

Results A curriculum model was developed to include the following topics:

- History of dying, cultural aspects and changes in society
- Public perception of dying and whether we should talk about it
- DNACPR
- An overview of palliative care in the UK
- Ethical issues at the end of life

Accompanying resource material was developed by the Specialist Palliative Care Team in collaboration with the school.

Conclusions This important work has the potential to increase the understanding of palliative care and end of life issues amongst young people in Gateshead and in schools more widely.

11 LIFE'S HARD AND THEN YOU DIE: PHD EXPLORING END OF LIFE PRIORITIES FOR PEOPLE EXPERIENCING HOMELESSNESS WITHIN THE UNITED KINGDOM

Wendy A Webb, Theresa Mitchell, Paul Snelling, Brian Nyatanga. *University of Worcester*

10.1136/spcare-2021-PCC.11

Background People experiencing homelessness often die young and without adequate support. In the UK, they fail to access palliative care services and their end-of-life priorities remain poorly understood. They are dying on the streets and in hostels without adequate support and, while there is ample literature surrounding the barriers to appropriate end of life care, the EoL priorities of people experiencing homelessness in the United Kingdom (UK) remain poorly understood. This study aims to bridge the gap in knowledge.

Aims To explore the end-of-life concerns, fears, preferences and priorities of a sample of people experiencing homelessness in the UK.

Methods This is an interpretive phenomenology. Data collected through semi-structured, audio-recorded, face-to-face interviews with 21 homeless participants in the UK were analysed iteratively using thematic analysis. Findings have been interpreted through the lens of Merleau-Ponty's philosophy.

Results Eight themes are reported: spiritual concerns; practical concerns; fear of needing care; fear of being forgotten; preference for dying suddenly; preference for being somewhere comfortable where people know me; prioritising autonomy and self-determination; and prioritising authenticity.

Conclusion Traditional palliative care services are possibly an unattractive resource for this population, so new approaches to care are required. Deeper understanding of the EoL concerns, fears, preferences and priorities of this marginalised population will support the development of accessible, culturally relevant, person-centred support for people experiencing homelessness with advanced ill-health in the UK. A strengths-based, trauma-informed, person-centred, collaborative 'compassionate community' approach to end of life care is recommended. Furthermore, the development of peer-support workers, trained in the principles of palliative care, should be actively encouraged and supported within the hostel as the hub of a compassionate palliative care community.

12 PROFESSIONALS', PATIENTS', AND FAMILIES' VIEWS ON THE USE OF OPIOIDS FOR BREATHLESSNESS: A RAPID SYSTEMATIC REVIEW USING THE FRAMEWORK METHOD AND PILLAR PROCESS

Florence Reedy, Mark Pearson, Miriam Johnson, Joseph Clark, Sarah Greenley, David Currow. *University of Hull, University of Technology Sydney*

10.1136/spcare-2021-PCC.12

Background In combination with disease-modifying therapies and non-pharmacological interventions, opioids can safely reduce breathlessness in patients with severe illness. However, implementation in clinical practice varies.

Methods Three electronic databases (MEDLINE and Embase via OVID and ASSIA via Proquest) were searched (March 2020) using a predefined search strategy. Studies were also citation chained from key papers in the field. Reviewers FR and JC double-screened titles and abstracts of papers against the a priori eligibility criteria. FR independently read and extracted data from included studies using the five-stage framework synthesis method: familiarization, framework selection, indexing, charting and mapping. FR then used the pillar process to synthesise qualitative and quantitative data in four stages: listing, matching, checking and pillar building. Reviewers FR, JC and MP critically appraised included studies using the MMAT.

Results 843 papers were identified from database searches and citation chaining after de-duplication. Following screening 22 studies were included in the synthesis. Five themes were developed which comprise of both barriers and enablers to opioid use for breathlessness: i) clinician/patient background, ii) education/knowledge/experience, iii) relationship between clinician/family, iv) clinician/patient fear of opioids and v) regulatory issues. The review highlights significant barriers and enablers to the use of opioids for the symptomatic treatment of breathlessness based on the knowledge, views and attitudes of clinicians, patients and families. The review shows clinicians' interactions with patients and their families strongly influences concordance with opioid treatment regimens for breathlessness.

Conclusions As clinicians', patients', and families' knowledge about the delicate balance between opioid benefits and risks is generally poor, education is likely to be a necessary but not sufficient factor for improving the implementation of opioids for breathlessness. Further research ought to address ways of improving clinician, patient and family therapeutic relationships and improving knowledge on opioid use for breathlessness.

Free papers 13–15 | supporting carers

13 HOW IS PROFESSIONAL 'TRUTH-TELLING' PERCEIVED BY CARERS OF PATIENTS WITH SEVERE STROKE?

Jennifer Mullin, Marilyn Kendall, Jonathan Koffman, Scott Murray, Gillian Mead. *Cicely Saunders Institute, King's College London, Usher Institute for Molecular, Genetic and Population Health Sciences, University of Edinburgh, Centre for Clinical Brain Sciences, University of Edinburgh*

10.1136/spcare-2021-PCC.13

Background Stroke is the second largest cause of death worldwide. Perceived poor communication is a major cause of

healthcare complaint, yet information-sharing following stroke is little-researched.

Aim To describe and explore: a) carers' experiences of professional truth-telling in the 6 months following severe stroke b) how carers process uncertainty

Methods Secondary analysis of semi-structured serial interviews with carers at 6 weeks and 6 months post-stroke, using Framework approach.

Population: Informal carers of severely-dependent adult patients with Total Anterior Circulation Stroke in Lothian (Scotland), including carers of patients who died during the study.

Sampling: Purposive sampling for maximal variation; secondary analysis sampled geographically.

Rigor: Analysis of deductive and inductive themes; discussion of emergent themes with primary data collectors; examination of deviant, negative and extreme cases.

Results 20 transcripts from 15 carers were analysed, including 6 bereavement interviews. All interviews referenced truth-telling by healthcare professionals, most frequently 'construction of truth as a process' and 'value of honesty/frankness'. Some carers described professionals intending to deceive. Most carers described uncertainty as something negative, using behaviours to reduce uncertainty. A minority described uncertainty as a positive or 'window for hope', using behaviours to increase uncertainty.

Carer, professional, patient and environmental factors influenced carers' experiences. What carers said was complex and views changed over time.

Discussion and conclusions We present a new visual model of truth-telling between healthcare professionals and carers. Truth-telling is a complex, two-way process. Carers and professionals view 'the truth' through 'lenses' of their own worldviews, experiences and knowledge. Carers' views of uncertainty affect engagement with truth-telling. The truth-telling system is open, asymmetrical and dynamic: with access of external information and a gradient of knowledge and power within each professional-carer dyad, which changes over time. Poor communication has important fall-out. Our visual model could help professionals approach information-sharing following severe stroke more confidently.

14

DEVELOPMENT OF A RESOURCE FOR FAMILY CARERS OF PEOPLE LIVING WITH DEMENTIA WITH NUTRITION AND HYDRATION DIFFICULTIES TOWARDS THE END-OF-LIFE

¹Yolanda Barrado-Martín, ¹Pushpa Nair, ^{2,3}Kanthee Anantapong, ^{2,4}Kirsten J Moore, ⁵Christina H Smith, ¹Greta Rait, ^{2,6}Elizabeth L Sampson, ⁷Jill Manthorpe, ^{1,2}Nathan Davies.

¹Research Department of Primary Care and Population Health, UCL; ²Marie Curie Palliative Care Research Department, UCL; ³Department of Psychiatry, Prince of Songkla University; ⁴National Ageing Research Institute, Parkville, Victoria, Australia; ⁵Language and Cognition, Division of Psychology and Language Sciences, UCL; ⁶Barnet Enfield and Haringey Mental Health Trust Liaison Team, North Middlesex University Hospital; ⁷NIHR Policy Research Unit in Health and Social Care Workforce Research Unit, and NIHR Applied Research Collaborative (ARC) South London, King's College London

10.1136/spcare-2021-PCC.14

Background Family carers often struggle to support relatives living with dementia with nutrition and hydration towards the end-of-life. The aim of this study was to co-design with family carers and professionals an information resource to support family carers with this task.

Methods This study consisted of four phases: 1) qualitative systematic review; 2) a scoping review of existing resources; 3) 61 qualitative interviews with people with dementia, professionals, and family carers; 4) data synthesis and co-design development of an information resource.

We constructed a matrix synthesising the key findings from phases 1–3, devising themes of the key content across the evidence and providing summaries from each source of evidence. The matrix provided a transparent pathway of the evidence and content for the design process.

For the co-design phase 18 participants were recruited, 9 family carers and 9 professionals, split into two mixed groups. Four co-design workshops were conducted (two with each group) to develop the resource. During the workshops participants were presented with a summary of results from the matrix. Using modified nominal group processes and a series of tasks including categorisation and ranking we produced an initial prototype of the resource. The prototype was refined in subsequent co-design meetings and via email with individual participants.

Results The main areas covered within the resource include: eating and drinking difficulties in dementia; end of life; managing swallowing difficulties; points to discuss with professionals in future appointments; support for family carers and further resources. Information is presented in a booklet with a mix of formats including: diagrams; quotes; top tips; flow charts; and visual images.

Conclusions This practical resource is the first to focus on nutrition and hydration towards the end-of-life in dementia care. This study provides a transparent stepwise approach to developing interventions, key for future similar studies.

15

DEATHBED ETIQUETTE-SUPPORT FOR BEING AT THE BEDSIDE OF THE PERSON YOU LOVE

Amy Gadoud, Karen Sanders, Amarachukwu Nwosu, Joanne Elverson, Lynn Bassett, Margaret Doherty. Lancaster Medical School and Trinity Hospice, Blackpool; Institute of Business, Law and Society, St Mary's University, Twickenham; Lancaster Medical School and Royal Liverpool Hospital; St Oswald's Hospice, Newcastle; Art of Dying Well, St Mary's University, Twickenham

10.1136/spcare-2021-PCC.15

Background People in the UK are often uncomfortable with supporting the dying. As the population ages we are less likely to have supported a loved one who has died.

Methods The Centre for the Art of Dying Well, with palliative care experts and experts by experience, created a resource to support someone at the deathbed of a loved one. This was updated for the COVID-19 pandemic. This abstract describes the wider public engagement with this resource, using content analysis to evaluate public sentiment and understanding of it.

Results Release of the original Guide coincided with a report assessing preparedness for supporting someone who is dying, a podcast and a press release. It was widely quoted in the news media with reports in The Times; local and national news (Radio Oxfordshire, Talk Radio, Channel 5 News). Google Analytics demonstrated 7,341 unique visitors to the Guide spending, on average, 2 minutes 2 seconds reading it. The version updated for COVID-19 was widely cited in the Financial Times, the Daily Mail, the Sun and Vatican News and an interview on 5 Live Radio. Based on an analysis of article comments, public sentiment and understanding were shown to