

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

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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

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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;

e) positive staff experiences; f) identified areas for service improvement.

Conclusion Persuasive evidence from the evaluation resulted in the service being commissioned. The report offers recommendations for adult hospices aspiring to develop young adult palliative care services.

How innovative or of interest is the abstract? To our knowledge this is the first young adult short break service in a UK adult hospice.

0-06

BEREAVEMENT PANDEMIC: DEVELOPING A MULTI-INTERVENTION MODEL FOR WELLBEING IN CARE HOME COMMUNITIES

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The pandemic has had a devastating impact on people in care home communities. At the peak in 2020, deaths in care homes rose by 159% (Healthwatch Suffolk, 2021). The Healthwatch Suffolk report indicates several areas for improvement in the support of bereaved people: 58% of family members related to a person who died in a care home were not present at death and of all people who were bereaved during this period, those bereaved of someone who died in a care home were least likely to be offered bereavement support (14% compared with 63% of those bereaved of someone who died in hospice). As well as people in care homes being less likely to have access to bereavement support, we also know that COVID deaths were often traumatic, potentially leading to a need for greater bereavement support (Spurio, 2021. *Psychiatr Danub.* 33,S.9:102).

This project addresses this inequity, embedding care home support into the hospice's open access bereavement services, in line with the ICS's commitment to ensure that 'people bereaved [should] have the support they need to cope with trauma and loss' (Healthwatch Suffolk, 2021). A multi-disciplinary model has been developed involving psychological services, chaplaincy services, community connectors and hospice neighbours. A targeted range of interventions is being delivered within care homes, focussing on:

- People that are the significant others of a person who died.
- Bereaved residents including those whose peer has died.
- Residents approaching the end of their lives and their significant others.
- Care home staff.

The initial pilot roll-out covers 3 care homes. Bespoke assessment tools have been developed in order to measure the impact of each of the interventions and the project as a whole. This paper outlines project design, key parameters and pilot data and will show how the reflexivity built into the design enables a continual process of service development.

0-07

IMPROVING ACCESS TO FINANCIAL SUPPORT FOR INDIVIDUALS NEARING THE END OF LIFE

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Background Fast-tracked access to financial support for those with less than 6 months to live was first introduced in 1990. In the following years, this process was applied to new benefits without any review (All-party Parliamentary Group for Terminal Illness, 2019). In 2019, an evaluation into this fast-tracked process was announced, with the intention of reviewing the criteria and improving implementation of this policy.

Aims Improve access to financial support for those nearing the end of life, regardless of their age or health condition; raise awareness of the financial support available for those nearing the end of life and their treating clinicians who provide medical evidence; integrate welfare support into the wider picture of health and social care.

Methods Evaluation – national survey of clinicians; comparison of international welfare systems; audit of medical evidence provided by clinicians to support fast-tracked claims; engagement sessions with clinicians, key medical organisations, end of life charities and individuals nearing the end of life or affected by terminal conditions; review of organisation's performance and process. Internal review of results culminated in new policy approach.

Results Legislation came into force on 4th April 2022 for two benefits to adopt a 12-month, end of life approach in place of the 6-month rule (The Universal Credit and Employment and Support Allowance (Terminal Illness) (Amendment) Regulations 2022). A Bill has been introduced to extend this change across the remaining benefits (Social Security (Special Rules for End of Life) Bill [HL] 2022-23). Guidance has been created for clinicians (Department for Work and Pensions, 2022), to support the provision of medical evidence whilst two sets of rules exist in the welfare system. Work continues to refine and optimise the fast-track application process.

Conclusion The adoption of the 12-month, end of life approach, aligns the welfare system with the definition of 'end of life' used in the NHS (NHS. What end of life care involves [Internet]; 2022). It is vital to use this opportunity to raise awareness across the palliative care community to ensure financial support is brought to mind when clinicians take a holistic approach to supporting patients who are nearing the end of life.

0-08

THE IMPACT OF FEAR OF FAILURE ON PHYSICIAN AND NURSE CONFIDENCE AND COMFORTABLENESS IN DELIVERING END-OF-LIFE CARE

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10.1136/spcare-2022-HUNC.8

Background Only one systematic review has examined the emotions and psychological processes that clinicians experience, when providing end-of-life care to patients. The authors of this review highlighted how emotions of fear, and a sense of personal and professional failure may influence interactions between clinicians and patients. Very few empirical studies have measured the impact of psychological processes on the delivery of end-of-life care.

Aims To investigate whether fear of failure (FOF) influences physician and nurse confidence and comfortableness in delivering end-of-life care.