Palliative Medicine & Care International Journal
ISSN: 2688-3821

Mini Review
Volume 1 Issue 3 - January 2019
DOI: 10.19080/PMCIJ.2019.01.555564

Palliat Med Care Int J

Engaging Black and Minority Ethnic (BME) elders in palliative care innovation through the Learning Alliance in Palliative and End of Life Care (LAPCEL) methodology

David M Smith[1]* and Carlos Moreno Leguizamon[2]

[1]*Reader in Social Policy Faculty of Health Education and Medical Science, Anglia Ruskin University, UK*

[2]*Senior Lecturer in Health Development Faculty of Education and Health, University of Greenwich, UK*

Submission: November 22, 2018; **Published:** January 04, 2019

***Corresponding author:** David M Smith, Reader in Social Policy Faculty of Health Education and Medical Science, Anglia Ruskin University, Chelmsford CM1 1SQ, Essex, UK

Keywords: Quality of death; Gender; Social class; Sexuality; Race; Ethnicity

Mini Review

In 2015 the UK was reported as having the best 'quality of death' out of 80 countries due to the quality of its palliative and end of life care services [1]. However, not everybody in the UK receives a 'good death' with inequalities of gender, social class, sexuality, race and ethnicity that persist throughout the life course reflected at the end of life. People from poorer and/or BME backgrounds are less likely to be referred to or access palliative care, are more likely to lack knowledge surrounding palliative care. In the context of increasing 'hyper-diversity' and the ageing of BME populations, health and palliative service providers face unprecedented challenges in responding to an increasing diversity of beliefs and practices surrounding death and dying. The potential for communicative difficulties, misunderstanding, distress and conflict for ethnic minority patients in a western medical system 'dominated by the principles of patient autonomy, beneficence, non-maleficence and avoiding futile care' remains high [2].

It was in this context of far reaching social and demographic change and the increasing focus on community engagement in designing health services that the LAPCEL project was formed by researchers at the University of Greenwich and Anglia Ruskin University in 2014 funded by Health Education England. Its aim was to form a Learning Alliance (LA) –a non-linear model of knowledge production in a network of academic researchers, policy makers, commissioners, health and palliative care service providers and community organizations representing different BME communities. Its aims were firstly to document the practices and customs surrounding death and dying in the main BME groups in the North and Mid Kent regions of the UK; secondly to raise awareness of what palliative and end of life care is and how to access it, and to make health and palliative service providers aware of particular issues and practices surrounding the end of life within and across those populations, and finally to co-develop solutions to any barriers and issues identified within the LA network. A series of focus groups with the largest BME populations (Black African, South Asian, East and Central European, Gypsy/Traveller) in the north and mid Kent region in south-east England were held. Many of the important themes and issues to emerge from the focus groups mirrored those of the white UK majority population. However, these universal concerns were amplified by language and cultural barriers; by poor awareness of palliative services; ideas about 'appropriate' forms of care for sick and dying relatives and who should provide that care; fears of discrimination and taboos around discussing death. There were also notable differences within specific ethnic populations by gender, social class and generation highlighting the problems inherent in categorizing people solely by ethnicity and neglecting how ethnicity intersects and interacts with other dimensions of social identity [3].

Low awareness surrounding the role and function of palliative care and poor understanding of where or how to access it emerged as important themes in the focus groups and in two LA facilitated workshops held in 2017 and 2018 for BME communities and health and palliative care providers. The issue then became how to develop inclusive forms of knowledge delivery and how to raise awareness given the heterogeneity of the BME population; different language anilities and intersectional issues that made generalizing based on ethnicity problematic. Visual imagery in the form of pictograms was explored as a possible medium to overcome language barriers, confront taboos surrounding death and dying and to inform people about palliative care and how to access it. BME members were invited to a workshop where they drew pictures that illustrated aspects of, and issues surrounding, death, dying and palliative care which were supplemented with personal narratives and experiences. The pictograms that were designed from this represent visual abstractions of the underlying themes such as fear; death as taboo; communication issues; the desire to return to country of origin to die and/or be buried for elderly first generation migrants; home versus hospice care etc. The pictograms convey universal messages and concerns in an inclusive medium that transcends ethnic/cultural and language barriers and were printed onto postcards, posters, banners and carrier bags to disseminate awareness and knowledge of palliative services in a novel and innovative way and as a means for stimulating discussions around death, dying and illness [4].

LAPCEL is one of few attempts to apply a LA methodology to health and social care and it did offer benefits in policy-oriented research with minority groups. In the early stages the LA were key in shaping and refining the research questions, data collection and analysis and meant it was possible to collect data from different vantage points (BME people; community leaders and organizations; health and palliative care providers; academic researchers) [5]. The sharing of control over defining the priorities and aims of the research facilitated inter-organizational learning by incorporating the LA partners' tacit knowledge into concrete knowledge via joint learning activities, by sharing and discussing findings within the LA network as they emerged and then later, through the dissemination activities. Detailed documentation of the process is a valuable data source and ensures that there is an element of evaluation built into the project from the outset. Potential difficulties are those which could impede any participatory project such as establishing trust and a common purpose during the project's implementation to minimize any latent tensions that may surface at a later stage [6]. Furthermore while strategic partnerships are often short-term and focused on a specific aim, sustainability should be a central objective for a LA and should function for at least two years to allow for the effective dissemination and consolidation of knowledge, and for innovative policy solutions and interventions to evolve that unlike traditional 'top down' models of policy development are evidence-based and formed in collaboration with the intended recipients of those innovations.

References

1. https://www.eiuperspectives.economist.com/sites/default/files/images/2015%20Quality%20of%20Death%20Index%20Country%20Profiles_Oct%206%20FINAL.pdf
2. Brown EA (2014) Ethnic and cultural challenges at the end of life: setting the scene. J Ren Care 1(Suppl 40): 2-5.
3. Smith D, Moreno C (2015) End of Life Practices and Palliative Care in Black and Minority Ethnic Groups, Health Education Kent Surrey and Sussex.
4. Wilcox T (2018) From Story to Picture: Spreading the Message of Palliative Care within Ethnic Minority Groups, Ellenor Hospice.
5. http://www.planetvillage.co.uk/wp-content/uploads/2018/08/Migrantas_LAPCEL_14_Posters.pdf
6. http://www.diversityhouse.org.uk/category/lapcel/

DOI: 10.19080/PMCIJ.2019.01.555564

How to cite this article: David M S, Carlos M L. Engaging Black and Minority Ethnic (BME) elders in palliative care innovation through the Learning Alliance in Palliative and End of Life Care (LAPCEL) methodology. Palliat Med Care Int J. 2019; 1(3): 555564. DOI: 10.19080/PMCIJ.2019.01.555564