

Impact of the APCA African Palliative care Outcome Scale (POS) on care and practice

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Introduction

Palliative care is defined by the World Health Organisation (WHO) as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patients illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”¹*

The WHO has related definitions of palliative care for people with HIV/AIDS and for children, addressing the role of palliative care from diagnosis during the course of HIV and the particular needs of children.

Palliative care, though well established in the developed world, is only accessed by a small proportion of those who need it. It is estimated that 80% of the world’s population live in countries with no or low access to treatment for moderate to severe pain². 42% of countries have no identified hospice and palliative care services³. 99% of people living with HIV and cancer with untreated pain are in the developing world⁴.

In sub-Saharan Africa, palliative care, though growing fast as a discipline, is still relatively in its infancy, with patchy coverage except in South Africa. One problem for palliative care practitioners is assessing the needs of patients. Palliative care is holistic care: that is it aims, as the WHO definition says, to deal

¹ WHO 2012

² WHO

³ World Palliative Care Alliance (WPCA) 2011

⁴ Global Access to Pain Relief Initiative (GAPRI) 2009 data

not only with physical pain and symptoms but also with psychological and spiritual care and with the needs of the family as well as the patient. Assessment of such wide needs, and having evidence that interventions work, is difficult and the POS was developed to enable this to happen effectively.

Scope of the report

This report does not cover use of the POS in all African countries. It concentrates on three countries; Kenya, South Africa and Uganda, but also gives examples of its use in other sub-Saharan countries (Botswana, Malawi, Namibia, Tanzania and Zimbabwe). Its primary focus is on the impact of the POS on clinical care, patient experience and services, The POS has also been used for research and a few examples of this are given in Appendix 2. The information has been gathered through phone interviews and email exchanges with palliative care practitioners in sub-Saharan Africa. Patients were not contacted for ethical reasons.

Origin of the Palliative Care Outcome Scale (POS)

The POS was developed in 1999 by Professor Irene Higginson, Head of the Department of Palliative Care and Director of Cicely Saunders Institute, King's College London and colleagues, for use with patients with advanced disease and to improve outcome measurement by evaluating many essential and important outcomes in palliative care. The Support Team Assessment Schedule (STAS), developed in 1986, was the precursor to POS. STAS was constructed to evaluate the work of palliative care support teams and consisted of 17 items, to be rated from 0 (best) to 4 (worst) by a professional caring for the patient.

The POS builds on some of the strengths of the STAS, such as clinical application and ease of use. Importantly, it also allows patients to use POS themselves. POS is therefore a patient reported outcome measure when the patient version of it is used. POS has demonstrated construct validity acceptable test/re-test reliability for seven items, and good internal consistency. POS takes less than 10 minutes to complete by staff or patients.

The African Palliative Care Association (APCA) African Palliative care Outcome Scale (POS)

The APCA POS was adapted for African use from the original POS, through a multi-dimensional and team process, led by Dr Richard Harding of King's College Department of Palliative Care, in close collaboration with APCA. It was piloted in 11 sites in 8 Eastern and Southern African countries: Botswana, Kenya, Malawi, South Africa, Tanzania, Uganda, Zambia and Zimbabwe. It was validated across 5 African services.

The POS has 10 questions, addressing the physical and psychological symptoms, spiritual, practical and emotional concerns and psychosocial needs of the patient and family. Questions 1-7 are directed at patients; questions 8-10 are directed at family and other informal caregivers. Although all answers are self-reported by patients and families, the responses are recorded by staff because of low levels of literacy in some communities.

A paediatric APCA POS is in the final stages of validation.

The impact of the POS

As mentioned above, palliative care is in the early stages of development in sub-Saharan Africa. Providing palliative care faces many of the same problems as providing all health care: poverty; weak economies and health systems; a lack of healthcare professionals and, in many cases, patients living in isolated rural areas far from healthcare facilities and with poor transport facilities⁵. In addition, for those delivering palliative care, it is particularly challenging to assess very ill and vulnerable patients and to ensure that the full range of their needs is understood and addressed.

Against this difficult background the POS helps enable those delivering palliative care at home and in healthcare institutions to ensure that the patient and their family is getting the best care available. Because the POS asks simple, direct questions, repeated over a short period (ideally seven days), it enables the palliative care team to assess and adjust the care given quickly, while a more detailed analysis of results gives an overview of areas for improvement in service delivery.

The POS is mainly used by hospices and palliative care organizations and primarily as a tool for quality improvement and audit. It is most widely used by hospices in South Africa, where the Hospice and Palliative Care Association (HPCA) has promoted the POS and has an accreditation programme for hospices that requires, in the Quality Management and Improvement section, information from a validated patient/family satisfaction audit tool. An additional reason for its use is that South Africa has a number of passionate champions of the POS who promote its value.

However, the use of the POS is spreading outside specialist palliative care organisations and it is also being used in hospitals, for example Mulago Hospital in Kampala, Uganda, in at least one community-based HIV programme, Kicoshep in Kenya and by an INGO in Tanzania that is training health professionals in its use. In South Africa, HPCA has been working with the prison

⁵ -Sub Saharan Africa has 11 percent of the world's population, bears 25 percent of the disease burden in the world, but has only 3 percent of the world's trained health workers. Sub Saharan Africa has about 18 medical doctors for every 100,000 individuals (for comparison the United States has 270 per 100.000 population); Aid for Africa April 2012

service and is hoping to introduce the POS into this work. In addition it is being used increasingly in research and as a method of demonstrating value to donors. It is a powerful advocacy tool as it can demonstrate objectively improved outcomes for patients and families receiving palliative care. Kath Defillipi, a senior palliative care nurse in South Africa described the POS as “a precious asset for quality improvement in palliative care and an important tool in advocacy to government and donors.” In Kenya advocacy for palliative care to government has been particularly successful and the POS is part of the Palliative Care Guidelines, which are currently (Autumn 2012) going through Ministry of Health approval and which will form part of government policy.

The impact on care and treatment of the POS can be identified in two ways. The impact is direct, where the use of the POS by organisations delivering palliative care has led to improvements in the way the care is delivered and indirect, where use of the APCA POS as an advocacy tool or as part of research, demonstrates the value of palliative care and leads to greater general access to it.

Direct Impact

The use of the POS has a direct impact on: improving the quality of care through analysis of the data leading to changes in how the organisation delivers care; on the staff who deliver the care; on the composition and training of the staff teams and on the quality of life of the patients and their families.

One large-scale example of direct impact of using the POS on patient outcomes was a five-year programme (2005-2010) in South Africa, funded by the Canadian International Development Agency and managed by the Hospice Palliative Care Association (HPCA). This involved 50 hospices with home based care programmes using the APCA POS for quality improvement. Results were analysed by the University of Cape Town and showed statistically significant changes e.g. a reduction from 4 -1 in pain over six weeks and 4-1 in worry. In Tanzania the POS was again used originally for a programme funded by USAID. Dr Kristopher Hartwig, who formerly worked for the Lutheran Hospitals in Tanzania observed “[Finally], the data itself, having hundreds of people living with HIV and/or cancer being "measured" has given us valuable insight on the quality of care in these rural sites, especially during the time before they could access oral morphine” which is crucial to controlling pain. In Namibia, Catholic AIDS Action (CAA) worked with APCA to use the POS for setting quality improvement priorities in patient care. It was also used to evaluate the impact on patient and carer outcomes of training and integrating palliative care into home based care. Palliative care has now been integrated into 96 service sites and CAA describe the advantages on its website in this way “... dramatically increased the quality of care. There have been increased referrals to and from facility-based services (hospitals and clinics), more timely and efficient identification and treatment of opportunistic infections, including tuberculosis, improved pain assessment and pain management, improved integration of family

and caregivers into the care and support of the identified patient, and improved psychosocial support provided by the volunteers, particularly with discussing issues of death and dying.”

Impact on staff

An essential for good palliative care is a motivated staff team who fully understand their role, are well-trained and have a mix of appropriate professional backgrounds and skills. The POS impacts staff attitudes and understanding, identifies further training needs and can improve morale. One impact of using the POS is that it underlines for staff the holistic nature of the care they should provide and shows where this is not being achieved. As Estelle du Toit, Nursing Director, Matlosana Hospice South Africa commented “because they (hospice staff) had to ask the questions about physical, emotional and spiritual issues, they were really confronted with palliative care as holistic care” while Mercy Owiti (Nursing Officer, Nyeri Hospice Kenya noted “The POS covers (the) holistic approach of care,(and so) the objective of offering quality palliative care is achieved”. Where staff teams are overstretched, it is easy for them to burn out, for standards to slip and for the benefits of the work to seem doubtful. Use of the POS can improve morale and help prevent this. Phil di Sorbo, International Technical Advisor, Africa Hospice Initiative and closely involved with Island Hospice Zimbabwe believes that the POS “has given direct feedback and encouragement to staff that their work is effective, documenting, via a continent-wide accepted measure, that patient’s lives have been improved through their efforts.”

Use of the POS can also identify training needs of staff and a lack of particular professional skills. As a result of seeing from the POS analysis that pain control was better managed in patients under the care of nurses with a formal qualification in palliative care, one hospice in South Africa changed its policy so that all staff needed to be trained in palliative care within two years of joining the organization. Estcourt Hospice, KwaZulu Natal Province, South Africa, had determined that they could not afford a social worker for the team. Analysing POS data demonstrated that there were significant unmet psycho-social needs and employing a social worker became a priority. In resource-scarce settings ensuring optimal use of staff is essential. The Lighthouse Hospice, also in KwaZulu Natal, has used the results of the POS to change their policies on how they used professional nurses. In South Africa the needs of a palliative care patient are graded 1-3, with three being those in most need. As a result of the POS analysis, it was agreed that professional nurses should only do home based care visits to patients in categories two and three and senior care-givers trained to visit patients in category 1 (those capable of getting out and about)

Several organizations mentioned that use of the APCA POS had improved referral systems. At Verulam Hospice “(The POS) enabled the carer to measure the degree of the patient’s pain regularly. For pain control, patients were promptly referred to the interdisciplinary team, hospitals and doctors, thus

reducing the pain and giving comfort to the patients.” At Estcourt Hospice too, a problem surfaced with referrals between caregivers and professional staff and a formal referral system was introduced, with a referral document, that also reflects on the care plan.

Currently, most palliative care is delivered by organizations outside the government health systems, though there is considerable work being done to integrate it fully. At Mulago Hospital in Kampala, Uganda, a national referral and teaching hospital linked to Makerere University, the POS is being used as an integral part of the work of its developing palliative care unit. It is currently being used as a screening tool for all new patients referred to the palliative care unit. It is planned that will form part of the audit and link nurses on the wards at Mulago Hospital will be trained to use the POS as an assessment tool so there is a robust referral system to the palliative care unit and patients that need palliative care receive it.

Julia Downing, Honorary Professor at Makerere University and an international palliative care consultant notes that: “even at this early stage the POS has had an impact on care. It has helped the nurses to ask questions they would not otherwise have asked and to deal with issues that they have not dealt with before”

Patients and families

Several respondents noted that, although the APCA POS was useful to provide an overall perspective in how well their organizations were doing in delivering quality palliative care, it had as much, if not more impact on the care of individual patients and their families. One crucial example is the impact of effective pain relief. Analysis of the data obtained from the POS also had an impact in looking beyond the immediate clinical needs of the patient. Two examples of this were given by Estelle du Toit, who emphasized the importance in looking for the ‘back-story’ where there were significant irregularities in patient scores. When one patient’s high pain score, which lowered significantly in weeks 2 and 3 after palliative care intervention and then rose again in week 4 further investigation showed that the patient had been given a food parcel in week one which had run out in week 4 so the pain score related to anxiety about hunger. On another occasion a patient described themselves as being at peace and then significantly changing the score. The problem lay not with their medical condition but with a neighbour’s dog that was coming into her home and stealing the food. These two examples demonstrate both the difficulty of analysing patient needs in a holistic way and the benefits of careful analysis of the POS.

Palliative care embraces the needs of the carers and families of patients. Most of the organizations contacted said that analysis of POS data had uncovered unmet needs in this group, which they then addressed. For example, Catherine Aguoga, Senior Nurse at Nairobi Hospice said ‘Not only has the APCA POS helped improve record-keeping and audit but it has also identified areas of

treatment and care that need a greater focus. For example we have started a relatives' support group after analysing the POS showed us that many family members were suffering from burn-out" Estcourt Hospice's analysis of recent APCA POS data showed that the patient care was excellent but "There is still however, a huge gap to fill with the family members/ caregivers, as the target achieved there, this year, was only 60% this year...The family members/ caregivers are not always available when we do our visits,(either working, or at school) and therefore don't receive as much attention as our patients. This is an area we can focus on in the future".

There has also been impact in empowering carers and families to look after patients better. M. Naicker, a nurse at Verulam Hospice South Africa noted the added value of using the POS in home-based care visits: "The POS visits resulted in a better relationship between the patient and family and enhanced family support. Through education and counseling sessions all questions were truthfully answered and adequate information of the illness was imparted to both patient and family, therefore the patient and family were more knowledgeable and were equipped to cope with the illness"

Indirect impact of the POS

The POS has an important role in evaluation. For example, the former M&E manager, Chenjerai Sisimayai said of Island Hospice Zimbabwe, "The POS gave Island an opportunity to track progress at all levels of the organisation's results chain or theory of change, including the quality of care of caregivers and the quality of life of patients" Not only has focusing on patient outcomes become embedded in the culture of Island Hospice but it also demonstrates to donors, partners and beneficiaries the positive changes being made by palliative care provision. In the three sites of Hospice Africa Uganda, the POS is being used as a proxy for a patient satisfaction survey in reporting to a major bi-lateral donor, as well as for quality improvement.

Operational research using the POS impacts care both by demonstrating better ways of delivering care and by providing an evidence base for palliative care organizations to take to advocate for funding from donors and for inclusion of palliative care in government health policies. It has also been used by Dr Jacinto Amandua, the Commissioner for Clinical services in the Ministry of Health in Uganda to assess the palliative care needs of hospital patients.

Conclusion

There is no doubt that, where the POS is used consistently, it has an enormous impact on the quality of the palliative care delivered to patients and their families in sub-Saharan Africa. However it was clear, in speaking to organisations, that there are barriers to its use and steps that could be taken to ensure that it is used more widely. Below are some recommendations:

1. **Marketing**

There does not seem to have been much active marketing of the POS in sub-Saharan Africa after the initial validation and clinical studies. It would be useful not only to contact all the relevant national and regional palliative care organisations again with information, including the availability of support through the POS Pal website (www.pos-pal.org) but also to explain to them the particular value of the POS.

2. **Training – in country champions**

It is clear that there needs to be training beyond an initial familiarisation with the use of the POS to ensure that practitioners use it on a continuing basis to improve quality and that its results are analysed correctly. For this to happen, it is important to identify in-country champions who have used and valued the POS and are willing to help other organisations use it. There may also be a need to identify additional resources for smaller organizations.

3. **Hearts and Minds**

It is not just a matter of formal training. Practitioners need to understand its value. One barrier to its use is that staff may feel that, if the POS shows that there are gaps in service delivery, it reflects badly on them rather than being an opportunity for quality improvement. The benefits need to be demonstrable for staff and patients and worth the discipline of using the POS regularly.

The POS is most widely and consistently used in South Africa, because the HPCA has made its use part of the system for accrediting hospices: other National Associations could find similar ways of incentivising hospices and palliative care organizations. But the most sustainable option for increased use of the POS is its integration into pre and post qualification training for health professionals within government health systems as part of the wider effort to integrate palliative care into health systems.

Appendix 1

List of People/Organisations contacted re use of the African Palliative care Outcome Scale

KENYA	Dr Zipporah Ali Executive Director	Kenya Hospice and Palliative Care Assoc. (KEHPCA)
	Mrs Seraphina Gichohi CEO	Nyeri Hospice
	Dr Bridgid Sirengo CEO Catherine Ajuoga Senior nurse	Nairobi Hospice
UGANDA	Professor Julia Downing	Mulago Hospital and freelance consultant
	Edith Alankwasa Training manager	Mildmay Kampala
	Rose Kiwanku CEO	Palliative Care Association of Uganda (PCAU)
	Zena Bernacca CEO Dr Eddie Mwebesa Medical Director	Hospice Africa Uganda
South Africa	Kath Defilippi	Ex HPCA and South Coast Hospice
	Zodwa Sithole	National Advocacy Manager and Regional Manager KWN HPCA
	Sheryl Wurst	PC development Officer KZN HPCA
	Sue Cameron	Regional Manager Guateng, North West, Limpopo, Mpumalanga HPCA
	Warren Oxford-Hugget	Msunduzi Hospice
	Rena Licen	
	Jaya Naicker	Verulam Hospice
	Liz Gwyther	HPCA
Estelle du Toit	Matlosana Hospice	
Malawi	Jane Bates	Tiyanjane Blantrye Malawi
Tanzania	Angela Kaiza	AIDSRelief
	Dr Paul Z. Mmbando	Manager- Evangelical Lutheran Church in Tanzania (ELCT) Palliative Care Programme
	Dr Kristopher Hartwig	Formerly at ELCT Hospitals
Zimbabwe	Phil di Sorbo	Island Hospice consultant
	Chenjerai Sisimayai	Consultant ex Island Hospice
Other organisations	Meg O'Brien	CEO Global Action for Pain Relief Initiative (GAPRI)
	Carla Horne	Fhi360 regional pc adviser
	Kim Green	Fhi360 Deputy Country Director Ghana
	Stephen Connor	WPCA
	Fatia Kiyange Eve Namisango	APCA

Examples of Research using the APCA POS

A Prospective Study Assessing Tumour Response, Survival, and Palliative Care Outcomes in Patients with HIV-Related Kaposi's Sarcoma at Queen Elizabeth Central Hospital, Blantyre, Malawi

H. Francis,¹ M. J. Bates,² and L. Kalilani³ AIDS Research and Treatment Volume 2012, Article ID 312564, 6 pages

Research in progress

TOPcare: a randomised controlled trial in Kenya and South Africa which aims to test the effectiveness of palliative care for people with HIV on antiretroviral therapy in primary care.

It is also being used as part of research projects for post-graduate degrees by practitioners: Dr Liz Gwyther, CEO of HPCA, is using the APCA POS to assess outcomes for 3 groups of patients with chronic illness prior to referral to palliative care as part of her thesis *How is Palliative Care part of the Right to Health? – the South African evidence* while Kath Defilippi is using the POS to evaluate the pc outcomes of hospitalized TB patients as part of her MPhil in palliative medicine.