

Oral Presentations

Parallel session 1.1 – Amplifying community voices: a focus on equity

(Tuesday 22 November, 13:30 – 14:45)

0-01

PLANNING FOR PARENTAL DEATH AND TRANSITIONS IN CARE FOR OLDER PEOPLE WITH LEARNING DISABILITIES: AN ADAPTED EXPERIENCE-BASED CO-DESIGN PROJECT

Richard Keagan-Bull, Rebecca Anderson, Jo Giles, Irene Tuffrey-Wijne. *Kingston University, London*

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Introduction Around two thirds of the 900,000 learning-disabled adults in the UK live with parent(s). Parents have expressed fears about what will happen to their sons and daughters when they die.

Aims To understand families' concerns about the future. To develop resources to help families plan for parental death.

Method An adapted Experience Based Co-Design approach:

- Interviews with 37 people including: learning-disabled adults (40+) living with parent(s); parents; and siblings.
- A film about participants' experiences.
- Twelve co-design group meetings to design future-planning resources.

The co-lead authors of this paper are a learning-disabled researcher and his non-learning disabled colleague, who planned and conducted this study together.

Results Parents' main end-of-life concerns were what would happen to their adult children. They could not consider advance care plans without first planning for their sons and daughters. Siblings often struggled to talk to their parents about what would happen after they die, and felt a lack of control over future plans. Some learning-disabled adults saw living away from parents as an opportunity to gain independence, but others worried support staff would limit their opportunities to do the things they love.

The co-design group created conversation cards to help families plan for the future. This included cards to help think about support needs and preparations for conversations with social workers. They created a set of cards called 'illness, death and dying'. These included prompts to talk about what would happen when parents get ill.

Conclusion For parents of learning-disabled adults, ensuring their son's or daughter's wellbeing is the priority for advance care planning. Focusing on the impact of end-of-life decisions on loved ones is not unique to this group, but it does require additional input from professionals, particularly social services. Enabling families to make plans helps them to live well now, without fears about what will happen after parents die.

0-02

COMPLEX, PROVOCATIVE, HUMBLING AND ENLIGHTENING – EQUALITY, DIVERSITY AND INCLUSION

Karen Clarke. *St Michael's Hospice, Hastings and Rother, Hastings, UK*

10.1136/spcare-2022-HUNC.2

Background An equality, diversity and inclusion (EDI) audit was commissioned to assess whether hospice stakeholders felt included, with their needs met and their contributions valued, and to ensure that unintentional bias had not crept in.

Aim(s)

- Assess policies, processes and EDI interventions' effectiveness.
- Understand EDI perceptions and aspirations, and stakeholders' 'lived experience'.
- Strategically address gaps identified.

Methods Policies, processes, equality monitoring data and external profile were reviewed, and questionnaires, listening groups and individual interviews were conducted with a range of stakeholders.

Findings Despite evidence of senior level commitment to improve, and pockets of significant EDI interest, knowledge and expertise, there was a lack of:

- A strategic EDI focus and the hospice was 'behind the curve'.
- Diversity in:
 - employee and volunteer profiles and therefore understanding of different lived experiences
 - the physical hospice environment, sending an inaccurate message to the community about the hospice's ethos and approach
 - inclusivity in hospice branding, meaning some local minority communities felt the hospice was 'not for them'.

There was an organisational EDI blind spot where unconscious bias played out in unintentionally exclusionary behaviours affecting culture and impeding inclusive service delivery.

Progress

- 'Proud to be' series, sharing lived experiences, launched.
- EDI Lead appointed, and governance framework implemented.
- EDI objectives agreed.
- Mandatory Conscious Inclusion training.
- Partnership working with local community.
- Regional EDI forum established.

How innovative or of interest is the abstract? EDI is complex and provocative, requiring humility and a willingness to learn. It requires courage to hold firm in the face of criticism by those whose own views of hospice may be challenged. The 'Proud to be' series and training has created the psychological safety for colleagues to share lived experiences without fear of judgment or adverse treatment. This has allowed the entire organisation to grow.

0-03

WORKING IN CO-PRODUCTION: CREATIVE APPROACHES TO ADVANCE CARE PLANNING WITH PEOPLE EXCLUDED BY IDENTITY, CULTURE, ETHNICITY AND RACE

^{1,2}Jed Jerwood, ²Gemma Allen. ¹University of Birmingham, Birmingham, UK; ²Mary Stevens Hospice, Stourbridge, UK

10.1136/spcare-2022-HUNC.3

Background The COVID-19 pandemic highlighted the health inequalities experienced by people from Black, Asian and minority ethnic people and communities in the UK (Chidiac, Feuer, Flatley, et al., 2020. *Palliat Med.* 34:1241). There is a lack of understanding of the needs of different BAME communities in the palliative care workforce (Hussain, Koffman &

Bajwah, 2021. *Palliat Med.* 35:810). Consequently, people from BAME communities have less access to advance care planning (ACP).

Aim(s) The research project had two main aims:

1. To explore whether our equity-focused, arts-based approach to advance care planning (the No Barriers Here model) could be further developed to gain better understanding of the needs and experiences of people excluded by identity, ethnicity, culture and race in the locality.
2. To take this understanding and develop an education programme for healthcare professionals to improve cultural competence in the workforce.

Methods A co-production group was formed including members of different communities often excluded by identity, culture, ethnicity or race. The co-production group supported the development of the model and recruitment of participants into three cohorts and each cohort took part in three arts-based ACP workshops. The data from the workshops were analysed using reflexive thematic analysis (Braun, Clarke, 2014. *Int J Qual Stud Health Well-being.* 9:1; Braun & Clarke, 2006. *Qual Res Psychol.* 3:77) and the findings used to inform the development of an education programme.

Results Key themes are developed within the data analysis and will be presented in the session (data analysis is currently ongoing at the time of writing).

Conclusions The conclusions will be presented at conference. Early indications highlight that adoption of co-production methods and an equity-focused, arts-based approach to advance care planning offer communities often excluded by identity, culture, ethnicity and race an opportunity to explore and share what matters most at the end of life, what barriers are experienced in accessing care and what services and support are available. The method appears to amplify voices of communities which organisations and healthcare professionals sometimes struggle to hear.

A film about the No Barriers Here study with people excluded due to identity, culture, ethnicity and race is available at: <https://youtu.be/G-ToRCT3UiU>

0-04 DESERVİȚI ȘI MARGINALIZAȚI... TIMPUL PENTRU SCHIMBARE

¹Gemma Allen, ²Jed Jerwood. ¹*The Mary Stevens Hospice, Stourbridge, UK;* ²*University of Birmingham, Birmingham, UK*

10.1136/spcare-2022-HUNC.4

Background Roma communities are one of the most marginalised in the UK, experiencing systematic barriers, structural racism and health inequity that results in lower life expectancy and inequitable access to palliative care. There is little evidence of research around advance care planning and Roma people.

Aims

- Work in co-production to explore views and experiences of care, advance care planning, death and dying.
- Provide equitable advance care planning for Roma people.

Methods A co-production group was formed, including a Roma community worker who supported recruitment. Three arts-based advance care planning workshops were delivered with information translated and interpreters present. Filmed footage provided further analytical information. A reflexive

thematic analysis was carried out and themes will be developed from analysis.

Results Participants expressed choices verbally and through art-making. Insight was gained from individual experiences shaped by practical, political, socio-economic and systematic barriers. Data analysis is on-going, and findings will be shared at conference.

Conclusion There are approximately 250,000 Roma people living in the UK and there is an urgent need for providers and stakeholders to understand what is important for this community. Study findings will support inclusive and personalised palliative care. A call for action is required for services to listen and embed change to meet the diverse needs of a community who for far too long been underserved. It's time for change.

Parallel session 2.1 – Care, comfort and confidence: supporting families and staff (Tuesday 22 November, 15:30 – 16:45)

0-05 'IT'S BRILLIANT! IT'S WORKING! IT'S NEEDED!' A HOSPICE SHORT BREAK INNOVATION FOR YOUNG ADULTS

Helen Finlison, Anna Spathis. *St Elizabeth Hospice, Ipswich, UK*

10.1136/spcare-2022-HUNC.5

Background More young adults with life-limiting conditions are surviving into adulthood needing adult palliative care (Gibson-Smith, Jarvis, Norman et al., 2021). The evidence on appropriate service models is sparse (Clark & Fasciano, 2015. *Am J Hosp Palliat Med.* 31: 101). Adult hospices report lack of competence and confidence in young adult complex care needs (Knighting, Bray, Downing, et al., 2018. *J Adv Nurs.* May 6). Loss of children's hospice short break provision after transition has been described by families as like 'falling off a cliff edge' (Knighting, Pilkington, Noyes, et al., 2021. *Health Serv Deliv Res.* 9, 6). There is a lack of equivalent provision in adult services (Together for Short Lives, 2015). To address unmet need, a pilot residential short break service in an adult hospice was co-produced and evaluated with families to determine future provision.

Aims With the aim of facilitating future service optimisation the service evaluation had the following objectives: a) to identify the outcomes and benefits; b) to enable learning; c) to explore staff experiences, training and support needs; d) to scope the financial and service delivery implications.

Methods A service evaluation of the pilot (delivered May 2019-March 2020,) including process data and feedback gathered using semi-structured questions via questionnaires, interviews and focus groups with young adults, siblings, parent/guardians and staff.

Results Sixty short breaks delivered, accessed by 15 young adults >18 years and their families. Evaluation participants: 3 young adults, 6 siblings, 10 parent/guardians, 11 staff. Highly positive feedback with no withdrawals from the pilot. Triangulated themes: a) social and developmental benefits for young adults; b) respite benefits for families; c) achieving parents' trust; d) ability of adult hospice to meet complex care needs;