Executive Summary

Spiritual care recommendations for people from Black and minority ethnic (BME) groups receiving palliative care in the UK

With special reference to the sub-Saharan African population

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With a Foreword by Archbishop Emeritus Desmond Tutu
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Foreword

Living with incurable progressive disease such as advanced cancer and HIV infection 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. It is 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 the UK is its true diversity, which brings with it a myriad of opportunities and challenges. As demonstrated by recent NHS publications, UK health services need to be able to meet the needs of a population which is varied in terms of culture, religion and ethnicity. However, until now there has been little explicit guidance for the provision of spiritual care for people from Black and minority ethnic groups receiving palliative care in the UK.
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, with an ongoing commitment to mutual education, training and support, is fundamental to this process.

The examples of good practice contained within this report highlight some of the innovative work already being carried out across the UK to widen access to palliative care, and to develop culturally sensitive services that are able to meet patients’ spiritual needs. 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 a diverse population, including the large numbers of Africans living with incurable, progressive disease in the UK. I hope that palliative care services nationally will adopt and implement the recommendations in this report, leading to a future in which services can meet the cultural and spiritual needs of all patients and families, regardless of ethnicity.

God bless you

†Archbishop Emeritus Desmond Tutu
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Executive Summary

1 Introduction

- The population served by the NHS has changed significantly with the rise in the number of immigrants to the UK over the previous decade. In 1999, approximately 97,000 people were accepted for settlement by the UK government, compared with 149,000 in 2008. According to 2008 figures, the two largest immigrant groups are from Africa (27.2%) and the Indian sub-continent (26.8%).

- The Black and minority ethnic (BME) population experiences a high burden of both non-communicable (e.g. cancer and organ failure) and communicable disease (e.g. HIV infection). It is therefore a group with considerable need for palliative care, which integrates the spiritual aspects of patient care alongside the physical and psychosocial. 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.’

- Health policy in the UK advocates that spiritual care is available to all patients receiving palliative care, recognising that spirituality and religion often play a key role in patients’ experience of serious illness. Many patients report becoming more religious or more spiritual following a diagnosis of an incurable, progressive condition. Religious faith and spiritual belief have been identified as important coping resources.

- Often patients wish to discuss their spiritual beliefs with their physicians, and may need spiritual support. Spiritual well being predicts coping with HIV, contributes to quality of life in cancer and heart failure, and protects against ‘death distress’ and end of life despair.

- There has been little work to date addressing spiritual care for BME populations, despite indications that some BME groups have a strong reliance on spiritual belief and practice. In particular, there is little guidance for palliative care services on how to meet the spiritual and cultural needs of people from BME groups. Specific challenges include a lack of evidence to inform service provision (e.g. evaluated service models and spiritual care services), and barriers to BME groups accessing palliative care (e.g. mistrust of medical institutions, fears of racism and misperceptions of palliative care).
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- The recommendations offered in this report aim to fill this gap in policy guidance. They combine three subjects identified by the NICE Guidance *Improving Supportive and Palliative Care for Adults with Cancer* (2004) as research priorities in palliative care – spiritual support, making services more sensitive to cultural differences, and improving care for underserved groups – hence adding to and building on Department of Health work in these key areas.

2 Aim, audience, development and structure

2.1 Aim

- The project aimed to inform the provision of spiritual care for people from BME groups receiving palliative care across the UK by providing evidence-based guidance for palliative care service providers.

2.2 Audience

- The intended audience includes palliative care service providers, spiritual care providers working with people from BME groups (including NHS chaplains, hospice spiritual care providers and community faith leaders), and healthcare policy makers, in the UK and globally.

2.3 Development

- The recommendations were generated during a project entitled ‘Spiritual care for patients from sub-Saharan Africa receiving palliative care in the UK’. The project aimed to translate findings from a study conducted in South Africa and Uganda to the UK context.

- 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; 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 subsequent UK-based involved working with an expert Advisory Group of palliative care researchers and providers, spiritual care providers and public health representatives. The Group considered applicability of the African study findings to the UK context and developed the recommendations on that basis.

- The recommendations were developed from during 2009. After initial drafting in collaboration with the Advisory Group, the recommendations were further developed.
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and refined through critical discussion in a variety of forums, including meetings of palliative care researchers, clinical staff and members of the King's College Hospital Foundation Trust Strategy Group for End of Life Care, and a Symposium on spiritual care held at King's College London, which was attended by 30 experts in the field.

2.4 Structure

- Examples of good practice are included throughout the recommendations. These originate from participants of the Symposium and from the literature, as well as stakeholders known to members of the Advisory Group.

- Quality markers associated with each recommendation category are presented throughout (summarised in the Appendix). 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.

3 Summary of the recommendations

3.1 Working with local faith communities

3.1.1 Mutual education and training

- Operate a ‘shared care’ model of spiritual care

- Offer mutual education, training and support by palliative care and local community and faith groups on an ongoing basis

- Encourage BME spiritual leaders/ faith groups to educate members of local palliative care teams regarding the spiritual needs of local BME populations and the resources/ support available

- Facilitate the above by inviting spiritual leaders to visit the unit and attend training events

3.1.2 Referral

- Ensure systems are in place and utilised for palliative care teams to refer to local BME spiritual leaders who have been trained in palliative care

- Raise awareness of palliative care amongst local BME spiritual leaders and in particular of how to refer to palliative care (e.g. via GP)
3.2 Spiritual assessment

3.2.1 Characteristics of spiritual assessment

- Assess spiritual well being/ spiritual needs regularly, with consent and in a way which respects patients’ personal boundaries and needs for information
- Ensure assessment results in culturally appropriate responses to spiritual need
- Document all assessments and interventions in patient records and convey important issues to the care team during meetings

3.2.2 Types of assessment

- Ensure brief and simple screening for spiritual needs is integrated into routine patient assessment on admission; ensure religious affiliation and appropriate faith leader (if applicable) are recorded in patient records, along with other cultural/ faith needs
- Recognise that patients with no formal religion may nevertheless have spiritual needs
- Conduct a wider exploration of spiritual history or a formal spiritual assessment once immediate reasons for admission are met
- Ensure all staff members conducting spiritual assessment are trained to do so
- Integrate the use of formal assessment tools into screening or spiritual assessment to facilitate the identification of spiritual needs
- Evaluate the quality of care and engage in ongoing service improvement through using outcome measurement tools and interviews with patients to explore the outcomes of spiritual care
- Ensure assessment tools and outcome measures are ‘fit for purpose’, i.e. validated, culturally appropriate and acceptable

3.3 Spiritual resources and care

- Offer a range of spiritual resources, including: access to a range of appropriate faith leaders, a ‘quiet space’, support groups, one-on-one counselling and non-verbal therapies; document their value and effectiveness in patient records
- Consider support groups designed for patients from a BME group where there is a large local population
- Advertise the availability of spiritual care services in a range of formats throughout the disease trajectory (e.g. through leaflets in multiple languages, large print and Braille)
- Document team members’ conversations about spiritual issues with patients in patient records as appropriate, while respecting patient confidentiality
• Document in patient records the spiritual care services and resources accessed by patients (both in the community and through the palliative care service) and their value and effectiveness for the patient

3.4 Spiritual care providers

3.4.1 Role of the spiritual care provider in palliative care

• Recognise diverse roles of the spiritual care provider (SCP): visiting, listening to and speaking with patients; acting as point of referral; liaising and sharing care with community SCPs (with the patient’s permission, and aiming to ensure the role of the palliative care-designated SCP is understood); educating and supporting other members of staff; public education

3.4.2 Choice of spiritual care providers

• Recognise that the choice of SCP depends on the individual – sometimes a ‘non-specialist’ may be the most appropriate person; designated SCPs should support and advise their colleagues as required

• Match SCP to patient and need (take into account language, ethnicity, gender and religion according to patient wishes)

3.4.3 Support for spiritual care providers

• Support SCPs through debriefing and access to their line managers, peer support and/or counseling as needed

3.5 Cultural sensitivity

3.5.1 Culturally competent care

• Ensure an ongoing commitment to cultural sensitivity among staff members and as an organisation

• Recognise the complexity and diversity of culturally specific beliefs and practices

• Treat the patient as a unique individual; ensure that learning about local cultures and ethnicities is not viewed as a ‘box-ticking’ exercise

• Explore patients’ and families’ beliefs about illness and the authority of healthcare staff and spiritual leaders on a case-by-case basis

• Try to identify any potentially harmful beliefs related to cultural or spiritual worldview, and present the palliative care perspective sensitively but explicitly
• Among staff members, encourage awareness of organisational processes and their own worldview and relationship to others, and foster a commitment to being empathetic, open-minded and reflective

• Ensure confidentiality is upheld by all members of staff and the community involved in patient care, including local spiritual leaders

3.5.2 Language and interpreters

• Recognise that concepts have different meanings in different languages and cultures, and discuss sensitive issues with care

• Ensure access to trained and supported interpreters

3.5.3 Patient and family expectations

• Explore patient and family expectations, identify areas of potential conflict and handle care provision with sensitivity

3.6 Organisational requirements

3.6.1 Implementing the recommendations

• Ensure an ongoing commitment to education, training and support in the field of spiritual care

• Raise awareness of spiritual dimensions of the illness experience; train and support all palliative care staff in basic spiritual care provision

• Recognise and accommodate the organisational implications of Recommendations 1-5, e.g. foster relationships with local faith leaders/community groups, document spiritual well being and resources in patient notes

3.6.2 Understanding of spiritual well being and care

• Consider spiritual well being intrinsic to quality of life and broader than religious belief and practice

• Consider spiritual care to be as important as other dimensions of care

3.6.3 Providing patient-centred care

• Refer patients to spiritual care with their permission and as part of routine practice, according to need

• Ensure inpatient units and outpatient and home care services are able to accommodate the religious needs of patients from BME groups (e.g. religious rituals, visits by members of faith community)

3.6.4 Staff support
• Take into consideration and provide for the spiritual well being of staff

3.6.5 Quality improvement

• Commit to ongoing quality monitoring and improvement in spiritual care (e.g. through audit of outcomes and meeting quality markers.

4 Adoption of the recommendations

Adopting these recommendations, and implementing strategies to meet the suggested quality markers, may potentially benefit patients, communities and palliative care services in a number of ways; for example, by leading to:

• Increased awareness of, and referral to, palliative care within the BME community, through local faith groups and spiritual leaders.

• Improved communication, and a mutually supportive relationship, between local spiritual leaders and faith groups and hospice and palliative care teams.

• Local spiritual leaders 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 the needs of people from BME groups, 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 patients who may require support in this area.
5 Future research

While these recommendations aim to assist services with meeting the spiritual needs of diverse communities, research into the provision of culturally sensitive spiritual care is urgently needed.

The following areas are identified as research priorities in this field:

1. Application, adoption and evaluation of the recommendations and quality markers presented here, using formal evaluation criteria.

2. Evaluation of the effectiveness of spiritual care models and interventions, and techniques and methodologies used to improve uptake of palliative care services by people from BME and other disadvantaged groups, using both qualitative and quantitative methods and measuring key outcomes (e.g. spiritual well being).

3. 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 in order to foster the skills and confidence to engage with the spiritual and religious resources available to patients and families.

4. Identification and psychometric evaluation of existing measures of spiritual well being (and related constructs) that may be appropriate for use in multi-cultural palliative care populations. Several existing tools have been criticised in the literature for conceptual imprecision, cultural and religious bias, and psychometric problems such as floor and ceiling effects.

5. Adaptation and validation of identified measures in ethnically diverse palliative care populations in the UK. 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

- These recommendations aim to assist in the development of palliative care services which are able to meet the spiritual care needs of a population that is increasingly diverse in terms of culture, spiritual beliefs and practices, and worldview.

- It is hoped 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.
## Appendix: Quality markers

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<tr>
<th>Category</th>
<th>Quality marker(s)</th>
<th>Measure(s)</th>
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</table>
| **Working with local faith and community groups** | Evidence of mutual training and education                                          | - Number of workshops/training courses held for members of local BME communities  
- List of forums where workshops were advertised  
- Numbers of workshop attendees from different BME groups and community organisations  
- Number of organised visits to the palliative care service by BME faith and community group representatives  |
|                                   | Evidence of referral to and from spiritual care providers in the community        | - Number of patients referred to spiritual leaders in the community for spiritual support  
- Number of patients referred to the palliative care service by members of faith/community groups, via GP or other healthcare professional  |
| **Spiritual assessment**          | Evidence of spiritual assessment                                                  | - Documentation showing every patient’s spiritual (including faith) needs are discussed at multi-disciplinary meetings  
- Documentation of spiritual needs in patients’ notes  |
|                                   | Evidence of the use of formal assessment tools in the audit of spiritual care      | - Documented ways in which data from formal assessment of outcomes of spiritual care have been used to influence service provision  |
| **Spiritual resources and care**  | Evidence that a range of appropriate spiritual care services are accessible to all patients | - Documentation in patient records of the spiritual care services patients utilise in/outside the healthcare setting, and their value and effectiveness for that patient  
- Diverse range of media produced and disseminated to advertise the spiritual care services available to patients, e.g., posters, leaflets in appropriate languages, Braille and large type  |
<p>|                                   | Evidence of patient and family satisfaction with spiritual care services          | - Data on patient and/or family satisfaction with the spiritual care services they have accessed through the palliative care service, generated through e.g., the inclusion of spiritual care in the standard form used to assess satisfaction with care, and capturing informal feedback, including thank you cards and other communications from patients and families to spiritual care  |
|                                   | Evidence that patients’ wishes for spiritual care are assessed and responded to continuously | - Documentation in patient records of patients’ spiritual care needs and resulting action taken at regular intervals throughout the disease trajectory  |</p>
<table>
<thead>
<tr>
<th>Spiritual care providers</th>
<th>Evidence of liasing and sharing care with local spiritual leaders</th>
<th>- Directory of local palliative care-trained faith leaders and representatives of faith and community groups held in the chaplain's office and inpatient areas</th>
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<td>Evidence of training staff in spiritual care provision</td>
<td>- Dedicated session on spiritual care provision in the induction program for all new staff; annual appraisal on spiritual care</td>
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<td></td>
<td></td>
<td>- Number of in-service training workshops on spiritual care provision and numbers and types of staff who attended</td>
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<td>- Attendance of spiritual care providers at national and/or international palliative care conferences</td>
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<td>Evidence of collaboration with training spiritual care providers in the community</td>
<td>- Number of clinical placements at the palliative care service taken up by (religious and non-religious) spiritual care providers from the community</td>
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<td>- Details of teaching by palliative care staff on theological/pastoral care/chaplaincy training courses and in other community forums (e.g. HIV NGOs)</td>
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<td>Cultural sensitivity</td>
<td>Evidence of organisational commitment to providing culturally competent care</td>
<td>- Assessment of staff members' cultural awareness and competence during induction and appraisals</td>
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<td>- In-service training to foster core skills among staff</td>
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<td>- Documented collaboration with local BME groups, e.g. conferences, visits by community members to the palliative care service (see Working with local faith and community groups)</td>
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<td>- List of trained and supported interpreters available to staff members</td>
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<td>Organisational requirements</td>
<td>Evidence of commitment to spiritual care provision</td>
<td>- 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</td>
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<td>Evidence of implementing recommendations</td>
<td>- Agenda for moving forward with these recommendations, including:</td>
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<td>o Prioritisation of specific recommendations and commitment to locally appropriate quality markers</td>
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<td>o Development of a timeframe for implementation of the recommendations</td>
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<td>o Incorporation of recommendations and quality markers into organisational policy, strategy, budget, training plan and appraisal system</td>
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<td>Evidence of commitment to widening access to palliative care for BME groups</td>
<td>- Percentage of patients and families accessing the palliative care service from specific BME groups in comparison with the percentage of people from those groups in the catchment area</td>
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<td>- Evaluation of patient and family satisfaction with the palliative care service according to ethnic group</td>
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Acknowledgements

These recommendations were produced during a project funded by the Sir Halley Stewart Trust. The recommendations incorporate group work conducted during the Sir Halley Stewart/COMPASS Symposium on Spiritual Care, 3rd November 2009, which was attended by 30 multi-professional experts in the spiritual and cultural aspects of palliative and supportive care.

The following members of the project advisory group are acknowledged for their comments on these recommendations: Fr Ezeakor Adolphus, Rev Jennifer Potter, Abena Konadu-Yiadom, and Dr Jonathan Koffman.

We would like to thank all the experts who contributed to these recommendations, the patients and staff in South Africa and Uganda who participated in the original study, and the Sir Halley Stewart Trust for supporting the analysis of the data, the generation of the recommendations and Lucy Selman’s PhD study.