EVALUATION OF THE HOSPICE PALLIATIVE CARE ASSOCIATION OF SOUTH AFRICA

EXECUTIVE SUMMARY

INSIDEOUT: M&E SPECIALISTS

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This evaluation of the Hospice Palliative Care Association of South Africa (HPCA) was conducted by Inside Out: M&E Specialists on behalf of the Palliative Care Initiative of The Diana, Princess of Wales Memorial Fund.

The following documents are also available:

- Evaluation of the Hospice Palliative Care Association of South Africa: Full Report
- A case study: The Alliance for Access to Palliative Care
- A case study: Strategic advocacy with The Department of Health
- A case study: Palliative care in prisons


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INTRODUCTION

The Hospice Palliative Care Association of South Africa (HPCA)

The first three hospices in South Africa were established in 1979 and 1980. The establishment of the Hospice Association of South Africa (HASA) followed in 1987 in response to the need expressed by hospices to establish a national organisation, and in 1992 a national office was established in Cape Town. The organisation drew its capacity from hospice staff who volunteered for the Hospice Association of South Africa (HASA). A sub-committee structure was conceptualised in 1997 and informed the way in which the organisation operated until early 2011. In 2003 the HASA changed its name to the Hospice Palliative Care Association (HPCA). An important milestone in the development of the organisation was the President’s Emergency Plan for AIDS Relief (PEPFAR) grant received in 2004 that enabled the organisation to employ staff rather than having to rely on volunteers from the member organisations. HPCA recently went through a process of restructuring which became effective as from April 2011. This was prompted in large measure by the heavy travel schedules of both managers and field staff, and the need to provide a more consolidated and streamlined service to the hospices. The restructuring is also intended to enhance relationships with provincial Departments of Health (DOH).

The HPCA is a voluntary association of organisations in South Africa providing palliative care services to those living with life limiting and life threatening illnesses, and their families. There are 185 active members situated across all nine provinces of South Africa. A major part of the HPCA’s work is assisting its members to provide quality palliative care to paediatric and adult patients. This assistance is provided through a range of support activities and a variety of training courses that are on offer. The main point of contact between the member hospices and the HPCA is through 17 provincial Palliative Care Development Officers (PCDOs) employed by the HPCA. Each PCDO is trained to offer the full range of services to the organisations allocated to their care.

At the time of conducting the research for this evaluation, the DOH was engaged in a process of revisiting its primary health care (PHC) strategy, referred to as the re-engineering of PHC. The HPCA saw this as a valuable opportunity to get palliative care into the public health care system and had embarked on an advocacy strategy that focused on including palliative care responsibilities in the community outreach teams.

In terms of positioning palliative care within the Department of Health structure, the HPCA would like to see palliative care situated in the Chronic Diseases Directorate, which includes the categories of rehabilitation and the terminally ill.

Evaluation of the HPCA

In April 2011, The Diana, Princess of Wales Memorial Fund (‘the Fund’) contracted Insideout: M&E Specialists to conduct an evaluation of the work of the HPCA, with the planned outputs of an evaluation and four case study reports (see page 2).

A variety of data collection methods were employed during the course of the evaluation. These included an extensive document review, 59 interviews, two focus groups and two surveys.
ACHIEVEMENTS AND CHALLENGES OF THE HPCA

The achievements of the HPCA can be categorised into three main areas, namely: (1) Promoting palliative care outside of hospices; (2) Support and monitoring services provided to member organisations; and (3) Improvements in patient care.

Promoting palliative care outside of hospices
There have been a number of achievements with regard to moving palliative care beyond the confines of hospices, including:
- the provision of HPCA palliative care courses to member organisations and a small number of staff from the Department of Health (DOH) and from other organisations
- palliative care training at tertiary institutions, most notably the University of Cape Town
- the promotion of palliative care at sub-district health level
- signing of Memoranda of Understanding (MOUs) with civil society organisations
- signing of MOUs with government departments including the DOH, the Department of Correctional Services (DCS) and the Department of Defence
- a palliative care pilot project in two prisons in partnership with the DCS
- advocacy with the DOH
- the establishment of the Alliance for Access to Palliative Care
- work with traditional healers
- involvement in international palliative care alliances.

With regard to these ten achievements, three achievements were explored in detail in the case studies that were undertaken as part of the evaluation:
- the advocacy work undertaken with the DOH
- the Alliance for Access to Palliative Care
- the palliative care work undertaken in partnership with the DCS.

A brief summary of these three case studies is presented below.

Advocacy with the Department of Health (DOH)
The HPCA’s advocacy strategy involves working at all levels of government:

At district level and sub-district level, HPCA member hospice nurses introduced palliative care to provincial hospitals and Primary Health Care (PHC) clinics. They also represent the HPCA at, for example, quarterly health consultative meetings and at AIDS Council meetings which are attended by various government departments and municipalities.

At provincial level, a number the HPCA’s Palliative Care Development Officers (PCDOs) and regional managers have met with provincial directors from the DOH and the Department of Social Development (DSD). Both of the latter who have since attended HPCA regional meetings in some provinces. Likewise, the HPCA also had representation at provincial events, for example, at the provincial bi-monthly Global Fund management meetings in the Western Cape.

At national level, the HPCA participates in a number of forums, for example, the South African National AIDS Council’s (SANAC) Technical Task Team for Treatment, Care and Support (TTT), providing a
valuable opportunity to input into the HIV/AIDS National Strategic Plan (NSP).

Since 2002, the HPCA has employed an advocacy manager funded by the Fund. As part of its organisational restructuring, the HPCA has begun training hospices in advocacy in order to strengthen their advocacy capability at sub-district, district and provincial levels.

There is evidence of greater awareness and understanding of palliative care on the part of the DOH stakeholders with whom the HPCA and its member organisations have interacted, resulting in greater support of palliative care. In some provinces, the HPCA’s relationship with the DOH has improved as a result of provincial and district level advocacy efforts.

In terms of advocating for policy and legislative change, significant achievements include:

- input into the National Palliative Care Strategy
- the drafting of clinical guidelines on palliative care (adult and paediatric)
- making a contribution to the new National Strategic Plan for HIV/AIDS, STIs and TB (NSP)
- advocating for nurses to prescribe pain-control medication
- making recommendations for nurse training on antiretroviral treatment (ART) and palliative care in NIMART\(^1\) guidelines
- input into the Community Caregiver Policy Framework
- undertaking advocacy efforts for paediatric palliative care.

Establishment of the Alliance for Access to Palliative Care

Towards the end of 2009, the HPCA established the Alliance for Access to Palliative Care. The Alliance is led by the HPCA which convenes and funds the meetings with funding from the Fund and PEPFAR.

There are approximately 20 active members on the Alliance representing multiple facets of the palliative care environment, including representatives from the provincial and national DOH; the South African National AIDS Council (SANAC); tertiary education institutions; the South African Nursing Council (SANC); donors; the South Africa Catholic Bishops Conference; NGOs and the DCS.

Six goals\(^2\) have been set by the Alliance focusing on advocacy and awareness raising for palliative care, in particular, the need for integrated palliative care, promotion of collaboration among organisations around issues of palliative care, promotion of the development of an evidence base and development of palliative care indicators.

The Alliance had been in existence for little more than two years at the time of the evaluation, however early achievements of the Alliance included the following:

- enhanced palliative care awareness and practice for member organisations
- improved networking, relationship building and broadening of perspectives for member organisations
- inputs drafted for government policy and planning
- enhanced government involvement in and awareness of palliative care.
Members made a number of recommendations to address the challenges faced by the Alliance. These suggest that it is time for the Alliance to consolidate its experience to date and develop clear strategies for action which should be supported by efficient communication, administration and monitoring systems. The Alliance will also benefit from strengthening the involvement of members, so as to create a sense of joint ownership amongst Alliance members, enhancing government representation and addressing its future sustainability. The Alliance needs to fundraise for its continued work, given that the Fund is closing at the end of 2012 and the focus of PEPFAR funding is changing.

The advocacy-related achievements of the HPCA need to be viewed within the current health-related context of the country, which presents notable challenges to the advocacy work of civil society. All of the HPCA’s advocacy-related efforts face certain common problems, namely:

- general difficulties in advocacy work with the DOH that include high staff turnover and the variances between provincial DOH structures
- poor understanding of palliative care among key stakeholders including DOH personnel
- other health concerns that are currently competing with palliative care for resources, namely the national health priorities of increasing life expectancy, decreasing maternal and child mortality, and reducing the incidence of HIV and tuberculosis.

**Palliative care pilot project in partnership with the Department of Correctional Services (DCS)**

A pilot project was implemented in two correctional facilities in KwaZulu-Natal with the aim of promoting the provision of palliative care services to prisoners. Launched in October 2009, the project is the result of a partnership between the DCS, the HPCA and two local member hospices responsible for working directly with the prisons involved.

The HPCA model for the pilot entailed a strategy of initially training members of the health units at the prisons (nurses, counsellors, doctors and social workers), with follow-up mentoring support for the members of these multidisciplinary teams. Both the training and follow-up mentoring were provided by the hospice assigned to each of the prisons.

The DCS is currently expanding this project to other prisons.

The actual number of prisoners benefiting from palliative care services was difficult to establish but appears to be small given the size of the prison population. However, it must be generally noted, that the initial results of the pilot project indicate that the project has led to improved care for terminally-ill offenders as a result of:

- changes in mindsets and attitudes about palliative care and health care in general at the prisons;
- greater access to family support for patients;
- more consistent palliative care through offenders trained in Home Based Care (HBC) within the prisons;
- improved access to palliative care drugs;
- the introduction of an exit strategy for released sick prisoners.
prisons, including those in other provinces. More advocacy work will need to be done to expand the definition of palliative care being used by Correctional Services which currently focuses on prisoners who are terminally ill.

**Support and monitoring services provided to members**

The support and monitoring that the HPCA offers to the hospices is a second category of HPCA’s achievements. The primary support offered to hospices is via hospice standards and the associated accreditation process; training in palliative care offered to hospices; the Hospice Data Management System (HDMS); channelling of PEPFAR funding to hospices; and the development of the sustainability guidelines.

The views of member organisations regarding the support received from the HPCA were gathered by means of an electronic survey that was sent to all accredited HPCA member organisations. A total of 58 member organisations returned completed questionnaires. A total of 78% of respondents believed that the HPCA worked in their interests either “all of the time” or “most of the time”. Many of the remaining 22% were involved in work that fell outside of the scope of the HPCA.

Members believed that they benefited in numerous ways from their involvement in the HPCA. In particular, the vast majority of respondents (between 82% and 91%) claimed that they had benefited as a result of the accreditation process which had improved the credibility of their organisation; enjoyed better skilled staff as a result of HPCA support and training; and had found the access to technical expertise offered by the HPCA to be very beneficial. These were the three most frequently mentioned benefits but many other benefits were also cited.

The development of the Hospice Palliative Care Standards and the associated accreditation process were held in very high regard by respondents, and the application of standards had yielded substantial benefits to the organisations. More than three quarters of the organisations had seen significant improvement in the following standards:

- holistic patient care
- access to care and patient rights
- support services
- administrative support
- risk management
- the use of inter-disciplinary teams.

The respondents’ descriptions of the challenges they faced in meeting standards included several common themes, largely related to a lack of funds or resources and a shortage of capacity and skills.

The HPCA envisions that its members will undertake local advocacy work and has made efforts to support them in doing so. Survey respondents were asked whether their organisations were involved in any local advocacy work. Only 38% of respondents said that they were, while 62% said that they were not. Advocacy training will be a focus of the HPCA’s support to hospices in the future.

When asked what support they require from the HPCA in the future, the most common responses from member organisations were:

- ongoing training opportunities for staff
- assistance with funding and improving the sustainability of their organisations
- practical and accessible mentorship through the PCDOs.
Improvements in patient care
The third area of HPCA’s achievements is in connection with the improvements in both the quality of patient care and the number of patients receiving care from hospices as a result of support from the HPCA.

In terms of patient numbers, there has been a consistent year-on-year growth in the number of patients receiving palliative care services over the past four years. The number of patients has more than doubled since 2007, with a 16% growth in the last year alone.

In addition, not only has there been a quantitative growth in the provision of palliative care services – there are also indications that the quality of the services has improved. The improvement in quality of palliative care was attributed to: (1) The HPCA standards; (2) The palliative care training of hospices; (3) Hospice Data Management System (HDMS); and (4) Treatment guidelines.

There has also been a dramatic increase in the number of sites providing paediatric palliative care services. There were 22 sites in 2008 and this number has grown by almost 150% to 51 in 2011.

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ORGANISATIONAL ASSESSMENT

There are a number of strengths and challenges facing the HPCA as an organisation that influence its ability to undertake its work. Six key issues were explored in the evaluation.

Human resource capacity and sustainability
The visionary leadership at the helm of the organisation was consistently acknowledged by respondents. The commitment and dedication of both the leadership as well as the field staff were considered a major strength of the organisation. However, the heavy workloads requiring long hours were a source of concern for some external stakeholders, particularly around the issue of sustainability, as were the dual role of the CEO and limited succession planning.

Financial sustainability
The HPCA receives support from a relatively large number of donors. However, there are substantial changes envisaged where future funding is concerned. While current donors hold the HPCA in high regard, financial sustainability requires continued attention and planning, and nurturing of donor relations including relatively small donors.

Systems and procedures
The Hospice Data Management System (HDMS) has made a significant contribution to the quality of the data collected, and as a result has improved reporting to donors and other stakeholders. However, there is still room for improvement in some of the organisation’s systems and procedures, in particular, with regard to the accessibility and reliability of monitoring data, especially in hospices not yet using the HMDS. In addition to improving monitoring practices, the HPCA could benefit from the practice of systematically evaluating all pilot projects before rolling such projects out further.

Public profile of the HPCA
Some respondents believed that a segment of the population held perceptions - about hospices in general and the HPCA in particular - that were not an accurate reflection of the organisations. For example, beliefs that hospices did not care for AIDS patients and that hospices and the HPCA were the domain of white South Africans. Respondents acknowledged that these beliefs were perceptual rather than factual in nature, due in large measure to the apartheid history of the country. However, the perceptions exist and as such need to be addressed through a clear national communication strategy to raise the profile of the HPCA among the South African public. It is noted that more than half of the HPCA staff consists of black employees – efforts to promote the visibility and role of senior black staff members should be continued.

Ability to provide training
The palliative care training provided by the HPCA is central to the future of the organisation, not only is it central to the HPCA’s strategy of moving palliative care into the public health sector, it also has the potential of becoming a funding stream which can contribute to the financial sustainability of the organisation and is required if the HPCA is to continue receiving PEPFAR funding. To maximise the potential of the training activities, the HPCA will need to strengthen its ability to deliver its training to the Department of Health (DOH). This will require, amongst other things, a close collaboration between the HPCA’s advocacy and training functions.
ASSESSMENT OF THE FUND’S FUNDING STRATEGY

Support provided by the Fund
In addition to providing funding, the Fund has been engaged in what is referred to as a ‘value added’ approach which has included:

• convening meetings between the HPCA and other funders and creating points of contact with donors who might be interested in supporting the work of the HPCA

• providing technical support such as monitoring and evaluation assistance, support with financial management, and giving feedback on reports received

• providing general support such as providing the funds to attend and present at local and international conferences.

Results of the work funded
The Fund has supported the HPCA through:

• funding the Advocacy Manager’s salary
• covering some of the costs of the Alliance for Access to Palliative Care meetings
• funding bursaries for University of Cape Town (UCT) students
• paediatric palliative care work, including the design of training and the Children’s Beacon Centre Training Project in three African countries, including South Africa.

As such, the Fund has contributed to some of the HPCA’s achievements, which have been made possible in part through their support, for example:

• the strengthening of paediatric palliative care
• the UCT training
• the work of the Advocacy Manager including the establishment of the Alliance for Access to Palliative Care; advocacy with the Department of Health (DOH); the pilot work with the Department of Correctional Services (DCS); and the recent work with traditional healers.
CONCLUSIONS AND RECOMMENDATIONS

Conclusions
The HPCA can lay claim to a long list of achievements. These achievements are all the more significant given the difficult context in which the HPCA works, a context of poor understanding and valuing of palliative care by decision-makers, as well as a number of competing health priorities. The HPCA possesses a number of internal organisational strengths and assets, not least of which is the dedication and passion of its staff and the visionary leadership of the organisation.

Internal difficulties that need to be managed include issues of human resource capacity; the need to improve on certain systems including reporting to donors (particularly financial reporting), administration and monitoring and evaluation systems; the need to strengthen the organisation’s ability to provide training which can play an important role in its sustainability and in promoting palliative care into the public health care system; and finally, a need for a communication strategy that can address some of the misconceptions that exist about the organisation.

Factors that support the organisation as it moves into the future include the high level of regard with which other palliative care and donors organisations hold the HPCA; the skills and experience of the staff at all levels of the organisation; and the capacity that has been built up in the hospices due to the efforts of the HPCA.

Recommendations
The following are recommendations to strengthen the work of the HPCA that have emerged from this evaluation study. The recommendations are presented in no particular order.

1. Develop a funding strategy for the future
One of the most urgent issues facing the HPCA at the time of this evaluation study was the funding for the future, post 2012, once changes have taken place in PEPFAR and the Fund has closed. HPCA’s efforts to promote the sustainability of hospices in the light of possible changes to funding that hospices receive should be continued. In addition, efforts to build relationships with new funders, especially funders that might be interested in providing resource or technical support to the hospices, should continue.

2. Continue with advocacy
The HPCA should continue with the relationship-building efforts that are already evident, focussing in particular on:

- continuing to enhance government representation on the Alliance, especially of senior national Department of Health staff
- continuing efforts to secure meaningful engagement with the Department of Social Development (DSD), given the latter’s involvement with community caregivers in non-profit organisations and the fact that many provincial departments tend to combine health and social development.

Advocacy efforts could benefit from evaluations of implemented projects, in that the research could identify areas where further advocacy
efforts are required. One example is the finding that the Department of Correctional Services (DCS) currently employs a limited definition of palliative care that refers only to terminally ill patients. Advocacy with provincial and national DCS could encourage the department to use a wider definition of palliative care services before rolling the programme out further.

3. Address the issue of human resource capacity

The HPCA staff should be acknowledged for their dedication and passion. However, consideration should be given to whether the workload especially of senior managers is sustainable, the consequences of which include limited time for reflection, evaluation and learning; and delayed reporting as was the case reported by one donor. Time should be set aside to reflect on the impact of the restructuring. While a talent management document has been developed, ongoing attention needs to be paid to issues of sustainability. Continuing with efforts to make black staff visible within the organisation is also important in order to counteract perceptions that the HPCA is a “white organisation”.

4. Strengthen the training function

The HPCA faces the challenge of “repositioning itself as an education and training organisation”, as described by one external stakeholder. There are three driving forces behind the need for such restructuring: the valuable role that training can play in promoting the inclusion of palliative care in the public health system; changes in PEPFAR’s funding strategy which will see technical assistance receiving support but not service provision; and the potential to generate income by providing training, especially to staff at the DOH. However, the HPCA’s training strategy is not yet functioning optimally. In particular, it is to be noted that very few people from the DOH have participated in HPCA training. The Department of Basic Education (DBE) also represents a training opportunity by providing bereavement counselling training for public school teachers that is not being fully utilised. More efforts should be made to engage these departments as major clients in the future.

5. Improve the monitoring of HPCA’s work

Readily available and reliable monitoring data remains a problem within the HPCA, despite the existence of the Hospice Data Management System (HDMS). Having an effective monitoring system in place would enable the HPCA to:

- manage its advocacy activities in a more proactive and strategic manner
- learn from its challenges and take corrective action
- collect evidence of its intermediate and longer-term successes.

6. Institutionalise a process of reflection, evaluation and learning

A number of pilot projects have been undertaken, including the Sustainable Palliative Care through Strategic Partnerships (SPCSP) project, Health Systems Strengthening, work with the DCS, and work with traditional healers. It should become standard practice to evaluate these programmes on an ongoing basis so that lessons can be learnt and any difficulties in the design of the project addressed before rolling them out to new sites.
7. Develop palliative care training at tertiary institutions

At UCT:

• promote the publication of work by MPhil research students to create a local evidence base for palliative care

• encourage accountability and commitment of graduates towards building palliative care by maintaining and supporting a network of course graduates

• continue efforts to enhance the capacity of the team responsible for the palliative care training at UCT, and develop a succession plan for the future of training.

Beyond UCT:

• co-ordinate efforts to include palliative care in tertiary institutions through structures such as the Committee of Deans and Professional Councils

• advocate for the creation of palliative care posts in the state sector to enable a formal career path for palliative care graduates.

8. Create a sense of joint ownership of the Alliance for Access to Palliative Care

A need was identified to build a wider sense of ownership amongst Alliance members to enhance their commitment and the quality and sustainability of their involvement. This will contribute to the sustainability of the Alliance, especially in the light of imminent changes, including the end of support to the Alliance by two of its funders, the Fund and PEPFAR.

9. Enhance communication and accountability to members

The HPCA needs to streamline its services and limit the amount of administration and reporting required from hospices, while also professionalising its communication and responses to members. Respondents recommended that the HPCA improve its communication with members and regional bodies in order to keep them informed and updated on the following: accreditation issues and training calendars; trends in the palliative care field; and developments in the policy and funding environments. The HPCA should also communicate with members about its responses to current issues and the work and strategic planning of its board and management committee.

10. Develop an external communication and public education strategy

It was felt that both the HPCA and the Alliance for Access to Palliative Care lacked sufficient public visibility and should be able to better engage with the media in order to promote understanding of palliative care. Strategically designed public communication campaigns about palliative care targeted separately at the level of policy-makers, professionals and the public have been suggested.
ENDNOTES

1NIMART = Nurse Initiation and Management of Antiretroviral Treatment

2Goal 1: To advocate for an integrated approach to palliative care for all persons (adults and children) affected by chronic illness at primary, secondary and tertiary levels and to promote awareness and understanding of palliative care with all relevant stakeholders including communities and government departments and amongst health care workers.

Goal 2: To promote collaborative working between organisations to strengthen health and community systems in order to improve access to an integrated palliative care approach at all levels of health care.

Goal 3: To identify and support champions within organisations to advance the provision of integrated palliative care within their organisation and partner organisations.

Goal 4: To influence professional councils, health education institutions, and other organisations to include palliative care training at all levels.

Goal 5: To promote the development of an evidence base for palliative care through research and documentation.

Goal 6: To contribute to the development of palliative care indicators that can be utilised in reporting on palliative care delivery.