

Next steps

Improving end of life care for Black, Asian and Minority Ethnic people in the UK

Everyone deserves care that works for them at the end of their lives. Access to that care should be determined solely by need, rather than by clinical diagnosis, ethnic background or any other factor.

However, long-term changes to demographics, disease progressions and other factors mean that we are in danger of failing to reach increasing numbers of people with the care they need, particularly those from Black, Asian and Minority Ethnic (BAME) backgrounds.

In June 2013, Marie Curie Cancer Care published a report on Palliative and End of Life Care for Black, Asian and Minority Ethnic Communities in the UK, commissioned by Marie Curie and Public Health England from the Cicely Saunders Institute at King's College London.

The report (available at mariecurie.org.uk/diversityreport) emphasised that people from BAME backgrounds will soon make up a significant proportion of people over 65.

It highlighted that the end of life care needs of BAME communities are varied, growing and, despite examples of good practice, overall not adequately understood or met.

Health and social care commissioners and providers must work more closely with local communities to make sure they understand their needs

Following the launch of the research, Marie Curie convened a discussion group in autumn 2013, including end of life policy-makers, practitioners, BAME community members and other stakeholders. Those discussions helped inform a forward plan and a call for government and stakeholders to address the priority recommendations set out in this paper.

Health and social care commissioners and providers must work more closely with local communities to make sure they understand their needs and develop care that is sensitive and responsive to them. This may mean significant changes to the way they have traditionally worked with patients and their families, as well as changes to how staff are recruited and trained.

At a time of major change in the commissioning environment, it is important that these issues stay on the agenda. Quick progress on these recommendations must be made across the entire health and social care system to ensure we are providing the right support for everyone at the end of their lives.

Marie Curie is calling on NHS England to take the lead and provide clear guidance to clinical commissioning groups and health and wellbeing boards about how to take into account the specific needs of people from BAME backgrounds in their commissioning strategies.

Imelda Redmond, Director of Policy and Public Affairs

Demographic change

It is well established that the UK's rapidly ageing population will see the number of people over the age of 85 double by 2030. It is less often acknowledged that the number of people from BAME communities will also increase significantly during this period. The Office for National Statistics projects that the UK's ethnic minority populations (including the 'Other White' category) will increase from 13% of the UK population in 2006 to 27 per cent by 2031 and to 43 per cent by 2056. The number of people from BAME backgrounds aged 65 and over is set to rise from just over half a million in 2001 to 1.3 million in 2026 and further by 2056.

Any plans to adapt end of life care provision to account for the UK's ageing population must therefore include a strong consideration of the increasing need for end of life care from BAME communities.

Recommendations

- The Health and Social Care Information Centre should review all relevant datasets to ensure comprehensive ethnicity data is being collected and analysed, including access and outcomes.
- Health and social care commissioners and the relevant agencies should map current and future demand from BAME communities.
- Members of Parliament, councillors and others with scrutiny roles should ask health and social care commissioners what they are doing to ensure that current and future demand from BAME communities is met.

Changing epidemiology and disease profiles

Among other changes to disease profiles, it is projected that the number of deaths from cancer will fall by 17 per cent by 2030, while over the same period there is predicted to be a 17 per cent increase in the total number of deaths. This means there is likely to be increased need for high quality end of life care for people with non-cancer diagnoses.

These changes will require health and social care providers to rethink how to deliver services that meet very different needs.

A focus on the needs of BAME communities, many of whom currently have a lower prevalence of cancer and higher prevalence of other, chronic conditions, must be at the heart of this rethinking.

Recommendations

- All relevant research commissioned and conducted by health and social care organisations and government agencies should include a focus on disease profiles among different BAME communities.
- Monitoring and disease profiling by government agencies and health and social care organisations should include BAME communities.
- In planning the next VOICES Survey of Bereaved People, NHS England/NHS Improving Quality should consider how they can strengthen the emphasis on the experiences of BAME people.

Breaking the reliance on hospitals

There is significant evidence that the health and social care system is experiencing unprecedented pressures, particularly in respect of the use of accident and emergency services and hospital services. We know that most people do not wish to die in hospital; around 40% of those dying in hospital have no clinical need to be there.

What is required is a fundamental shift away from hospital services to fund more community-based services, such as the Marie Curie Nursing Service. However, any changes must include a clear focus on the current and future needs of different BAME communities.

Meeting the challenge

Better integration of health and social care services is a primary way we can ensure the more effective use of limited financial resources. Again, integration presents an opportunity for radical change. It is therefore important that all such efforts include a consideration of the impact for BAME communities.

Recommendations

- NHS England, Clinical Commissioning Groups and local authorities should ensure that current and future BAME needs are taken into consideration in newly integrated services and use Equality Impact Assessments to determine whether these services will meet the needs of people from BAME communities.

Reshaping end of life care

In July 2013, the Neuberger Review of the implementation of the Liverpool Care Pathway (LCP) in England recommended that the LCP should be phased out. This is an opportunity to reshape end of life care in a way which embraces the diversity of the UK's population and includes a strong focus on culturally appropriate care.

We must ensure that all communities understand the choices available to them; that people, carers, families and health professionals are empowered to have the right conversations about death and dying; and people from all communities are treated with dignity and respect.

Recommendations

- NHS England should ensure that whatever replaces the Liverpool Care Pathway, including any relevant approaches to training, includes a strong emphasis on the cultural diversity of BAME communities.
- Health and social care organisations should ensure that all consultations and discussions about the future shape of end of life care include people from different BAME communities.
- Health Education England and its partners should collate and disseminate effective practice examples showcasing work with BAME communities.

Reshaping and refocusing the workforce

Given the fundamental challenges outlined above, it is clear that in future we will need a very different health and social care workforce delivering services for terminally ill people in very different ways. It is vital that we recruit, nurture and develop a diverse workforce which has the skills, knowledge and confidence to deliver culturally appropriate services for people from all communities and backgrounds.

Recommendation

- Health Education England and Local Education and Training Boards should review existing training programmes to ensure that they are future proof, particularly around the effectiveness of cultural competency training.

BAME communities dealing with death and dying

With a significant increase in both the size and diversity of the UK's ageing population, we will need to change the way we all discuss death and dying; we will particularly need a better understanding of how different cultures deal with these issues.

It is vital that we encourage people from all communities to talk about death and dying and to make informed choices about the type of care that they and their loved ones receive. Key aspects of this will be ensuring that relevant information is available and accessible to all, including younger people, and recognising different cultural needs around death and dying.

Recommendation

- Marie Curie and other providers of care to terminally ill people and their families and carers should provide tailored information to BAME groups to inform choice and make their services accessible to all.

What are we doing?

Marie Curie is taking steps to address the above challenges in how we plan and deliver our services. We are:

- embedding diversity considerations and Equality Impact Assessments into our business planning process to help address issues around equality of access, quality of service and outcomes
- developing our accessibility policy to help communicate information about our services in an accessible way
- developing a learning resource for our staff to ensure that they are able to deliver the highest quality care to terminally ill people and their families and carers from BAME communities
- developing a plan of action to implement BAME research findings and outcomes from our consultation event in autumn 2013
- building relationships with local BAME communities, and identifying barriers to access to palliative care and sharing effective practice and lessons learned
- offering tours of the Cardiff and the Vale Hospice to groups of BAME people and gathering feedback on how such environments could be more welcoming and accommodating of their needs
- using service users' feedback to drive service improvements, focusing on access, quality of care and outcomes for people from all backgrounds

In future, we plan to:

- improve monitoring of service users by ethnic background
- apply relevant research findings, focus group outcomes and feedback from BAME groups to help with developing policy and services

Conclusion

Over the coming decades, the UK faces a range of profound challenges which will mean health and social care needs to be delivered in different ways and by staff with a fresh set of skills. As key decision makers consider the implications of these challenges and seek solutions, they must include a focus on the future needs of BAME communities. The experiences, expectations and needs of BAME people are a vital component of how we will deal with our ageing population, changing disease profiles, workforce change and our entire approach to death and dying as a society.

It is crucial that NHS England offers clear guidance to clinical commissioning groups and health and wellbeing boards about how to take into account the specific needs of people from BAME groups in their commissioning strategies.

Next steps

This paper identifies a number of actions for Marie Curie and other stakeholders to help us take forward our work with BAME communities. We will continue to work with partner organisations and stakeholders to take forward these actions and then report back on progress.

For more information

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Marie Curie Cancer Care gives people with all terminal illnesses the choice to die at home. Our nurses provide them and their families with free hands-on care and emotional support, in their own homes, right until the end.

mariecurie.org.uk

