End of Life Care
In
Black and Minority Ethnic Communities

Eunice Sirkett
Lecturer in Adult Nursing and End of Life Care
University of Hertfordshire

TEF Gold Teaching Excellence Framework

University of Hertfordshire

Learning Outcomes

- Develop an understanding of Ethnicity, Race and Culture
- Understand how culture can impact care
- Recognise the barriers to delivering EOLC in Black & Minority Ethnic (BAME) communities.
- Identify solutions to overcome the identified challenges and barriers

What do we mean by BAME and BME?

- Black and Minority Ethnic (BME)
- Black, Asian and Minority Ethnic Groups (BAME)
- Terminology normally used in the UK to describe people of non-white descent. Groups involved are Arabs, Asian, Asian British, black/black British, Chinese, mixed, white-gypsy, traveller
- What if none of the above apply?

- Outdated, unsuitable and unnecessary?
- “People of colour” or “visible minorities” a better option?

What do we understand by race, ethnicity and culture?

- Race: The classification of people on the basis of their physical appearance – with skin colour the most popular characteristic

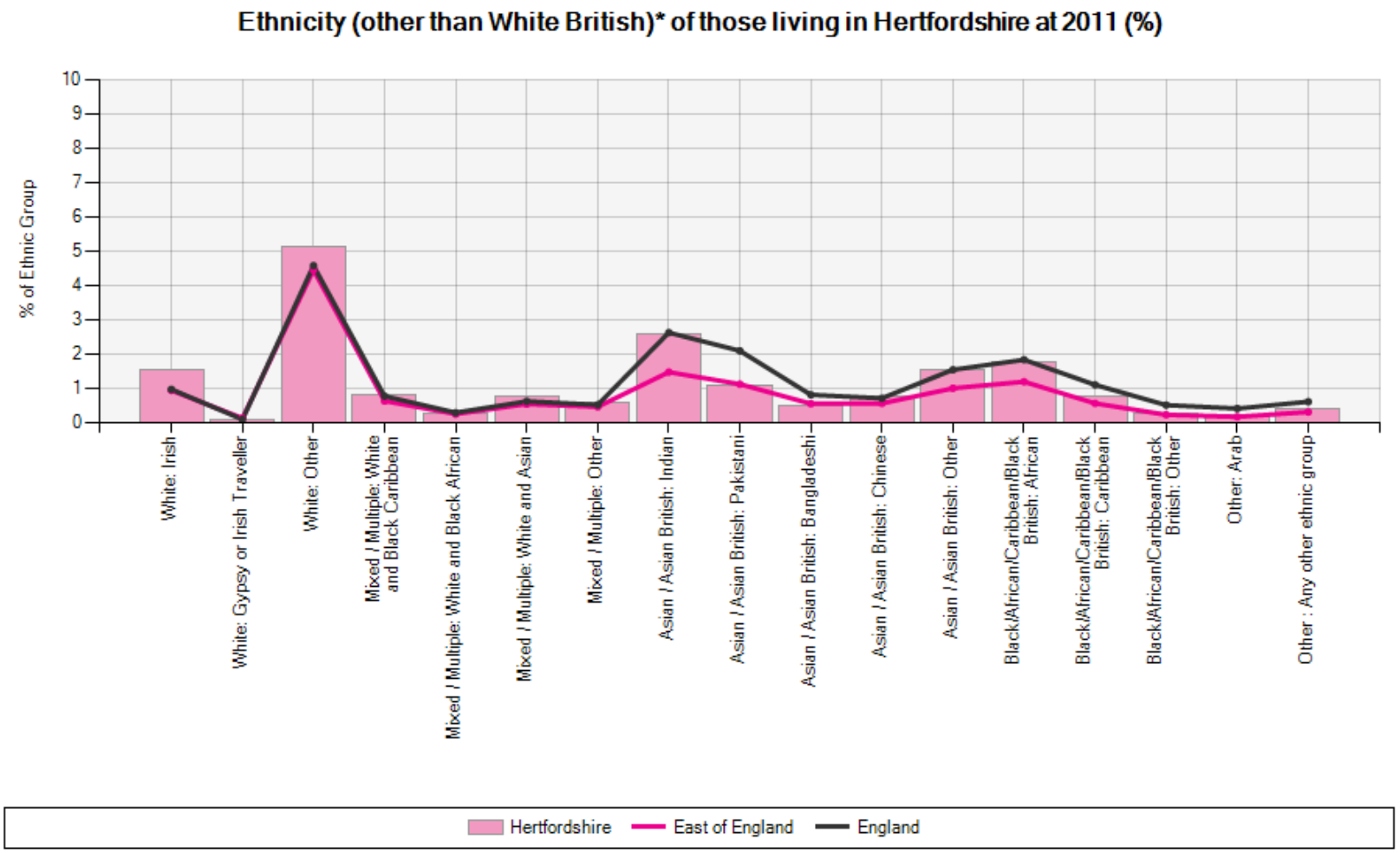
- Ethnicity: Shared origins or social backgrounds; shared culture and traditions that are distinctive, maintained between generations, and lead to a sense of identity and group; and a common language or religious tradition" (Senior & Bhopal, 1994)

- Culture: A pattern of behavioural response that develops over time as a result of imprints on the mind through social, religious, intellectual and artistic structures.

UK Statistics

- The UK has become more ethnically diverse in the past 20 years
- In England BAME's represent around 15% of the population (2011 Census)
- Around 12.5% of the population in Hertfordshire are from BAME backgrounds
- In London BAME's represent around 44% of the population
- There has been a substantial increase in the number of older people from BAME communities

Statistics in Hertfordshire



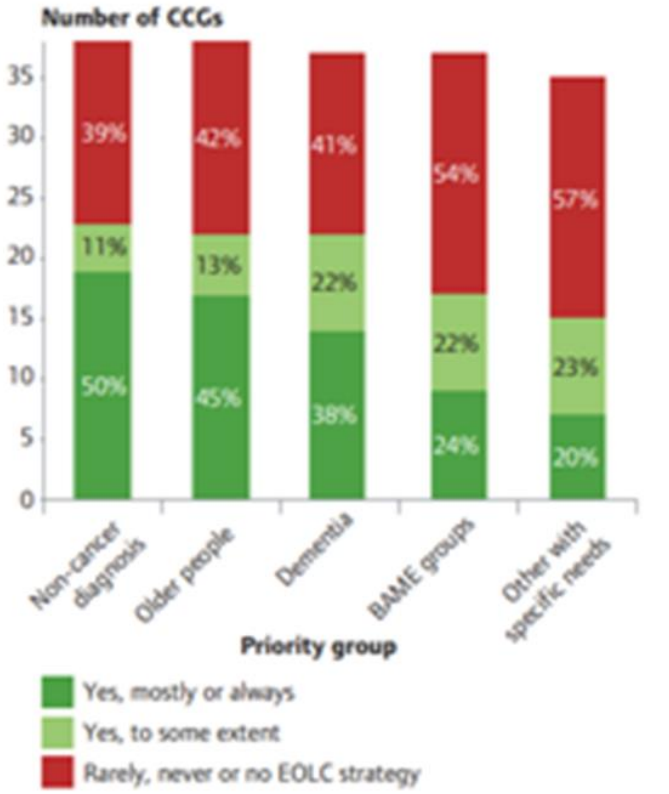
Source: Office for National Statistics, 2011 Census,

Why is this important?

- Ethnic and cultural differences can influence patterns of advanced disease, illness experience, healthcare seeking behaviour, the use of healthcare services (CQC, 2016)
- Although much has been done, inequalities still exist (End of life care strategy, 2008)
- People from BME communities report a poorer quality of end of life care (Marie Curie, 2014)
- Ambitions for Palliative and End of life care (2015) recommends that everyone has fair access to palliative and end of life care

A different Ending: Addressing Inequalities in end of life care (CQC, 2016)

FIGURE 4: NUMBER OF CCGS CONSIDERING DIFFERENT GROUPS IN THEIR END OF LIFE CARE STRATEGY, BASED ON 38 RESPONSES



Source: CQC survey of CCGs, November 2014

Lack of awareness of people's individual needs is a barrier to good care

Turn and chat

- What are some of the cultural/religious beliefs/practices of BAME population on death and dying are you aware of?

BAME wishes and preferences at the end of life.

- Age and ageing in South Asian cultures is a process accompanied by respect as well as a decline in health. Participants were keen to discuss EoL issues but not had the opportunity to do so previously (Wilkinson et al, 2018).

- Eastern Europeans and Asia/pacific groups: Accepts death as a apart of life but it should be avoided at all costs. 80% want to be told the truth and they will also tell their families if they are dying (Ohr et al, 2016).

- Sub-Saharan Africans more likely to want everything possible to be done. Stems from a religious conviction for the sanctity of life and reluctant to make decisions to withdraw treatment. (Selman et al, 2014)

The NHS Constitution

The NHS belongs to the people.

It is there to improve our health and wellbeing, supporting us to keep mentally and physically well, to get better when we are ill and, when we cannot fully recover, to stay as well as we can to the end of our lives. It works at the limits of science – bringing the highest levels of human knowledge and skill to save lives and improve health. It touches our lives at times of basic human need, when care and compassion are what matter most.

The 1st Principle of the NHS Constitution

The NHS provides a comprehensive service, available to all irrespective of gender**, race**, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status. The service is designed to diagnose, treat and improve both physical and mental health. It has a duty to each and every individual that it serves and must respect their human rights. At the same time, it has a wider social duty to promote equality through the services it provides and to pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population.

Global overview

- There is irrefutable evidence globally that people from black and minority ethnic backgrounds (BME) that live in white majority countries like the US, UK, Canada, Australia and New Zealand have poorer life chances and experiences compared to their white counterparts. Across all indicators this is true
- *Health – More likely to get chronic diseases and die sooner*
- *Wealth – make less money over their life course*
- *Employment – Less likely to be promoted*
- *Housing - live in poorer areas*
- *Judiciary – more likely to be imprisoned*

Unconscious Bias

- Unconscious bias refers to a bias that we are unaware of, and which happens outside of our control. It is a bias that happens automatically and is triggered by our brain making quick judgments and assessments of people and situations, influenced by our background, cultural environment and personal experiences (ECU: 2013 Unconscious bias in higher education).

- https://www.youtube.com/watch?v=dVp9Z5k0dEE

- Implicit bias test https://implicit.harvard.edu/implicit/takeatest.html

Biological Weathering – Arline Geronimous

- Chronological age captures duration of exposure to risks for groups living in adverse living conditions
- Blacks are experiencing greater physiological wear and tear, and are aging, biologically, more rapidly than whites
- It is driven by the cumulative impact of repeated exposures to psychological, social, physical and chemical **stressor**s in their residential, occupational and other environments, and coping with these stressors
- Compared to whites, blacks experience higher levels of stressors, greater clustering of stressors, and probably greater duration and intensity of stressors

Micro assaults or stressors

- Being the only BME person in a room
- Not being able to readily get the foods you like, products for your hair, skin
- Not seeing many people that look like you on billboards, magazines and Journals or on TV, few role models
- Feeling ‘other’ as your cultural norms are different
- Receiving a reduced service in healthcare and in society generally
- Knowing that you have to be twice as good to go half as far
- People not believing you or your lived experience

The consequences for people

- **Disillusionment**
- **Unhappiness**
- **Depression**
- **Lack of confidence**
- **Anger/Rage**
- **Lack of belief in the system**
- **Depression**
- **Sadness**
- **Lack of engagement and buy in**
- **Resentment**

Possible impact on End of Life care

- BAME population do not readily engage in research studies
- May not engage with end of life care services available
- Organ and tissue donation: Black, Asian and minority ethnic communities will wait six months longer for a kidney transplant than a white patient.
- BAME population are more likely to receive aggressive treatment towards the end of life

What are the issues to be addressed?

- Access to care
- Experience of care
- Staff and organisational issues

Access to care

- Lack of awareness of relevant services
- Previous bad experiences when accessing care
- Lack of information in relevant languages or formats
- Lack of referrals
- Conflicting family or religious views
- Structural barriers

Experience of care

- Patient Centred Care
- Culture sensitive palliative and end of Life Care
- Communication:
- Comprehension
- Customs and religion Cultural Values and beliefs around death and dying
- Expression of grief
- Family dynamics, desired and actual level of involvement
- intergenerational and language barriers

Person Centred Care (The Health Foundation 2015)

- Health and well-being enable us to live our lives as we choose – this might include everyday activities such as having a family, enjoying time with friends, and working. Person-centred care means providing care that supports people to achieve the health outcomes that give them the best opportunity to lead the life that they want.
- Its starting point is valuing the patient as a ‘whole person’ and respecting their autonomy through sharing of power and responsibility.

Relationship Centred Care (Nolan et al 2006)

- We ALL need to feel these ie. Patients, Nurses, Doctors
- Sense of purpose
- Sense of belonging
- Sense of security
- Sense of significance
- Sense of continuity
- Sense of fulfilment

Staff and organisational Issues

- Commissioning
- Culturally diverse teams
- BAME Staff in senior leadership teams, role models, mentoring
- Include BAME service users in design and delivery of services
- Encourage open and honest communication. “ Do not be afraid to say – I am not sure what to say or do”
- Active engagement with BAME communities.
- Cultural competence
- Staff training- Equality and Diversity
- Unconscious Bias Training

Film clips from Life after death

- Floating Harbour Films Production for (Kings College London)
- https://www.youtube.com/watch?v=oiMTu9PMaig

Some Tips

- Do not make assumptions
- Learn from the person and their family
- Learn the basic values of that cultural group
- Be sensitive to a persons past
- Be aware of the different cultural approaches towards illness and dying
- Provide clear information – Use interpreters if necessary
- Explain treatments and rationale behind treatments
- Be aware of your implicit bias

“There is nothing more unfair than the equal treatment of unequal people.”
- Thomas Jefferson 1743 - 1826

EQUALITY VERSUS EQUITY

In the first image, it is assumed that everyone will benefit from the same supports. They are being treated equally.

In the second image, individuals are given different supports to make it possible for them to have equal access to the game. They are being treated equitably.

In the third image, all three can see the game without any supports or accommodations because the cause of the inequity was addressed. The systemic barrier has been removed.

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Any Questions?