

TITLE

(15)Deathbed etiquette-support for being at the bedside of the person you love

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JOURNAL

BMJ Supportive & Palliative Care

DATE DEPOSITED

1 May 2024

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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.

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

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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.

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

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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

be varied including very positive and very negative reactions. There was widespread individual engagement online and off-line and also endorsement by organisations such as Marie Curie and Health Improvement Scotland. The Guide for COVID-19 had 2,545 unique page reviews with users spending on average 2 minutes 50 seconds on the page. Analysis of Twitter data demonstrated a wide level of engagement with the content of both guides, and discussions occurring across a diverse range of individuals.

Conclusions There has been widespread uptake. Public reception, as evaluated in the content analysis, will guide future research to explore the Guide's impact.

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16 HOW COVID19 CHANGED DYING IN MILTON KEYNES UNIVERSITY HOSPITAL

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10.1136/spcare-2021-PCC.16

Introduction The Coronavirus pandemic (COVID19) brought unprecedented challenges to healthcare, and changed how we interact with patients. Recognising the dying patient is essential to deliver compassionate End of Life Care; allowing patients and loved ones to prepare for death, and facilitates opportunities for comfort and dignity. We have reviewed how COVID19 has influenced our approach to the dying patient.

Method We reviewed the electronic notes of all hospital inpatients who died at Milton Keynes University Hospital between 30/03/2020–31/05/2020 and compared key areas to the same period in 2019.

Results In 2020 there were more deaths (207 vs 143) and more occurred within 48 hours of admission (24% vs 18%). In 2020 more treatment escalation plans were completed (98% vs 85%), there were fewer deaths at 'arrest calls' (2 vs 7) and more deaths were anticipated (87% vs 83%). Further analysis of expected deaths occurring >48 hours of admission have shown that in 2020 (vs 2019) dying patients were more often:

- recognised as dying (84% vs 70%)
- reviewed by the Palliative Care team (74% vs 66%)
- on a personalised care plan for the dying patient (89% vs 82%)
- prescribed a syringe driver (50% vs 31%)/anticipatory medications (84–91% vs 79–85%)

However, patients:

- less frequently had visitors (44% vs 93%)
- less often discussed their preferred place of death (27% vs 43%).

Discussion We have reviewed how the pandemic changed our management of dying inpatients. Despite the increased number of deaths there were positive changes in our approach. Possible influencing factors are the perceived increased burden on ITU and encouragement of early discussion about escalation. Challenges like facilitating visitors have also been identified. It is vital that we learn from this experience to ensure our dying patients are managed compassionately, irrespective of the ongoing global crisis.

17 ADVANCE CARE PLANNING FOR ADOLESCENTS AND YOUNG ADULTS WITH CANCER: A RETROSPECTIVE BASELINE AUDIT FROM A PRINCIPAL TREATMENT CENTRE IN THE UK

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10.1136/spcare-2021-PCC.17

Introduction and aims Patient experiences at life's end remain poor, especially with regards to discussing and planning death.¹ Adolescent and Young Adult (AYA) cancer patients represent an important demographic with unique needs. Unfortunately, little is known about the extent of Advance Care Planning (ACP) within this group.² The aims of this study were to determine what, if any, ACP occurred with AYA patients and whether preferences for care/death were met.

Methods A retrospective case note audit was conducted of all AYA cancer patients known to the Principal Treatment Centre in Birmingham, UK, who died between 2013 and 2019. Patients whose care was provided by children's services were excluded. Case notes were scrutinised for evidence of ACP, involvement of palliative care services, and place of death. Data were entered into an Excel spreadsheet for analysis.

Results 84 AYA patients (64% male) met the inclusion criteria. 57% of primary diagnoses were oncological; 43% haematological. Evidence of ACP was recorded in the notes of 67% of patients. ACP discussions were facilitated by oncology/haematology doctors in 61% of cases and by palliative care specialists in 23%. 29% of patients died on a dedicated AYA cancer unit within a specialist tertiary care centre, 26% died at home, and 12% died in hospice. Place of death reflected a patient's ACP in 42% of cases.

Discussion and conclusions Our results demonstrate inconsistent ACP amongst AYA cancer patients. Many patients died in their preferred setting, but almost one third of case notes showed no evidence of ACP. The reasons for this are not clear. Nor is it appreciated whether the topics of death and dying were broached at all in this patient group. Further research is urgently called for to help AYA patients feel more empowered and understood as they approach the close of life.

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18 CONTINUOUS SUBCUTANEOUS INFUSIONS IN DYING PATIENTS: A CASE NOTE COMPARISON OF HOSPITAL AND HOSPICE SETTINGS

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10.1136/spcare-2021-PCC.18

Background In the light of the Gosport Independent Panel Report (June 2018), we conducted a comparison of continuous subcutaneous infusions (CSCI) at end of life in hospital and hospice settings.