Celebrating Life

An innovative community engagement project with Minortised Ethnic populations living in areas of socio-economic deprivation in North London: A Service Evaluation

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Background

In the UK, access to palliative care is inequitable, disproportionately affecting global majority communities who are 16 % of the UK population (2021).

Aim

The Celebrating Life project is an innovative community engagement initiative whose aim is to explore the death and bereavement systems and to promote the knowledge that global majority communities need, to gain access to and make informed choices about, end of life and after death care.

The service evaluation aims at exploring the usefulness of these workshops in increasing knowledge of palliative care and of Marie Curie services and facilitating exploration of community members perspectives and concerns.

Method

Over a series of workshops held in local community centres in North London, conversations were facilitated to encourage reflection on what matters most and who and what informs treatment choices in advancing frailty and increasing symptom burden towards the end of life. De-identified qualitative data was collected to develop themes. The project was approved by Marie Curie Community Engagement Manager.

Key Findings:

A total of eight workshops were undertaken, from August-October 2023 (n=185 participants).

Main Themes:

- **Filial Cultures with communal decision making as a family unit, usually male-led, although women have advocacy voice.**
- **Death is not openly discussed. Euphemistic language for death informed by religious frameworks of the meaning and purpose behind birth, life and death.**
- **Hospice is a foreign concept as in these communities, death happens either at home or increasingly in hospitals.**
- **Language barriers and language discordant care was a major challenge, made them feel "invisible", unable to advocate for their needs or their wishes. Low levels of health literacy made them access unplanned care out of fear.**
- **Stigma within communities and pervasive institutional mistrust. Poor health literacy and poor knowledge of their health morbidities and its prognosis, fuelled misinformation on opioid use.**
- **Caregiving is a gendered expectation with female caregiving the accepted norm.**
- **Participants appeared generally unaware of research in palliative care**

Service Evaluation:

The workshops demonstrated a significant improvement in participant knowledge across the three domains: 1. Knowledge of Palliative Care 2. Knowledge of Autonomy 3. Knowledge of Marie Curie

Knowledge of Palliative Care what it is, who offers it, how to access, where to seek help and support		Knowledge of Autonomy What it means in palliative care decision making, knowledge of ACP		Knowledge of Marie Curie What are our nursing services in London, Wills service, ACP service	
BEFORE	AFTER	BEFORE	AFTER	BEFORE	AFTER
No Knowledge 180(97%)	0	No Knowledge 181 (98%)	0	No Knowledge 181 (98%)	0
Some Knowledge 1	2 (1%)	Some Knowledge 0	39 (21%)	Some Knowledge 4	18 (10%)
Good Enough Working Knowledge 4 (3%)	183 (99%)	Good Enough Working Knowledge 4	146 (79%)	Good Enough Working Knowledge 0	167 (90%)

Notes: further details here (or delete)

Recommendations:

Celebrating Life Workshops

- **Effective** in improving their knowledge of palliative care, of care planning and of Marie Curie services
- **Share the findings** from the Celebrating Life workshops amongst hospices locally and nationally, and in national conferences like Hospice UK conference

Marie Curie

- Further research into developing the **role of a link worker** with a view to build trust, support and advocate for health and social care needs of palliative patients and their family caregivers from resource-poor minoritized communities.
- Further research of **models of care to support family caregivers** of palliative patients.

ICB's

- To **routinely collect data on the outcomes of care or people's experience**, to reflect the specific needs and preferences of people from different ethnic minorities
- To **involve people** in saying what is needed with patient participation groups (PPG's) in GP practices and Patient and Public Involvement Groups in research studies

What Minoritised Ethnic populations told us:

"We in our community don't think about place of care, place of death as you were saying in your talk. God's will prevails. Why should we waste time thinking about these sad things. What will be will be. If God decides I die in hospital, I am ok. He says die at home, I am fine".

"You see madam, we don't know what hospice means. For us, we know hospital only. So we think dying means home or hospital. Back home poor people dying home and rich people in private ward".

"Camden council is all online. Health information is online in English. My mother has very poor English, she could not go to school either here or back home because of how poor we were, so we have to do all her translation and filling out of forms. I can see how much she does not like that depending upon us…."

"My mother would take me to see the doctor about her female problems and I would have to face the school authorities who said well your mother needs to learn English if she wants to live here".

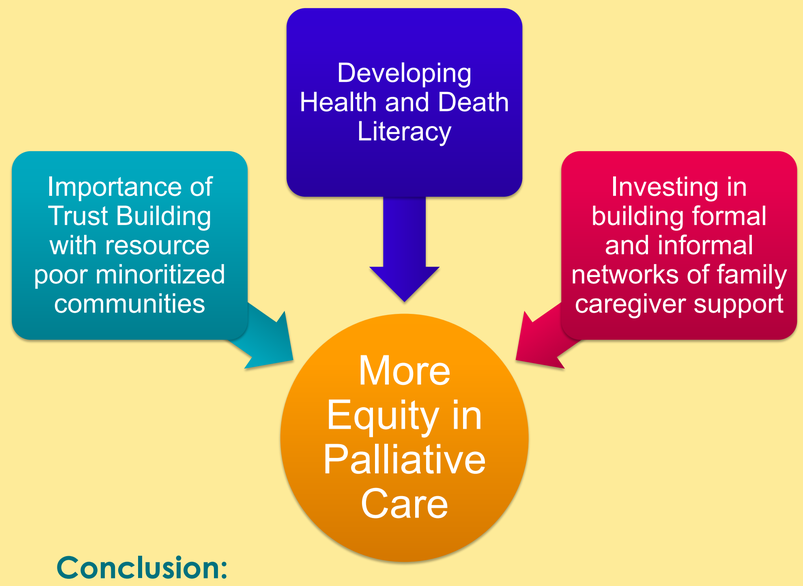
"I don't know what's happening in disease (weekly dialysis). No one tell me what to expect. My BP get high. I get scared sometime. I go to A and E. I am tired like this. Death is good for me".

"I think morphine will make death come quick. I don't want it".

"Caring very hard. It make me tired, angry, sad…I feel helpless you know. How much can family support you? They have their own lives".

"Hey sister, you want to know my view on research. All posh people talking about us….do they really care? Ha ha ha…more like care about making a name for themselves from our problems. Big university people sit in posh conferences and shake their head …tut tut poor lonely black people and brown peoples they have "researched"….and accept awards for "great work" for us…while we live in damp and die in squalor. Has any of their research mean better care for us lot. Not really? Sorry, we are not fodder".

Celebrating Life Workshops: Key Messages



Conclusion:

Illness, frailty, death and dying are not a bio-medical event in the life course of individuals for minoritised ethnic communities. Instead, these are psycho-social processes informed by their religious and cultural frameworks. Care that is informed by this knowledge and grounded in cultural humility builds trust and encourages engagement with care planning. Not all lives are equal, but equity in care at the end of life is a fundamental healthcare obligation.

Marie Curie