

# Spiritual care recommendations for people receiving palliative care in sub-Saharan Africa

With special reference to South Africa and Uganda

Authors:

Lucy Selman, Dr Richard Harding, Godfrey Agupio,  
Rev Peter Fox, Rev David Galimaka, Keletso Mmoledi,  
Prof Irene Higginson and the  
Spiritual Care in sub-Saharan Africa Advisory Group

With a Foreword by Archbishop Emeritus Desmond Tutu



Sir Halley Stewart Trust



# Contact

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For further information on the recommendations or the project funded by the Sir Halley Stewart Trust, please contact:

Lucy Selman, Research Associate  
Department of Palliative Care, Policy & Rehabilitation  
King's College London  
Cicely Saunders Institute  
Bessemer Road  
London, UK  
Email [lucy.selman@kcl.ac.uk](mailto:lucy.selman@kcl.ac.uk)  
Tel. 020 7848 5566  
<http://www.kcl.ac.uk/palliative>

The development of these recommendations was supported by:

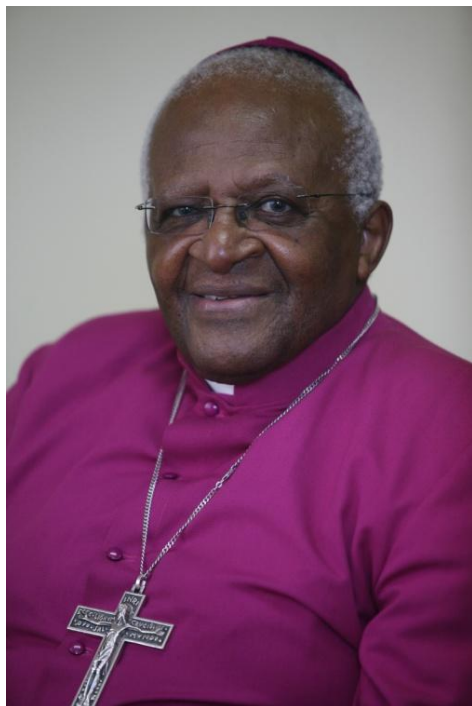
The African Palliative Care Association (APCA)  
<http://www.apca.org.ug>

The Hospice Palliative Care Association of South Africa (HPCA)  
<http://www.hospicepalliativecaresa.co.za>

Cicely Saunders International  
<http://www.cicelysaundersinternational.org>

# Foreword

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Living with incurable progressive disease such as HIV infection and advanced cancer has implications far beyond the physical dimension. The experience of illness can have a profound effect on one's spiritual well being, leading to times of crisis as well as opportunities for growth. Spiritual suffering may be further compounded by socio-economic deprivation and inequities in healthcare provision. It is therefore imperative that healthcare services recognise the spiritual aspects of illness, and are tailored to support people spiritually as well as physically. This becomes even more essential in the context of palliative care, which aims to provide what Dame Cicely Saunders described as 'total care' for patient and family.

One of the strengths of sub-Saharan Africa is its true diversity, which brings with it a myriad of opportunities and challenges. As demonstrated by recent African Palliative Care Association publications, sub-Saharan palliative care services need to be able to meet the needs of a population which is varied in terms of culture, religion and language. However, until now there has been little explicit guidance for the provision of spiritual care within the context of African health care services.

The recommendations in this report offer a way forward in developing health care services that are truly sensitive to the diverse needs of the communities they serve.

Collaboration between health care professionals, community and faith groups, spiritual leaders and traditional healers is fundamental to this process, and an ongoing commitment to mutual education, training and support is essential.

The examples of good practice contained within this report highlight some of the innovative work already being carried out by palliative care services across sub-Saharan Africa in the field of spiritual care. However, there remains much to be done. These recommendations provide direction and support, but action from palliative care services and communities is needed at a grass-roots level. The quality markers presented here give clear and practical guidance for service providers to monitor their progress towards the aim of equitable, culturally sensitive palliative care.

I am therefore pleased to support these recommendations, which I believe to be an important step towards meeting the spiritual care needs of people living with incurable, progressive disease in sub-Saharan Africa. I hope that palliative care services across the region will adopt and implement the recommendations in this report, so that the spiritual needs of all patients and families will be met.

God bless you

A handwritten signature in black ink, appearing to read 'Desmond Tutu', followed by several horizontal strokes that suggest a flourish or the end of a signature.

†Archbishop Emeritus Desmond Tutu

# Acknowledgements

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These recommendations were produced by an expert panel under a grant provided by the Sir Halley Stewart Trust. We would like to thank all the experts who contributed to these recommendations, the clients, spiritual care providers and other staff in South Africa and Uganda who participated in the study, and the Sir Halley Stewart Trust for supporting the analysis of the data and the generation of the recommendations.

These recommendations would not have been possible without the contribution of the following people, members of the Spiritual Care in sub-Saharan Africa Advisory Group:

<b>NAME</b>	<b>ORGANISATION</b>	<b>COUNTRY</b>
Godfrey Agupio, Quality Assurance Nurse	Hospice Africa Uganda	Uganda
Rev Richard W. Bauer, Executive Director	Catholic AIDS Action	Namibia
Dr Charmaine Blanchard, Pall. Care Specialist	Baragwanath Hospital	South Africa
Dr Julia Downing, Palliative Care Specialist	Palliative Care Association of Uganda	Uganda
Rev Peter Fox, Spiritual Care Team Coordinator	St Luke's Hospice	South Africa
Rev David Galimaka, Chaplain	Mildmay	Uganda
Dr Kristopher Hartwig, Pall. Care Coordinator	Evangelical Lutheran Church in Tanzania	Tanzania
Jenny Hunt, Pall. C. & Bereavement Consultant	Independent	Zimbabwe
Rose Kiwanuka, National Co-ordinator	Palliative Care Association of Uganda	Uganda
Sr. Gloria Knox, Spiritual Care Coordinator	Houghton Hospice	South Africa
Val Maasdorp, Clinical Manager	Island Hospice & Bereavement Service	Zimbabwe
Joan Marston, Paed. P.C. Development Coordinator	HPCA	South Africa
Anne Merriman, Founder	Hospice Africa Uganda	Uganda
Dr Paul Mmbando, Project Manager	Evangelical Lutheran Church in Tanzania	Tanzania
Keletso Mmoledi, Palliative Care Team Leader	Witwatersrand Palliative Care	South Africa
Dr Lydia Mpanga Sebuyira, Head of Training	Infectious Diseases Institute	Uganda
Christine Nachmann, Spiritual Counsellor	St Luke's Hospice	South Africa
Sue Nieuwmeyer, Social worker	HPCA	South Africa
Julie Palmer, Bereavement Counsellor	South Coast Hospice	South Africa
Dr Pramda Ramasar, President	Chatsworth Hospice	South Africa
Brigid Sirengo, CEO	Nairobi Hospice	Kenya
Rev Prebendary Peter Speck, Researcher	King's College London	UK
Dr Stephen Williams, Medical Director	Island Hospice & Bereavement Service	Zimbabwe

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# Executive Summary

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- In 2008 there were 22.4 million people living with HIV infection in sub-Saharan Africa – two thirds (67%) of the global total with HIV. In the same year, it is estimated that 1.9 million adults and children became infected with HIV, and 1.4 million adults and children died of AIDS.
- As the availability of ART improves, mortality rates among people with HIV will continue to decrease, but, in the absence of effective behavioural change programmes, HIV prevalence will remain high.
- While access to ART is crucial to prolong life, patients on ART continue to experience pain and other chronic symptoms caused by the underlying disease progression, co-morbidities and opportunistic infections, as well as the significant psychosocial and spiritual problems related to living with the diagnosis.
- In addition to the burden of HIV, cancer and other non-communicable diseases are becoming urgent public health issues in Africa, with one in five deaths in sub-Saharan Africa due to cancer; in females, the lifetime risk of dying from cancer in Africa is almost double the risk in developed countries.
- The number of people in Africa over 60 years old is projected to quadruple by 2050, with the lifetime risk of cancer expected to increase by 50–60%, and the annual number of cases to rise from 650, 000 to 2.2 million.
- In this context, palliative care, which integrates the spiritual aspects of patient and family care alongside the physical and psychosocial, is an essential component of public health in sub-Saharan Africa. Palliative care is defined by the World Health Organization (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.’*
- According to WHO estimates, approximately 8.2 million people are currently in need of palliative care in sub-Saharan Africa.
- The African Palliative Care Association (APCA) has made a significant contribution in developing standards and core competencies for palliative care which include spiritual care, recognising that spirituality and religion often play a key role in the experience of serious illness. There is evidence that spirituality is an important coping resource in sub-Saharan populations, and that patients experience spiritual distress.



- However, up to now there has been little guidance for palliative care services on how to meet patients' and family members' spiritual needs. In sub-Saharan Africa specific challenges include responding to the multi-dimensional distress of a growing population in need of palliative care, with limited resources and a lack of local research to inform service development and provision.
- The evidence-based recommendations offered in this report aim to fill this gap in policy guidance building, on APCA's standards and core competencies to bolster service development in the important but neglected field of spiritual care.

## **1. Aim, audience, development and structure**

### **1.1. Aim**

- These recommendations aim to inform the provision of spiritual care for people receiving palliative care in sub-Saharan Africa by providing evidence-based guidance for palliative care service providers. The recommendations are designed to be broad and adaptable to different local conditions, so that they are applicable across sub-Saharan Africa, and to complement and facilitate the attainment of the APCA standard on spiritual care.

### **1.2. Audience**

- The intended audience for these recommendations includes palliative care service providers, spiritual care providers, educators and healthcare policy makers in sub-Saharan Africa and globally.

### **1.3. Development**

- The recommendations were generated during a study entitled '*Spiritual care for patients receiving palliative care in sub-Saharan Africa*'.
- The study investigated patients' spiritual well being and the provision of spiritual care at four palliative care services in South Africa and one in Uganda. The data (in preparation for publication at the time of press) comprises 72 qualitative interviews with patients receiving palliative care; survey data on spiritual well being from 285 patients; 21 interviews with spiritual care providers (both in the community and at the services); data from four seminars attended by spiritual care providers, local faith leaders and palliative care staff; and interviews with the four research nurses who conducted the patient interviews.
- The recommendations were developed during 2010 with the support of APCA and HPCA and in collaboration with an expert advisory group of spiritual care providers, palliative care clinicians and researchers. The recommendations were launched at the APCA conference in Namibia in September 2010.

## **1.4. Structure**

- Examples of good practice are included throughout the recommendations. These were identified by the authors and members of the Advisory Group.
- Quality markers associated with each recommendation category are presented throughout. Quality markers are explicitly defined and measurable items referring to the outcomes, processes, or structure of care. Quality markers for spiritual, religious and existential aspects of palliative care are currently lacking. As quality markers are currently adopted voluntarily, they offer a framework for a palliative care organisation to define and track its progress against its own targets.

## **2. The Recommendations: summary**

The recommendations are divided into five categories, summarised below.<sup>1</sup>

### **1. Identifying spiritual needs**

#### **1.1. What are spiritual needs?**

Understand spiritual needs broadly, as including all the existential concerns with which a client may require support

Offer spiritual care to family members and carers as well as to patients, and to children as well as adults

Integrate spiritual care into bereavement support

#### **1.2. Assessment of spiritual needs**

##### **1.2.1. Screening**

In line with the APCA standards, ensure all team members have the appropriate training and support to be able to initiate discussions of spiritual issues and identify and assess spiritual pain (i.e. screen for spiritual distress)

Integrate screening for spiritual distress, immediate spiritual needs and other needs associated with culture and/ or faith into routine assessment of all clients on registration with the service

Follow the detailed guidance for the topics to cover during screening

Ensure all team members are able to respond to identified spiritual needs through providing basic spiritual care, initiating a full spiritual assessment (see 1.2.2.) and/ or referral

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<sup>1</sup> See the Appendix 1, page 90 for the full recommendations in Table form.

Ensure screening is documented in client records

### **1.2.2. Spiritual assessment**

Conduct a full spiritual assessment with all clients as part of a spiritual history-taking/ formal spiritual assessment

Follow the detailed guidance included in the recommendations on when and how to conduct a spiritual assessment

Ensure spiritual assessment leads to appropriate responses to spiritual need where support is required

Ensure spiritual assessment is documented in client records as appropriate

Convey important issues arising out of the assessment to the rest of the care team during regular meetings, while respecting client confidentiality

### **1.2.3. Formal assessment tools**

Use formal assessment tools to identify spiritual needs in a timely manner, and to assess the outcomes of spiritual care, while recognising their inherent limitations

Evaluate the outcomes of spiritual care; consider using both qualitative and quantitative methods

Choose formal assessment tools according to the aims of assessment, the properties of the tools, the context in which they are to be used, and their ease of use

## **2. Responding to spiritual needs**

### **2.1. The ingredients of spiritual care**

Ensure identified spiritual pain is addressed, either by palliative care staff or through referral

Offer clients access to a range of spiritual care services, including those which are not religious

Provide access to a range of spiritual care services for adults and children, as detailed in the guidance

Recognise that social support will also be necessary for some clients in order to alleviate financial concerns and allow them to attend to spiritual concerns; if possible assist clients in these areas, e.g. by identifying sources of support

Make information about the availability of spiritual care services available to all clients throughout the disease trajectory and into bereavement

Provide information in a range of languages spoken in the local community, and make provisions for clients who are not able to read

Protect clients from potentially damaging forms of spiritual intervention

Document the spiritual care resources accessed by clients in their records, along with their value and effectiveness for the client

### **3. Working with the community**

#### **3.1. Sharing spiritual care**

Implement a 'shared care' model of spiritual care provision, in which:

- The palliative care team aims to meet the spiritual needs of patients, their friends and family by working together with sources of support already available in the local community
- The spiritual care provided by faith groups is recognised and built upon and the significant influence that spiritual leaders may have is harnessed
- Mutual education and training is facilitated (see 3.2.), and palliative care providers and members of local faith and community groups are enabled to support each other

There is awareness of palliative care in the local community, including how to refer to and access service providers

#### **3.2. Education and training**

To establish an effective 'shared care' model of spiritual care, design and implement training and education programmes for spiritual leaders and traditional healers in the community

In order to be effective, training programmes should aim to follow the detailed guidance given regarding content and type of training

As part of a programme of ongoing continuing education, provide opportunities for spiritual leaders and traditional healers in the community to educate each other and palliative care staff regarding their beliefs and practices

Implement a programme of continuing education for palliative care staff about local spiritual beliefs and practices and their impact on the individual care of clients

#### **3.3. Referral**

Put in place referral systems for palliative care providers to refer to local spiritual leaders and traditional healers trained in palliative care, and ensure the referral systems are utilised

Allow any member of the care team to refer to an appropriate, trained spiritual care provider in the community; however, ideally appoint a designated spiritual care co-ordinator or another member of staff who is responsible for referral

Ensure that referral to spiritual care providers in the community always occurs with the client's consent (or, where a patient is unable to provide consent, with the consent of the family or primary carer) and with due respect for the client's confidentiality and autonomy

Raise awareness of palliative care, what the palliative care team provides and how to refer to the service among community leaders and faith and community groups

Ensure that spiritual leaders and traditional healers who have received training in palliative care are familiar with the referral system and know how to refer people with suspected life-limiting conditions in the community to palliative care (via their local doctor where necessary)

## **4. Spiritual care providers**

### **4.1. Attributes of a spiritual care provider**

Follow the detailed guidance regarding attributes which are conducive to good spiritual care and are to be fostered in spiritual care providers

Support spiritual care providers in their cultivation of these attributes, through training and access to support services (see 4.4)

### **4.2. Role of the spiritual care provider in palliative care**

Recognise the many roles of designated spiritual care providers described in the guidance

Support spiritual care providers in fulfilling these roles

### **4.3. Choice of spiritual care providers by the palliative care team**

#### **4.3.1. Members of the palliative care team**

Ensure that, as required by the APCA competency framework, all palliative care staff members have received training in the provision of basic spiritual care, including the identification of spiritual distress (see 1.2.1.)

In this training, include the basic principles of providing spiritual care for children, as this is likely to be an area in which confidence is lacking

Select the most appropriate spiritual care provider for a client on an individual basis, and recognise that a trained non-specialist in the care team may be the best person to provide spiritual care for a given client

When a non-specialist is providing spiritual care, ensure he or she receives support and advice from the designated spiritual care expert(s) in the team as required

#### **4.3.2. Spiritual care providers outside the healthcare setting**

Communicate with clients' faith leaders and/ or traditional healers to ascertain their familiarity with palliative care and identify potential conflicts with the palliative care perspective which could negatively affect client well being

Where a client does not have a local resource for spiritual care but would like to be referred to someone, take into account whether the person has received training in palliative care, the languages they speak, and their ethnicity, gender and religion, according to clients' wishes

On the basis of these considerations, refer the client to a spiritual carer inside or outside the healthcare setting, as is most appropriate

Ensure all spiritual care providers referred to by the palliative care team have received palliative care training, and are supported by the palliative care team

Respect clients' worldviews, but also investigate and caution against potentially harmful religious practices and forms of traditional healing

In order to safeguard patients and families, consider linking only with community spiritual care providers who belong to formal or official groups, e.g. through registered NGOs, established and well-known churches or pastoral training providers

Before linking with a religious institution such as a church, consider requesting a statement of faith or investigating the guiding principles of the church in order to anticipate or prevent potential conflicts

Screen volunteers wishing to provide spiritual care to clients, including faith leaders in the community, before they join the service, and ensure they are properly trained in the palliative care approach to spiritual care

If possible, reimburse volunteers' travel expenses and subsistence

#### **4.4. Support for spiritual care providers**

Recognise the impact of providing spiritual care on the spiritual care provider, and provide support for all spiritual care providers (whether paid or voluntary), in the form of debriefing and access to their line managers, peer support and/ or counselling as necessary

Ask spiritual care providers whether the support they receive is sufficient, in order to ascertain whether further support is required, and to identify problems with current support structures

### **5. Organisational requirements**

#### **5.1. Implications of recommendations 1-4**

Understand and fulfil the organisational implications of adopting each recommendation, for example:

- From recommendations 1 and 2: document spiritual well being and spiritual interventions in client records for all staff members to access
- From recommendation 3: recognise the importance of and foster relationships with local spiritual leaders, traditional healers and faith groups, with the palliative care organisation building on the support structures already in place in the local community
- From recommendation 4: identify, train and support spiritual care providers with diverse backgrounds and belief systems, and demonstrate that their role in patient and family care is valued

## **5.2. Training, education and support**

In line with the APCA standards and competencies, ensure all staff have training in basic spiritual care which includes the topics detailed in the guidance

Provide additional training as required according to staff members' roles and levels of contact with clients

## **5.3. Understanding of spiritual well being and care**

Understand spiritual well being in broader terms than religious belief and practice, to include notions of personal philosophy, coping and transcendence

Recognise the importance of religion to many clients, and aim to meet clients' religious needs

Consider spiritual well being intrinsic to quality of life

Consider spiritual care equally important as other dimensions of palliative care, and reflect this in the provision of adequate resources for spiritual care

Where a chaplain/ spiritual care provider is appointed, see and treat him/ her as an essential and valued part of the care team

Ensure curricula for palliative care professionals and training courses for volunteers reflect palliative care's commitment to meeting clients' spiritual needs

Ensure all staff members are aware of the spiritual dimension of the illness experience, feel confident talking to clients about their spiritual needs, and are able to refer to spiritual care providers appropriately

## **5.4. Culturally competent care**

Aim to provide culturally competent care; this requires a commitment to being reflective about the way your service operates and how care is provided, paying attention to the cultural appropriateness and acceptability of the service to the local community.

### **5.4.1. Cultural sensitivity**

In line with the APCA competencies, foster staff members' cultural sensitivity by encouraging empathy, open-mindedness and reflexivity among staff members, and providing staff training on best practice in multi-cultural care, particularly in the areas described in the guidance.

Ensure all members of staff and the community involved in client care, including local spiritual leaders and traditional healers, understand the importance of upholding client confidentiality, avoiding stereotyping, and providing client-centred care (see 5.5.)

Where staff and family members are utilised as interpreters, ensure clients are involved in selecting an appropriate interpreter

Ensure staff and family members acting as interpreters receive appropriate guidance/ training and support

Ensure challenges relating to culture are handled with diplomacy, sensitivity and awareness of the ethical norms of medical practice in your country

Support staff members in their individual negotiations of multi-cultural care

### **5.5. Providing client-centred care**

Ensure referral to spiritual care occurs with clients' consent, according to a system embedded in routine care

Ensure clients are considered and cared for as individuals, and explore patients' and families' cultural and spiritual beliefs and needs on a case-by-case basis

Ideally, ensure inpatient and daycare units can accommodate the spiritual needs of clients from diverse groups, including needs for rituals and visits by faith leaders, members of the faith community and traditional healers, and for a space for worship

### **5.6. Staff support**

Take into consideration the spiritual well being of staff and foster a culture of support in the organisation, ensuring at all times that the diverse nature of people's beliefs and wishes in this regard is respected

When staff members meet to explore and receive support for emotional and psychological needs related to their work, include opportunities to identify and explore any spiritual needs

Consider staff training in techniques such as 'mindfulness' or, for Christian staff members, 'centering prayer'



### **5.7. Quality improvement**

Commit to and carry out ongoing quality improvement in spiritual care, for example through clinical audit, assessment of the outcomes of spiritual care, and the adoption of quality markers and associated measures for spiritual care

## **3. Adoption of recommendations**

Adopting these recommendations, and implementing strategies to meet the suggested quality markers, may potentially benefit clients, communities and palliative care services in a number of ways:

- Increased awareness of, and referral to, palliative care within the local community, through local faith groups, spiritual leaders and traditional healers.
- Improved communication, and a mutually supportive relationship, between local spiritual leaders, traditional healers and faith groups and hospice and palliative care teams.
- Local spiritual leaders and traditional healers who are better informed about palliative care needs, the philosophy of palliative care and wider spiritual aspects of the illness experience, and who are supported in their work through palliative care teams.
- Palliative care teams who are better informed about patients' and family members' spiritual needs, and are able to refer to trained spiritual care experts in the local community when necessary.
- Better assessment of spiritual well being in clinical practice. While some palliative care practitioners express fears that formal assessment tools may turn spiritual care provision into a 'box-ticking' exercise, there is a strong argument that good assessment of spiritual well being is needed in order to screen for spiritual distress, and identify clients who may require support in this area.

## **4. Future research**

Failure to identify clients' sources of spiritual support, making assumptions about clients' spiritual beliefs and needs, insensitive approaches to spiritual assessment, and ignoring expressed spiritual need may cause considerable distress. While these recommendations aim to assist services with meeting the spiritual needs of diverse communities, more evidence relating to the provision of spiritual care in the context of African palliative care is urgently needed. On the basis of the work conducted during this project, the following areas are identified as research priorities in this field:

- Application, adoption and evaluation of the recommendations and quality markers presented here. Evaluation criteria recently formulated for quality indicators include

importance (the extent to which indicators capture key aspects of care that require improvement); scientific acceptability (the degree to which indicators produce consistent and credible results when implemented, including validity, evidence of improved outcomes, reliability, responsiveness, and variability); usability; and feasibility.

- Evaluation of the effectiveness of spiritual care models and interventions in the sub-Saharan African context, using both qualitative and quantitative methods and measuring key outcomes (e.g. spiritual well being) using validated tools.
- Paediatric spiritual care, including the identification and assessment of spiritual needs in children and young adults and the evaluation of spiritual care interventions in these populations.
- Evaluation of alternative methods of identifying and assessing spiritual care needs. Promising methods are likely to combine the use of good formal assessment tools with the staff training and support needed to foster the skills and confidence to engage with the spiritual resources available to patients and families.
- Adaptation or development and validation of existing measures of spiritual well being (and related constructs) in the context of African palliative care. As spiritual well being is embedded within culture, measures used in clinical practice and research need to be developed and validated in the specific populations in which they are to be utilised.

## **5. Concluding comments**

The population seen by palliative care services in sub-Saharan Africa is becoming increasingly diverse in terms of culture, spiritual beliefs and practices, and worldview. This report aims to assist in the development of palliative care services which are able to meet the spiritual care needs of patients with incurable, progressive disease and their families in the diverse communities they serve. In doing so, it builds on APCA's standards and competency framework for spiritual care provision, puts forward a public health model of spiritual care provision integrated into the local community, and suggests avenues for future research.

It is expected that service providers will prioritise the recommendations according to their own aims, and adapt the guidance for their own circumstances. The 'shared care' model most appropriate for a palliative care team based in an urban hospital environment, for example, will look very different from that of a home care service in a rural area.

The quality markers suggested here aim to guide services in monitoring their progress towards fulfilling those recommendations which they adopt. However, services need to adapt the quality markers presented here and develop individualised and detailed quality markers based on local context. For example, formulating specific numerators and denominators would make some of

the markers more explicit and facilitate the measurement of progress. Future revisions of these recommendations will take into account local experiences, practice and innovations in the provision of spiritual care in sub-Saharan Africa. Cross-site comparison of data generated through the measures associated with specific quality markers could also play an important role in setting national (and international) standards for the provision of the spiritual dimension of palliative care.

Finally, the authors and contributors hope these recommendations will contribute to a much-needed debate on the best construction of a multi-faith response to incurable, progressive illness that meets the needs of patients and families in sub-Saharan Africa.

September 2010

# Overview

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This report and the recommendations presented herein are a result of the Sir Halley Stewart Trust-funded project, '*Spiritual care for patients receiving palliative care in sub-Saharan Africa*'. The project is based on findings from a study conducted in South Africa and Uganda and in collaboration with an expert advisory group.

The report comprises two main sections with supporting Appendices. Section One presents the background to the recommendations and their aim, development and structure. The purpose of the recommendations is to inform the provision of spiritual care for people with incurable, progressive disease in sub-Saharan Africa by providing evidence-based guidance for service delivery. Section Two outlines the recommendations themselves, which are designed to be broad and adaptable to different local conditions. The intended audience includes palliative care service providers, spiritual care providers working with people with incurable, progressive conditions (including chaplains, hospice spiritual care providers and community faith leaders), palliative care educators and healthcare policy makers, in Africa and beyond.

The expert advisors who collaborated on this project included representatives from spiritual care, palliative care and research from Africa and the UK. The recommendations include in each category examples of good practice from across sub-Saharan Africa. The recommendations build on the APCA standards (1) and core competencies (2) for spiritual care, and include quality markers for the provision of spiritual care so that services can monitor their progress against the recommendations they adopt. Section Two ends with some thoughts on the adoption of the recommendations and what their implementation may achieve, highlights areas for future research, and offers some concluding comments.

The recommendations are divided into five categories<sup>2</sup>:

- 1 *Identifying spiritual needs*: The process and importance of screening for spiritual distress, conducting a spiritual assessment and choosing a formal assessment tool are described. The importance of evaluating the outcomes of care in order to monitor and improve the quality of care is also discussed.
- 2 *Responding to spiritual needs*: The range of spiritual care services that may assist patients are described, along with ways of advertising services to ensure spiritual care is accessed, and the need to document the value of services to clients.

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<sup>2</sup> A more detailed summary of the recommendations is available in table form in Appendix 1, page 90.

- 3 *Working with the community:* A 'shared care' model of spiritual care is described, in which palliative care services collaborate with diverse local agencies as appropriate, and facilitate mutual education, training, support and referral.
- 4 *Spiritual care providers:* The range of roles played by the spiritual care provider in the multi-professional team are described, including liaison with members of the community and the education and support of other members of staff. Choice of an appropriate spiritual care provider is recognised to be dependent on the individual client.
- 5 *Organisational requirements:* The organisational factors necessary in order to implement the recommendations are outlined, including providing culturally competent care; engaging with potentially harmful beliefs and practices in a sensitive but effective way; providing client-centred care; taking into account the spiritual well being of staff members; and committing to ongoing quality monitoring and improvement in spiritual care (e.g. through meeting the quality markers defined throughout the recommendations).

# Glossary

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The following terms used throughout this document are defined as follows:

<b>Term</b>	<b>Definition</b>
<i>Spirituality</i>	A universal search for existential meaning which may or may not include belief in a higher power (includes existentialist/ humanist positions). 'Spirituality' is used here to include personal religious beliefs (3-7); however, spiritual needs may or may not be expressed within a religious framework.
<i>Spiritual well being</i>	The concept of spiritual well being (understood as a continuum from spiritual pain or distress to spiritual wellness or growth) has developed as a way of conceptualising the health of the spiritual aspect of a person (8). It can be understood as the spiritual dimension of quality of life.
<i>Religion</i>	A pre-existing but dynamic set of narratives, beliefs and practices, shared by a social group, which provides a 'platform' for the expression of spirituality (3-7).
<i>Existential</i>	In this context, relating to questions such as 'Who am I?', 'Does my life have any purpose?', and 'Has this illness the power to destroy me?' Existential questions or concerns may or may not be expressed in religious terms (7).
<i>Culture</i>	The various ways of living and thinking that are built up and shared by a particular group of people (9;10), comprising shared rules, values, beliefs and meanings that guide decision making and action (11).
<i>Sub-Saharan Africa</i>	The area of the African continent which lies south of the Sahara or those African countries which are fully or partially located south of the Sahara.
<i>Cultural competence</i>	The ability, of an individual or organisation, to interact effectively with people of different cultures. A culturally competent organisation can be understood as one that acknowledges and incorporates - at all levels - the importance of culture, assessment of cross-cultural relations, vigilance toward the dynamics that result from cultural differences, expansion of cultural knowledge, and adaptation of services to meet culturally unique needs (12).
<i>Cultural sensitivity</i>	An individual's awareness of the potential and actual cultural factors that affect their interactions with others, e.g. in healthcare, a professional's effort to be aware of such factors in their interactions with patients and families, and willingness to work in a culturally competent way. Cultural sensitivity is considered to be a necessary component of cultural competence (12).

<i>Palliative care</i>	An approach that improves the quality of life of patients and their families facing the problems 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 (13).
<i>Client</i>	Throughout this document the term ‘client’ is used to refer to a person receiving palliative care. As the unit of care in the palliative approach is the person with incurable progressive disease and his or her family (13), ‘client’ refers to both patient and family member unless otherwise specified. ‘Patients’ in this context refers people living with incurable, progressive and life-limiting conditions (e.g. HIV, advanced cancer) who are receiving palliative care, including people living with HIV who are on anti-retrovirals and functionally stable.

# Section One: Background

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## 1 Literature review: Spiritual care in palliative care in sub-Saharan Africa

Although spiritual care is considered an intrinsic component of palliative care in Africa (1) and globally (14), there is little guidance for services on how to meet clients'<sup>3</sup> spiritual needs. In sub-Saharan Africa specific challenges include responding to the multi-dimensional distress of a growing population in need of palliative care, with limited resources and a lack of local research to inform service development and provision.

This review describes the need for palliative care in sub-Saharan Africa, the role of spirituality in illness and in the sub-Saharan context, and relevant policy guidance, in order to contextualise the recommendations presented in Section Two.

### 1.1. Epidemiology and symptoms of HIV in sub-Saharan Africa

In 2008 there were 22.4 million people living with HIV infection in sub-Saharan Africa – two thirds (67%) of the global total with HIV (15). In the same year, it is estimated that 1.9 million adults and children became infected with HIV, and 1.4 million adults and children died of AIDS (15). Provision of ART has expanded dramatically in sub-Saharan Africa. As of December 2008, 44% of adults and children (nearly 3 million people) in need of antiretroviral therapy in the region were estimated to be receiving such services. Five years earlier, the estimated regional treatment coverage was only 2% (16). As the availability of ART improves, mortality rates among people with HIV will continue to decrease, but, in the absence of effective behavioural change programmes, HIV incidence and prevalence will remain high (17).

While access to ART is crucial to prolong life, patients on ART continue to experience pain and other chronic symptoms caused by the underlying disease progression (18-20), co-morbidities (21;22) and opportunistic infections (23). Tuberculosis is the most common opportunistic infection for people living with HIV, including those on ART, and a leading cause of death for people living with HIV in low- and middle-income countries (24;25). Other prevalent opportunistic infections include *Pneumocystis jiroveci* pneumonia, cytomegalovirus retinitis, various oral diseases and complications, changes in bone mass and increased risk of bone disease, and cervical cancer (25).

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<sup>3</sup> Clients includes both patients and family members – see Glossary p 18.



In addition, up to half of HIV patients receiving ART experience adverse side-effects of treatment (26), which include hypersensitivity, lactic acidosis, increases in blood lipids, bleeding events, anaemia, neuropathy, lipodystrophy, and pancreatitis, and can be life-threatening (27;28). As a leading HIV clinician has stated, “The success of [antiretrovirals] comes at a price” (29) – that price is paid by the person taking the drugs (25). UNAIDS states that management of side-effects is an essential phase of ART administration, but also recognises that this is difficult in resource-limited settings, where drug substitution is not always feasible due to limited access to the full array of antiretroviral drugs licensed for use in high-income countries (25).

In sub-Saharan Africa, although the burden of HIV-related mortality and morbidity has been widely reported, few studies have examined the impact of HIV on peoples’ everyday lives. Given the lack of access to ART, many people with HIV infection in sub-Saharan Africa experience life without the drugs they need to prolong their lives. In Southern Africa (South Africa, Botswana, Lesotho and Swaziland), Makoe et al conducted a survey of 743 people with HIV who did not have access to ART (30). They report a high symptom burden; the five most prevalent physical symptoms were fatigue (55.7%), weakness (53.8%), concern over weight loss (47.9%), coughing (45.2%), and painful joints (45.1%). Simms et al recently reported the results of survey of 438 adults recruited within 14 days of testing HIV-positive at 11 outpatient centres in Uganda and Kenya (31). People with HIV experienced poor quality of life at diagnosis and rapid improvement over three months. However, this gain was not associated with receipt of anti-retrovirals, and the authors concluded that it is more likely to be a consequence of the multidimensional, holistic care received.

### **1.1.1. Living with HIV: Psychosocial and spiritual problems**

As well as the physical symptoms associated with the disease, there is evidence that adults with HIV experience significant psychosocial (19;32-34) and spiritual problems (35-37) related to living with the diagnosis. For example, a study of 376 seriously ill HIV patients in the USA found high prevalence rates for worry (51-53%) and feeling sad (43-50%) (19). It is estimated that nearly half of all people living with HIV worldwide will suffer at some point from clinical depression (38). In addition to its psychosocial consequences, HIV infection can have important biological effects on mental health functioning, resulting in cognitive impairment and dementia (39). HIV also presents a unique set of spiritual and existential challenges to patients as they confront aspects of living with a progressive, incurable disease that is highly stigmatised in many parts of the world (37;40).

Psychosocial problems are likely to be exacerbated in resource-limited settings, where stigma, unemployment and poverty can adversely affect patients’ lives in significant ways. Hunger and malnourishment further compromise the immune systems of people living with HIV, diminishing the body’s ability to fight infection (41;42), and making adherence to complex ART regimes difficult or impossible (43). Approximately 35% of the population of the most impoverished countries in the world suffers from inadequate nutrition (44). In their survey of symptoms in African adults with HIV, Makoe et al found prevalence rates of 45.4% for fear or worry, 40.2% for depression and 26.8% for anxiety (30). They report that ‘people living with HIV/ AIDS experience significant psychological symptoms, including fear, distress, and anxiety.

In fact, such symptoms are reported more frequently than are physiological symptoms', concluding, 'Strategies to help clients manage fear and anxiety are as important as developing strategies to manage their pain or diarrhea' ((30), p.31).

Although research is lacking regarding HIV patients' spiritual well being in sub-Saharan Africa, evidence suggests that levels of spiritual distress may be high. In a study of 64 HIV+ patients attending a hospice inpatient and homecare service in South Africa, Shawn et al found that psychological symptoms that may relate to existential concerns were highly prevalent: feelings of anger (66%), loneliness (50%), hopelessness (42%), an increased sense of guilt or punishment (39%) and a decreased sense of usefulness (27%) (45). There is also evidence that spirituality and religion play an important role in coping with HIV in sub-Saharan African populations, influencing psychological well being (46-48).

## **1.2. Cancer and other conditions**

In addition to the burden of HIV, cancer and other non-communicable diseases are becoming urgent public health issues in Africa. In a recent review, Parkin et al. (49) report that approximately one in five deaths in sub-Saharan Africa is due to cancer; in females, the lifetime risk of dying from cancer in Africa is almost double the risk in developed countries. Resource and infrastructure deficits mean that African governments are not able to meet the current disease burden. Survival rates are significantly poorer than those in developed countries, and patient expectations for curative oncological treatment are low (50;51). The situation is likely to worsen as the population ages. The number of people in Africa over 60 years old is projected to quadruple by 2050, with the lifetime risk of cancer expected to increase by 50–60%, and the annual number of cases to rise from 650, 000 to 2.2 million (49).

Patients with advanced cancer experience a well-documented and significant physical and psychological symptom burden (52-54), as well as social and spiritual problems (55-57) associated with an incurable, progressive diagnosis. A recent systematic review found that five symptoms (fatigue, pain, lack of energy, weakness, and appetite loss) occurred in more than 50% of incurable cancer patients (52). With respect to psychological symptoms, reviews suggest that, across studies, the median prevalence of major depression is about 15% among patients with advanced cancer (58), with many other patients experiencing milder depressive symptomatology associated with significant distress (59;60). Anxiety disorders, although less studied, are also relatively common among patients with cancer (61;62). Mental disorders have been linked to pain (59;63;64), weakness or fatigue (60;65), and low functional status (59;66). In addition, spiritual distress, although relatively under-researched, has been identified in cancer patients (67-69). Research into the experience of cancer in Africa is lacking.

## **1.3. The need for palliative care in sub-Saharan Africa**

Given the growing epidemiological burden of HIV and cancer in sub-Saharan Africa, and the extent of the problems faced by cancer and HIV+ patients, palliative care is an essential phase of

public health services in the region. The 2008 UNAIDS report on the HIV epidemic recognises that palliative care is integral to national HIV responses, and that existing palliative care programmes are under immense pressure to meet the growing needs of patients and their families ((25), Chapter 5, p.151). The number of deaths from HIV and cancer provides a lower limit for an estimate of the number of persons needing palliative care, as those suffering from a serious illness but not dying the same year, and those dying from diseases other than HIV/AIDS or cancer, also have palliative care needs. Based on an analysis of five countries of sub-Saharan Africa (Botswana, Republic of Tanzania, Uganda, Ethiopia and Zimbabwe), the WHO estimates that about 1% of the total population is in need of palliative care (50;70). Extrapolating across the sub-Saharan region, which had a population of 819 million in 2009 (71), gives an estimate of 8.2 million currently in need of palliative care. This need is rising – the UN predicts the region will have a population of over 1.7 billion in 2050 (72), which extrapolates to a population of 17 million in need of palliative care.

#### **1.4. Spirituality in incurable, progressive disease**

Evidence from the UK and USA suggests that spiritual and religious belief and practice play a key role in patients' experience of serious illness (73-75). In the UK, King et al. found that 71% of people in a study conducted at an acute hospital had what they considered to be an important spiritual belief, even though many did not express that in a religious way (73). Spirituality and religion may be of particular importance in incurable progressive conditions such as HIV or cancer, a diagnosis of which often has a significant impact on one's spirituality. In a study of 347 patients with HIV infection in the USA, Cotton et al found that 25% reported becoming more religious and 41% more spiritual since their diagnosis, and 50% thought spirituality or religion had helped them live longer (40). Approximately 1 in 4 participants also reported that they felt more alienated by a religious group since their HIV/AIDS diagnosis and approximately 1 in 10 reported changing their place of religious worship because of HIV/AIDS. In the UK, qualitative studies have found that religion and spirituality are important sources of support for HIV+ Africans (76-78).

There is also evidence from the UK and USA that patients with serious illness wish to discuss their spiritual beliefs with their physicians (79-81) and may have a need for spiritual support. Moadel et al, for example, found that in a group of 248 ethnically diverse cancer patients 42% indicated that they wanted help with finding hope and 40% with finding meaning in life (82). In addition, there is a body of evidence suggesting that spirituality and religion may have a beneficial effect on a range of patient outcomes. Religious faith and spiritual belief have been identified as important coping resources (83;84), and strength of belief has been found to predict clinical outcome (73). Spiritual activities such as meditation and prayer have been linked to perceptions of well being among long-term survivors of AIDS (85). Spiritual well being has been found to predict perceptions of living with HIV (86), contribute to quality of life in cancer (87;88) and heart failure (89), and protect against 'death distress' (90) and end of life despair (91). 'Positive religious coping' (e.g. religious forgiveness, seeking spiritual support, collaborative religious coping, spiritual connection, benevolent religious reappraisals)(92) is reported to protect from the stress of negative life events, while religiosity has been found to protect against depression (93).

However, a minority of studies have also reported less beneficial effects (94;95), particularly in relation to negative patterns of religious coping methods (for example, reappraisals of God as punishing, pleading for direct intercession, demonic reappraisal and reappraisals of God's powers) (92;96). This suggests that the relationship between spirituality, religion and health is not a straight-forward one. There is also debate regarding the mechanisms by which spirituality may influence health outcomes (96;97), although the influence of culture in these areas is acknowledged (98-100). More research is required in these areas, but it is clear that spiritual distress (also called spiritual pain) may have a profoundly negative effect on patients' quality of life. Spiritual distress can be defined as the suffering that occurs when a person becomes estranged from the essence of who he or she is (4;101), loses any sense of meaning in life (4;7), becomes demoralised (102) and feels a growing sense of fragmentation or disconnection (6;7). Through somatisation spiritual distress may result in physical symptoms (4;6;7), such as intractable pain, as well as having psycho-spiritual (4;6;7;103;104), religious (6;7) and social manifestations (6;7;104). Investigating the aetiology of pain, including the potential spiritual components of apparently physical pain, is crucial in order to relieve patient suffering, particularly if such is pain is proving unresponsive to pharmacological treatment. Spiritual care may therefore play an important role in the alleviation of the experience of pain – a notion captured in Cicely Saunders' concept of 'total pain' (105) – and further research in this area is required.

### **1.5. Spiritual care needs among carers and family members**

The burden of care giving is well-described in the literature. Research from North America and Europe has shown that carers of patients receiving specialist palliative care experience high levels of anxiety (106-109), distress (110), vulnerability (111), depression (108;112;113), and strain (110;114), as well as unmet needs for information and financial and domestic support (107;108;115-120).

In a recent study Tsigaropoulos et al surveyed 76 caregivers of patients with advanced cancer in Greece and found the most frequently reported problem was anxiety regarding the patient's future (61.8%) (108). Unhappiness or depression (48.7%) and emotional upset (47.4%) were also highly prevalent. Evidence suggests that physical problems with somatic elements are also highly prevalent amongst carers. The same study found that 38.2% of caregivers usually suffered from body pain or other somatic symptoms and 27.6% usually suffered from sleeping disorders (108). Similarly, Osse et al found high levels of stress-related symptoms such as muscle pains or painful joints (47%) and fatigue (65%) among 67 caregivers in the Netherlands (107).

While relatively little research has focused specifically on carers' spiritual needs, there is evidence that spiritual concerns may be highly prevalent during care-giving.<sup>4</sup> Tsigaropoulos et al found that in their religious sample (only 2.8% did not believe in God), 22.2% of carers reported becoming more religious since their loved one became ill (108). Osse et al found that carers' personal problems most frequently concerned coping with the situation mentally, their

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<sup>4</sup> Psychological and spiritual problems may be particularly acute in parents of children with life-limiting, progressive conditions (121); see 1.6. below for more information in this regard.

fears, and existential/spiritual questions (107). Caregivers reported fear of an unpredictable future (80%), and problems regarding the acceptance of the patient's disease (69%), hope for the future (68%), the meaning of death (54%) and trust in God or religion (10%) (107). In the USA, studies by Hileman and colleagues (116;117) also report spiritual needs to be one of the categories of need identified by carers of patients with cancer. Similarly, in a study by Harrington et al caregivers of clinic cancer patients (n=25) ranked "hope for the future" and "a strong faith in God" in the top 10 needs they identified as 'very important'. In the same study, the caregivers of hospice patients (n=30) ranked "prayers from others" and "a strong faith in God" among their top 10 needs.

That spiritual needs are reported by care givers is in line with the evidence that spirituality acts as a buffer against the stressors of care-giving for HIV patients (122;123), elderly adults with chronic illness (124), women with breast cancer (125), and men with dementia (126). These studies suggest that caregivers use spirituality to find meaning and purpose in their stressful situations, and that spiritual support may be both needed by carers and effective in improving their experience of caring.

There is also evidence that spirituality may play an important role in bereavement. Although the nature of the relationship between spiritual belief and bereavement outcomes is unclear (127;128), several studies have identified spiritual needs during the bereavement phase (129;130), particularly in parents of children who have died (131). Spiritual care may therefore be particularly important in supporting grieving family members and other key caregivers.

## **1.6. Spiritual care needs among children**

Little is currently known about the illness experience of children with life-limiting, incurable conditions, or their symptoms other than pain (132;133). In a landmark study of the parents of 103 children who died at Children's Hospital and the Dana-Farber Cancer Institute in Boston (USA), Wolfe et al found that children who died of cancer experienced substantial suffering in the last month of life (134). 57% of children experienced a great deal or a lot of suffering from fatigue in the last month of life. In the same period, approximately 46% experienced that degree of suffering from pain and 42% from dyspnoea. During the last month of life the majority of children had little or no fun (53%), were more than a little sad (61%), and were not calm and peaceful most of the time (63%), according to their parents. 21% were described as often being afraid. The authors also found that earlier discussion of hospice care was associated with a greater likelihood that parents would describe their child as calm and peaceful during the last month of life.

The majority of literature concerning spirituality does not include discussion of children's spirituality and spiritual needs, focusing instead on adults and, especially, older people (135). This is a serious omission if spirituality is considered as something universal to all of us, no matter what our age or stage of development. In fact, childhood may be a time of increased awareness and openness to spiritual experiences, in part due to the relative lack of cultural pressures, and this may be particularly true for children experiencing illness or bereavement

(136). Children in these circumstances are striving to understand not only what is happening to them, but why (135;136).

However, little is known regarding the experiences and needs of children with incurable, progressive disease, or of children who have been recently bereaved. The evidence that does exist in this area comes from studies of parents of children with serious illnesses (137-139), and suggests that spirituality is an important coping strategy and factor in decision-making in this population. A recent Canadian study of 25 parents whose children had died of brain tumours identifies finding spiritual strength, through maintaining hope and witnessing the resilience of their child, to be an important parental coping mechanism (140). Similarly, in a qualitative study from the USA, Robinson et al interviewed 56 parents whose children had died in paediatric intensive care units after the withdrawal of life-sustaining therapies (141). The authors found that many parents drew on and relied on their spirituality to guide them in end-of-life decision-making, to make meaning of the loss, and to sustain them emotionally. Overall, spiritual themes were included in the responses of 41 of the 56 parents asked about what had been most helpful to them and what advice they would offer to others at the end of life. Four explicitly spiritual themes emerged: prayer, faith, access to and care from clergy, and belief in the transcendent quality of the parent-child relationship that endures beyond death. Parents also identified several themes which the authors describe as implicitly spiritual, including insight and wisdom; reliance on values; and virtues such as hope, trust, and love.

There is also evidence that spiritual support in paediatric care may be beneficial in a number of ways (142). In a retrospective review of deceased patients' medical records in a children's hospital, for example, Tan et al report that spiritual support (defined as a documented visit from non-denominational hospital-based clergy) was associated with an increased likelihood of starting an end of life care discussion, and an increased use of opioid analgesics and sedatives (143).

## **1.7. Spirituality and religion in sub-Saharan Africa**

In developing spiritual care recommendations for the sub-Saharan context, the religious and cultural environment in which palliative care services function is paramount. The societies of sub-Saharan Africa are in general highly religious. For example, in the 2001 South African census 0.3% of the population self-identified with traditional African religion, while 79.8% identified as Christian. In Uganda, the 2002 census found 1% identified with traditional religions while 85.1% identified as Christian. However, religion is culturally embedded and adapted according to the specifics of the communities in which it is found; hence Christianity in these contexts may look very different from the Christianity prevalent and studied in the USA. In sub-Saharan Africa, the religious acculturation<sup>5</sup> that has occurred as traditional religion has encountered Christianity has involved the fusion of elements of the new religion and the old tradition. The resultant forms of religious syncretism form the new religious movement of the Independent African churches, in which biblical and African worldviews are combined in meaningful ways (144).

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<sup>5</sup> Acculturation is the process whereby the attitudes and/or behaviours of people from one culture are modified as a result of contact with a different culture.

Attitudes to illness in Africa are influenced by traditional spiritual views of the world and our place within it (145;146). The use of traditional and herbal medicine is common (147), with a survey of palliative care services reporting that 80% of patients seek the advice of traditional healers (148). Ancestor reverence or veneration is widespread in many African societies, with the ancestors representing a powerful moral sanction that affirms the values upon which society is based ((149), p39). The good deeds of the ancestors spur the living on to good conduct, while the threat of punishment by ancestors deters violation of sanctioned mores; “Ancestral beliefs, in summary, underscore certain social ideals: the vibrant reality of the spiritual world or ‘an alive universe’, the continuity of life and human relationship beyond death, the unbroken bond of obligations and the seamless web of community.” ((150), p55) Death may be seen as a ‘mere passage from the human world to the spirit world’, (150) enhancing spiritual powers and enabling one to operate as a family guardian or protective spirit. Belief in reincarnation is prevalent, with ancestors seen as returning through their children.

In the countries of sub-Saharan Africa, furthermore, religious and political histories are often inextricably linked. Writing of South Africa, for example, De Gruchy states:

*‘The transformation of Christianity, from a white, European-dominated settler religion, with expatriate missionaries engaged in evangelising the indigenous people of the country, to a black-majority religion rooted in African culture and engaged in the struggle against white social, political and ecclesial domination, is undoubtedly the most significant development of twentieth century Christianity in South Africa.’ ((151), p.83).*

Another aspect of sub-Saharan African culture relevant here is the idea of ‘*Ubuntu*’<sup>6</sup>, a philosophy which underpins sub-Saharan social mores and ideals of leadership, governance and justice. Archbishop Emeritus Desmond Tutu has described the concept of *Ubuntu* as follows:

*‘One of the sayings in our country is Ubuntu - the essence of being human. Ubuntu speaks particularly about the fact that you can't exist as a human being in isolation. It speaks about our interconnectedness. You can't be human all by yourself, and when you have this quality - Ubuntu - you are known for your generosity... We think of ourselves far too frequently as just individuals, separated from one another, whereas you are connected and what you do affects the whole world. When you do well, it spreads out; it is for the whole of humanity.’*

The concept of *Ubuntu* is expressed in the isiZulu maxim *umuntu ngumuntu ngabantu* (‘a person is a person through (other) persons’); i.e. the person one becomes by behaving with humanity is an ancestor worthy of respect or veneration. Those who uphold the principle of *Ubuntu* throughout their lives will, in death, achieve a unity with those still living (152).

Given the cultural, historical and religious specificities of the African worldview outlined only briefly here, it is unlikely that findings from research in the developed world into the existential aspects of patients’ experience of illness are directly transferable to an African context.

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<sup>6</sup> The concept of *Ubuntu* appears in many African languages, e.g. ‘*ubuntu*’ (isiZulu, Kinyarwanda, Kirundi), ‘*unhu*’ (Shona), ‘*botho*’ (Setswana), ‘*obuntu*’ (Luganda, Runyakitara)

While there has been little research in this area in Africa, existing evidence suggests religion and spirituality are at least as important to patients in sub-Saharan Africa as those in the USA and Europe, acting as key coping resources for patients with HIV infection and their families (46;47;153;153-155). In an ethnographic study involving in-depth interviews with 10 HIV+ women, and focus group discussions with 25 HIV+ support group members and 3 volunteer workers, turning to religion and tradition were found to be important coping strategies for black, rural South African women with HIV/AIDS (46). Prayers and singing are described as a distraction from negative thoughts about HIV/AIDS and turning to God as a way of maintaining hope. A qualitative study of 18 adults bereaved by AIDS deaths in KwaZulu Natal, 13 of whom were HIV+, identified three ways of coping, two of which were spirituality and maintaining hope (154). A main theme identified was participants' reliance on faith as a way to understand their loss, as well as a source of strength and comfort as they coped with life without their loved one. In a grounded theory study Greeff et al also found spirituality to be an important coping resource amongst 51 Xhosa-speaking families in South Africa that had recently experienced the death of a child or a serious financial setback (156). In another Xhosa study of 172 Black women in a South African township, engagement in formal religion was found to buffer the effects of stress (157). Similarly, a small, qualitative study of 7 Ugandan women with HIV disease reports that spiritual beliefs provide purpose in life and help the women maintain hope (47).

## **1.8. Palliative care and policy**

Given the importance of spirituality in the experience of serious illness, it is appropriate that spiritual care is considered one of the key components of palliative care. Palliative care is defined by the 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'* (13).

The importance of attending to the spiritual dimensions of the child receiving palliative care is also increasingly recognised, as reflected in the WHO definition of palliative care for children as *'the active total care of the child's body, mind and spirit'* (14).

In common with palliative care guidance globally (158-162), the APCA *Standards for Providing Quality Palliative Care Across Africa* (1) stipulate spiritual care provision and assessment:

*'Standard 2.8: The spiritual needs of the patient and family are assessed, and spiritual care is well-planned and coordinated in all settings.'*

The standards acknowledge that spirituality can help patients cope with the uncertainty of their illness, instil hope, bring comfort and support from others, and resolve existential concerns, particularly the fear of death. Common spiritual needs are identified, no matter what a person's belief system: a search for the meaning of life and purpose of living, receiving and giving love, having a sense of forgiveness, hope and creativity, and feelings of completion, responsibility and control. In order to alleviate the spiritual pain that can result from the fear of dying, anger, suffering, guilt and a search for the meaning of life or the purpose of living, the standards



recommend that patients should be encouraged to talk about their feelings. The standards also suggest that healthcare workers can reach into the spiritual aspects of themselves to draw on the sensitivity and compassion needed to share with patients and their families what is important to them in facing chronic illness, death and grief. Elaborating the requirements of services further, the standard is divided into three sections, for primary/ basic level services, secondary/ intermediary level and tertiary/ specialist level respectively.

In conjunction with the standards document, APCA will be launching later in 2010 a set of core competencies for palliative care providers (2). The topic 'Spiritual and Cultural' is included under the category of 'Therapeutic relationship' (1.c.). The competencies set out what is required of palliative care staff working at four levels: Level N: Non-professional caregivers, Level A: Basic; Level B: Intermediate; and Level C: Specialist. The competencies require that all staff members are capable of at least basic assessment of spiritual and cultural needs; are able to offer basic spiritual support, referring where necessary; and are able to provide culturally sensitive care. Competencies for staff members at levels A-C make further requirements in the areas of:

- Initiating discussions of spiritual and cultural beliefs (Level A)
- Self-awareness of one's own spiritual and cultural beliefs and how they impact one's work (Level A)
- Undertaking more complex assessment in the areas of spirituality and culture (Level B)
- Incorporating spiritual and cultural needs into the care plan (Level B)
- Understanding and appreciating wider cultural and spiritual needs of the population (Level B)
- Skilled counselling (Level B)
- Fostering and implementing a culturally and spiritually sensitive environment of care (Level C)
- Ability to discuss different models of spiritual assessment and care (Level C)
- Ability to identify and elicit appropriate spiritual and cultural support for the family (Level C)
- Ability to develop appropriate models of spiritual care (Level C)

## **1.9. The need for these recommendations**

Within palliative care, research into spiritual well being and care is still at a developmental stage, despite the recognition that spiritual 'problems' need to be identified, assessed and 'treated' (13). The concept of spirituality is the subject of major debate (5;163-167), and the meaning of spiritual well being to patients is not clear (168-170). The majority of studies of spirituality are conducted in culturally- and ethnically-specific USA population groups, and are not easily transferrable to the African context. While a small number of models of spiritual care and intervention appear in the literature (e.g. (171-174)), the majority were developed in the USA and have not been evaluated. It is not known how appropriate they would be outside of North American populations with specific cultural and religious characteristics. If spiritual care provision in sub-Saharan Africa is to be evidence-based, further research in these areas is essential (175;176).

APCA has made important inroads in the provision of spiritual care within the context of African palliative care by launching its standards (1) and developing the core competency frameworks to be launched later in 2010 (2). In order to meet the standards, palliative care services and programmes require evidence-based guidance on how to achieve the requirements APCA has set out. Examples of good practice in spiritual care in Africa are also important in order to share knowledge and facilitate networking between services. These recommendations are designed to complement and build on the APCA standards and competencies by offering such guidance and examples of good practice from sub-Saharan Africa.

## 2 Background to the recommendations

These recommendations were generated by a programme entitled '*Spiritual care for patients receiving palliative care in sub-Saharan Africa*'. The project aimed to develop a set of spiritual care recommendations on the basis of data from a study investigating patients' spiritual well being and the provision of spiritual care at palliative care services in South Africa and Uganda. This study, currently in its final year, uses data from a number of sources:

- Survey data on spiritual well being from 285 patients attending five specialist palliative care services (four in South Africa and one in Uganda)
- 72 qualitative interviews with patients receiving palliative care at four of these services (three in South Africa and one in Uganda)
- 21 interviews with spiritual care providers (both in the community and at the four services) in South Africa and Uganda
- Data from four seminars attended by spiritual care providers, local faith leaders and palliative care staff in South Africa and Uganda
- Interviews with the four research nurses who conducted the patient interviews

This data represents an innovative and large body of work on patients' spiritual needs and resources, and the role of spiritual and religious belief in the illness experience. Data from spiritual care providers and other stakeholders complement this by documenting experiences of providing spiritual care to patients and family members, the challenges faced in this kind of work, spiritual care providers' recommendations for how best to meet clients' spiritual needs, and what works well (and not so well) in the provision of spiritual care for this client group.<sup>7</sup> In drafting the recommendations, findings from all data sources were taken into account; qualitative data from spiritual care providers were particularly valuable. Quotations from the interviews with spiritual care providers are presented throughout in coloured speech bubbles.

The Advisory Group comprised researchers, palliative care providers, spiritual care providers and representatives of national and international African organisations (see page 4). The Group played a central role in formulating the recommendations, which were developed and finalised through a series of consultation phases described below (2.3 Development methods).

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<sup>7</sup> Findings from the study will be published in 2011.

Although the data that informs these recommendations is from South Africa and Uganda, members of the Advisory Group confirmed that our findings regarding spiritual care needs were relevant more widely to other sub-Saharan African groups, which share similar worldviews and healthcare contexts. Given its rich and novel nature, the dataset utilised to generate these recommendations has also been translated into the UK context through expert consultation. This resulted in the launch, in May 2010, of a set of spiritual care recommendations for Black and minority ethnic people receiving palliative care in the UK (177).

These recommendations are presented in response to the critical need for spiritual care guidance, and as a contribution to the ongoing process of improving the spiritual care of people receiving palliative care in sub-Saharan Africa. In applying the recommendations and incorporating them in training programmes it is hoped that palliative care services will make their own adaptations based on their local context. In the future, revised drafts of the recommendations will take into account the lessons learnt during adoption and application at the service level, highlight further examples of good practice, and further develop suggested quality markers.

## **2.1. Aim**

These recommendations aim to inform the provision of spiritual care for people receiving palliative care in sub-Saharan Africa by providing evidence-based guidance for palliative care service providers. The recommendations are designed to be broad and adaptable to different local conditions, so that they are applicable across sub-Saharan Africa. They are also designed to complement and facilitate the attainment of the APCA standard on spiritual care.

In addition, the authors hope these recommendations will contribute to a much-needed debate on the best construction of a multi-faith response to incurable, progressive illness that meets the needs of patients and families.

## **2.2. Audience**

The intended audience for these recommendations includes palliative care service providers, spiritual care providers and educators working in sub-Saharan Africa, and healthcare policy makers, in Africa and globally.

## **2.3. Development methods**

The development of the recommendations involved the following steps, undertaken during 2010:

1. After data analysis, APCA and HPCA were contacted by Lucy Selman regarding the development of the recommendations. Both organisations offered support for the recommendations and agreed to collaborate.

2. Potential members of the Advisory Group were identified and invited by Lucy Selman, with assistance from APCA and HPCA. Further invitations were sent out to experts recommended by the initial contacts. This resulted in a group of 23 members who contributed to the recommendations (see page 4).
3. Specific contacts known to Lucy Selman and members of the Advisory Group were emailed to request good practice examples for the recommendations.
4. On the basis of the analysed data (see page 33), the first draft of the recommendations was written by Lucy Selman and circulated to the co-authors and members of the Group. All members submitted comments on the first draft, appraising their local acceptability and appropriateness. In particular, Group members were asked to consider:
  - The practicality, feasibility and appropriateness of the recommendations
  - Whether anything relevant was omitted from the recommendations
  - Which recommendations were ranked as most important and why
5. The comments of the Group were then incorporated into a second draft which was sent back to members of the Group for additional comments.
6. The third draft of the recommendations was then formulated and agreed by all members of the group.
7. The recommendations were launched at the APCA conference in Namibia in September 2010.

## **2.4. Dissemination**

These spiritual care recommendations will be disseminated nationally and internationally through:

- Collaboration with national and international associations, policy makers, NGOs and palliative care service providers, including members of the Advisory Group
- Publication in a peer-reviewed journal (manuscript in preparation)
- Presentation at the 3<sup>rd</sup> APCA conference (Windhoek, Namibia, September 2010)

## 2.5. Structure

The recommendations are presented in five categories with sub-categories, as follows:

<b>1. Identifying spiritual needs</b>	1.1. What are spiritual needs?
	1.2. Assessment of spiritual needs
<b>2. Responding to spiritual needs</b>	2.1. The ingredients of spiritual care
<b>3. Working with the community</b>	3.1. Sharing spiritual care
	3.2. Education and training
	3.3. Referral
<b>4. Spiritual care providers</b>	4.1. Attributes of the spiritual care provider
	4.2. Role of the spiritual care provider in palliative care
	4.3. Choice of spiritual care providers by the palliative care team
	4.4. Support for spiritual care providers
<b>5. Organisational requirements</b>	5.1. Implementing the recommendations
	5.2. Culturally competent care
	5.3. Understanding of spiritual well being and care
	5.4. Providing client-centred care
	5.5. Staff support
	5.6. Quality improvement

For each category, the background or rationale for the recommendations is presented first, followed by a box stating the recommendations for that category.

Education, training and support on an ongoing basis are themes that cut across all five categories. For a summary of the recommendations by category, see Appendix 1, page 90.

### 2.5.1. Quotations from spiritual care providers

Quotations from the spiritual care providers in South Africa and Uganda who were interviewed for the study are given in speech-bubbles throughout the recommendations. These serve as examples of the data informing each section of the recommendations. Each spiritual care provider has been given an identification code and the quotations have been anonymised.

### **2.5.2. Good practice examples**

Examples of good practice have been incorporated into each section of the recommendations to inform service provision.<sup>8</sup> The examples were provided by members of the Advisory Group, and demonstrate the creativity and dedication of teams working in a number of sub-Saharan African countries (South Africa, Uganda, Namibia, Kenya, Tanzania and Zimbabwe). These examples are evidence of the possibility of developing and maintaining good practice in the provision of spiritual care, despite the challenges of working with limited resources.

### **2.5.3. Quality markers**

Quality markers (also called quality indicators) are explicitly defined and measurable items referring to the outcomes, processes, or structure of care (178). Their purpose is to provide a framework for a palliative care organisation to define and track its progress against its own targets. Quality markers are useful in healthcare as a way of monitoring and improving the quality of care and ensuring a seamless service that is organised round the individual (179).

A recent systematic review found few quality markers for spiritual, religious and existential aspects of palliative care, and none at all for cultural aspects (180). The 2009 USA symposium on quality indicators in end- of-life cancer care reports similar findings (181).

In light of the lack of quality markers in the spiritual and cultural domains and in order to guide service evaluation, quality markers have been suggested for each of the recommendations presented here (summarised in Appendix 2, page 102). In line with recent guidelines (182), the proposed quality markers are:

- Based on evidence and expert opinion;
- Supported by stakeholders;
- Publicly reported (in this document as well as through journal publication and conference presentation); and
- Amenable to feedback from health care services and professionals.

The quality markers are suggested as a way for services that are committed to implementing the recommendations to track their progress. It is expected that service providers will prioritise recommendation categories according to their own aims, and develop individualised and more detailed quality markers based on local context (for example, numerators and denominators are required to make some of the markers more explicit (180)). As such, the quality markers aim to guide service providers in developing their own set of achievable yet aspirational indicators for audit purposes.

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<sup>8</sup> The term 'good practice' rather than 'best practice' is used as the examples do not represent evaluated models of care provision.

# Section Two: The Recommendations

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## 1 Identifying spiritual needs

### 1.1. What are spiritual needs?

Clients' spiritual needs are integrated with other dimensions of need, including the social, psychological and physical. Some spiritual concerns may be religious, but many will not be.<sup>9</sup> The subjects and questions which may arise for patients include (but are not limited to) the following:

- Meaning, e.g. *What does life mean to me and my family now?*
- Purpose, e.g. *What is the point of living?*
- Hope, e.g. *What hope is there for me, if there is no cure for my disease?*
- Identity, e.g. *How can I still be a good father or mother to my children?*
- Acceptance, e.g. *Why has this happened to me? Will I really have this illness forever?*
- Bargaining, e.g. *If I pray harder, will my disease be cured? I promise to donate to the church if I am alive in a year.*
- Guilt, e.g. *This must have happened to me because I did not obey my ancestors' wishes.*
- Shame, e.g. *God punished me for my sins by giving me this disease.*
- Forgiveness, e.g. *How do I forgive my husband for giving me HIV?*
- Unfinished business, e.g. *I have not seen my parents since they excluded me from the house; now I am worried who will look after my children when I am gone. Can you help me contact them?*
- Making amends, e.g. *It's been years since I spoke to my sister; it doesn't feel good. Maybe we can meet?*
- Anger, e.g. *Why has God let this happen to me when I have been faithful all my life? What have I done to deserve this?*
- Fear, e.g. *What is going to happen to me in the future? How will I be judged when I die?*
- Feeling a burden, e.g. *All our money has been spent on my treatment, and now my wife stays at home to take care of me. It would be better if I left this life.*
- Carrying out rituals, e.g. *How can I satisfy my ancestors and return to my village? What rituals can my parent/ spouse/ siblings/ physicians do to appease the ancestral spirits?*
- Sadness and loss, e.g. *I am so sad to be leaving my family/ children/ parents.*
- Worry, e.g. *I am the breadwinner for my family. How will they cope without me?*
- Changes in belief, including loss of faith, e.g. *My old faith seems empty and meaningless. I no longer believe in God and I don't want to talk about religion.*

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<sup>9</sup> See Glossary p. 18 for the definition spirituality used in this report.

*"In their spiritual counselling they ask, 'Why did God do this to me?' Some of them will tell you, 'I wasn't even a womaniser, but this thing just happened to me. Why?' They've got a sad heart, whatever. They have got a cry in their hearts."*

Spiritual care provider CTLH\_SCP03, Cape Town

Family members will face many concerns similar to those faced by patients, and the distress of bereavement may also have a spiritual dimension. Some of the additional concerns that may arise for family members include:

- Feeling inadequate, e.g. *I don't know how to nurse my wife – what if I do the wrong thing?*
- Guilt, e.g. *Why did this happen to my child and not to me? God must be punishing me for my sins.*
- Burden of caring, e.g. *I am so tired and I have no time for myself. Sometimes I get angry and frustrated, but then I feel bad about myself.*
- Anxiety about the future, e.g. *How will I cope when my loved one is gone?*
- Grief, both anticipatory and post-bereavement, e.g. *I miss my aunty so much. I feel as if my life has no meaning any more.*
- 'Survivor guilt', e.g. *My daughter suffered so much, and now she is gone while I am still alive. Why didn't God take me instead?*

Whether patients, family members or orphans, children are especially vulnerable, and also experience spiritual distress. Children's spiritual needs vary according to developmental stage and their unique individual circumstance. Their spirituality is likely to be centred around their understanding of life as they experience it on a day-to-day basis rather than in relation to a religious framework (183). However, as children get older they may adopt their family's belief system or develop their own interpretation of religion, and may sometimes request religious rituals (e.g. baptism). While children may experience any of the concerns listed above, other worries, such as loneliness and fear of separation (from parents, siblings, friends or pets), may be more acute. The types of questions which may arise for children include:

- *Who will love me now my mother is dead?*
- *Who will take care of me now that my parents are no longer here?*
- *Will I be able to go to school if my father dies?*
- *I was there when my father died and I saw how much pain he was in. Will I suffer when I die?*
- *Will I ever see my family again?*
- *Will I be forgotten?*
- *Will I be replaced?*

Children are likely to express their spirituality, needs and concerns differently from adults. For example, children may use play and story-telling to express their spiritual beliefs, describe their fears and dreams, and convey their needs. Children may talk about 'magical' and non-human



beings such as angels, fairies or monsters (183). Listening to these stories can help us to understand children's current spirituality, fears, worries and needs for support.

Parents of children with incurable, progressive illnesses are also likely to have specific spiritual concerns and may have a number of questions; for example:

- *Does my child have a sense of his/ her own meaning?*
- *Does my child understand our faith?*
- *Will my child continue living in an afterlife?*
- *When should I have started teaching my child what to believe? Is it now too late?*

The death of a child can be particularly traumatic, and family members may feel a profound sense of loss: of faith in life or God, and of hopes and dreams for the future. The spiritual component of bereavement support becomes particularly important in this context.

### **1.1. Recommendations**

- Understand spiritual needs broadly, as including all the existential concerns with which a client may require support
- Offer spiritual care to family members and carers as well as to patients, and to children as well as adults
- Integrate spiritual care into bereavement support

### **1.2. Assessment of spiritual needs**

Clients may convey their spiritual concerns and distress to healthcare staff in many different ways; for example, by asking some of the questions listed in the previous section. However, some patients may not express their spiritual concerns directly. They may become depressed, distance themselves from their family, or become very angry or very sad. Clients may also express spiritual distress somatically, i.e. through their bodies; for example, spiritual distress may contribute to patients' experience of pain and might make that pain difficult to treat pharmacologically. Given the fact that spiritual concerns and distress may not be expressed directly, and may be easily confused with the psychological, physical and social states to which they are intimately related, proper assessment of spiritual need is essential.

Assessment of spiritual needs by a member of the care team is the first step towards being able to respond to those needs. The APCA standard on spiritual care therefore requires that *'The spiritual needs of the patient and family are assessed, and spiritual care is well-planned and coordinated in all settings.'* (2.8) Assessments of spiritual need can be categorised into three types, which are discussed in turn:

- Screening (on registration with the service)
- Spiritual assessment (once immediate concerns are met – unless these concerns are themselves spiritual in nature), and
- Assessment using formal tools (which may be integrated into screening or assessment, if appropriate).

### 1.2.1. Screening

The APCA standards state that at minimum there should be ‘*an assessment of basic spiritual needs of the patient and their family, aimed at identifying needs and providing basic support*’. This is reflected in the APCA competencies, in which the ability to conduct a basic assessment of spiritual needs is a requirement at Non-professional care giver and Basic levels, while Intermediate and Specialist levels require the ability to undertake more complex assessments.

Identification of spiritual needs is also known as *screening* for any immediate spiritual need or pain. It is important to recognise that clients with no formal religious beliefs or affiliations may still have urgent spiritual needs which might need attention.

*‘I think there is definitely still some room for improvement, because there is no standardised way that we are assessing spiritual need. I would love to see that there is a certain question or a certain form that we could ask or fill in that will give a clear indication of the spiritual need of the patient.’*

Spiritual care provider CTLL\_SCP01, Cape Town

### **1.2.1. Recommendations**

- In line with the APCA standards, ensure all team members have the appropriate training and support to be able to initiate discussions of spiritual issues and identify and assess spiritual pain (i.e. screen for spiritual distress)
- Integrate screening for spiritual distress, immediate spiritual needs and other needs associated with culture and/ or faith into routine assessment of all clients on registration with the service (e.g. first homecare visit or on admission to the inpatient unit)
- During screening:
  - Ask whether the client has a particular faith which they practice, whether it has been affected by illness and if so, how<sup>1</sup>
  - If they are religious, ask if they would like access to an appropriate faith leader, either as soon as possible or in future (for example, in the event of a life-threatening crisis)
  - If they are not religious, ask if they would like access to a member of the care team who may be able to help with any spiritual concerns they may have (e.g. a spiritual counsellor or a nurse/ social worker with training in spiritual care)
  - Record the contact details of the appropriate faith leader, or ask permission to refer to one of the spiritual care team (e.g. a spiritual counsellor, a nurse/ social worker with training in spiritual care, or a pastor with training in palliative care)
  - Inform the client of the spiritual care services available through the palliative care service
  - Identify any immediate spiritual concerns which require attention, so that these can be prioritised when planning the client's care
  - Where clients indicate that they have no spiritual needs at present, this should be recorded in their records for further exploration once immediate needs are met
  - Record important additional information related to culture and/ or faith, e.g. specific dietary needs, the need for water for cleansing before prayer, space for private prayer, or a same-sex health care professional)
- Ensure all team members are able to respond to identified spiritual needs through providing basic spiritual care, initiating a full spiritual assessment (see 1.2.2.) and/ or referral
- Ensure screening is documented in client records

### 1.2.2. Spiritual assessment

A detailed spiritual assessment is a requirement at the tertiary level described in the APCA standards, which suggest the use of simple questions on spirituality, such as those contained in the FICA acronym, in client assessment tools (see Box 1 for further guidance).

Careful observation of children's behaviour, interactions and emotions is an important way of ascertaining their needs for further support, and involving the child in play and drawing can highlight spiritual questioning or distress. Children respond to a constant and caring presence, and may only feel comfortable expressing their spiritual needs and fears once a relationship of trust has been established.<sup>10</sup> However, many children and adolescents feel more comfortable discussing these questions with "outsider" (e.g. a staff member, community caregiver or volunteer) than a family member.

In assessing clients' spiritual needs and helping them explore their spiritual history and well being, the complex and shifting nature of the illness experience needs to be taken into account. Patients' and family members' needs may change considerably as illness progresses and new questions and concerns arise.

Which member of staff is most appropriate to conduct a spiritual assessment with a client depends on the structure of the multidisciplinary team (see 4.3.); however, it is crucial that staff members conducting spiritual assessments are properly trained to do so. The ability to tailor spiritual assessment to the individual client is particularly important given the cultural and linguistic diversity of sub-Saharan Africa.

*"You need to have a diverse range of people providing spiritual care, and a huge range of questions to catch that underlying spiritual need. Like, 'At this point of your life, how do you make sense of your life's journey?' Some people will think, 'What is he talking about?' They have never talked in those words, thought about them: life as a journey? Where? No, their concerns are food, money for the end of the month – a different language. So we need to ask, what language are the people speaking in? And I don't just mean Xhosa or Tswana or whatever, I'm thinking the deep meaning of language: what do words mean in their language?"*  
Spiritual care provider CTLK\_SCP01, Cape Town

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<sup>10</sup> See 'Spirituality' in *Children's Palliative Care in Africa*, ed. Justin Amery for more details on spiritual care for children (183).

### **Box 1: Conducting a spiritual assessment**

An effective starting point for spiritual assessment is a private exploration with clients of the treatment and care issues that are currently important to them, and their past and current coping resources. To initiate an exploration of these issues the following questions may be useful:

- When life has been difficult for you, what has enabled you to cope?
- What sources of strength do you look to when life is difficult?
- How do you make sense of what is happening to you?
- Do you have particular beliefs that help you to make sense of life?
- What is really important to you at the moment? Would you like to talk further to someone about these issues?
- Would you find it helpful to talk to someone about spirituality/faith?
- Do you have a religious faith? Can you tell me about that?
- [If appropriate] Has this illness had any impact on your relationship with God?
- [If appropriate] It appears most people in this community are Christian, and it might be difficult if someone had different beliefs, or found themselves with questions about religion. Is this something that concerns you right now?

In working with children, the following questions may also be useful:

- What is helpful to you when you are sick?
- Do you have a special place where you go?
- Who/ what makes you feel safe? (Children can also be asked to draw their circle of support and safety)
- Who/ what is closest to your heart?
- What makes you happy/ sad/ frightened?
- What is important to you in life?
- What does this illness mean to you?
- What do you know about the illness?
- Have you known someone/ a pet who has died? How did you feel?
- When someone dies, where do they go? Why?
- What do they find there when they die?
- [If appropriate] Do you have a special place you go to pray?
- [If appropriate] How do you view God?

These questions are suggested as an informal guide to aid discussion of spiritual resources, beliefs and needs. Each spiritual care provider will find their own way of asking these types of questions, and individual discussions should be tailored to the client.

Other aids in discussing spirituality within a clinical context include *aide memoires* such as:

- FICA (Faith/ Beliefs, Importance/ Influence, Community, Address in care or action) (184)
- HOPE (Hope, Organized religion, Personal spirituality, Effects on care and decisions) (185)
- SPIRIT (Spiritual belief system, Personal spirituality, Integration, Rituals/ restrictions, Implications, and Terminal events) (186)

### **1.2.2. Recommendations**

- Conduct a full spiritual assessment with all clients as part of a spiritual history-taking/ formal spiritual assessment

#### **When to assess**

- Skilfully initiate assessment of spiritual needs rather than wait for the client to raise the topic
- If a person registers with the palliative care service who appears to be in severe spiritual distress or who has urgent spiritual concerns (see 1.1.), conduct a full spiritual assessment as soon as possible
- If a person is referred to the service with problems that seem primarily non-spiritual in nature (e.g. uncontrolled physical symptoms,<sup>11</sup> or financial concerns), conduct a more thorough assessment of wider spiritual concerns once the immediate reasons for referral have been attended to
- Ensure staff members are sensitive to potential changes in spiritual beliefs and needs
- Assess spiritual needs at regular intervals throughout the disease trajectory and into the bereavement phase

#### **How to assess**

- Ensure staff members conducting a full spiritual assessments are properly trained to do so (to Intermediate or Specialist levels of the APCA competency framework)
- Obtain consent from the client (or, where a patient unable to provide consent, from the family or primary carer) prior to assessment
- Respect clients' personal boundaries and needs for information
- Assess a child's spiritual needs according to their developmental stage, using the three languages: verbal, non-verbal and play (183)

#### **What next?**

- Ensure spiritual assessment leads to appropriate responses to spiritual need where support is required
- Ensure spiritual assessment is documented in client records as appropriate
- Convey important issues arising out of the assessment to the rest of the care team during regular meetings, while respecting client confidentiality

<sup>11</sup> Although see page 27 regarding the somatisation of spiritual pain.

### 1.2.3. Formal assessment tools

Outcome measurement tools or questionnaires play an important role in the assessment of spiritual needs or spiritual well being as part of the provision of good quality spiritual care.

While never a replacement for sensitive and open discussion of spiritual needs (as might be initiated by the questions in Box 1), the use of assessment tools in the context of a respectful and exploratory conversation about spirituality can facilitate the identification of spiritual distress and/ or topics the client wishes to discuss. This may be particularly useful for palliative care staff members who are not specialists in spiritual care, in order to identify clients who may require input from a spiritual care expert (for example, those experiencing spiritual distress or with specific religious needs). However, it is important to remember that formal assessment is a means of identifying care needs, and not the end point.

Using validated and appropriate measurement tools to assess the outcomes of spiritual care plays a key role in service improvement or audit and generates much-needed data on the effectiveness of spiritual care. However, given its complex, relational and often non-cognitive nature, there are likely to be elements of spiritual care which exceed the limits of what is measureable. Thorough evaluation of spiritual care at the service level therefore also requires qualitative work interviewing clients and staff members.

The appropriate choice of assessment tool depends on the intended purpose (for example, screening for spiritual distress, clinical audit or research). Several tools have been validated in palliative care populations (Box 2), but only the Missoula Vitas Quality of Life Index and the APCA African POS have been tested in African populations. Often it may be more feasible to use a multi-dimensional measure containing spiritual elements (e.g. the APCA African POS) rather than a longer tool solely focused on spiritual aspects. However, for some research purposes more detailed tools are needed.

#### **Box 2: Examples of tools for assessing patients' spiritual well being**

JAREL Spiritual Well-being Tool (187)

Peace, Equanimity and Acceptance in the Cancer Experience (PEACE) (188)

APCA African Palliative Outcome Scale (POS) (189;190)

Needs at the End-of-Life Screening Tool (NEST) (191;192)

Missoula Vitas Quality of Life Index (MVQOLI) (193;194)

McGill Quality of Life questionnaire (MQOL) (87;195)

World Health Organization Quality of Life in HIV instrument (WHOQOL-HIV) (196-199)

Note: These tools have been validated in patients receiving palliative care and/ or living with HIV infection or advanced cancer; however, only the APCA African POS and the MVQOLI have been validated in African contexts. In recognition of the need for child-appropriate measures of outcomes in palliative care, a paediatric version of the African Palliative Outcome Scale is currently in development.

### **1.2.3. Recommendations**

- Use formal assessment tools to identify spiritual needs in a timely manner, and to assess the outcomes of spiritual care, while recognising their inherent limitations
- Evaluate the outcomes of spiritual care; consider using both qualitative and quantitative methods (e.g. a validated outcomes measurement tool or questionnaire and in-depth client interviews regarding the spiritual care they have received)
- Choose formal assessment tools according to the aims of assessment, the properties of the tools, the context in which they are to be used, and their ease of use (e.g. if the tool is to be used for audit purposes, it should be easily incorporated into routine clinical practice)



## **Good practice examples: Spiritual assessment**

### **Helderberg Hospice, Western Cape, South Africa**

Helderberg Hospice was established as a Christian Foundation serving patients and families of all faiths in 1986. The predominant faith in the Helderberg is Christianity and there is also a strong Islamic community, which is expanding as people from other parts of Africa migrate to the area. Judaism, Buddhism and Hinduism are represented in smaller numbers. Christianity and traditional African religion are also practiced side-by-side by many people.

Initial spiritual assessment is carried out by the professional nurse in patients' homes during home-based care visits or in the in-patient unit. New patients are asked about their beliefs and whether they belong to a faith-based community. Sometimes a patient will make it quite clear that he or she does not want to talk about spiritual or religious issues and this is respected.

When further spiritual assessment and counselling are required, the professional nurse refers to the social workers (the main spiritual care providers) to do this. The social workers will provide a relaxed counselling space in which the patient is free to share what is important to him or her. The conversation will cover the holistic spectrum, since spiritual issues overlap with physical symptoms, emotional concerns, worries about finances and the need for practical help.

If patients belong to a religious group (church, mosque, fellowship, cell-group), they are asked if they would like to see a particular pastor/minister/Imam/ Teacher or lay preacher. If so, the social worker requests permission to request a visit from that individual. Sometimes the patient is not practising any religion but has spiritual questions which he or she wishes to discuss with the social worker or the hospice chaplain, a volunteer retired minister. The chaplain provides spiritual counselling and refers patients to leaders of other religious groups where appropriate. The social work manager may introduce a volunteer lay counsellor, trained in spiritual work (one of five volunteers), to provide on-going patient support after initial assessment.

The team finds that the FICA Spiritual Care Assessment tool (184) provides an easy entrance into spiritual conversations. The acronym works as follows:

- F: (Faith or beliefs): "Can you tell me if you have any particular belief system or faith?"
- I: (Importance and Influence): "I am wondering, how does your faith influence the way you respond to this illness?"
- C: (Community): "Are you a member of a faith community (Church, Mosque etc)?" "Is this a support to you?"
- A: (Address): "Would you like to talk about this? Is there any special way you would like me to address these issues?"

In the Day Hospices there is also spiritual input, initiated by the Volunteer Manager and assisted by a team of volunteer helpers. A group of ministers take turns in giving spiritual encouragement.

For more information, contact Gill Wasserfall: [gill@helderberghospice.org.za](mailto:gill@helderberghospice.org.za)

### **Hospice Africa Uganda, Uganda**

The spiritual assessment form at Hospice Africa Uganda utilises the following questions to elicit patients' needs for support and ascertain a patient's current relationship to their spirituality:

- What is your relationship with God? (Not religion but relationship e.g. belief, talking to and communicating with God)
- What religion were you raised in?
- What is your religion now?
- Why did you change?
- Are you at peace with the present religion?
- Has your illness in any way affected your relationship with God? In what way?
- Do you pray with others? Does it help you?
- Are you at peace with your God?
- Are you at peace with your family?
- Can we help in any way?

Patients' stage of spirituality is assessed on a scale from 1 to 4, developed on the basis of Scott Peck's theory of spiritual development (200):

Stage 1= Compared to the child under 5 who cannot discern good from evil and will tell a lie automatically, without conscience; does not appear to have a relationship with God.

Stage 2= Compared to the child from 6 to 12 years who fits into a rhythm at school and at home; follows the principles and structures of the church and is very unsettled if these structures are moved

Stage 3= Compared to the teenage rebel; leaving the church, searching for meaning. Described as a very important stage in spirituality, God and a way to Him is sought, possibly through religion.

Stage 4 = Appears spiritually at peace; where the relationship with God is larger than any religion and God is very present in their lives.

Stage 4 is the stage which it is hoped patients will reach before they die, where they are at peace with God and their families and friends.

For more information, contact Anne Merriman: [hospug@yahoo.com](mailto:hospug@yahoo.com)

## Quality markers: Identifying spiritual need

### 1. Evidence of spiritual assessment

Measures:

- Documentation showing every clients' spiritual (including faith) needs are discussed at multi-disciplinary meetings
- Documentation of spiritual needs in client notes (including children's notes)

### 2. Evidence of the use of formal assessment tools in the audit of spiritual care

Measures:

- Data from formal assessment of outcomes of spiritual care are used to influence service provision in demonstrable ways

## 2 Responding to spiritual needs

### 2.1. The ingredients of spiritual care

The APCA standards state that it is a basic requirement for palliative care staff to ensure that identified spiritual pain is addressed, either by them or through referral (with consent and respect), and that this should be documented.

Spiritual care may involve a number of resources and activities, depending on the individual needs and characteristics of the client and the resources available at the palliative care service. For some clients, social support is an essential part of or requirement for spiritual care.

*'My belief and my policy is that you can't preach or pray for a person who has got an empty stomach, because he's not going to concentrate on what you are saying. You need to hear first what their needs are, and attend to them.'*

Spiritual care provider PS\_SCP02, Port Shepstone

*'Providing spiritual care is important, but it has to be supported by some of these practical things because they also communicate a message, you know. A message of love and care and compassion.'*

Spiritual care provider PS\_SCP01, Port Shepstone

It is essential that clients are protected from potentially damaging forms of spiritual intervention. Inappropriate spiritual interventions which may have profound negative consequences for clients' quality of life include:

- Forms of spiritual counselling which foster guilt or blame the client for their current situation, e.g. *You're dying from AIDS because you had sex outside of marriage and 'the wages of sin is death.'*
- Advice which discourages patients from taking prescribed medical treatment, e.g. *We are praying for you, so you don't need to take your medication any more.*
- Potentially damaging interventions by traditional healers, e.g. *I will cure your colon cancer by removing the serpent from your body which is causing it.*

See Recommendations 3.2. (page 58) and 4.1. (page 64) for further information regarding inappropriate and appropriate spiritual care.

## 2.1. Recommendations

- Ensure identified spiritual pain is addressed, either by palliative care staff or through referral
- Offer clients access to a range of spiritual care services, including those which are not religious
- Provide access to:
  - Appropriate faith leaders and traditional healers for religious support, prayer and ritual. Ideally, faith leaders should be acknowledged and/or accredited by their faith community (see 4.3)
  - The means to facilitate non-religious (as well as religious) rituals
  - Religious services: prayer, bible reading, group services, religious celebrations, religious counselling
  - One-on-one counselling (with either a spiritual or psychological approach, as appropriate for the client) through the palliative care service
  - Community support groups facilitated by trained volunteers, palliative care staff or trained spiritual leaders
  - Complementary therapies, including art and music therapy
  - A 'quiet space', in inpatient units, for clients' and staff members' personal reflection and prayer<sup>12</sup>
- For children, in addition provide access to/ facilitate (183):
  - Poetry and journal writing
  - Memory book keeping
  - Reading, writing and telling stories
  - Painting and drawing
  - Displaying of ideas, pictures, stories, plays etc.
- Recognise that social support (e.g. income generation, food parcels, school fees, secure housing) will also be necessary for some clients in order to alleviate financial concerns and allow them to attend to spiritual concerns; if possible assist clients in these areas, e.g. by identifying sources of support
- Make information about the availability of spiritual care services available to all clients throughout the disease trajectory and into bereavement
- Provide information in a range of languages spoken in the local community, and make provisions for clients who are not able to read
- Protect clients from potentially damaging forms of spiritual intervention
- Document the spiritual care resources accessed by clients in their records, along with their value and effectiveness for the client

<sup>12</sup> A labyrinth could also be laid for meditative walking, as at St Luke's Hospice, Cape Town.

## **Good practice examples: Responding to spiritual needs**

### **The Infectious Disease Institute, Uganda**

The Infectious Disease Institute (IDI) in Kampala acknowledges the importance of involving 'Friends' (patients) in leadership, and aims to enable people living with HIV/AIDS to play an ever-increasing role, in keeping in line with the emerging global Greater Involvement of People Living with HIV/AIDS (GIPA) movement. Friends lead the Creativity Initiative at IDI. The Friends hold daily prayer and worship sessions in the clinic, where they provide mutual spiritual support through sharing testimonies and stories, and praying for and encouraging one another. Psychological and spiritual support is provided alongside:

- Income-generating activities such as bead-making, painting, weaving;
- Community sensitization and prevention messages through music, dance and drama in the community and indoor games in the clinic;
- A Friends Resource Centre, overseen by Friends, including internet access, educational materials and access to training/ learning/ empowerment opportunities.

Friends also supervise the distribution of basic health care packages and work as volunteers in the nearby hospital, counselling patients who have just received results of their HIV testing, to encourage enrolment in care and treatment, and to support them spiritually and psychologically.

Further information on the Creativity Initiative can be found on the IDI website: [www.idi.ac.ug](http://www.idi.ac.ug)

### **Mildmay, Uganda**

Clients at Mildmay have access to a spiritual care team that includes Anglican, Roman Catholic and Muslim faith leaders with training in non-denominational pastoral care. A chapel is available for quiet reflection and prayer and the Imam's counselling room provides a venue for Muslim prayer for patients, family members and staff. Morning devotions as well as on-going spiritual support are provided by the spiritual care team for all inpatients and caregivers. Home visits are carried out for clients who are unable to come to the centre but need spiritual care, as reported by the caregiver.

Chaplains also attend patient burials and provide bereavement counselling and follow-up support to the caregiver and relatives when needed. On the last Wednesday of October an annual memorial service is held for all the clients who have passed away in the previous year. Family members gather to light candles in memory of their loved ones.

For more information, contact Rev David Galimaka: [david.galimaka@mildmay.or.ug](mailto:david.galimaka@mildmay.or.ug)

### **South Coast Hospice, South Africa**

At South Coast Hospice in Port Shepstone there are teams of trained caregivers headed by registered nurses who attend to both the physical and spiritual needs of rural patients and their families. Spiritual care given may take the form of simply listening, which may be all that is required to help the client re-establish their own spirituality. For those patients who are well enough (often those receiving chemo- or radiotherapy treatments, or in remission), weekly meetings are offered in the hospice lounge. These meetings, usually attended by 6-8 patients, are overseen by a Sister, with a spiritual care provider in attendance. A range of therapeutic activities are offered at the meeting, including painting, bead work, pottery, shell work, collages, singing, massage, relaxation and imagery. These get-togethers are more than 'arts and crafts' meetings. The activities create spontaneous sharing, and this time is offered to patients as a means of emotional, social and spiritual support. Over time, many patients experience the death of one of their circle of friends. The group provides an opportunity for patients to deal with bereavement and examine their own attitudes towards death and dying.

For more information, contact Julie Palmer: [julie@schospice.co.za](mailto:julie@schospice.co.za)

### **Sunflower Children's Hospice, South Africa**

Sunflower Hospice in Bloemfontein has a Children's Chaplain who makes regular visits to the children, to identify spiritual needs, and answer the questions and concerns of the children, families and the staff. A separate spiritual assessment form is used for each child. Special ceremonies are held when a child dies, and the name of each child who has died is placed on a Wall of Sunflowers which forms part of the children's playground. In this way each child knows they will always be remembered. Each year a service is held to remember the children who have died, and balloons with their names on them are released.

For more information, contact Richard Marston: [childhospbfm@telkomsa.net](mailto:childhospbfm@telkomsa.net)

### **Quality markers: Responding to spiritual needs**

#### **1. Evidence that a range of appropriate and effective spiritual care services are accessible to all clients**

Measures:

- Database of the spiritual care services available through the service, including a list of contact details for local, trained spiritual leaders of different denominations and traditional healers of different backgrounds
- Documentation in client records of the spiritual interventions they access, along with their effectiveness and value<sup>13</sup>
- Range of media produced and disseminated to advertise the spiritual care services available to clients, e.g. posters, leaflets in appropriate languages, large type

#### **2. Evidence of client satisfaction with spiritual care services**

Measures:

- Assess patient and/ or family satisfaction with the spiritual care services they have access to through the palliative care service, e.g. through the inclusion of spiritual care in any satisfaction with care assessment forms and capturing informal feedback, including thank you cards and other communications from clients to spiritual care

#### **3. Evidence that clients' wishes for spiritual care are assessed regularly**

Measures:

- Documentation in client records of clients' spiritual care needs and resulting action taken at regular intervals throughout the disease trajectory

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<sup>13</sup> This information could also be shared (anonymously) during staff/ volunteer training on the importance of spiritual care.

## 3 Working with the community

### 3.1. Sharing spiritual care

The APCA standard for spiritual care states that at the primary/ basic level, there should be *'collaboration with spiritual care providers of all religious denominations in the community'*. Collaboration with the community, including local spiritual leaders, faith and community groups and traditional healers, is central to ensuring good quality spiritual care reaches all who require spiritual support. Traditional African healing, focused on restoring wholeness and peace, plays an important role in the illness experience of many patients. Good communication and collaboration with diviners, healers and traditional healers are therefore highly desirable.

A 'shared care' model of spiritual care provision covers diverse agencies and a broad range of people; the specific form a shared care model takes depends on the local context. As well as facilitating spiritual care provision, raising awareness of palliative care and enhancing community ownership of palliative care services, shared care models are likely to break down stigma in church communities, improve social cohesion and increase the acceptance of people with HIV.

*'Spiritual things are raised in other guises sometimes: 80 per cent of people that attend clinics at some time or other will be seeing a traditional healer. Traditional healers are also supplying emotional and spiritual healing; we're very aware of that. They have a role to play.'* Spiritual care provider CTHH\_SCP01, Cape Town

#### 3.1. Recommendations

- Implement a 'shared care' model of spiritual care provision, in which:
  - The palliative care team aims to meet the spiritual needs of patients, their friends and family by working together with sources of support already available in the local community
  - The spiritual care provided by faith groups is recognised and built upon and the significant influence that spiritual leaders may have is harnessed
  - Mutual education and training is facilitated (see 3.2., below), and palliative care providers and members of local faith and community groups are enabled to support each other
  - There is awareness of palliative care in the local community, including how to refer to and access service providers



### **Good practice example: Sharing spiritual care**

The CHAT (Continuum of Care for people living with HIV & AIDS in Tanzania) programme of the Evangelical Lutheran Church in Tanzania (ELCT) is funded through the United States government's PEPFAR (President's Emergency Plan for AIDS Relief) initiative. CHAT took a pre-existing palliative care programme, with hospital-based teams scattered throughout Tanzania within ELCT's health system, and built up a system of home-based care and services for vulnerable children. To date the programme has served over 13,000 individuals, most of whom live with HIV, along with an additional >12,000 children who have received focused assistance towards schooling, bedding, or nutrition.

As a faith-based service, health outreach for the ELCT has always faced the challenges of working within diverse faith communities. Palliative care work, offering holistic – including spiritual – care, also respects the faith and backgrounds of individuals and their families. The core teams of each hospital each include a Chaplain, who has received an additional four months of training at the Kilimanjaro Christian Medical Centre (KCMC, a teaching hospital also of the ELCT) in Clinical Pastoral Education. This KCMC education emphasises both the particular challenges of working with HIV as well as across the spectrum of faiths.

The hospital teams supervise large volunteer cadres, thereby expanding coverage and linking closely with their respective communities. While these volunteers are actually chosen by the community, through the governmental system, there is also an additional linkage to the local network of Lutheran churches. Church workers assist in the identification of children who require services, collaborating with volunteers, local government, and the core palliative care team. Church involvement widens the community sense of accountability, and by handling the logistics of services (e.g. school uniform and bedding acquisition) the palliative care team is freed up to deliver more clinical services. Church leaders are also included in periodic national meetings of the palliative care teams, ensuring that consistent messages are being delivered by the church, especially in the areas of stigma reduction and HIV prevention.

Additionally, the Lutheran churches are asked to help with the professional teams' specific outreaches. Mobile team outreaches are usually hosted by the Lutheran parish in a particular community, and include refreshments for clients. Regular gatherings of children who are either affected by HIV or bereaved are also hosted by the churches. Hospitality in this regard fits well with the overall mission and work of the faith communities.

For more information regarding the ELCT palliative care programme, and CHAT, contact Dr. Paul Mbandoo ([mmbandozebs@yahoo.com](mailto:mmbandozebs@yahoo.com)) or Dr. Kristopher Hartwig ([hartwig@elct.or.tz](mailto:hartwig@elct.or.tz))

## **3.2. Education and training**

In order to establish an effective 'shared care' model of spiritual care, training and education programmes are required for spiritual leaders and traditional healers in the community. One of the challenges for religious leaders is that clients may potentially feel unable to express themselves openly, out of fear of expressing different or 'unacceptable' spiritual beliefs, or of losing the benefits of care. Involving spiritual leaders and traditional healers who have already had training in palliative care in teaching other spiritual leaders and traditional healers may be

particularly effective in training programmes owing to similarities in their non-medical perspective.

*'For church men to get a good firsthand knowledge of what palliative care is really about and for them to become familiar with the hospices in their area – I think that would be great.'*  
Spiritual care provider PS\_SCP04, Port Shepstone

*'It is really important for people to understand the hospice, you know, what hospice is all about. That's number one. Number two, palliative care: what do you mean when you talk about palliative care? That is the second part. The third one is the diseases that people are suffering from in palliative care. And then of course, the spirituality part of it. Belief is very important.'* Spiritual care provider PS\_SCP02, Port Shepstone

Ongoing mutual education of palliative care staff, spiritual leaders and traditional healers may help identify areas of potential conflict, and improve understanding and collaboration between these groups. Another potential benefit is establishing good personal relationships between palliative care staff and spiritual leaders and traditional healers in the community. These personal relationships will in turn facilitate the process of selecting the most appropriate individual to provide spiritual care for a client (see 4.3.2.). Raising awareness about palliative care and physical pain management is also an important way of harnessing the influence of spiritual leaders in the community; for example, it may help ensure the availability of opioid analgesics and counter client opiophobia.

### 3.2. Recommendations

- To establish an effective 'shared care' model of spiritual care, design and implement training and education programmes for spiritual leaders and traditional healers in the community
- In order to be effective, training programmes should aim to:
  - Raise awareness and counter misperceptions of palliative care (including its philosophy, purpose, intended recipients, and access to and location of local services)
  - Raise awareness of, and advocate against, forms of spiritual counselling and care that are potentially harmful (for example, views which promote feelings of guilt or shame in clients, advice which discourages patients from taking prescribed medical treatment, or practices which may cause physiological damage), in order to avoid forms of spiritual care which are inappropriate in the context of palliative care
  - Educate spiritual leaders about the diseases which bring people to palliative care (e.g. types of cancer, organ failure, motor neurone disease, multiple sclerosis and HIV-related illnesses)
  - Educate spiritual leaders about common symptoms in these diseases (pain, breathlessness, depression, worry, etc.) and their treatment, particularly opioid analgesics
  - Discuss and raise awareness of wider spiritual aspects of incurable, progressive illness and the provision of palliative care, including the experiences and care of children
  - Discuss and emphasise clients' vulnerability and its implications for spiritual care, in particular the need for self-awareness and sensitivity among spiritual leaders and traditional healers
  - Train spiritual leaders to recognise, assess and respond to wider existential needs (which may not be overtly religious), including in children
  - Discuss clients' experiences of crises of faith and loss of belief in God, and educate spiritual leaders to respond in a non-judgemental, supportive way which allows a deeper exploration of their feelings and avoids pressurising the client
  - Educate and support spiritual leaders and traditional healers in managing patient and family expectations, maintaining confidentiality and providing information
  - Educate and train spiritual leaders and traditional healers in good

communication and counselling skills, including active listening and self-awareness.<sup>14</sup> Emphasise the following areas in this regard:

- The skill required to hear the voice of someone who believes and feels differently from oneself, and who may be angry at God
  - The need to be aware of how one's own attributes (e.g. body language, wearing a cross) influence one's interactions and relationships with clients, sometimes negatively
  - The need for spiritual counsellors to be non-judgemental and flexible, and to avoid being overly prescriptive; this may at first appear contrary to spiritual leaders' training
  - The relational and visceral nature of the spiritual encounter
  - How to care for oneself as spiritual care provider (see 4.4.)
- Support spiritual leaders and traditional healers in meeting clients' spiritual needs, through access to the advice and support of the palliative care team when necessary (including telephone contact and referral)
  - Offer continuing education for spiritual leaders and traditional healers in the community
  - Listen and learn from the experiences shared by participants in the course of training
- As part of a programme of ongoing continuing education, provide opportunities for spiritual leaders and traditional healers in the community to educate each other and palliative care staff regarding their beliefs and practices
  - Implement a programme of continuing education for palliative care staff about local spiritual beliefs and practices and their impact on the individual care of clients

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<sup>14</sup> The need for self-awareness is reflected in the APCA competency framework for the Basic level upwards, which states that staff should be aware of their own spiritual and cultural beliefs and how these may have an impact on their work. The importance of good counselling skills is recognised for Intermediate and Specialist levels, which states that staff should be able to help patients and families clearly identify their spiritual and cultural needs through skilled counselling.

## **Good practice examples: Education and training**

### **Island Hospice and Bereavement Service, Zimbabwe**

Island Hospice and Bereavement Service was the first hospice service in Africa. It followed the tenets of the modern hospice movement, and from the outset “spiritual pain” was recognised as one of the essential components of the “total pain” model. In the early years a pastoral committee was formed and members of this group would make themselves available for spiritual counselling. Two problems arose: firstly, it was found that most of these members regarded spirituality purely from a religious standpoint (and tended to be too rigid and prescriptive); and, secondly, there was controversy when it was suggested that “traditional healers” be included on this committee (many believing that these people belonged to the domain of witchcraft).

The pastoral committee fell away, and, instead, the organisation now aims to empower both its staff and volunteer caregivers to undertake spiritual counselling themselves. Spirituality is included in every training course, be it for health professionals, medical students, or volunteers. Training in spiritual care includes training in spiritual assessment; managing signs of spiritual distress; standard counselling approaches (in particular, being non-judgemental); and encouraging patients not to stop taking their current palliative care medications when they are keen to consult a traditional healer. Training also raises awareness that, in the black population, both Christianity and traditional animistic belief systems can co-exist, and that this duality can be a source of both comfort and confusion (and that different family members might exert pressures on the patient to veer towards one or the other).

Recently the hospice has provided training courses for pastors. These courses cover the following subjects:

- Principles of Palliative Care
- Death Awareness
- Fears and Losses of a Life Threatening Illness
- Principles of Communication
- Teamwork
- Spiritual and Cultural Issues
- HIV/ AIDS & Universal Precautions
- Communication Skills and Role Plays
- Stigma and Discrimination
- Anti Retroviral Therapy
- Gender Issues
- Tuberculosis (TB)
- Cancer
- Working with Families
- Conducting a home visit
- The Dying Process
- Breaking Bad News
- Bereavement Awareness
- Burnout and Self Care

The nature of “spiritual pain” is explored, and advice given on how to help the client approach the distress.

For more information, contact Dr Steve Williams: [drshwilliams@yahoo.com](mailto:drshwilliams@yahoo.com)

### **Hospice Africa Uganda**

Hospice Africa Uganda (HAU) runs a 5-day training course for spiritual carers and support workers from the community. The course aims to make them more aware of the spiritual and other holistic needs of people with HIV/AIDS and cancer, and increase their confidence in addressing issues of spirituality in an open and accepting manner. The training targets spiritual carers of all religious denominations (e.g. Muslim, Catholic, Anglican, Pentecostal and Adventist) who are providing spiritual support to people suffering from life-limiting illnesses at home or in the community. To date, HAU has trained 316 spiritual carers from various districts in Uganda.

The course content is the distillation of all that the trainers have learnt while working with and training spiritual carers in Uganda over the last 15 years, and is designed to be appropriate given local needs and available resources. It aims to provide spiritual carers with the basic knowledge, skills and counselling ability to care for patients and their loved ones from the onset of illness through to the end of life, and to support families during the bereavement period. Due consideration is given to the diverse religious denominations.

HAU provides each course participant with a training manual. As well as being used as a training tool for spiritual carers attending the course, the manual is used as reference material by spiritual carers after the course, and by other individuals and organisations needing information on specific topics in palliative care.

Trained participants are expected to be able to pass on the knowledge to their colleagues on a day-to-day basis. Trained spiritual carers also perform a special role in identifying patients who require hospice support in their communities, many of whom may never have accessed a health worker and may be in severe pain from cancer, AIDS or other conditions. Spiritual carers are educated about other support organisations working in their area that can assist with support for children, food provision, will making and other issues that arise for clients.

Owing to their role in the community, spiritual carers are usually very aware of the cultural and spiritual pressures on clients. They may also know the local traditional healers in whom clients have confidence. Spiritual carers are encouraged to work with traditional healers as colleagues; however, if they think the traditional treatment prescribed may be harmful to the patient or family, they are advised to discuss this with the Hospice support team and together decide the best way to ensure all clients' well being.

HAU also runs separate 5-day courses for traditional health practitioners. The hospice collaborates with traditional healers associations/organisations in Uganda to organise and facilitate these courses.

All the courses are highly interactive and utilise problem-based learning approaches. HAU trainers are the key trainers; however, some trained spiritual leaders and traditional healers are also invited to teach on the courses.

*"I have been changed holistically compared to how we were before attending the course. For some of us this is our first time to sit together regardless of our religious differences."* Muslim spiritual carer and past course participant.

For more information, contact: Alfred Duku, [aduku@hospiceafrica.or.ug](mailto:aduku@hospiceafrica.or.ug)

### 3.3. Referral

Good referral pathways between the community and palliative care are central to effective shared care and collaboration. Having efficient, well-utilised referral systems in place is essential to ensuring that palliative care reaches all those in need in the community, and that spiritual care is provided for all clients who require spiritual support.

*'The religious leaders who have attended the training course refer to us and also at the same time the community volunteers refer to us, and we also refer our patients to them. If we identify a patient who has a spiritual problem in a particular area we can contact the spiritual leader at that area to go and address that problem.'*  
Spiritual care provider UG\_SCP01, Kampala

#### 3.3. Recommendations

- Put in place referral systems for palliative care providers to refer to local spiritual leaders and traditional healers trained in palliative care, and ensure the referral systems are utilised
- Allow any member of the care team to refer to an appropriate, trained spiritual care provider in the community; however, ideally appoint a designated spiritual care co-ordinator or another member of staff who is responsible for referral
- Ensure that referral to spiritual care providers in the community always occurs with the client's consent (or, where a patient is unable to provide consent, with the consent of the family or primary carer) and with due respect for the client's confidentiality and autonomy
- Raise awareness of palliative care, what the palliative care team provides and how to refer to the service among community leaders and faith and community groups
- Ensure that spiritual leaders and traditional healers who have received training in palliative care are familiar with the referral system and know how to refer people with suspected life-limiting conditions in the community to palliative care (via their local doctor where necessary)

## Quality markers: Sharing spiritual care

### 1. Evidence of mutual training and education

Measures:

- Number of workshops/ training courses held for members of the community;
- List of ways in which workshops were advertised
- Numbers of attendees from different community groups (e.g. church groups, traditional healers)
- Number of organised visits to palliative care service by faith group representatives or traditional healers

### 2. Evidence of referral to and from spiritual care providers in the community

Measures:

- Number of clients referred to spiritual leaders and traditional healers in the community for spiritual support
- Number of clients referred to the palliative care service by spiritual leaders/ traditional healers, via healthcare professional

## 4 Spiritual care providers

### 4.1. Attributes of the spiritual care provider

A range of professional and volunteer members of staff and of the community may play the role of spiritual care provider for a client receiving palliative care. However, a number of attributes are desirable in all spiritual care providers.

*'If I could recommend anything, it would be to approach patients with humility, and with a listening ear that is beyond this physical ear. Approach them with an open heart and willingness to be with these people, to be there. You show your care by being, not by the words.'*

Spiritual care provider CTLK\_SCP02, Cape Town

*'In providing spiritual care to people that are very sick, you have to be very, very careful not to focus on your theological differences, because the person that you're working with at that point in his or her life is not concerned about theology!'*

Spiritual care provider PS\_SCP01, Port Shepstone



#### **4.1. Recommendations**

- Foster attributes in spiritual care providers which are conducive to good spiritual care, in particular<sup>15</sup>:
  - The ability to focus on broader spiritual needs, not just religion
  - The ability to put aside religious differences and focus on client need
  - The ability to win clients' trust
  - The ability meet the client where he/she "is"
  - Tolerance and a non-judgmental attitude
  - A balanced and undogmatic worldview
  - Empathy with the client and a compassionate attitude
  - Humility
  - Openness: the ability to share one's experiences and views, but only as far as this will facilitate meeting the clients' needs
  - Self-awareness as the foundation for the above (e.g. the ability to notice and attend to one's personal barriers to being non-judgemental and open)
  - Familiarity with different spiritual and cultural beliefs and practices<sup>16</sup>
- Support spiritual care providers in their cultivation of these attributes, through training and access to support services (see 4.4)

#### **4.2. Role of the spiritual care provider in palliative care**

While it is recommended that all members of the palliative care team are confident and skilled in discussing spiritual aspects of illness, designated spiritual care providers play a specific and important role in client care. Liaison with the community is essential in order to ensure good relationships with local spiritual leaders and traditional healers and an efficient model of shared

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<sup>15</sup> Also see Recommendations 3.2. (page 58) for more information on the attributes to be fostered in spiritual care providers.

<sup>16</sup> This reflects the APCA competency framework for staff at Intermediate and Specialist levels, which states that staff should be able to understand and appreciate the wider spiritual and cultural needs of the population.

care. In particular, clarity regarding the designated spiritual care provider's role and its limitations is important in order to reduce any risk of perceived competitiveness.

*'If they could have somebody who would just provide spiritual care it would be good. But this person needs to be neutral – a person who can meet people of different faiths halfway, who's been trained in most of the religions, would be an ideal person.'*

Spiritual care provider JO\_SCP02, Johannesburg

#### **4.2. Recommendations**

- Recognise the many roles of designated spiritual care providers in:
  - Providing an open, inclusive and safe space for spiritual insights to be shared
  - Visiting, listening to and speaking with clients in a sensitive, confidential, open-minded and respectful way which fosters trust
  - Acting as a point of referral for the rest of the care team
  - Recognising their limitations and asking for advice/ referring on when necessary
  - Liaising with and referring to spiritual care providers in the community (e.g. local church ministers and pastors, traditional healers), with the client's permission
  - Communicating with and educating spiritual care providers in the community to ensure the role of the palliative care-designated spiritual care provider is understood
  - Supporting and training other members of staff (e.g. through teaching, advising and providing spiritual support)
  - Interacting compassionately with other staff members as they experience loss, and providing spiritual care to members of the team
  - Representing the spiritual aspect of the palliative care service's work (e.g. through ensuring the spiritual perspective is expressed at the organisational level)
  - Working cooperatively with other members of the team and of the community
  - Taking and storing detailed notes on clients with care and confidentiality
  - Playing a role in public education
- Support spiritual care providers in fulfilling these roles

### **4.3. Choice of spiritual care providers by the care team**

#### **4.3.1. Members of the palliative care team**

The relationship between spiritual care provider and client is central to the effectiveness of spiritual care, and the choice of an appropriate spiritual care provider depends on the individual client and his or her needs. At times, members of the palliative care team who are not formally specialists in spiritual care, but who have received training in its provision (e.g. a nurse or social worker), may be the most appropriate candidate for the provision of spiritual care to a particular client, owing to their personal relationship.

#### **4.3.1. Recommendations**

- Ensure that, as required by the APCA competency framework, all palliative care staff members have received training in the provision of basic spiritual care, including the identification of spiritual distress (see 1.2.1.)
- In this training, include the basic principles of providing spiritual care for children, as this is likely to be an area in which confidence is lacking
- Select the most appropriate spiritual care provider for a client on an individual basis, and recognise that a trained non-specialist in the care team may be the best person to provide spiritual care for a given client
- When a non-specialist is providing spiritual care, ensure he or she receives support and advice from the designated spiritual care expert(s) in the team as required

#### **4.3.2. Spiritual care providers outside the healthcare setting**

Many clients will wish to receive spiritual care from the faith leader at the church they usually attend, or the traditional healer they usually see.<sup>17</sup> Good communication with the client's faith leader or traditional healer is required in order to ascertain their familiarity with palliative care, and to identify potential conflicts with the palliative care perspective that could negatively affect client well being.

Selecting the best person to provide spiritual care for a client will not always be a matter of 'matching' them with someone from the 'right' faith tradition. For example, sometimes someone from a different faith tradition, or someone who is spiritual but not religious, may be more appropriate for a client raised as a Catholic than a Catholic priest, and at other times someone with non-Christian beliefs may request to see a Christian minister. In choosing the best person

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<sup>17</sup> Where the patient is a child, parents or other primary care providers may nominate their family's faith leader or traditional healer.

to provide spiritual care for a specific client, the network of active relationships between the palliative care service and the community therefore becomes important (see 3.2).

Members of the community working voluntarily or for minimal payment are an essential part of most palliative care services, and play an important role in the provision of spiritual care. The volunteers that work with a service will ideally represent the local community in terms of ethnicity, spiritual beliefs, and language. Paying volunteers' travel and subsistence costs is a way of recognising their contribution and allows a wider section of the community to volunteer. Working as a volunteer, particularly in spiritual care provision, may raise personal and spiritual concerns, and volunteers themselves require support (see section 4.4.).

The APCA spiritual care standard (2.8) states that *'the patient's and family's background, beliefs, rituals and practices are respected by care providers, with no intentions to change them but to support them within their context.'* While it is essential to respect clients' worldviews in this way, this needs to be balanced with the duty of the palliative care team to protect clients from potentially harmful advice or activities. Those with incurable, progressive diseases are at a vulnerable time in their lives – spiritually, physically, psychologically and socially – and insensitive or inappropriate guidance can do lasting damage, cause distress and create rifts within families

The screening and training of volunteers are therefore required to protect clients from potentially damaging advice or attitudes. It is important that potential spiritual care providers from the community are properly trained, as training to be a traditional healer or a religious leader (such as a pastor or imam) does not necessarily prepare you to provide spiritual care to seriously ill people.

*"There are some fanatics who tend to go to the sick people always. And they want to change their faith, you see. That creates another problem. If I am a carer and I'm interested in you becoming like me, then I am not going there for you, I am going there for my own interest."*

Spiritual care provider UG\_SCP02, Kampala

*"There are people who come and say, 'I sense a call' or 'I heard God as I was praying.' I say to them, 'You need to join the Fraternal so that I can know you more and more.' The Fraternal is a pastors' meeting held every Wednesday in the community, whereby you listen to the pastors speak."*

Spiritual care provider CTLH\_SCP03, Cape Town

#### **4.3.2. Recommendations**

- Communicate with clients' faith leaders and/ or traditional healers to ascertain their familiarity with palliative care and identify potential conflicts with the palliative care perspective which could negatively affect client well being
- Where a client does not have a local resource for spiritual care but would like to be referred to someone, take into account whether the person has received training in palliative care, the languages they speak, and their ethnicity, gender and religion, according to clients' wishes
- On the basis of these considerations, refer the client to a spiritual carer inside or outside the healthcare setting, as is most appropriate
- Ensure all spiritual care providers referred to by the palliative care team have received palliative care training, and are supported by the palliative care team
- Respect clients' worldviews, but also investigate and caution against potentially harmful religious practices (such as using prayer as a substitute for medical treatment), and forms of traditional healing (such as the physical extraction of bad spirits)
- In order to safeguard patients and families, consider linking only with community spiritual care providers who belong to formal or official groups, e.g. through registered NGOs, established and well-known churches or pastoral training providers
- Before linking with a religious institution such as a church, consider requesting a statement of faith or investigating the guiding principles of the church in order to anticipate or prevent potential conflicts
- Screen volunteers wishing to provide spiritual care to clients, including faith leaders in the community, before they join the service, and ensure they are properly trained in the palliative care approach to spiritual care
- If possible, reimburse volunteers' travel expenses and subsistence

## **Good practice examples: Spiritual care providers**

### **Kilimanjaro Christian Medical Centre, Tanzania**

The Clinical Pastoral Education (CPE) Programme at Kilimanjaro Christian Medical Centre (KCMC) in Moshi, Tanzania, was started by The Good Samaritan Foundation of Tanzania (GSF) and KCMC in 1971. The CPE programme provides education in Pastoral Care and Counselling for ministers and other professionals of the social welfare, health care, educational, and hospital administration sectors from Tanzania and other East African countries. Two four-month courses are taught every year for students of all Christian denominations, the first intake being aimed primarily at women participants.

The CPE courses use a highly practical approach to enhance trainees' communication skills, sending them to the wards of the referral hospital for pastoral care experience and working on their perception of self and others in the peer group setting. The spiritual aspect of all areas of work forms the basis for the CPE programme. The CPE courses thus provide fruitful input from the Gospel to church-related health care-related, educational, and diaconic activities in society.

Since 2004 the CPE courses have included a three-week course in HIV/AIDS counselling which follows the curriculum of the National AIDS Control Programme of the Ministry of Health. Since 2008 a three-day seminar on Palliative Care has been part of the programme. Other subjects taught on the course include Pastoral Care and Counselling, Chaplains' Responsibility, Counselling Skills, Emotions, Prayer, Anger Management, Conflict Management, Pastoral Care to Unconscious Patients and to Muslims, Grief and Loss Counselling, The Use of Biblical Stories in Counselling, Marriage Counselling, and a seminar on Mental Disorders.

The principal of the programme is Rev. Archiboldy Lyimo, who is also the Head of the Chaplaincy Department. Another Lutheran and an Anglican chaplain cooperate with him in teaching the CPE courses, together with a CPE supervisor from Germany who was assigned as a senior expert from 2007 to 2010. Each participant receives individual supervision from one of the teachers.

Since 1972, 86 CPE courses have been taught with initially between five and nine participants; recently the attendance rose to between twelve and fifteen on average. Approximately 600 persons have been trained in the CPE programme so far. The participants usually are sent by their dioceses or institutions, some of them coming by their own initiative and paying for themselves. During the courses the students stay in the dormitory of the programme; they live and work together.

The evaluations written by the participants upon graduating from the courses indicate a high motivation among them to tend to the needs of people suffering from severe physical and mental problems. Graduates from the course often go on to work with organisations that care for people living with HIV/AIDS and/ or provide palliative care.

For more information about the CPE programme at KCMC, see [www.kcmc.ac.tz/chaplains](http://www.kcmc.ac.tz/chaplains) or contact the chaplaincy department: [chaplaincy@kcmc.ac.tz](mailto:chaplaincy@kcmc.ac.tz)

### **Selian Hospice and Palliative Care Programme, Tanzania**

The Selian Hospice and Palliative Care (SHPC) programme was started in 1999 to address the needs of those affected by the AIDS epidemic and the rising numbers of people with cancer and other chronic diseases in Arusha, Tanzania. The SHPC programme is integrated in the hospitals of Arusha Lutheran Medical Centre, Arusha City, and the Selian Lutheran Hospital at Ngaramtoni, which serves as the district hospital for the Arumeru district. The programme is supported by the Foundation for Hospices in Sub-Saharan Africa (FHSSA) and Denver hospice, USA.

The SHPC programme aims to:

- Maximise patients' quality of life
- Restore hope and relieve the suffering of patients with life threatening incurable diseases and
- Provide holistic, continuous care to patients and their families in a compassionate way that includes physical, medical, spiritual, social and psychological care.

The programme does this through ensuring the availability of and access to quality holistic palliative care services for patients and their families in the programme area; sensitising the community on home-based care and palliative care services; providing training for home-based care and palliative care providers, and engaging in advocacy and networking.

At present the programme has 16 full time employees and serves >3,000 patients in 37 wards in 4 districts of the Arusha and Manyara regions. It has trained 250 community volunteers to date, with 50 more volunteers completing training in the near future. The programme also offers training and mentoring for church leaders in the area of palliative care.

Additional activities include purchasing essential drugs and non-consumables, providing material support (e.g. nutritional support, mosquito nets and bedding to clients in need, distribution of tools to volunteers and supervisors), conducting regular monitoring and supervision of home-based care and palliative care activities, and collecting and completing home-based care and palliative care reports on a monthly basis.

For more information, contact Rev. Gabriel Kimirei: [gkimirei@yahoo.com](mailto:gkimirei@yahoo.com)



#### **4.4. Support for spiritual care providers**

Providing spiritual care for people with incurable, progressive disease is a significant responsibility requiring the ability to face one's own mortality and the deep existential questions this raises.

##### **4.4. Recommendations**

- Recognise the impact of providing spiritual care on the spiritual care provider, and provide support for all spiritual care providers (whether paid or voluntary), in the form of debriefing and access to their line managers, peer support and/ or counselling as necessary
- Ask spiritual care providers whether the support they receive is sufficient, in order to ascertain whether further support is required, and to identify problems with current support structures

## **Good practice example: Support for spiritual care providers**

### **St Luke's Hospice, Cape Town**

St Luke's Hospice was founded in 1979, and has had a spiritual care team since 1996, when Peter Fox, a Presbyterian Minister, was employed as a full-time Counsellor committed to the focus of Spiritual Care. The spiritual care team now consists of 27 selected and trained volunteers, including retired clergy, lay counsellors, psychologists and doctors with an interest in spiritual care. Students from the local College of Applied Psychology also join the team for field work placements. The team includes Buddhist, Christian, Muslim, Jewish, Quaker, Unitarian and Agnostic adherents; additional key clergy from these groupings are involved in visits to the wards when specific faith rituals are required. The team shares a great desire to provide spiritual care with skill and insight and to be honest about their experiences.

In total, about 25% of patients receiving care from the hospice are seen by the spiritual care team. The team adopts an inclusive definition of spiritual care which includes music therapy, art therapy, storytelling, poetry, journal writing and movement as well as counselling. Spiritual care for patients is provided on the ward, in day care facilities and in the community as requested by the patients or the social workers or nurses representing the patients' concerns. Involvement with patients can be from a week's accompaniment to months or years of weekly visits. A prayer room in the ward garden is available to patients, family members and staff, providing space for quiet and stillness. The team documents the care provided to patients to facilitate multi-professional care, and provides staff training and education. Five officiants in the team are able to provide funeral services when required.

In view of the exacting, focused and challenging nature of the 'soul care' which members of the team provide, volunteers are supported in a number of ways. The team meets twice monthly: once for a case study supervision meeting and once for a general meeting where book reviews, speakers, meditations and resources are shared. The case study group is an opportunity for spiritual care providers to reflect on their clinical work and how this affects and challenges them. The structure is informal and the atmosphere supportive, beginning with a period of silent reflection. All team members are welcome to join these meetings in a spirit of sharing and learning. The team also organises an annual retreat, and maintains a website (<http://sites.google.com/a/cuspcode.net/spirit-cares/>). The website contains extensive resource material to augment and support team members' work and to advertise conferences, journal publications and speakers. A hard-copy file of training material and resources is also available through the team leader. Each team member is routinely involved in bereavement follow up work when a patient they have been seeing dies.

For more information, contact Rev Peter Fox: [peterf@stlukes.co.za](mailto:peterf@stlukes.co.za)

## **Quality markers: Spiritual care providers**

### **1. Evidence of liaising and sharing care with local spiritual leaders**

Measures:

- Directory of local palliative care-trained faith leaders and representatives of faith and community groups is held in the chaplain's office and in-patient areas

### **2. Evidence of training staff in spiritual care provision**

Measures:

- Inclusion of spiritual care provision as a dedicated session in the induction programme for all new staff and is appraised annually
- Number of in-service training workshops on spiritual care provision and numbers and types of staff who attended
- Attendance of spiritual care providers at national and/ or international palliative care conferences

### **3. Evidence of collaboration with training spiritual care providers in the community**

Measures:

- Number of clinical placements at the palliative care service taken up by (religious and non-religious) spiritual care providers from the community
- Details of teaching by palliative care staff on theological/ pastoral care/ chaplaincy training courses and other community forums (e.g. HIV NGOs)

## **5. Organisational requirements**

### **5.1. Implications of recommendations 1-4**

Recommendations 1-4 have specific implications for the organisation and delivery of palliative care. Sections 5.2.-5.7. describe additional organisational requirements.

### **5.1. Recommendations**

- Understand and fulfil the organisational implications of adopting each recommendation, for example:
  - From recommendations 1 and 2: document spiritual well being and spiritual interventions in client records for all staff members to access
  - From recommendation 3: recognise the importance of and foster relationships with local spiritual leaders, traditional healers and faith groups, with the palliative care organisation building on the support structures already in place in the local community
  - From recommendation 4: identify, train and support spiritual care providers with diverse backgrounds and belief systems, and demonstrate that their role patient and family care is valued

### **5.2. Training, education and support**

An ongoing commitment to education, training and support in the field of spiritual care is a cross-cutting theme of central importance in actualising the recommendations outlined here. As reflected in the APCA standards and core competencies, all staff members working within supportive and palliative care services need access to basic training in spiritual care.

## 5.2. Recommendations

- In line with the APCA standards and competencies, ensure all staff have training in basic spiritual care which includes the following topics:
  - Understanding the spiritual needs of religious and non-religious clients, staff members and volunteers
  - Children’s spirituality and needs, and the “language of play” required to care for children
  - Assessment of spiritual need, including in children
  - The religious needs and rites common in different faith groups, particularly those prevalent locally
  - The spiritual needs and rituals common in traditional belief systems, particularly those practiced commonly locally
  - The inter-relationships between culture, ethnicity and belief
  - How to respond to spiritual need (including referral pathways)
- Provide additional training as required according to staff members’ roles and levels of contact with clients; see Recommendations 3.2., (page 58-59) for more information on training

## 5.3. Understanding of spiritual well being and care

Spiritual well being can be understood as the spiritual aspect of quality of life (see Glossary page 21). It encompasses broader domains of experience than solely religious beliefs and practices, although for many clients religious beliefs, practices and their relationship to God and the church community will be important factors in their spiritual well being. It is crucial that services understand spiritual well being and care in broad terms, and that palliative care training programmes reflect this understanding.

*‘There’s spirituality in everybody. It might not be a traditional Christian or Muslim belief, a religious belief. But it will be something. It might be nature... There’s this inner soul to every single person that helps us through suffering. You’ve just got to find it; you’ve just got to tap that.’*  
Spiritual care provider CT\_SCP02, Cape Town

*“Spirituality falls through the cracks, because we have to get funds from outside, because it’s not ‘core’. This, for me, is the paradox: anybody working at a hospice would understand that spirituality is the key essence of what’s going down, besides the medical care and support, but, in reality, we’re factored in with small letters, not with capitals.”*  
Spiritual care provider CTLK\_SCP03, Cape Town

### **5.3. Recommendations**

- Understand spiritual well being in broader terms than religious belief and practice, to include notions of personal philosophy, coping and transcendence
- Recognise the importance of religion to many clients, and aim to meet clients’ religious needs
- Consider spiritual well being intrinsic to quality of life
- Consider spiritual care equally important as other dimensions of palliative care, and reflect this in the provision of adequate resources for spiritual care
- Where a chaplain/ spiritual care provider is appointed, see and treat him/ her as an essential and valued part of the care team
- Ensure curricula for palliative care professionals and training courses for volunteers reflect palliative care’s commitment to meeting clients’ spiritual needs
- Ensure all staff members are aware of the spiritual dimension of the illness experience, feel confident talking to clients about their spiritual needs, and are able to refer to spiritual care providers appropriately (see Box 3)

### **Box 3: The Fellow Traveller Model for Spiritual Care**

The Fellow Traveller Model was developed by Margaret Holloway in the UK as a way of conceptualising spiritual care (201;202). Although the model is based on the role of social workers in the provision of spiritual care, the model is also applicable more widely to other members of a palliative care team. Four intervention levels are described as follows (adapted from (202)):

1. *Joining (requiring spiritual awareness)*: Every team member should be able to engage in spiritual care at this level. What this means is that they are sufficiently spiritually aware to recognise the spirituality of the service user and to identify those people for whom spiritual concerns are important.
2. *Listening (requiring spiritual sensitivity)*: The ability to listen with an attuned ear is an essential component of the core set of palliative care team members' skills. All team members should be able to 'hear' what the client is saying and pick up the clues as to what they mean as well as what they are not saying (level 1). In level 2, a preliminary assessment of the nature and significance of the spiritual issues is made through 'active listening'. At this point the staff member may set up 'joint care' with one or more other members of the interdisciplinary team; refer to a spiritual care professional; seek the advice of a spiritual care professional; or, if both staff member and service user feel comfortable, the spiritual engagement moves to a deeper level.
3. *Understanding (requiring spiritual empathy)*: At this level, the staff member providing spiritual care needs to be able to understand and convey empathy with the kind of spiritual issues and dilemmas that may concern the service user, as well as the high points of spiritual experience, and understand how spiritual resources might be utilised. In order to provide this kind of spiritual care, a staff member probably needs to have (or have had in the past) an active spiritual life. This is not necessarily through committed adherence to a particular religious faith, but the staff member does need to have a strong awareness of their own spiritual identity and journey.
4. *Interpreting (requiring spiritual exploration)*: Sometimes there is a need to go still further into the spiritual issues. In the journeying metaphor, the traveller may enter a dark valley or rocky or hazardous terrain in which s/he is reliant on the knowledge, experience and expertise of the guide. The spiritual care provider will be willing to make her/ himself vulnerable through choosing to travel with the other person. Crucial tools here are the use of meaning-making and the ability to engage with hope. This kind of depth work needs to be conducted with great care; often (but not always) a professional spiritual care provider will be the most appropriate person to engage with service users at this level.

Reproduced in adapted form with kind permission of M. Holloway.

## **5.4. Culturally competent care**

Cultural competence is a core value in modern healthcare, but in order to be effective it needs to be interpreted as more than a 'box-ticking' exercise (see Glossary, page 21). A commitment to cultural competence involves ongoing reflexivity about the structure of the service and the process of care delivery. In relation to spiritual care, for example, it is important that services are aware of the influence on clients of overt religiosity. For example, a service which aims to be

non-/ inter-denominational may nevertheless represent a certain form of religiosity which prevents some clients from being open about their beliefs, experiences, feelings and needs. In order to provide culturally competent care which is responsive to the needs of clients, it is essential that organisations think critically about their approach to care provision and their relationship with the communities they serve. An active engagement with the goal of cultural competence includes training staff in best practice and supporting them in their individual negotiations of multi-cultural care.

#### **5.4. Recommendations**

- Aim to provide culturally competent care; this requires a commitment to being reflective about the way your service operates and how care is provided, paying attention to the cultural appropriateness and acceptability of the service to the local community. For example. ask yourself:
  - Are there sections of the community which are not accessing your service?
  - If so, why and what can you do to widen access?
  - Is spiritual care provided in a way which is supportive of all clients?
  - Could spiritual care be made more sensitive and appropriate to the needs of the local population?

##### **5.4.1. Cultural sensitivity**

A requirement of cultural competence is a commitment to cultural sensitivity from all members of staff (see Glossary, page 21). This is reflected in the APCA competency framework, which states that all staff members, from non-professional care givers to specialists, are able to provide culturally sensitive care. Cultural sensitivity requires critical awareness of organisational processes, one's own worldview and relationship to others. Fostering cultural sensitivity is an ongoing process, and involves recognising the complexity and range of culturally conditioned beliefs and practices, often related to religious or tribal affiliation. Syncretistic beliefs<sup>18</sup>, for example, are common throughout sub-Saharan Africa, and need to be recognised and discussed owing to their affect on clients' illness beliefs, behaviour and spiritual needs. While staff familiarity with the different cultures and ethnicities in the local area is desirable, this is not a 'recipe book' exercise that can be reduced to learning fact-sheets about different cultures and/or religions.<sup>19</sup>

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<sup>18</sup> E.g. faith in a Christian God combined with reverence of the ancestors.

<sup>19</sup> See 'Culture is not enough: A critique of multi-culturalism in palliative care', Y Gunaratnam (203) for more on this topic.



As discussed in 4.3., respect for clients' beliefs and worldviews needs to be balanced with the healthcare professional's duty of care towards clients. Other important areas related to the provision of culturally competent care include:

- *Negotiating authority:* For cultural or personal reasons, some clients may see staff members to have special authority e.g. doctors may be given a significant degree of trust, and may be expected to play a role as counsellors and advisors. Similarly, some clients may see local community leaders, religious leaders or traditional healers as having special authority, knowledge and ability.
- *Language and interpreters:* A shared language does not necessarily entail shared meaning and interpretation; social class, age and ethnic group may all impact on how language is interpreted and responded to. This is particularly important to bear in mind when communicating with someone in a language which is either not their first language or not your own. As language is embedded within a belief system and worldview, interpretation and translation require sensitivity to linguistic and cultural differences. The direct translation of terms from one language into another is not always possible, owing to variation in the structure, content and limitations of individual languages. Sensitivity to this is particularly important when discussing complex or abstract terms such as may arise in discussions of spiritual and religious belief.

Ideally, palliative care services would have access to trained and supported interpreters working in languages common in the local community. In resource-limited conditions this kind of service is rarely available, and staff and family members usually play the role of interpreter. It is important that the characteristics of the interpreter (e.g. gender, age and group affiliation), their relationship to the client and their understanding of the interpreting role are taken into consideration, as these factors may influence communication (e.g. what it is socially permissible to say).

- *Negotiating patient and family expectations:* Clients' expectations are culturally mediated and may lead to particular challenges in care provision, e.g. patients may expect their spiritual leader or care providers to tell their family members things they can't say themselves, family members may expect care providers not to tell the patient a poor prognosis, or parents may request ongoing treatment for their child even when clinicians believe this is not in the child's best interest.

#### **5.4.1. Recommendations**

- In line with the APCA competencies, foster staff members' cultural sensitivity by encouraging empathy, open-mindedness and reflexivity among staff members, and providing staff training on best practice in multi-cultural care, particularly in areas such as:
  - Identifying, discussing and understanding potentially harmful beliefs related to clients' cultural or spiritual worldview, and presenting the palliative care perspective sensitively but explicitly
  - Exploring clients' beliefs about the authority and abilities of staff members and local community leaders, religious leaders or traditional healers, and handling this sensitively, in consultation with the individual(s), if possible
  - Discussing sensitive issues such as spiritual beliefs, particularly in a language which is either not the staff member's first language or not the client's
  - Negotiating patient and family expectations of care and the care team
- Ensure all members of staff and the community involved in client care, including local spiritual leaders and traditional healers, understand the importance of upholding client confidentiality, avoiding stereotyping, and providing client-centred care (see 5.5.)
- Where staff and family members are utilised as interpreters, ensure clients are involved in selecting an appropriate interpreter
- Ensure staff and family members acting as interpreters receive appropriate guidance/ training and support
- Ensure challenges relating to culture are handled with diplomacy, sensitivity and awareness of the ethical norms of medical practice in your country
- Support staff members in their individual negotiations of multi-cultural care

## **Good practice example: Culturally competent care**

### **Chatsworth Hospice, South Africa**

The township of Chatsworth is a dormitory suburb within the City of Durban, created in the 1960s by the Apartheid Government's Policy of Group Areas to house thousands of displaced working class people of Indian origin. It was served by R. K. Khan Hospital, a State Health care facility that was part of the separate development structures. The Chatsworth Regional Hospice Association (CRHA) was established in 1991 and formally launched in 1992 by a small band of doctors and senior nurses working at R. K. Khan Hospital and members of the local community. It was received with great enthusiasm by representatives of health, welfare and cultural organisations and the Chatsworth community.

Chatsworth Hospice now serves clients from areas well beyond the immediate Chatsworth region, providing home care services, a day care centre and an inpatient unit to a diverse population predominantly of Indian and African origin. Clients are mainly Hindu; however, there are a growing number of people who have converted to Christianity, and of isiZulu-speaking people with traditional African belief systems, as well as a smaller Muslim population.

Given the ethnic and religious diversity of the local population, cultural sensitivity has always been a key tenet of the hospice's ethos and caregiver training programme. In 2003-2004, the CRHA, through its erstwhile Interdisciplinary Standing Committee, decided that as part of its aim of providing holistic care it would strengthen its focus on meeting the spiritual needs of patients and their families. The hospice firmly believes that in giving services of a spiritual nature it should emphasise aspects of care that value the presence of a sensitive soul.

Guided by its philosophy, vision and mission, the CRHA conducted a series of workshops on the concepts of spirituality, presented from the perspectives of all mainstream religions by faith leaders from those traditions. The core leadership and guidance for such a step was given by his Holiness Swami Saradaprabhananda of the Ramakrishna Centre. Through his spiritual and philosophical practice, academic accomplishments and wealth of experiences, the Swami has acquired expertise of immense depth on matters relating to spirituality, death and dying, and this was invaluable in formulating the programme. The course was advertised through the attending spiritual leaders as well as the hospice, and was well-attended by staff members, volunteers and members of the local community. The workshops served as an opportunity to share knowledge and experience, raise awareness of palliative care and the role of the hospice, and focus on the spiritual commonalities across faith traditions, as well as gain a better understanding of the differences.

The hospice's basic commitment to spiritual care has neither diminished nor been dampened by delays caused by limited resources and other pressures. The CRHA is currently exploring methods of improving and adapting spiritual care; part of this process is a review of the Spirituality Standing Committee and its terms of reference. With the Swami's encouragement the CRHA is also exploring the feasibility of developing a Certificate Course in Spiritual Counselling and Death Education. In future the CRHA hopes this course, based on philosophical and spiritual principles and experiential learning, will provide caregivers of different levels with the skills to meet all clients' spiritual needs, regardless of their faith or ethnic background.

For more information, contact Dr Pramda Ramasar: [info@chatshospice.co.za](mailto:info@chatshospice.co.za)

## 5.5. Providing client-centred care

A commitment to providing client-centred care which is responsive to the individual client's needs, considers each client on a case-by-case basis, and is sensitive to his or her worldview is a key principle of palliative care.

### 5.5. Recommendations

- Ensure clients are considered and cared for as individuals, and explore patients' and families' cultural and spiritual beliefs and needs on a case-by-case basis
- Ensure referral to spiritual care occurs with clients' consent, according to a system embedded in routine care
- Ideally, ensure inpatient and daycare units can accommodate the spiritual needs of clients from diverse groups, including needs for rituals and visits by faith leaders, members of the faith community and traditional healers, and for a space for worship

## 5.6. Staff support

Paying attention to the spiritual well being of staff and supporting staff members in cultivating and listening to the spiritual aspect of themselves contributes to a motivated, healthy palliative care team, and may help prevent burn-out.

### 5.6. Recommendations

- Take into consideration the spiritual well being of staff and foster a culture of support in the organisation, ensuring at all times that the diverse nature of people's beliefs and wishes in this regard is respected
- When staff members meet to explore and receive support for emotional and psychological needs related to their work, include opportunities to identify and explore any spiritual needs
- Consider staff training in techniques such as 'mindfulness' (204;205) or, for Christian staff members, 'centering prayer' (206;207)

## 5.7. Quality improvement

Quality monitoring and improvement is essential in spiritual care, just as it is in all other domains of palliative care. As discussed in 1.2.3., measuring the outcomes of care using formal assessment tools enables specific models of spiritual care to be evaluated and plays an important role in improving the quality of spiritual care. Qualitative work exploring clients' experiences of spiritual care can also be used to inform and improve practice. Evaluative work of this kind, when published, also contributes to the evidence-base required to inform and develop spiritual care as a discipline.

### 5.7. Recommendations

- Commit to and carry out ongoing quality improvement in spiritual care, for example through clinical audit, assessment of the outcomes of spiritual care, and the adoption of quality markers and associated measures for spiritual care

## Good practice examples: Organisational requirements

### Nairobi Hospice, Kenya

Nairobi Hospice was established in 1988, the first charitable organisation of its kind in East Africa. The hospice cares for and supports patients and families facing life limiting illnesses, particularly cancer, HIV and AIDS. Services are provided at the Hospice on an out-patient basis, in hospitals and at clients' homes within a 20km radius.

Nairobi Hospice is a non-denominational institution, open to people of all beliefs. The hospice does not employ a chaplain; however, the hospice team recognises that when faced with a life limiting illness and the prospect of death, spiritual issues come to the fore. The team also recognises the importance of focusing on the spiritual aspect of distressing symptoms such as pain, given the way spirituality modulates the patient's experience of illness.

The patient's assessment tool facilitates exploration of spiritual needs. For example, we ask: "Do you have a faith or belief that helps you in your illness?", "Do you belong to any religion?", "How do you feel about the illness?" The response usually leads the way for further exploration of the patient's and family's needs. Clients may request us to pray with them, or that we remember them in our prayers, and we are happy to do so. We also work closely with clients' spiritual leaders and Christian communities where appropriate to provide necessary support. Every Thursday during day care patients share their experiences of illness; encourage one another; read the Bible; and sing and pray together. Staff and volunteers also participate. From time to time, (e.g. during Easter and Christmas), we receive church choirs who come to pray, encourage patients and sing for them.

In providing spiritual care, the team holds dear the following guidelines, adapted from Poletti (1988):

1. Spiritual care starts with myself; who I am
2. Providing spiritual care requires:
  - An openness towards and positive acceptance of all the different expressions of spiritual and religious needs;
  - A positive acceptance of and a non-judgmental attitude towards all clients with whom we come in contact;
  - The capacity to listen: to be centred totally on the message being given by the other person;
  - A willingness to share the spiritual pain. This may mean simply being with the person in the silence of mutual presence and mutual vulnerability;
  - Some knowledge of the religious customs of the client;
  - Working in such a way as to preserve the client's dignity;
  - Working together as a team, appreciating and supporting one another.
3. Spiritual care means:
  - Helping the client to fulfil spiritual needs; for example, by assisting him/ her to accomplish some religious act;
  - Showing love in every gesture.

Nairobi Hospice runs palliative care courses for health care professionals and volunteers. One session focuses on spiritual issues, including assessing and identifying spiritual needs and providing spiritual support. It is a requirement that every new employee and volunteer attends.

For more information, contact Dr Brigid Sirengo: [ceo@nairobihospice.or.ke](mailto:ceo@nairobihospice.or.ke)

## **Quality markers: Organisational requirements**

### **1. Evidence of commitment to spiritual care provision**

Measures:

- Allocation of appropriate resources to the provision of spiritual care, including the time and funds for staff to provide spiritual care and receive spiritual care training

### **2. Evidence of organisational commitment to providing culturally competent care**

Measures:

- Assessment of staff members' cultural awareness and sensitivity during induction and appraisals
- In-service training to foster core skills among staff
- Documented collaboration with local ethnic groups, e.g. conference, invitations to community members to visit the palliative care service
- Where available, list of trained and supported interpreters available to staff members
- Guidance/ training in interpreting available to all staff

### **3. Evidence of implementing recommendations**

Measures:

- Agenda for moving forward with the recommendations, including:
  - o Prioritisation of recommendations and commitment to appropriate quality markers for the service;
  - o Development of a timeframe for implementation of the recommendations;
  - o Incorporation of recommendations and quality markers into organisational policy, strategy, budget, training plan and appraisal system.

## 6. Adoption of the Recommendations

Adopting these recommendations, and implementing strategies to meet the suggested quality markers, may potentially benefit clients, communities and palliative care services in a number of ways:

- Increased awareness of, and referral to, palliative care within the local community, through local faith groups, spiritual leaders and traditional healers.
- Improved communication, and a mutually supportive relationship, between local spiritual leaders, traditional healers and faith groups and hospice and palliative care teams.
- Local spiritual leaders and traditional healers who are better informed about palliative care needs, the philosophy of palliative care and wider spiritual aspects of the illness experience, and who are supported in their work through palliative care teams.
- Palliative care teams who are better informed about patients' and family members' spiritual needs, and are able to refer to trained spiritual care experts in the local community when necessary.
- Better assessment of spiritual well being in clinical practice. While some palliative care practitioners express fears that formal assessment tools may turn spiritual care provision into a 'box-ticking' exercise (208), there is a strong argument that good assessment of spiritual well being is needed in order to screen for spiritual distress, and identify clients who may require support in this area (100;176;209-212).



## 7. Future Research

Failure to identify clients' sources of spiritual support, making assumptions about clients' spiritual beliefs and needs, insensitive approaches to spiritual assessment, and ignoring expressed spiritual need may cause considerable distress. While these recommendations aim to assist services with meeting the spiritual needs of diverse communities, more evidence relating to the provision of spiritual care in the context of African palliative care is urgently needed. On the basis of the work conducted during this project, the following areas are identified as research priorities in this field:

1. Application, adoption and evaluation of the recommendations and quality markers presented here. Evaluation criteria recently formulated for quality indicators include importance (the extent to which indicators capture key aspects of care that require improvement); scientific acceptability (the degree to which indicators produce consistent and credible results when implemented, including validity, evidence of improved outcomes, reliability, responsiveness, and variability); usability; and feasibility (182).
2. Evaluation of the effectiveness of spiritual care models and interventions in the sub-Saharan African context, using both qualitative and quantitative methods and measuring key outcomes (e.g. spiritual well being) using validated tools.
3. Paediatric spiritual care, including the identification and assessment of spiritual needs in children and young adults and the evaluation of spiritual care interventions in these populations.
4. Evaluation of alternative methods of identifying and assessing spiritual care needs. Promising methods are likely to combine the use of good formal assessment tools with the staff training and support needed to foster the skills and confidence to engage with the spiritual resources available to patients and families.
5. Adaptation or development and validation of existing measures of spiritual well being (and related constructs) in the context of African palliative care. As spiritual well being is embedded within culture, measures used in clinical practice and research need to be developed and validated in the specific populations in which they are to be utilised.

## 6. Concluding comments

The population seen by palliative care services in sub-Saharan Africa is becoming increasingly diverse in terms of culture, spiritual beliefs and practices, and worldview. This report aims to assist in the development of palliative care services which are able to meet the spiritual care needs of patients with incurable, progressive disease and their families in the diverse communities they serve. In doing so, it builds on APCA's standards and competency framework for spiritual care provision, puts forward a public health model of spiritual care provision integrated into the local community, and suggests avenues for future research.

As discussed in Section One, it is expected that service providers will prioritise the recommendations according to their own aims, and adapt the guidance for their own circumstances. The 'shared care' model most appropriate for a palliative care team based in an urban hospital environment, for example, will look very different from that of a home care service in a rural area.

The quality markers suggested here aim to guide services in monitoring their progress towards fulfilling those recommendations which they adopt. However, services need to adapt the quality markers presented here and develop individualised and detailed quality markers based on local context. For example, formulating specific numerators and denominators would make some of the markers more explicit and facilitate the measurement of progress (180). Future revisions of these recommendations will take into account local experiences, practice and innovations in the provision of spiritual care in sub-Saharan Africa. Cross-site comparison of data generated through the measures associated with specific quality markers could also play an important role in setting national (and international) standards for the provision of the spiritual dimension of palliative care.

Finally, the authors and contributors hope these recommendations will contribute to a much-needed debate on the best construction of a multi-faith response to incurable, progressive illness that meets the needs of patients and families in sub-Saharan Africa.

September 2010

# Appendix 1: Summary of the Recommendations

	Categories	Sub-categories	Recommendations
Ongoing education, training and support (cross-cutting theme)	1 Identifying spiritual needs	1.1. What are spiritual needs?	<p>Understand spiritual needs broadly, as including all the existential concerns with which a client may require support</p> <p>Offer spiritual care to family members and carers as well as to patients, and to children as well as adults</p> <p>Integrate spiritual care into bereavement support</p>
		1.2. Assessment of spiritual needs	<p>In line with the APCA standards, ensure all team members have the appropriate training and support to be able to initiate discussions of spiritual issues and identify and assess spiritual pain (i.e. screen for spiritual distress)</p> <p>Integrate screening for spiritual distress, immediate spiritual needs and other needs associated with culture and/ or faith into routine assessment of all clients on registration with the service (e.g. first homecare visit or on admission to the inpatient unit)</p> <p>During screening:</p> <ul style="list-style-type: none"> <li>- Ask whether the client has a particular faith which they practice, whether it has been affected by illness and if so, how</li> <li>- If they are religious, ask if they would like access to an appropriate faith leader, either as soon as possible or in future (for example, in the event of a life-threatening crisis)</li> <li>- If they are not religious, ask if they would like access to a member of the care team who may be able to help with any spiritual concerns they may have (e.g. a spiritual counsellor or a nurse/ social worker with training in spiritual care)</li> <li>- Record the contact details of the appropriate faith leader, or ask permission to refer to one of the spiritual care team (e.g. a spiritual counsellor, a nurse/ social worker with training in spiritual care, or a pastor with training in palliative care)</li> <li>- Inform the client of the spiritual care services available through the palliative care service</li> <li>- Identify any immediate spiritual concerns which require attention, so that these can be prioritised when planning the client's care</li> <li>- Where clients indicate that they have no spiritual needs at present, this should be recorded in their</li> </ul>

			<p>records for further exploration once immediate needs are met</p> <ul style="list-style-type: none"> <li>- Record important additional information related to culture and/ or faith, e.g. specific dietary needs, the need for water for cleansing before prayer, space for private prayer, or a same-sex health care professional)</li> </ul> <p>Ensure all team members are able to respond to identified spiritual needs through providing basic spiritual care, initiating a full spiritual assessment (see 1.2.2.) and/ or referral</p> <p>Ensure screening is documented in client records</p> <p>Conduct a full spiritual assessment with all clients as part of a spiritual history-taking/ formal spiritual assessment</p> <p><b>When to assess</b></p> <ul style="list-style-type: none"> <li>- Skilfully initiate assessment of spiritual needs rather than wait for the client to raise the topic</li> <li>- If a person registers with the palliative care service who appears to be in severe spiritual distress or who has urgent spiritual concerns (see 1.1.), conduct a full spiritual assessment as soon as possible</li> <li>- If a person is referred to the service with problems that seem primarily non-spiritual in nature (e.g. uncontrolled physical symptoms,<sup>20</sup> or financial concerns), conduct a more thorough assessment of wider spiritual concerns once the immediate reasons for referral have been attended to</li> <li>- Ensure staff members are sensitive to potential changes in spiritual beliefs and needs</li> <li>- Assess spiritual needs at regular intervals throughout the disease trajectory and into the bereavement phase</li> </ul> <p><b>How to assess</b></p> <ul style="list-style-type: none"> <li>- Ensure staff members conducting a full spiritual assessments are properly trained to do so (to Intermediate or Specialist levels of the APCA competency framework)</li> <li>- Obtain consent from the client (or, where a patient unable to provide consent, from the family or primary carer) prior to assessment</li> <li>- Respect clients' personal boundaries and needs for information</li> <li>- Assess a child's spiritual needs according to their developmental stage, using the three languages: verbal, non-verbal and play</li> </ul> <p><b>What next?</b></p> <ul style="list-style-type: none"> <li>- Ensure spiritual assessment leads to appropriate responses to spiritual need where support is required</li> </ul>
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<sup>20</sup> Although see page 21 regarding the somatisation of spiritual pain.

		<ul style="list-style-type: none"> <li>- Ensure spiritual assessment is documented in client records as appropriate</li> <li>- Convey important issues arising out of the assessment to the rest of the care team during regular meetings, while respecting client confidentiality</li> </ul>
	<b>1.3. Formal assessment tools</b>	<p>Use formal assessment tools to identify spiritual needs in a timely manner, and to assess the outcomes of spiritual care, while recognising their inherent limitations</p> <p>Evaluate the outcomes of spiritual care; consider using both qualitative and quantitative methods (e.g. a validated outcomes measurement tool or questionnaire and in-depth client interviews regarding the spiritual care they have received)</p> <p>Choose formal assessment tools according to the aims of assessment, the properties of the tools, the context in which they are to be used, and their ease of use (e.g. if the tool is to be used for audit purposes, it should be easily incorporated into routine clinical practice)</p>
<b>2 Responding to spiritual needs</b>	<b>2.1. The ingredients of spiritual care</b>	<p>Ensure identified spiritual pain is addressed, either by palliative care staff or through referral</p> <p>Offer clients access to a range of spiritual care services, including those which are not religious</p> <p>Provide access to:</p> <ul style="list-style-type: none"> <li>- Appropriate faith leaders and traditional healers for religious support, prayer and ritual. Ideally, faith leaders should be acknowledged and/or accredited by their faith community (see 4.3)</li> <li>- The means to facilitate non-religious (as well as religious) rituals</li> <li>- Religious services: prayer, bible reading, group services, religious celebrations, religious counselling</li> <li>- One-on-one counselling (with either a spiritual or psychological approach, as appropriate for the client) through the palliative care service</li> <li>- Community support groups facilitated by trained volunteers, palliative care staff or trained spiritual leaders</li> <li>- Complementary therapies, including art and music therapy</li> <li>- A 'quiet space', in inpatient units, for clients' and staff members' personal reflection and prayer</li> </ul> <p>For children, in addition provide access to/ facilitate:</p> <ul style="list-style-type: none"> <li>- Poetry and journal writing</li> <li>- Memory book keeping</li> <li>- Reading, writing and telling stories</li> <li>- Painting and drawing</li> <li>- Displaying of ideas, pictures, stories, plays etc.</li> </ul> <p>Recognise that social support (e.g. income generation, food parcels, school fees, secure housing) will also</p>

			<p>be necessary for some clients in order to alleviate financial concerns and allow them to attend to spiritual concerns; if possible assist clients in these areas, e.g. by identifying sources of support</p> <p>Make information about the availability of spiritual care services available to all clients throughout the disease trajectory and into bereavement</p> <p>Provide information in a range of languages spoken in the local community, and make provisions for clients who are not able to read</p> <p>Protect clients from potentially damaging forms of spiritual intervention</p> <p>Document the spiritual care resources accessed by clients in their records, along with their value and effectiveness for the client</p>
	<b>3 Working with the community</b>	<b>3.1. Sharing spiritual care</b>	<p>Implement a 'shared care' model of spiritual care provision, in which:</p> <ul style="list-style-type: none"> <li>- The palliative care team aims to meet the spiritual needs of patients, their friends and family by working together with sources of support already available in the local community</li> <li>- The spiritual care provided by faith groups is recognised and built upon and the significant influence that spiritual leaders may have is harnessed</li> <li>- Mutual education and training is facilitated (see 3.2.), and palliative care providers and members of local faith and community groups are enabled to support each other</li> <li>- There is awareness of palliative care in the local community, including how to refer to and access service providers</li> </ul>
		<b>3.2. Education and training</b>	<p>To establish an effective 'shared care' model of spiritual care, design and implement training and education programmes for spiritual leaders and traditional healers in the community</p> <p>In order to be effective, training programmes should aim to:</p> <ul style="list-style-type: none"> <li>- Raise awareness and counter misperceptions of palliative care (including its philosophy, purpose, intended recipients, and access to and location of local services)</li> <li>- Raise awareness of, and advocate against, forms of spiritual counselling and care that are potentially harmful (for example, views which promote feelings of guilt or shame in clients, advice which discourages patients from taking prescribed medical treatment, or practices which may cause physiological damage), in order to avoid forms of spiritual care which are inappropriate in the context of palliative care</li> <li>- Educate spiritual leaders about the diseases which bring people to palliative care (e.g. types of cancer, organ failure, motor neurone disease, multiple sclerosis and HIV-related illnesses)</li> <li>- Educate spiritual leaders about common symptoms in these diseases (pain, breathlessness, depression, worry, etc.) and their treatment, particularly opioid analgesics</li> <li>- Discuss and raise awareness of wider spiritual aspects of incurable, progressive illness and the</li> </ul>

			<p>provision of palliative care, including the experiences and care of children</p> <ul style="list-style-type: none"> <li>- Discuss and emphasise clients' vulnerability and its implications for spiritual care, in particular the need for self-awareness and sensitivity among spiritual leaders and traditional healers</li> <li>- Train spiritual leaders to recognise, assess and respond to wider existential needs (which may not be overtly religious), including in children</li> <li>- Discuss clients' experiences of crises of faith and loss of belief in God, and educate spiritual leaders to respond in a non-judgemental, supportive way which allows a deeper exploration of their feelings and avoids pressurising the client</li> <li>- Educate and support spiritual leaders and traditional healers in managing patient and family expectations, maintaining confidentiality and providing information</li> <li>- Educate and train spiritual leaders and traditional healers in good communication and counselling skills, including active listening and self-awareness.<sup>21</sup> Emphasise the following areas in this regard: <ul style="list-style-type: none"> <li>o The skill required to hear the voice of someone who believes and feels differently from oneself, and who may be angry at God</li> <li>o The need to be aware of how one's own attributes (e.g. body language, wearing a cross) influence one's interactions and relationships with clients, sometimes negatively</li> <li>o The need for spiritual counsellors to be non-judgemental and flexible, and to avoid being overly prescriptive; this may at first appear contrary to spiritual leaders' training</li> <li>o The relational and visceral nature of the spiritual encounter</li> <li>o How to care for oneself as spiritual care provider (see 4.4.)</li> </ul> </li> <li>- Support spiritual leaders and traditional healers in meeting clients' spiritual needs, through access to the advice and support of the palliative care team when necessary (including telephone contact and referral)</li> <li>- Offer continuing education for spiritual leaders and traditional healers in the community</li> <li>- Listen and learn from the experiences shared by participants in the course of training</li> </ul> <p>As part of a programme of ongoing continuing education, provide opportunities for spiritual leaders and traditional healers in the community to educate each other and palliative care staff regarding their beliefs and practices</p> <p>Implement a programme of continuing education for palliative care staff about local spiritual beliefs and practices and their impact on the individual care of clients</p>
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<sup>21</sup> The need for self-awareness is reflected in the APCA competency framework for the Basic level upwards, which states that staff should be aware of their own spiritual and cultural beliefs and how these may have an impact on their work. The importance of good counselling skills is recognised for Intermediate and Specialist levels, which states that staff should be able to help patients and families clearly identify their spiritual and cultural needs through skilled counselling.

		<b>3.3. Referral</b>	<p>Put in place referral systems for palliative care providers to refer to local spiritual leaders and traditional healers trained in palliative care, and ensure the referral systems are utilised</p> <p>Allow any member of the care team to refer to an appropriate, trained spiritual care provider in the community; however, ideally appoint a designated spiritual care co-ordinator or another member of staff who is responsible for referral</p> <p>Ensure that referral to spiritual care providers in the community always occurs with the client's consent (or, where a patient is unable to provide consent, with the consent of the family or primary carer) and with due respect for the client's confidentiality and autonomy</p> <p>Raise awareness of palliative care, what the palliative care team provides and how to refer to the service among community leaders and faith and community groups</p> <p>Ensure that spiritual leaders and traditional healers who have received training in palliative care are familiar with the referral system and know how to refer people with suspected life-limiting conditions in the community to palliative care (via their local doctor where necessary)</p>
	<b>4 Spiritual care providers</b>	<b>4.1. Attributes of the spiritual care provider</b>	<p>Foster attributes in spiritual care providers which are conducive to good spiritual care, in particular:</p> <ul style="list-style-type: none"> <li>- The ability to focus on broader spiritual needs, not just religion</li> <li>- The ability to put aside religious differences and focus on client need</li> <li>- The ability to win clients' trust</li> <li>- The ability meet the client where he/she "is"</li> <li>- Tolerance and a non-judgmental attitude</li> <li>- A balanced and undogmatic worldview</li> <li>- Empathy with the client and a compassionate attitude</li> <li>- Humility</li> <li>- Openness: the ability to share one's experiences and views, but only as far as this will facilitate meeting the clients' needs</li> <li>- Self-awareness as the foundation for the above (e.g. the ability to notice and attend to one's personal barriers to being non-judgemental and open)</li> <li>- Familiarity with different spiritual and cultural beliefs and practices</li> </ul> <p>Support spiritual care providers in their cultivation of these attributes, through training and access to support services (see 4.4)</p>
		<b>4.2. Role of spiritual care provider in palliative care</b>	<p>Recognise the many roles of designated spiritual care providers in:</p> <ul style="list-style-type: none"> <li>- Providing an open, inclusive and safe space for spiritual insights to be shared</li> <li>- Visiting, listening to and speaking with clients in a sensitive, confidential, open-minded and respectful way which fosters trust</li> <li>- Acting as a point of referral for the rest of the care team</li> </ul>



		<p><b>team</b></p>	<ul style="list-style-type: none"> <li>- Recognising their limitations and asking for advice/ referring on when necessary</li> <li>- Liaising with and referring to spiritual care providers in the community (e.g. local church ministers and pastors, traditional healers), with the client's permission</li> <li>- Communicating with and educating spiritual care providers in the community to ensure the role of the palliative care-designated spiritual care provider is understood</li> <li>- Supporting and training other members of staff (e.g. through teaching, advising and providing spiritual support)</li> <li>- Interacting compassionately with other staff members as they experience loss, and providing spiritual care to members of the team</li> <li>- Representing the spiritual aspect of the palliative care service's work (e.g. through ensuring the spiritual perspective is expressed at the organisational level)</li> <li>- Working cooperatively with other members of the team and of the community</li> <li>- Taking and storing detailed notes on clients with care and confidentiality</li> <li>- Playing a role in public education</li> </ul> <p>Support spiritual care providers in fulfilling these roles</p>
		<p><b>4.3. Choice of spiritual care providers by the care team</b></p>	<p>Ensure that, as required by the APCA competency framework, all palliative care staff members have received training in the provision of basic spiritual care, including the identification of spiritual distress (see 1.2.1.)</p> <p>In this training, include the basic principles of providing spiritual care for children, as this is likely to be an area in which confidence is lacking</p> <p>Select the most appropriate spiritual care provider for a client on an individual basis, and recognise that a trained non-specialist in the care team may be the best person to provide spiritual care for a given client</p> <p>When a non-specialist is providing spiritual care, ensure he or she receives support and advice from the designated spiritual care expert(s) in the team as required</p> <p>Communicate with clients' faith leaders and/ or traditional healers to ascertain their familiarity with palliative care and identify potential conflicts with the palliative care perspective which could negatively affect client well being</p> <p>Where a client does not have a local resource for spiritual care but would like to be referred to someone, take into account whether the person has received training in palliative care, the languages they speak, and their ethnicity, gender and religion, according to clients' wishes</p> <p>On the basis of these considerations, refer the client to a spiritual carer inside or outside the healthcare</p>

			<p>setting, as is most appropriate</p> <p>Ensure all spiritual care providers referred to by the palliative care team have received palliative care training, and are supported by the palliative care team</p> <p>Respect clients' worldviews, but also investigate and caution against potentially harmful religious practices (such as using prayer as a substitute for medical treatment), and forms of traditional healing (such as the physical extraction of bad spirits)</p> <p>In order to safeguard patients and families, consider linking only with community spiritual care providers who belong to formal or official groups, e.g. through registered NGOs, established and well-known churches or pastoral training providers</p> <p>Before linking with a religious institution such as a church, consider requesting a statement of faith or investigating the guiding principles of the church in order to anticipate or prevent potential conflicts</p> <p>Screen volunteers wishing to provide spiritual care to clients, including faith leaders in the community, before they join the service, and ensure they are properly trained in the palliative care approach to spiritual care</p> <p>If possible, reimburse volunteers' travel expenses and subsistence</p>
		<b>4.4. Support for spiritual care providers</b>	<p>Recognise the impact of providing spiritual care on the spiritual care provider, and provide support for all spiritual care providers (whether paid or voluntary), in the form of debriefing and access to their line managers, peer support and/ or counselling as necessary</p> <p>Ask spiritual care providers whether the support they receive is sufficient, in order to ascertain whether further support is required, and to identify problems with current support structures</p>
	<b>5 Organisational requirements</b>	<b>5.1. Implementing the recommendations</b>	<p>Understand and fulfil the organisational implications of adopting each recommendation, for example:</p> <ul style="list-style-type: none"> <li>- From recommendations 1 and 2: document spiritual well being and spiritual interventions in client records for all staff members to access</li> <li>- From recommendation 3: recognise the importance of and foster relationships with local spiritual leaders, traditional healers and faith groups, with the palliative care organisation building on the support structures already in place in the local community</li> <li>- From recommendation 4: identify, train and support spiritual care providers with diverse backgrounds and belief systems, and demonstrate that their role in patient and family care is valued</li> </ul>

		<p><b>5.2. Training, education, and support</b></p>	<p>In line with the APCA standards and competencies, ensure all staff have training in basic spiritual care which includes the following topics:</p> <ul style="list-style-type: none"> <li>- Understanding the spiritual needs of religious and non-religious clients, staff members and volunteers</li> <li>- Children’s spirituality and needs, and the “language of play” required to care for children</li> <li>- Assessment of spiritual need, including in children</li> <li>- The religious needs and rites common in different faith groups, particularly those prevalent locally</li> <li>- The spiritual needs and rituals common in traditional belief systems, particularly those practiced commonly locally</li> <li>- The inter-relationships between culture, ethnicity and belief</li> <li>- How to respond to spiritual need (including referral pathways)</li> </ul> <p>Provide additional training as required according to staff members’ roles and levels of contact with clients</p>
		<p><b>5.3. Understanding of spiritual well being and care</b></p>	<p>Understand spiritual well being in broader terms than religious belief and practice, to include notions of personal philosophy, coping and transcendence</p> <p>Recognise the importance of religion to many clients, and aim to meet clients’ religious needs</p> <p>Consider spiritual well being intrinsic to quality of life</p> <p>Consider spiritual care equally important as other dimensions of palliative care, and reflect this in the provision of adequate resources for spiritual care</p> <p>Where a chaplain/ spiritual care provider is appointed, see and treat him/ her as an essential and valued part of the care team</p> <p>Ensure curricula for palliative care professionals and training courses for volunteers reflect palliative care’s commitment to meeting clients’ spiritual needs</p> <p>Ensure all staff members are aware of the spiritual dimension of the illness experience, feel confident talking to clients about their spiritual needs, and are able to refer to spiritual care providers appropriately</p>
		<p><b>5.4. Culturally competent care</b></p>	<p>Aim to provide culturally competent care; this requires a commitment to being reflective about the way your service operates and how care is provided, paying attention to the cultural appropriateness and acceptability of the service to the local community. For example. ask yourself:</p> <ul style="list-style-type: none"> <li>- Are there sections of the community which are not accessing your service?</li> <li>- If so, why and what can you do to widen access?</li> <li>- Is spiritual care provided in a way which is supportive of all clients?</li> <li>- Could spiritual care be made more sensitive and appropriate to the needs of the local population?</li> </ul>

			<p>In line with the APCA competencies, foster staff members' cultural sensitivity by encouraging empathy, open-mindedness and reflexivity among staff members, and providing staff training on best practice in multi-cultural care, particularly in areas such as:</p> <ul style="list-style-type: none"> <li>- Identifying, discussing and understanding potentially harmful beliefs related to clients' cultural or spiritual worldview, and presenting the palliative care perspective sensitively but explicitly</li> <li>- Exploring clients' beliefs about the authority and abilities of staff members and local community leaders, religious leaders or traditional healers, and handling this sensitively, in consultation with the individual(s), if possible</li> <li>- Discussing sensitive issues such as spiritual beliefs, particularly in a language which is either not the staff member's first language or not the client's</li> <li>- Negotiating patient and family expectations of care and the care team</li> </ul> <p>Ensure all members of staff and the community involved in client care, including local spiritual leaders and traditional healers, understand the importance of upholding client confidentiality, avoiding stereotyping, and providing client-centred care (see 5.5.)</p> <p>Where staff and family members are utilised as interpreters, ensure clients are involved in selecting an appropriate interpreter</p> <p>Ensure staff and family members acting as interpreters receive appropriate guidance/ training and support</p> <p>Ensure challenges relating to culture are handled with diplomacy, sensitivity and awareness of the ethical norms of medical practice in your country</p> <p>Support staff members in their individual negotiations of multi-cultural care</p>
		<p><b>5.5. Providing client-centred care</b></p>	<p>Ensure clients are considered and cared for as individuals, and explore patients' and families' cultural and spiritual beliefs and needs on a case-by-case basis</p> <p>Ensure referral to spiritual care occurs with clients' consent, according to a system embedded in routine care</p> <p>Ideally, ensure inpatient and daycare units can accommodate the spiritual needs of clients from diverse groups, including needs for rituals and visits by faith leaders, members of the faith community and traditional healers, and for a space for worship</p>
		<p><b>5.6. Staff support</b></p>	<p>Take into consideration the spiritual well being of staff and foster a culture of support in the organisation, ensuring at all times that the diverse nature of people's beliefs and wishes in this regard is respected</p> <p>When staff members meet to explore and receive support for emotional and psychological needs related to</p>

			<p>their work, include opportunities to identify and explore any spiritual needs</p> <p>Consider staff training in techniques such as ‘mindfulness’ or, for Christian staff members, ‘centering prayer’</p>
		<p><b>5.7. Quality improvement</b></p>	<p>Commit to and carry out ongoing quality improvement in spiritual care, for example through clinical audit, assessment of the outcomes of spiritual care, and the adoption of quality markers and associated measures for spiritual care</p>

## Appendix 2: Quality Markers

Category	Quality marker(s)	Measure(s)
<b>Identifying spiritual need</b>	<b>Evidence of spiritual assessment</b>	<ul style="list-style-type: none"> <li>- Documentation showing every clients' spiritual (including faith) needs are discussed at multi-disciplinary meetings</li> <li>- Documentation of spiritual needs in client records (including children's records)</li> </ul>
	<b>Evidence of the use of formal assessment tools in the audit of spiritual care</b>	<ul style="list-style-type: none"> <li>- Data from formal assessment of outcomes of spiritual care are used to influence service provision in demonstrable ways</li> </ul>
<b>Responding to spiritual needs</b>	<b>Evidence that a range of appropriate spiritual care services are accessible to all clients</b>	<ul style="list-style-type: none"> <li>- Database of the spiritual care services available through the service, including a list of contact details for local, trained spiritual leaders of different denominations and traditional healers of different backgrounds</li> <li>- Documentation in client records of the spiritual interventions they access, along with their effectiveness and value<sup>22</sup></li> <li>- Range of media produced and disseminated to advertise the spiritual care services available to clients, e.g. posters, leaflets in appropriate languages, large type</li> </ul>
	<b>Evidence of client satisfaction with spiritual care services</b>	<ul style="list-style-type: none"> <li>- Assess patient and/ or family satisfaction with the spiritual care services they have access to through the palliative care service, e.g. through the inclusion of spiritual care in any satisfaction with care assessment forms and capturing informal feedback, including thank you cards and other communications from clients to spiritual care</li> </ul>
	<b>Evidence that clients' wishes for spiritual care are assessed regularly</b>	<ul style="list-style-type: none"> <li>- Documentation in client records of clients' spiritual care needs and resulting action taken at regular intervals throughout the disease trajectory</li> </ul>
<b>Working with the community</b>	<b>Evidence of mutual training and education</b>	<ul style="list-style-type: none"> <li>- Number of workshops/ training courses held for members of the community;</li> <li>- List of ways in which workshops were advertised;</li> <li>- Numbers of attendees from different community groups (e.g. church groups, traditional healers);</li> <li>- Number of organised visits to palliative care service by faith/ community group/ traditional healer representatives</li> </ul>

<sup>22</sup> This information could also be shared (anonymously) during staff/ volunteer training on the importance of spiritual care.

	<b>Evidence of referral to and from spiritual care providers in the community</b>	<ul style="list-style-type: none"> <li>- Number of clients referred to spiritual leaders and traditional healers in the community for spiritual support;</li> <li>- Number of patients referred to palliative care service by spiritual leaders/ members of community groups/ traditional healers , via healthcare professional</li> </ul>
<b>Spiritual care providers</b>	<b>Evidence of liaising and sharing care with local spiritual leaders</b>	<ul style="list-style-type: none"> <li>- Directory of local palliative care-trained faith leaders and representatives of faith and community groups is held in the chaplain's office and in-patient areas</li> </ul>
	<b>Evidence of training staff in spiritual care provision</b>	<ul style="list-style-type: none"> <li>- Inclusion of spiritual care provision as a dedicated session in the induction programme for all new staff and is appraised annually</li> <li>- Number of in-service training workshops on spiritual care provision and numbers and types of staff who attended</li> <li>- Attendance of spiritual care providers at national and/ or international palliative care conferences</li> </ul>
	<b>Evidence of collaboration with training spiritual care providers in the community</b>	<ul style="list-style-type: none"> <li>- Number of clinical placements at the palliative care service taken up by (religious and non-religious) spiritual care providers from the community</li> <li>- Details of teaching by palliative care staff on theological/ pastoral care/ chaplaincy training courses and other community forums (e.g. HIV NGOs)</li> </ul>
<b>Organisational requirements</b>	<b>Evidence of commitment to spiritual care provision</b>	<ul style="list-style-type: none"> <li>- Allocation of appropriate resources to the provision of spiritual care, including the time and funds for staff to provide spiritual care and receive spiritual care training</li> </ul>
	<b>Evidence of organisational commitment to providing culturally competent care</b>	<ul style="list-style-type: none"> <li>- Assessment of staff members' cultural awareness and sensitivity during induction and appraisals</li> <li>- In-service training to foster core skills among staff</li> <li>- Documented collaboration with local ethnic groups, e.g. conference, invitations to community members to visit the palliative care service</li> <li>- Where available, list of trained and supported interpreters available to staff members</li> <li>- Guidance/ training in interpreting available to all staff</li> </ul>

	<p><b>Evidence of implementing recommendations</b></p>	<ul style="list-style-type: none"> <li>- Agenda for moving forward with the recommendations, including: <ul style="list-style-type: none"> <li>o Prioritisation of recommendations and commitment to appropriate quality markers for the service;</li> <li>o Development of a timeframe for implementation of the recommendations;</li> <li>o Incorporation of recommendations and quality markers into organisational policy, strategy, budget, training plan and appraisal system.</li> </ul> </li> </ul>
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## Reference List

- (1) African Palliative Care Association. Standards for Providing Quality Palliative Care Across Africa. Kampala: African Palliative Care Association; 2010. For availability, contact: info@apca.org.ug
- (2) African Palliative Care Association (in press). Core Competencies for Palliative Care in Africa. Kampala: African Palliative Care Association; 2010. For availability, contact: info@apca.org.ug
- (3) Burkhardt MA. Spirituality: an analysis of the concept. *Holist Nurs Pract* 1989 May;3(3):69-77.
- (4) Heyse-Moore LH. On spiritual pain in the dying. *Mortality* 1996;1:297-315.
- (5) Dyson J, Cobb M, Forman D. The meaning of spirituality: a literature review. *J Adv Nurs* 1997;26:1183-8.
- (6) Kearney M, Mount BM. Spiritual care of the dying patient. In: Chochinov HM, Breitbart W, editors. *Handbook of Psychiatry in Palliative Medicine*. 2000 ed. OUP; 2000. p. 357-73.
- (7) Speck P. Spiritual Concerns. In: Sykes N, Edmonds P, Wiles J, editors. *Management of Advanced Disease*. 4 ed. Arnold; 2004.
- (8) Ellor J. Spiritual well-being defined. *Aging and Spirituality* 1997;xi(1).
- (9) Taylor EJ. Spirituality, culture, and cancer care. *Semin Oncol Nurs* 2001 Aug;17(3):197-205.
- (10) Martsolf DS. Cultural aspects of spirituality in cancer care. *Semin Oncol Nurs* 1997 Nov;13(4):231-6.
- (11) Kim-Godwin YS, Clarke PN, Barton L. A model for the delivery of culturally competent community care. *J Adv Nurs* 2001 Sep;35(6):918-25.
- (12) Betancourt JR, Green AR, Carrillo JE, Ananeh-Firempong O. Defining cultural competence: a practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Rep* 2003 Jul;118(4):293-302.
- (13) WHO. WHO definition of palliative care. World Health Organisation website 2006 [cited 2008 Jun 23]; Available from: URL: <http://www.who.int/cancer/palliative/definition/en/>
- (14) WHO. WHO definition of palliative care. World Health Organisation website 2006 [cited 2008 Jun 23]; Available from: URL: <http://www.who.int/cancer/palliative/definition/en/>

- (15) UNAIDS. 2009 AIDS epidemic update. Geneva: World Health Organisation; 2009.
- (16) World Health Organization, United Nations Children's Fund, UNAIDS. Towards universal access: scaling up priority HIV/AIDS interventions in the health sector. Progress report 2009. Geneva: World Health Organization; 2009.
- (17) UNAIDS. AIDS Epidemic Update 2007. Geneva: World Health Organisation; 2007 Nov.
- (18) Harding R, Molloy T, Easterbrook P, Frame K, Higginson IJ. Is antiretroviral therapy associated with symptom prevalence and burden? *Int J STD AIDS* 2006 Jun;17(6):400-5.
- (19) Karus D, Raveis VH, Alexander C, Hanna B, Selwyn P, Marconi K, et al. Patient reports of symptoms and their treatment at three palliative care projects servicing individuals with HIV/AIDS. *J Pain Symp Manage* 2005;30(5):408-17.
- (20) Larue F, Fontaine A, Colleau SM. Underestimation and undertreatment of pain in HIV disease: multicentre study. *BMJ* 1997 Jan 4;314(7073):23-8.
- (21) Hicks C, Currier J, Sax P, Sherer R, Wanke C. Current management challenges in HIV: tolerability of antiretrovirals and metabolic complications. *AIDS Patient Care & Stds* 2003 May;17(5):221-33.
- (22) Sperber K, Shao L. Neurologic consequences of HIV infection in the era of HAART. *AIDS Patient Care & Stds* 2003 Oct;17(10):509-18.
- (23) Selwyn PA, Rivard M. Palliative care for AIDS: challenges and opportunities in the era of highly active anti-retroviral therapy. *J Palliat Med* 2003 Jun;6(3):475-87.
- (24) Egger M. Outcome of antiretroviral therapy in resource-limited and industrialized countries. Conference on Retroviruses and Opportunistic Infections, Los Angeles USA. 2007.

Ref Type: Abstract

- (25) UNAIDS. 2008 Report on the global AIDS epidemic. Geneva: World Health Organisation; 2008.
- (26) Fellay J, Boubaker K, Ledergerber B, Bernasconi E, Furrer H, Battegay M, et al. Prevalence of adverse events associated with potent antiretroviral treatment: Swiss HIV Cohort Study. *The Lancet* 2001 Oct 20;358(9290):1322-7.
- (27) National Institute of Allergy and Infectious Diseases. HIV/ AIDS Treatment. National Institute of Health (US) 2009 Available from: URL: <http://www3.niaid.nih.gov/topics/HIVAIDS/Understanding/treatment.htm>
- (28) Heath KV, Montaner JS, Bondy G, Singer J, O'Shaughnessy MV, Hogg RS. Emerging drug toxicities of highly active antiretroviral therapy for human immunodeficiency virus (HIV) infection. *Curr Drug Targets* 2003 Jan;4(1):13-22.

- (29) Lange JMA. Antiretroviral treatment and care of HIV. In: Beck EJ, Mays N, Whiteside AW, Zuniga JM, editors. The HIV Pandemic: local and global implications. Oxford, UK: Oxford University Press; 2006.
- (30) Makoae LN, Seboni NM, Molosiwa K, Moleko M, Human S, Sukati NA, et al. The symptom experience of people living with HIV/AIDS in southern Africa. *JANAC* 2005;16(3):22-32.
- (31) Simms V, Harding R, Penfold S, Powell RA, Downing J, Namisango E, et al. Quality of life improves after HIV diagnosis, but ART is not the cause: a multicentre longitudinal study in Kenya and Uganda. (Abstract no. WEPE0596). 2010 Jul 19; Vienna, Austria 2010.
- (32) Heckman TG, Somlai AM, Kelly JA, Stevenson LY, Galdabini K. Reducing barriers to care and improving quality of life for rural persons with HIV. *AIDS Patient Care STDS* 1996 Feb;10(1):37-43.
- (33) Chuang HT, Devins GM, Hunsley J, Gill MJ. Psychosocial distress and well-being among gay and bisexual men with human immunodeficiency virus infection. *Am J Psychiatry* 1989 Jul;146(7):876-80.
- (34) Kalichman SC, Sikkema KJ, Somlai A. People living with HIV infection who attend and do not attend support groups: a pilot study of needs, characteristics and experiences. *AIDS Care* 1996 Oct;8(5):589-99.
- (35) Guillory JA, Sowell R, Moneyham L, Seals B. An exploration of the meaning and use of spirituality among women with HIV/AIDS. *Altern Ther Health Med* 1997 Sep;3(5):55-60.
- (36) Hall BA. Patterns of spirituality in persons with advanced HIV disease. *Res Nurs Health* 1998 Apr;21(2):143-53.
- (37) Schwartzberg SS. Struggling for meaning: How HIV-positive gay men make sense of AIDS. *Professional Psychology: Research and Practice* 1993;24(4):483-90.
- (38) Miller G. Mental health in developing countries. The unseen: mental illness's global toll. *Science* 2006 Jan 27;311(5760):458-61.
- (39) Freeman M, Patel V, Collins P, Bertolote J. Integrating mental health in global initiatives for HIV/AIDS. *The British Journal of Psychiatry* 2005 Jul 1;187(1):1-3.
- (40) Cotton S, Tsevat J, Szaflarski M, Kudel I, Sherman S, Feinberg J, et al. Changes in religiousness and spirituality attributed to HIV/AIDS. *Journal of General Internal Medicine* 2006 Dec 12;21(0):S14-S20.
- (41) Food and Nutrition Technical Assistance. HIV/AIDS: A Guide for Nutritional Care and Support. Washington, DC: Academy for Educational Development; 2004.

- (42) Jones CY, Tang AM, Forrester JE, Huang J, Hendricks KM, Knox TA, et al. Micronutrient levels and HIV disease status in HIV-infected patients on highly active antiretroviral therapy in the Nutrition for Healthy Living cohort. *J Acquir Immune Defic Syndr* 2006 Dec 1;43(4):475-82.
- (43) Marston B, De Cock KM. Multivitamins, Nutrition, and Antiretroviral Therapy for HIV Disease in Africa. *N Engl J Med* 2004 Jul 1;351(1):78-80.
- (44) UNDP. Human Development Report 2007/2008. New York: United Nations Development Programme; 2007.
- (45) Shawn ER, Campbell L, Mnguni MB, Defilippi KM, Williams AB. The spectrum of symptoms among rural South Africans with HIV infection. *J Assoc Nurses AIDS Care* 2005 Nov;16(6):12-23.
- (46) Dageid W, Duckert F. Balancing Between Normality and Social Death: Black, Rural, South African Women Coping With HIV/AIDS. *Qual Health Res* 2008 Feb 1;18(2):182-95.
- (47) Withell B. A study of the experiences of women living with HIV/AIDS in Uganda. *International Journal of Palliative Nursing* 2000;6(5):234-44.
- (48) Sukati NA, Mndebele SC, Makoa ET, Ramukumba TS, Makoe LN, Seboni NM, et al. HIV/AIDS symptom management in Southern Africa. *J Pain Symptom Manage* 2005 Feb;29(2):185-92.
- (49) Parkin DM, Sitas F, Chirenje M, Stein L, Abratt R, Wabinga H. Part I: Cancer in Indigenous Africans - burden, distribution, and trends. *The Lancet Oncology* 2008;9(7):383-692.
- (50) Sepulveda C, Habiyambere V, Amandua J, Borok M, Kikule E, Mudanga B, et al. Quality care at the end of life in Africa. *BMJ* 2003 Jul 26;327(7408):209-13.
- (51) Ramsay S. Raising the profile of palliative care for Africa. *Lancet* 2001 Sep 1;358(9283):734.
- (52) Teunissen SC, Wesker W, Kruitwagen C, de Haes HC, Voest EE, de GA. Symptom prevalence in patients with incurable cancer: a systematic review. *J Pain Symptom Manage* 2007 Jul;34(1):94-104.
- (53) Cooley ME. Symptoms in adults with lung cancer. A systematic research review. *J Pain Symptom Manage* 2000 Feb;19(2):137-53.
- (54) Solano JP, Gomes B, Higginson IJ. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. *J Pain Symp Manage* 2006 Jan 1;31(1):58-69.

- (55) Krupski TL, Kwan L, Fink A, Sonn GA, Maliski S, Litwin MS. Spirituality influences health related quality of life in men with prostate cancer.[see comment]. *Psychooncology* 2006 Feb;15(2):121-31.
- (56) Tarakeshwar N, Vanderwerker LC, Paulk E, Pearce MJ, Kasl SV, Prigerson HG. Religious Coping is Associated with the Quality of Life of Patients with Advanced Cancer. *J Palliat Med* 2006 Jun 15;9(3):646-57.
- (57) McIlmurray MB, Francis B, Harman JC, Morris SM, Soothill K, Thomas C. Psychosocial needs in cancer patients related to religious belief. *Palliative Medicine* 2003 Jan 1;17(1):49-54.
- (58) Hotopf M, Chidgey J, Addington-Hall J, y KL. Depression in advanced disease: a systematic review Part 1. Prevalence and case finding. *PALLIAT MED* 2002 Mar;16(2):81-97.
- (59) Harter M, Reuter K, Aschenbrenner A, Schretzmann B, Marschner N, Hasenburger A, et al. Psychiatric disorders and associated factors in cancer: results of an interview study with patients in inpatient, rehabilitation and outpatient treatment. *Eur J Cancer* 2001 Jul;37(11):1385-93.
- (60) Kissane DW, Grabsch B, Love A, Clarke DM, Bloch S, Smith GC. Psychiatric disorder in women with early stage and advanced breast cancer: a comparative analysis. *Aust N Z J Psychiatry* 2004 May;38(5):320-6.
- (61) Stark D, Kiely M, Smith A, Velikova G, House A, Selby P. Anxiety disorders in cancer patients: their nature, associations, and relation to quality of life. *J Clin Oncol* 2002 Jul 15;20(14):3137-48.
- (62) Stark DP, House A. Anxiety in cancer patients. *Br J Cancer* 2000 Nov;83(10):1261-7.
- (63) Ciaramella A, Poli P. Assessment of depression among cancer patients: the role of pain, cancer type and treatment. *Psychooncology* 2001 Mar;10(2):156-65.
- (64) Chen ML, Chang HK. Physical symptom profiles of depressed and nondepressed patients with cancer. *PALLIAT MED* 2004 Dec;18(8):712-8.
- (65) Jacobsen PB, Donovan KA, Weitzner MA. Distinguishing fatigue and depression in patients with cancer. *Semin Clin Neuropsychiatry* 2003 Oct;8(4):229-40.
- (66) Ell K, Sanchez K, Vourlekis B, Lee PJ, Dwight-Johnson M, Lagomasino I, et al. Depression, correlates of depression, and receipt of depression care among low-income women with breast or gynecologic cancer. *J Clin Oncol* 2005 May 1;23(13):3052-60.
- (67) Bolmsjo I. Existential issues in palliative care - interviews with cancer patients. *J Palliat Care* 2000;16(2):20-4.

- (68) Hamrick N, Diefenbach MA. Religion and spirituality among patients with localized prostate cancer. *Palliative and Supportive Care* 2006;4:345-55.
- (69) Miller DK, Chibnall JT, Videen SD, Duckro PN. Supportive-affective group experience for persons with life-threatening illness: Reducing spiritual, psychological, and death-related distress in dying patients. *J Palliat Med* 2005;8(2):333-43.
- (70) World Health Organization. A Community Health Approach to Palliative Care for HIV/AIDS and Cancer Patients. Geneva, Switzerland: WHO; 2004 Aug 15.
- (71) World Bank Group. World Development Indicators database, 2009. World Bank Group; 2009.
- (72) Population Division of the Department of Economic and Social Affairs of the United Nations Secretariat. *World Population Prospects: The 2008 Revision*. 2009 Mar 31.
- (73) King M, Speck P, Thomas A. The Royal Free Interview for spiritual and religious beliefs: development and validation of a self-report version. *Psychological Medicine* 2001;31:1015-23.
- (74) Speck P, Higginson IJ, Addington-Hall J. Spiritual needs in health care. *BMJ* 2004;329:123-4.
- (75) Reed PG. Spirituality and well-being in terminally ill hospitalized adults. *Res Nurs Health* 1987 Oct;10(5):335-44.
- (76) Anderson J, Doyal L. Women from Africa living with HIV in London: a descriptive study. *AIDS Care* 2003;16(1):95-105.
- (77) Doyal L, Anderson J. 'My fear is to fall in love again...' How HIV-positive African women survive in London. *Soc Sci Med* 2005 Apr;60(8):1729-38.
- (78) Ndirangu E, Evans C. Experiences of African Immigrant Women Living with HIV in the U.K.: Implications for Health Professionals. *Journal of Immigrant and Minority Health*.
- (79) The George H.Gallup International Institute. Spiritual beliefs and the dying process: A report on a national survey. New York: Nathan Cummings Foundation; 1997. Report No.: 2.
- (80) Ehman JW, Ott BB, Short TH, Ciampa RC, Hansen-Flaschen J. Do patients want their physicians to inquire about their spiritual or religious beliefs if they become gravely ill? *Arch Intern Med* 1999;159:1803-6.
- (81) King DE, Bushwick B. Beliefs and attitudes of hospital inpatients about faith healing and prayer. *J Fam Pract* 1994 Oct;39(4):349-52.

- (82) Moadel A, Morgan C, Fatone A, Grennan J, Carter J, Laruffa G, et al. Seeking meaning and hope: self-reported spiritual and existential needs among an ethnically-diverse cancer patient population. *Psychooncology* 1999 Sep;8(5):378-85.
- (83) Dein S, Stygall J. Does being religious help or hinder coping with chronic illness? A critical literature review. *Palliat Med* 1997 Jul;11(4):291-8.
- (84) Cotton S, Puchalski C, Sherman SN, Mrus JM, Peterman AH, Feinberg J, et al. Spirituality and religion in patients with HIV/AIDS. *J Gen Intern Med* 2006;21:S4-S13.
- (85) Carson V, Soeken KL, Shanty J, Terry L. Hope and spiritual well-being: essentials for living with AIDS. *Perspect Psychiatr Care* 1990;26(2):28-34.
- (86) Szaflarski M, Neal Ritchey P, Leonard AC, Mrus JM, Peterman AH, Ellison CG, et al. Modeling the Effects of Spirituality/Religion on Patients' Perceptions of Living with HIV/AIDS. *Journal of General Internal Medicine* 2006;21(s5):S28-S38.
- (87) Cohen SR, Mount BM, Bruera E, Provost M, Rowe J, Tong K. Validity of the McGill Quality of Life Questionnaire in the palliative care setting: a multi-centre Canadian study demonstrating the importance of the existential domain. *PALLIAT MED* 1997;11:3-20.
- (88) Brady MJ, Peterman AH, Fitchett G, Mo M, Cella D. A case for including spirituality in quality of life measurement in oncology. *Psychooncology* 1999;8:417-28.
- (89) Beery TA, Baas LS, Fowler C, Allen G. Spirituality in persons with heart failure. *Journal of Holistic Nursing* 2002 Mar;20(1):5-30.
- (90) Chibnall JT, Videen SD, Duckro PN, Miller DK. Psychosocial-spiritual correlates of death distress in patients with life-threatening medical conditions. *PALLIAT MED* 2002 Jul;16(4):331-8.
- (91) McClain CS, Rosenfeld B, Breitbart W. Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients. *Lancet* 2003 May 10;361(9369):1603-7.
- (92) Pargament KI, Smith BW, Koenig HG, Perez L. Patterns of positive and negative religious coping with major life stressors. *Journal for the Scientific Study of Religion* 1998;37:710-24.
- (93) Koenig HG, George LK, Peterson BL. Religiosity and remission of depression in medically ill older patients. *Am J Psychiatry* 1998 Apr;155(4):536-42.
- (94) Connor KM, Davidson JR, Lee LC. Spirituality, resilience, and anger in survivors of violent trauma: a community survey. *J Trauma Stress* 2003 Oct;16(5):487-94.
- (95) King M, Speck P, Thomas A. The effect of spiritual beliefs on outcome from illness. *Soc Sci Med* 1999 May;48(9):1291-9.

- (96) Koenig HG, Pargament KI, Nielsen J. Religious coping and health status in medically ill hospitalized older adults. *The Journal of Nervous and Mental Disease* 1998;186(9):513-21.
- (97) Pargament KI, Koenig HG, Perez LM. The many methods of religious coping: development and initial validation of the RCOPE. *J Clin Psychol* 2000 Apr;56(4):519-43.
- (98) Loewenthal KM, Cinnirella M, Evdoka G, Murphy P. Faith conquers all? Beliefs about the role of religious factors in coping with depression among different cultural-religious groups in the UK. *British Journal of Medical Psychology* 2001;74:293-303.
- (99) Lewis LM. Spiritual assessment in African-Americans: A review of measures of spirituality used in health research. *Journal of Religion and Health* 2007 Dec 20.
- (100) Cobb M. *The dying soul: spiritual care at the end of life*. Buckingham: Open University Press; 2001.
- (101) Millspaugh D. Assessment and response to spiritual pain: part 1. *J Palliat Med* 2005;8(5):919-23.
- (102) Kissane DW, Clarke DM, Street AF. Demoralization syndrome--a relevant psychiatric diagnosis for palliative care. *J Palliat Care* 2001;17(1):12-21.
- (103) Murata H. Spiritual pain and its care in patients with terminal cancer: construction of a conceptual framework by philosophical approach. *Palliat Support Care* 2003 Mar;1(1):15-21.
- (104) Byock I. *Dying well: the prospect for growth at the end of life*. New York: Riverhead Books; 1997.
- (105) Saunders C. *Spiritual pain*. Hospital Chaplain 1988.
- (106) Higginson I, Priest P. Predictors of family anxiety in the weeks before bereavement. *Social Science and Medicine* 1996;43(11):1621-5.
- (107) Osse BH, Vernooij-Dassen MJ, Schade E, Grol RP. Problems experienced by the informal caregivers of cancer patients and their needs for support. *Cancer Nurs* 2006 Sep;29(5):378-88.
- (108) Tsigaropoulos T, Mazaris E, Chatzidarellis E, Skolarikos A, Varkarakis I, Deliveliotis C. Problems faced by relatives caring for cancer patients at home. *Int J Nurs Pract* 2009 Feb;15(1):1-6.
- (109) Grunfeld E, Coyle D, Whelan T, Clinch J, Reyno L, Earle CC, et al. Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *Canadian Medical Association Journal* 2004 Jun 8;170(12):1795-801.



- (110) Payne S, Smith P, Dean S. Identifying the concerns of informal carers in palliative care. *PALLIAT MED* 1999 Jan 1;13(1):37-44.
- (111) Proot IM, Abu-Saad HH, Crebolder HF, Goldsteen M, Luker KA, Widdershoven GA. Vulnerability of family caregivers in terminal palliative care at home; balancing between burden and capacity. *Scand J Caring Sci* 2003 Jun;17(2):113-21.
- (112) Siegel K, Karus DG, Raveis VH, Christ GH, Mesagno FP. Depressive distress among the spouses of terminally ill cancer patients. *Cancer Practice* 1996;4(1):25-30.
- (113) Goldstein LH, Adamson M, Jeffrey L, Down K, Barby T, Wilson C, et al. The psychological impact of MND on patients and carers. *Journal of the Neurological Sciences* 1998;160(SUPPL. 1).
- (114) Hinton J. Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives? *Palliative Medicine* 1994;8(3):183-96.
- (115) Jones RVH, Hansford J, Fiske J. Death from cancer at home: The carers' perspective. *British Medical Journal* 1993;306(6872):249-51.
- (116) Hileman JW, Lackey NR. Self-identified needs of patients with cancer at home and their home caregivers: a descriptive study. *Oncology Nursing Forum* 1990;17(6):907-13.
- (117) Hileman JW, Lackey NR, Hassanein RS. Identifying the needs of home caregivers of patients with cancer. *Oncology Nursing Forum* 1992;19(5):771-7.
- (118) Grbich C, Parker D, Maddocks I. The emotions and coping strategies of caregivers of family members with a terminal cancer. *J Palliat Care* 2001;17(1):30-6.
- (119) Grbich C, Parker D, Maddocks I. Communication and information needs of caregivers of adult family members at diagnosis and during treatment of terminal cancer. *Progress in Palliative Care* 2000;8:345-50.
- (120) Jones RV, Hansford J, Fiske J. Death from cancer at home: the carers' perspective. *BMJ* 1993 Jan 23;306(6872):249-51.
- (121) Steele R, Davies B. Impact on parents when a child has a progressive, life-threatening illness. *Int J Palliat Nurs* 2006 Dec;12(12):576-85.
- (122) Poindexter CC, Linsk NL. Sources of support in a sample of HIV-affected older minority caregivers. *Fam Soc* 1998;79:491-503.
- (123) Poindexter CC, Linsk NL, Warner RS. "He listens...and never gossips": spiritual coping without church support among older, predominantly African-American caregivers of persons with HIV. *Rev Relig Res* 1999;40:230-43.
- (124) Forbes EJ. Spirituality, aging, and the community-dwelling caregiver and care recipient. *Geriatr Nurs* 1994 Nov;15(6):297-302.

- (125) Kim Y, Wellisch D, Spillers R, Crammer C. Psychological distress of female cancer caregivers: effects of type of cancer and caregivers' spirituality. *Supportive Care in Cancer* 2007 Dec 1;15(12):1367-74.
- (126) Kaye J, Robinson KM. Spirituality among caregivers. *Image J Nurs Sch* 1994;26(3):218-21.
- (127) Wortmann JH, Park CL. Religion and Spirituality in Adjustment Following Bereavement: An Integrative Review. *Death Studies* 2008;32(8):703-36.
- (128) Becker G, Xander CJ, Blum HE, Lutterbach J, Momm F, Gysels M, et al. Do religious or spiritual beliefs influence bereavement? A systematic review. *PALLIAT MED* 2007 Apr 1;21(3):207-17.
- (129) Richards TA, Folkman S. Spiritual aspects of loss at the time of a partner's death from AIDS. *Death Stud* 1997 Oct;21(6):527-52.
- (130) Richards TA, Acree M, Folkman S. Spiritual aspects of loss among partners of men with AIDS: post-bereavement follow-up. *Death Studies* 1999;23(2):105-27.
- (131) Meert KL, Thurston CS, Briller SH. The spiritual needs of parents at the time of their child's death in the pediatric intensive care unit and during bereavement: A qualitative study \*. *Pediatric Critical Care Medicine* 2005;6(4).
- (132) Collins JJ, Grier HE, Kinney HC, Berde CB. Control of severe pain in children with terminal malignancy, , . *The Journal of Pediatrics* 1995 Apr;126(4):653-7.
- (133) Sirkia K, Hovi L, Pouttu J, Saarinen-Pihkala UM. Pain Medication During Terminal Care of Children with Cancer. *Journal of Pain and Symptom Management* 1998 Apr;15(4):220-6.
- (134) Wolfe J, Grier HE, Klar N, Levin SB, Ellenbogen JM, Salem-Schatz S, et al. Symptoms and Suffering at the End of Life in Children with Cancer. *New England Journal of Medicine* 2009 Aug 20;342(5):326-33.
- (135) Hufton E. Parting gifts: the spiritual needs of children. *Journal of Child Health Care* 2006 Sep 1;10(3):240-50.
- (136) Coles R. *The Spiritual Life of Children*. Boston, MA: Houghton Mifflin; 1990.
- (137) Contro N, Larson J, Scofield S, Sourkes B, Cohen H. Family perspectives on the quality of pediatric palliative care. *Arch Pediatr Adolesc Med* 2002 Jan;156(1):14-9.
- (138) Davies B, Brenner P, Orloff S, Sumner L, Worden W. Addressing spirituality in pediatric hospice and palliative care. *J Palliat Care* 2002;18(1):59-67.
- (139) Dell'Orfano S. The meaning of spiritual care in a pediatric setting. *J Pediatr Nurs* 2002 Oct;17(5):380-5.

- (140) Zelcer S, Cataudella D, Cairney AE, Bannister SL. Palliative Care of Children With Brain Tumors: A Parental Perspective. *Archives of Pediatrics Adolescent Medicine* 2010 Mar 1;164(3):225-30.
- (141) Robinson MR, Thiel MM, Backus MM, Meyer EC. Matters of spirituality at the end of life in the pediatric intensive care unit. *Pediatrics* 2006 Sep;118(3):e719-e729.
- (142) McSherry M, Kehoe K, Carroll JM, Kang TI, Rourke MT. Psychosocial and Spiritual Needs of Children Living with a Life-Limiting Illness. *Pediatric Clinics of North America* 2007 Oct;54(5):609-29.
- (143) Tan GH, Totapally BR, Torbati D, Wolfsdorf J. End-of-life decisions and palliative care in a children's hospital. *J Palliat Med* 2006 Apr;9(2):332-42.
- (144) Olupona JK. Major Issues in the Study of African Traditional Religion. In: Olupona JK, editor. *African Traditional Religions in Contemporary Society*. New York: Paragon House; 1991. p. 25-33.
- (145) Powell RA, Downing J, Radbruch L, Mwangi-Powell F, Harding R. Advancing palliative care research in sub-Saharan Africa: from the Venice declaration, to Nairobi and beyond. *PALLIAT MED* 2008;22:885-7.
- (146) Furnham A, Akande D, Baguma P. Beliefs about health and illness in three countries: Britain, South Africa and Uganda. *Psychology, Health & Medicine* 1999 May;4(2):189-201.
- (147) Nelms LW, Gorski J. The role of the African traditional healer in women's health. *J Transcult Nurs* 2006 Apr;17(2):184-9.
- (148) Harding R, Stewart K, Marconi K, O'Neill JF, Higginson IJ. Current HIV/AIDS end-of-life care in sub-Saharan Africa: a survey of models, services, challenges and priorities. *BMC Public Health* 2003 Oct 23;3:33.
- (149) Opoku KA. *West African Traditional Religion*. Accra, Ghana: Fep International Private Limited; 1978.
- (150) Kalu OU. Ancestral Spirituality and Society in Africa. In: Olupona JK, editor. *African Spirituality: Forms, Meanings, and Expressions*. New York: Herder & Herder; 2000. p. 54-84.
- (151) De Gruchy JW. Christianity in Twentieth-Century South Africa. In: Prozesky M, De Gruchy JW, editors. *Living Faiths in South Africa*. London: Hurst & co.; 1995. p. 83-115.
- (152) Samkange S, Samkange TM. *Hunhuism or Ubuntuism: a Zimbabwe indigenous political philosophy*. Salisbury: Graham; 1980.

- (153) Murray SA, Grant E, Grant A, Kendall M. Dying from cancer in developed and developing countries: lessons from two qualitative interview studies of patients and their carers. *BMJ* 2003 Feb 15;326(7385):368.
- (154) Demmer C. Coping with AIDS-related bereavement in KwaZulu-Natal, South Africa. *AIDS Care* 2007;19(7):866-70.
- (155) Grant E, Murray SA, Brown J. A good death in rural Kenya? Listening to Meru patients and their families talk about care needs at the end of life. *J Palliat Care* 2003;19(3):159-67.
- (156) Greeff AP, Loubser K. Spirituality as a resiliency quality in Xhosa-speaking families in South Africa. *Journal of Religion and Health* 2007 Dec 29.
- (157) Copeland-Linder N. Stress among black women in a South African township: the protective role of religion. *Journal of Community Psychology* 2006;34(5):577-99.
- (158) NICE. Improving Supportive and Palliative Care for Adults with Cancer. 2004.
- (159) National Quality Forum (USA). A National Framework and Preferred Practices for Palliative and Hospice Care Quality. National Quality Forum (USA); 2006 Jan 12. Report No.: NQFCR-16-06.
- (160) Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M, Lamontagne C, et al. A Model to Guide Hospice Palliative Care. Ottawa, ON: Canadian Hospice Palliative Care Association; 2002 Jan 3.
- (161) National Consensus Project for Quality Palliative Care (US). Clinical Practice Guidelines for Quality Palliative Care, 2nd edition. Pittsburgh, PA: National Consensus Project for Quality Palliative Care; 2009.
- (162) Palliative Care Australia. Standards for providing quality palliative care for all Australians. Canberra: PCA; 2005.
- (163) Walter T. The ideology and organization of spiritual care: three approaches. *PALLIAT MED* 1997 Jan 1;11(1):21-30.
- (164) Salander P. Letter: Who needs the concept of 'spirituality'? *Psychooncology* 2006;15:647-9.
- (165) Brennan J. Letter: A conflation of existential and spiritual beliefs. *Psychooncology* 2006;15:933-4.
- (166) Breitbart W. Editorial: Who needs the concept of spirituality? Human beings seem to! *Palliat Support Care* 2007;5:105-6.
- (167) Bregman L. Spirituality: A glowing and useful term in search of a meaning. *OMEGA--Journal of Death and Dying* 2006 Aug 1;53(1):5-26.

- (168) Williams AL. Perspectives on spirituality at the end of life: a meta-summary. *Palliat Support Care* 2006 Dec;4(4):407-17.
- (169) Dobratz MC. Life-closing spirituality and the philosophic assumptions of the Roy adaptation model. *Nurs Sci Q* 2004 Oct;17(4):335-8.
- (170) Fryback PB, Reinert BR. Spirituality and people with potentially fatal diagnoses. *Nurs Forum* 1999 Jan;34(1):13-22.
- (171) Breitbart W, Gibson C, Poppito SR, Berg A. Psychotherapeutic interventions at the end of life: a focus on meaning and spirituality. *Can J Psychiatry* 2004;49(6):366-72.
- (172) Breitbart W. Spirituality and meaning in supportive care: spirituality- and meaning-centered group psychotherapy interventions in advanced. *Support Care Cancer* 2001 Aug 28.
- (173) Rodin G, Gillies LA. Individual psychotherapy for the patient with advanced disease. In: Chochinov HM, Breitbart W, editors. *Handbook of Psychiatry in Palliative Medicine*. 2000 ed. OUP; 2000. p. 189-96.
- (174) Yalom ID, Greaves C. Group therapy with the terminally ill. *Am J Psychiatry* 1977 Apr;134(4):396-400.
- (175) Speck P. The evidence base for spiritual care. *Nurs Manag (Harrow)* 2005 Oct;12(6):28-31.
- (176) Hunt J, Cobb M, Keeley VL, Ahmedzai SH. The quality of spiritual care--developing a standard. *Int J Palliat Nurs* 2003 May;9(5):208-15.
- (177) Selman L, Harding R, Speck P, Robinson V, Aguma A, Rhys A, et al. Spiritual care recommendations for people from Black and minority ethnic groups receiving palliative care in the UK. Dept. Palliative Care, Policy & Rehabilitation, King's College London; 2010.
- (178) Campbell SM, Braspenning J, Hutchinson A, Marshall MN. Research methods used in developing and applying quality indicators in primary care. *BMJ* 2003 Apr 12;326(7393):816-9.
- (179) Department of Health. End of Life Care Strategy: Quality Markers and measures for end of life care. Department of Health; 2009. Report No.: 12035.
- (180) Pasma HR, Brandt HE, Deliens L, Francke AL. Quality indicators for palliative care: a systematic review. *J Pain Symptom Manage* 2009 Jul;38(1):145-56.
- (181) Seow H, Snyder CF, Shugarman LR, Mularski RA, Kutner JS, Lorenz KA, et al. Developing quality indicators for cancer end-of-life care: proceedings from a national symposium. *Cancer* 2009 Sep 1;115(17):3820-9.

- (182) Seow H, Snyder CF, Mularski RA, Shugarman LR, Kutner JS, Lorenz KA, et al. A Framework for Assessing Quality Indicators for Cancer Care at the End of Life. *J Pain Symp Manage* 2009;38(6):903-12.
- (183) Amery J, Garanganga E, Horne C. Spirituality. In: Amery J, editor. *Children's Palliative Care in Africa*. Oxford: Oxford University Press; 2009. p. 271-87.
- (184) Puchalski C, Romer AL. Taking a Spiritual History Allows Clinicians to Understand Patients More Fully. *J Palliat Med* 2000;3(1):129-37.
- (185) Anandarajah G, Hight E. Spirituality and medical practice: Using the HOPE questions as a practical tool for spiritual assessment. *American Family Physician* 2001;63(1):81-8.
- (186) Maugans TA. The SPIRITual history. *Arch Fam Med* 1996 Jan;5(1):11-6.
- (187) Hungelmann J, Kenkel-Rossi E, Klassen L, Stollenwerk R. Focus on spiritual well-being: harmonious interconnectedness of mind-body-spirit--use of the JAREL spiritual well-being scale. *Geriatr Nurs* 1996 Nov;17(6):262-6.
- (188) Mack JW, Nilsson M, Balboni T, Friedlander RJ, Block SD, Trice E, et al. Peace, Equanimity, and Acceptance in the Cancer Experience (PEACE): validation of a scale to assess acceptance and struggle with terminal illness. *Cancer* 2008 Jun;112(11):2509-17.
- (189) Harding R, Selman L, Agupio G, Dinat N, Downing J, Gwyther L, et al. Validation of a core outcome measure for palliative care in Africa: the APCA African Palliative Outcome Scale. *Health and Quality of Life Outcomes* 2010;8(1):10.
- (190) Powell RA, Downing J, Harding R, Mwangi-Powell F, Connor S. Development of the APCA African Palliative Outcome Scale. *J Pain Symp Manage* 2007;33(2):229-32.
- (191) Emanuel LL, Alpert HR, Baldwin DCJ, Emanuel EJ. What Terminally Ill Patients Care About: Toward a Validated Construct of Patients' Perspectives. *J Palliat Med* 2000;3(4):431.
- (192) Emanuel LL, Alpert HR, Emanuel EE. Concise screening questions for clinical assessments of terminal care: the needs near the end-of-life care screening tool. *J Palliat Med* 2001;4(4):465-74.
- (193) Byock I, Merriman MP. Measuring quality of life for patients with terminal illness: the Missoula-VITAS quality of life index. *PALLIAT MED* 1998;12:231-44.
- (194) Namisango E, Katabira E, Karamagi C, Baguma P. Validation of the Missoula-Vitas Quality-of-Life Index among patients with advanced AIDS in urban Kampala, Uganda. *J Pain Symptom Manage* 2007 Feb;33(2):189-202.

- (195) Cohen SR, Mount BM, Strobel MG, Bui F. The McGill Quality of Life Questionnaire: a measure of quality of life appropriate for people with advanced disease. A preliminary study of validity and acceptability. *Palliat Med* 1995 Jul;9(3):207-19.
- (196) O'Connell K, Skevington S, Saxena S, WHOQOL HIV Group. Preliminary development of the World Health Organization's Quality of Life HIV instrument (WHOQOL-HIV): analysis of the pilot version. *Soc Sci Med* 2003 Oct;57(7):1259-75.
- (197) O'Connell KA, Saxena S, Skevington SM. WHOQOL-HIV for quality of life assessment among people living with HIV and AIDS: Results from the field test. *AIDS Care* 2004;16(7):-889.
- (198) The WHOQOL HIV Group. Initial steps to developing the World Health Organization's Quality of Life Instrument (WHOQOL) module for international assessment in HIV/AIDS. *AIDS Care* 2003 Jun;15(3):347-57.
- (199) The WHOQOL-HIV Group. WHOQOL-HIV for quality of life assessment among people living with HIV and AIDS: results from the field test. *AIDS Care* 2004 Oct;16(7):882-9.
- (200) Peck SM. *The Road Less Traveled and Beyond: Spiritual Growth in an Age of Anxiety*. New York: Simon & Schuster; 1997.
- (201) Lloyd M. *Embracing the Paradox: Pastoral Care with Dying and Bereaved People*. Contact Pastoral Monographs 1995;5.
- (202) Holloway M, Moss B. *Spiritual Care. Spirituality and Social Work*. Palgrave; 2010.
- (203) Gunaratnam Y. Culture is not enough: A critique of multi-culturalism in palliative care. In: Field D, Hockey J, Small N, editors. *Death, Gender and Ethnicity*. 1997 ed. Routledge; 1997. p. 167-86.
- (204) Baer RA. Mindfulness training as a clinical intervention: a conceptual and empirical review. *Clin Psychol Sci Prac* 2003;10:125-43.
- (205) Bruce A, Davies B. Mindfulness in hospice care: practicing meditation-in-action. *Qual Health Res* 2005 Dec;15(10):1329-44.
- (206) Keating T. *Manifesting God*. New York: Lantern Books; 2005.
- (207) Robins CJ, Schmidt H, Linehan MM. Dialectical behavior therapy. In: Hayes SC, Follette VM, Linehan MM, editors. *Mindfulness and acceptance: Expanding the cognitive-behavioral tradition*. New York: Guilford; 2004. p. 30-44.
- (208) Bradshaw A. The spiritual dimension of hospice: the secularization of an ideal. *Soc Sci Med* 1996 Aug;43(3):409-19.
- (209) Association of Hospice and Palliative Care Chaplains. *Standards for Hospice and Palliative Care Chaplaincy (2nd ed.)*. London; 2006.

- (210) Byrne M. Spirituality in palliative care: what language do we need? *Int J Palliat Nurs* 2002 Feb;8(2):67-74.
- (211) Johnson CP. Assessment tools: are they an effective approach to implementing spiritual health care within the NHS? *Accid Emerg Nurs* 2001 Jul;9(3):177-86.
- (212) Lo B, Chou V. Directions in research on spiritual and religious issues for improving palliative care. *Palliative and Supportive Care* 2003;1:3-5.





