P-12 DEVELOPMENT OF THE PREPARATION STAR™-A TOOL TO SUPPORT HOLISTIC ASSESSMENT AND VITAL CONVERSATIONS

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Background The government is committed to increasing access to palliative care that meets best-practice guidelines advocating patient-centred and holistic support (*Our commitment to you for end of life care. The government response to the review of choice in end of life care*. Department of Health, 2016; Siouta, van Beek, Preston, Hasselaar *et al.*, 2016). The Preparation Star was developed in response to this commitment, and to calls within the palliative care sector for a tool to empower patients to talk with professionals, family or support workers about what is important for them and make plans when approaching end of life.

Aims The development of the Preparation Star addressed the need for a collaborative tool as identified above, particularly in relation to psychosocial support needs. Specific aims were to determine the outcome areas and the Journey of Change describing movement in each area, and to conduct initial validation work on the pilot version.

Methods A literature review informed the first focus group, which included professionals from two hospices and two organisations managing care homes. Scales were drafted and discussed at a second focus group and refinements made before piloting in the organisations. Patient feedback and pilot data was discussed at two final focus groups before further refinements.

Results The Preparation Star identified patients' needs, with 91% reporting significant issues in at least one area. All patients reported that completing the Preparation Star was positive and 88% felt it provided a helpful picture of their situation. It was completed most successfully in hospice outpatient facilities with those not immediately facing end of life. Internal consistency was good ($\alpha=0.79$) and there was no item redundancy.

Conclusions Initial findings suggest that the Preparation Star has good psychometric properties and is perceived as acceptable and useful. It may be best suited for use earlier in the end of life pathway. Further research is planned to conduct a full validation of the psychometric properties of this Star including factor analysis and responsiveness.

P-13 DYING THROUGH THE LOOKING GLASS-MEDIA INFLUENCES ON DEATH AND DYING

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This research contributes to the professional understanding of the contextual conditions that exist in end of life care. Using a Foucauldian lens, this research explores the apparatus and *technologies* of power at play and considers the impact of mainstream media on discursive practice in end of life care. Mass media campaigns have had a

significant impact on end of life care, developing a sense of scandal and moral panic amongst the population. This research highlights the tensions, challenges and possibilities that emerge from the intersection between media and healthcare practice.

Foucauldian discourse analysis has provided a philosophical lens through which to view this research and explore the professional contexts in which we operate. Collection and analysis of media artefacts from journalistic press in the form of broadsheet newspapers and terrestrial television (factual outputs) were undertaken. In addition, self-recorded narratives from nine healthcare professionals working in end of life care were transcribed and analysed.

The findings from this research have given rise to discourses that have been aligned to specific domains of understanding – *technologies*. *Technologies* enable us to highlight the way in which structures and functions within political and social institutions can manipulate populations or individuals, or indeed how power can shape human conduct. The *technologies* are: *technologies* of caring; *technologies* of power; *technologies* of self; and *technologies* of representation and professional apparatus.

The mainstream media influences discursive practice in end of life care; therefore, professionals need an appreciation of how they might deal with the challenges and opportunities posed. Exposing dying and the discursive formations in this research offers a novel insight into how healthcare professionals are not immune to, but are part of, the influences that mediate how care is delivered at the end of life; how, indeed the media can have such a strong influence on perceptions and understanding.

P-14 THE BEST DEATH I'VE EVER WITNESSED: EXAMINING RESPONSES TO NEW NARRATIVES AROUND END OF LIFE CHOICE

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Background Dr David Juurlink recently used Twitter (18 May 2019) to describe why one of his patients requested assistance to die under Canada's Medical Aid in Dying (MAiD) law. Dr Juurlink's tweet has over 31k retweets, 71k likes and 1.2k comments.

Aims To analyse responses to Dr Juurlink's tweet.

Methods A thematic analysis of responses to Dr Juurlink's tweet was conducted.

Results Responses were overwhelmingly positive.

Expressing gratitude:

'...Thank you for being open-minded and respectful of her and her families wishes. Thank you for easing her pain ... thank you to MAiD who gave her dignity and autonomy on her last journey.'

Sharing experiences:

'Thank you for sharing... I painfully watched my mother take a week to pass away when the end was inevitable. It will haunt me for the rest of my life.'

Segueing into broader end-of-life issues:

'...your patient was able to bring her life to a close in comfort and with dignity not only because of MAiD, but also her willingness to openly discuss her mortality and wishes with both her MDs and her family ...'

'As an anesthesiologist (who is often the first to have a goals of care discussion with a surgical patient) & also as a daughter of a father who died in an ICU w the support of #palliativecare, I think u... We need to be having these conversations'

And also prompting different perspectives on MAiD:

'...Hospice is what she needed! It already exists and would have had the same outcome ...'

Conclusions As more jurisdictions legalise assisted dying, stories such as Dr Juurlink's will increasingly enter public discourse. Assisted dying narratives can be used to promote broader conversations around death and dying. Twitter seems a receptive environment for narratives to be shared and discussed.

Communities and Community Engagement

P-15 BOSNIAN COMMUNITIES: UNDERSTANDING AND SUPPORTING THE REFUGEE EXPERIENCE OF END OF LIFE CARE

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Over 10,000 Bosnian refugees came to the UK, mainly in 1995, fleeing from war zones or concentration camps at the height of the holocaust. The Bosnian and Herzegovina UK Network (BHUKN) was set up in 1996 to represent this community, providing access to culturally appropriate psychological and social support. It was recognised by the Community that there were increasing numbers of traumatic deaths, with people experiencing poor outcomes.

The Community approached St Christopher's Hospice to support them to design a programme of education to enable volunteers to be able to support end of life care at home. St Christopher's Hospice approached Birmingham St Mary's Hospice to work in partnership. The QELCA model was agreed as an appropriate method to support the aims of the programme.

Aim To empower key members of the Bosnian community to provide emotional support and practical skills to those facing end of life to enable them to have the best possible experience.

A successful funding bid was submitted to Dunhill Medical. Two facilitators from Birmingham St Mary's Hospice were trained as QELCA facilitators and supported in the delivery of the programme by the Director of Education from St Christopher's Hospice. Five community development workers from the BHUKN attended the QELCA programme which included; setting objectives, practice placement, taught sessions, reflective practice and action planning.

Outcomes Together we have learned so much. Practice placements threw up organisational challenge and the model of educational delivery may have not given us the time to truly hear and understand the experiences of the Bosnian Community. QELCA supports a facilitation approach and has previously been used to support clinicians in practice, so may need some adaption to be used in a Community Development context. We are looking forward to the opportunity to build relationships with the Community in the next stage of the programme.

P-16 THE EVOLUTION OF CULTURAL LINK WORKERS IN PALLIATIVE CARE IN THE MIDLANDS

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Background Research has shown that people from Black Asian Minority Ethnic (BAME) communities may access hospice palliative care services less often than other groups. Preventing factors could be lack of understanding of hospice services; accessibility; potentially the belief that the service is not appropriate for their cultural needs. BAME communities experience greater stigma attached to palliative and life-limiting conditions. Some hospices with large diverse demographic populations have responded by employing Cultural Link Workers (CLWs). A group of CLWs from three hospices (one adult, two children) in partnership with NHS have met in the Midlands since 2012.

Aims CLWs in the Midlands aim to:

- Raise awareness of hospice services within BAME communities;
- Identify gaps and actively support families from BAME communities to access culturally appropriate services;
- Promote understanding of BAME communities and varying cultural needs within the hospice; provide education and resources to health care professionals (HCPs).

Method CLWs have been assessing the impact of their roles by:

- Sharing information and good practice about their individual roles in their respective workplaces;
- Engaging with faith and BAME communities by attending and giving talks at community events, places of worship and holding information events at the hospices;
- Offering cultural and language support to patients and families.

Results

- Increase in patients/families accessing palliative care services and empowering them to make informed choices;
- Reducing stigma and myths around palliative and end of life care;
- Hospices being more aware of the need for diversity in their workplace.

Conclusion Communities and demographics in local populations are always changing and CLWs in palliative care settings continue to respond to these. Working together with other professionals to engage and make links within education, business, health and social care. The work of CLWs is essential and challenging. It enables HCPs to have confidence in delivering a patient-centred service.

P-17 UNDERSTANDING YOUNG PEOPLE'S EXPERIENCE OF HOSPICE CARE

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Background Following a review of how we heard the user voice at Keech Hospice Care, I began to question our involvement of young people in this. As a hospice providing care for both adults and children, we have children and