagnosis-related distribution of patients in these hospices showed a different picture compared to what is normally observed at hospices in developed countries. Only 10% of the patients were diagnosed specifically with cancer. The majority of the patients (58%) were HIV positive with or without TB co-infection. Almost a third of the patients were admitted specifically with chronic conditions such as diabetes, epilepsy, hypertension and depression, which normally do not require palliative care. Evidently the latter group of patients required palliative care although their conditions were not life-threatening as such. According to literature, non-communicable diseases, mainly

cardiovascular diseases, cancer, chronic respiratory diseases and diabetes, account for 36 million or 63% of global deaths. Nearly 80% of these deaths occur in low- and middle- income countries (Traue & Ross, 2005; WHO, 2010). Palliative care could benefit many of these people and yet it is often not available.

The availability and accessibility of pain medication at the hospices was a problem. The pain rating on the APCA African POS indicated that the majority of patients suffered moderate to severe pain.

According to the WHO pain ladder guidelines, moderate to severe pain should be treated with an opioid analgesic (WHO, 2002), but none of the patients were on a strong opioid analgesic. Only one of the five hospices kept pain medication in stock, which ranged from non-opioids to weak opioids. None of the hospices kept strong opioids, classified as Schedule 5 and Schedule 6 medicines and regulated in South Africa by the Medicines and Related Substances Control Act, No.101 of 1965 (South Africa, 1965).

According to these regulations, all Schedule 5 and Schedule 6 medicines must be recorded in a register every time it is issued to a patient (South African Pharmacy Council, 2010).

A pain scale is recommended to rate and monitor patients' pain and guide pain treatment (Harding et al., 2010). All palliative care workers reported that they have adequate knowledge regarding the *assessment of pain*, which was also evident from the explanations provided on how pain is assessed, using different techniques. A pain scale was used at all the hospices to rate the patients' pain but it was not used to guide the patients' analgesic treatment. Conversely, none of the palliative care workers were adequately trained in the *management of pain* and pain management guidelines were available for use at only two hospices. All the hospices had nurses providing care, while only one hospice had a visiting medical practitioner.

From the family carer interviews it was evident that they were worried about the patients who were experiencing more severe pain. Responses of family carers about the extent of being worried concerning the patient, showed a positive correlation with the patients' level of pain experienced. Average APCA African POS scores for all patients indicated that although patients received palliative care, they were still affected by severe symptoms, worried a lot of the time and felt at peace only some of the time. It was noticeable that patients agreed that they felt life was worthwhile for them, 'some of the time' to 'most of the time', which indicated the value of the care they received.

Limitations

The study had some limitations in terms of sample size. The sample was limited by the number of patients at the hospices. Data could be collected at only one hospice at a time, which stemmed from the fact that all the data were collected by only one person, which subsequently affected the sample size. Most of the hospices did not have an adequate number of palliative care workers, which explains the small number of palliative care workers interviewed. This also affected the sample of patients included in the study, as most of the hospices did not have enough resources and appropriate infrastructure to accommodate a large number of patients.

Recommendations

Recommendations based on the results of this study include regular assessment and monitoring of patients' pain and care received with the APCA African POS, availability of appropriate analgesics at the hospices, human resources in the form of a medical practitioner to do clinical rounds and prescribe appropriate pain medication, and the services of a pharmacist for management of medicines and compliance with legislation. Additional training of palliative care workers on effective pain management and palliative care is essential.

Conclusion

The majority of the patients suffered moderate to severe pain and were not managed accordingly. None of the hospices had access to appropriate medication to manage the severity of the pain experienced by the patients. Key challenges to effective palliative care and pain relief identified by this study were the lack of access to appropriate analgesics, lack of training of health professionals in effective pain management and palliative care and limited resources. Recommendations offered to overcome these challenges are essential and require action by the management of these facilities. Effective strategies to achieve good palliative care of suffering patients should be developed and implemented as a priority.

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