

Palliative and end of life care for Black, Asian and Minority Ethnic Groups in Scotland

Exploring the Barriers

Policy and Public Affairs, Scotland

07 September 2015



Care and support
through terminal illness

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Black, Asian and Minority Ethnic Groups in Scotland

Introduction

Marie Curie believes that everyone living with a terminal illness should be able to get high quality care when they need it regardless of their condition, background and location.

Someone has a terminal illness when they reach a point where their illness is likely to lead to their death. Depending on their condition and treatment, they may live for days, weeks, months or even years after this point.

A palliative approach is often recommended for people living with a terminal illness. Palliative care includes pain and symptom management, as well as physical, emotional and spiritual support. It has proven to benefit people with many different illnesses including dementia, motor neurone disease, multiple sclerosis and heart failure.

In recent years, Scotland has made good progress in developing care for people living with a terminal illness. However it is clear that not everyone is getting the care they need. Research carried out by the London School of Economics (LSE) and Political Science suggests that nearly 11,000 people who need palliative care in Scotland each year are not accessing it¹.

In particular, there is evidence to show that many of those from Black, Asian and minority ethnic (BAME) communities in Scotland are not accessing palliative care and that palliative care is not necessarily sensitive to the different needs of minority ethnic groups in Scotland.

The LSE study highlighted a range of barriers faced by BAME communities. These include lack of cultural and religious sensitivity in how services are delivered, discrimination (and/or fear of it), absence of translation resources, different cultural views regarding the acceptability of openly discussing death, shortages of female doctors for Muslim women and assumptions that family members from BAME backgrounds will be able and willing to care for relatives at home. The LSE study repeatedly refers to US studies, or those with small samples. It also highlights that many of the proposals for tackling these barriers lack evidence.

There clearly needs to be greater research in this area, particularly at a local level, in order to support evidence-based solutions.

In Scotland, research carried out in central Scotland and published in February 2009 concluded that 'most [palliative care] services struggled to deliver responsive, culturally appropriate care'².

In order to improve access to palliative care for this group of people it is important to understand and detail the different reasons why such inconsistencies exist in order to develop an approach to tackle these barriers.

This report aims to consider this issue from a Scottish perspective, while looking at research and examples of good practice from across the UK. In particular, the report aims to build on the analysis carried out in our 2013 report, '*Palliative and end of life care for BAME groups in the UK*'³.

This report will highlight the differing needs of the BAME communities in relation to end of life care and the challenges that may arise in meeting them. The report will also attempt to measure the progress made in Scotland and suggest recommendations to improve access to palliative care.

BAME Groups in Scotland

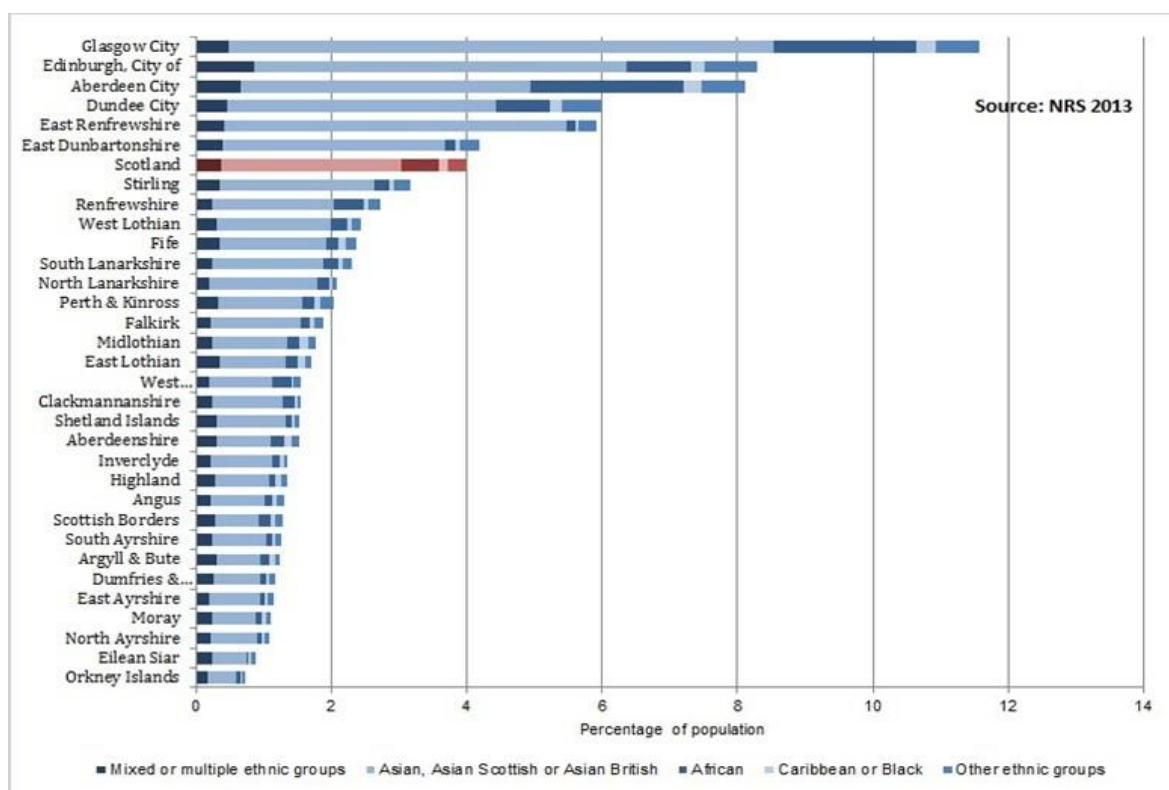
Scotland's Census⁴, suggests that the minority ethnic population has doubled since 2001 from 100,000 to 200,000.

In England and Wales BAME groups were estimated to account for 14.1% of the population, significantly more than Scotland's (4%). Despite an increasing minority ethnic population in Scotland there is still a significant variance between Scotland's profile compared to England and the rest of the UK.

The majority of the BAME population in Scotland are situated in urban areas predominately in the cities of Glasgow, Edinburgh, Aberdeen and Dundee. Significantly, 38.7% of the total Scottish BAME population live in the Greater Glasgow area.

The Asian population was the largest BAME group (3% of the total population or 141,000 people) and has seen an increase of 1 percentage point (69,000) since 2001. Furthermore, Scotland as a whole tends to attract younger migrants compared to the rest of the UK and generally large proportions of asylum seekers⁵. According to the 2011 census, 19% of people from the white groups in Glasgow were of pensionable age or over whereas just over 5% of the BAME population were in this age group.

Scotland's BAME demographic is far from universal in its distribution and as such it is important that policy-makers and service planners consider developing a health response that is tailored to fit those needs.

Figure 1. Scotland's BAME communities by location

Accessing palliative care for BAME communities

The Scottish Migrant and Ethnic Health Strategy (SMEHRS) states that greater research is required in order to fully understand the health characteristics of BAME groups⁶.

In Scotland, as in other parts of the UK, South Asians have a higher incidence of coronary heart disease, cardio vascular disease and diabetes than the overall population⁷. People from BAME groups in Scotland have lower cancer rates compared to white Scots⁸. In particular, those from an Indian background had the lowest rate of all cancers while people from the Chinese community had the second lowest rates overall. Also, Scotland's Pakistani community had the lowest rate of individual cancers such as lung, colorectal, breast and prostate⁹. This could suggest that BAME communities are more likely to need palliative care for non-cancer diagnoses than the wider Scottish population.

Historically there has been a perception that palliative care services are primarily for people with cancer. Recent research has suggested that people terminally ill with non-malignant conditions are not accessing palliative care to the same extent as those with terminal cancer¹⁰.

It has been suggested that the differences in disease risk among BAME groups may contribute to the lower access to palliative care experienced by them¹¹. Worryingly a range of studies carried out across the UK suggest that BAME people tend to be diagnosed when their condition is more advanced.

The LSE report suggests that there is evidence that people from BAME backgrounds are less likely to experience high quality care in the last three months of life, overall and particularly from care homes¹².

Studies have also shown that there may be a reluctance by BAME groups to refer or be referred for palliative care. This may be because of misunderstandings regarding what palliative care actually offers and underlying cultural and religious issues that have not been considered.

A study carried out in Scotland concluded that an inability to speak English was perceived as a major disadvantage in accessing palliative care services. For example, trying to organise interpreters at short notice was seen as “impossible”, which created problems for those trying to access services at the end of life¹³.

A lack of awareness around palliative care amongst BAME communities and a lack of awareness and understanding by health professionals of the needs of BAME communities are barriers that also need to be addressed. Studies also suggest that many health professionals are unaware of any training in diversity and cultural awareness available to them. Others suggested that existing approaches were ineffective in changing services and attitudes at the end of life¹⁴.

A number of solutions have been suggested across a range of studies and reports. These include:

- A collective effort to ensure that palliative care for non-cancer patients is offered to everyone and particularly BAME communities.
- Raise awareness of the services on offer and understanding around palliative and end of life care services.
- Appropriate training for nurses and health professionals especially regarding ‘cultural competency’ in hospices and hospitals.
- Responsive and flexible translation and communication services should be offered where suitable.
- Avoid stereotypes, sensitivity and non-judgemental conversations are essential.
- Involve and engage BAME communities.
- Raise awareness of services on offer through outreach events.

Policy and approach

There are signs that the Scottish Government has attempted to address health inequalities concerning BAME communities through relevant legislation and policy documents. For example, the Race Relations (Amendment) Act 2000 states that “NHS Scotland must address inequalities in health experienced by minority ethnic populations¹⁵”.

Living and Dying Well, the national action plan for palliative and end of life care, which was published by the Scottish Government in 2008 includes a number of general aims related to equality¹⁶ and the need to undertake equality impact assessments¹⁷. However, there is no mention or reference to BAME communities in this key palliative care policy framework.

BAME communities and representatives should be involved when policies and strategies are devised to ensure they adequately reflect the needs of these groups.

Research Limitations

A major concern regarding the understanding of the health needs of BAME communities and planning appropriate services is a lack of available data.

The Scottish Migrant and Ethnic Health Research Strategy (SMEHRS) and the Health in our multi-ethnic Scotland report explicitly state that high quality ethnicity and health research is needed in Scotland¹⁸.

According to Audit Scotland, hospices and NHS boards are not able to demonstrate that different ethnic and social groups have equal access to specialist palliative care services as they do not routinely monitor who receives these services¹⁹.

Scotland, along with the rest of the UK, can improve its data collection and look at examples from other countries. For example, in the United States, a legal requirement has existed since 1993 for all clinical research studies to include members of minority and their subpopulations. The report also reiterates that “there is little evidence that research institutions in the United Kingdom had policies which actively promoted research related to ethnicity”²⁰.

In general there are well known logistical complications to consider when carrying out research for “hard to reach” populations²¹. In particular, identifying and encouraging participants from underrepresented BAME communities continues to be an issue that prevents a satisfactory and cohesive assessment of services and policies.

The Scottish Government’s national end of life indicator, which measures the percentage of time spent by people in the last 6 months of life at home or in a community setting, fails to include data on ethnicity. The figures provide a breakdown by gender, age, deprivation and rurality but not on ethnicity. Similarly, the Hospital Standardised Mortality Ratios also do not include data of hospital deaths by ethnicity. As a result it is difficult to get a picture of what end of life care looks like for BAME communities.

The concerns raised are not only unique to BAME people. Scottish data regarding end of life and palliative care is lacking in general. Scotland does not currently collect and analyse enough data to show the provision of palliative care across the country. However, Scottish Government, NHS Boards, and other colleagues across a range of organisations recognise the need for a clear shared vision on the future of palliative and end of life care in Scotland²².

It is clear that much more could be done from both a research and policy standpoint to ensure that there is clear data to show where there are gaps in care for BAME communities. Marie Curie urges the new Strategic Framework for Action on Palliative and End of Life Care to focus on collecting more robust data, including for BAME communities.

Examples of good practice

Examples of best practice are often found in local communities. They can highlight practical models where successes and learning can be evaluated and potentially rolled out. In Scotland, such instances are currently rare. However, there are a number that can be learned from.

The Prince and Princess of Wales Hospice, Glasgow

The Prince and Princess of Wales Hospice, situated in south Glasgow, serves a relatively diverse community, particularly from a South Asian background. However, in the year 2006/07 only 16 referrals to the hospice were from the minority ethnic community (1.8%). This is in contrast with the proportion of the local population from these groups which is 5.8%. The majority of these are of South Asian origin and predominantly Muslim and in some areas such as Govanhill represent up to 40% of the local population²³.

As a result, steps were made to provide services more suited to the needs of these communities. The hospice set up a Minority Ethnic Project (ME) which included:

- An awareness raising project.
- Creating links between the South Asian Community (recruitment of 5 minority ethnic volunteers to support the project).
- Developing culturally appropriate care - this included members of staff receiving training, with local participants from the minority ethnic community

In its second year, the hospice had an increase in referrals from the targeted groups.

Securing Care for Ethnic Elders (SCEES)

SCEES is a recent project exclusive to Scotland and managed by Policy Research Institute on Ageing and Ethnicity (PRIAE)²⁴. Funded by the Scottish Government, the project aims to improve and manage dignified and active ageing life for Scotland's (BME) elders. SCEES is the first development of its kind dedicated to minority ethnic elders in Scotland. The project aims to improve service provision for this group in three areas:

1. Active ageing
2. Patient centred care
3. Palliative care

In this last area, SCEES has worked with the Palliative Managed Clinical Networks in Edinburgh, Glasgow and Forth Valley in delivering six Palliative Listening Events to the Chinese and South Asian communities. The following events were held:

- Edinburgh St Columbas Hospice South Asian Event
- Edinburgh Marie Curie Hospice Chinese Listening Event
- Forth Valley Strathcarron Hospice Chinese Listening Event
- Glasgow Prince and Princess of Wales Hospice South Asian Listening Event
- Glasgow Marie Curie Chinese Listening Events

These events were intended to raise the awareness and understanding of palliative care in those communities. In particular, the main aims were as follows:

- For the hospice multi-disciplinary team to learn about the needs of the South Asian and Chinese communities and in particular the provision of a culturally sensitive services.
- To understand the best methods of communication for the palliative team to improve the service provided to the South Asian and Chinese communities.
- To understand how the participants feel about palliative care.

The SCEES project found that there are doubts among BAME communities about using palliative care services and especially hospices. These revolve round the cultural and religious aspects of death and dying, and also, closely related, social aspects such as the role of the family and friends in caring for the individual concerned. There are also gender issues about mixed/separate facilities²⁵.

Conclusion

Scotland's ethnic minority population is expected to increase over the coming years, as part of Scotland's wider projected population increase. There will, as a result, be a growing need for end of life care for BAME communities.

Scotland's BAME communities are currently concentrated within specific geographical areas which must be considered when developing any policy response and services. A structured, coordinated national approach is needed to ensure an accessible and equitable service for all²⁶.

The Scottish Government and partners have made efforts to address the imbalances in health inequality. However they must address the needs of the BAME communities, and as part of this, palliative and end of life care. In particular, the lack of routine information concerning the health of BAME communities prevents a detailed and comprehensive evaluation of the issue in Scotland. This should be a priority and could lead to health and social care providers developing more specialist services, which incorporates the needs of BAME communities.

As palliative care is taken forward by the new Integrated Joint Boards for health and social care, there is an opportunity for Boards to ensure that their services incorporate the needs of BAME communities. This could be embedded in strategic and local delivery plans.

The Scottish Government should specifically address the needs of BAME communities in the upcoming Strategic Framework for Action on Palliative and End of Life Care, focusing on access to appropriate services, measuring outcomes and collating data, and recognising cultural and spiritual needs.

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