

## 6 END OF LIFE AND BEREAVEMENT EXPERIENCES DURING THE COVID-19 PANDEMIC: INTERIM RESULTS FROM A NATIONAL SURVEY OF BEREAVED PEOPLE

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**Background** COVID-19 represents a mass bereavement event, with 80,000+ excess UK deaths. The unprecedented clinical and social restrictions are potential risk factors for poor bereavement outcomes. This study investigates the bereavement experiences, support needs and support use of people bereaved during the pandemic.

**Methods** Interim findings from the first round of a mixed methods longitudinal survey of people bereaved in the UK since 16

March 2020. The survey was disseminated via media, social media, national associations and community/charitable organisations. Grief was assessed using the Adult Attitude to Grief Scale.

**Results** 532 bereaved people participated (91% female). Place of death: hospital (55%), home (22%), care home (15%), hospice (5%); 46% of deaths were confirmed/suspected COVID-19. Experiences of end of life care varied: 23% were 'never' involved in decisions about their loved one's care, 36% felt 'not at all' supported by healthcare professionals after the death, 51% were not provided with information about bereavement support. Respondents reported high levels of problems specific to the pandemic bereavement context (e.g. 56% unable to visit prior to death, 67% social isolation and loneliness). Over half of participants demonstrated 'severe' (28%) or 'high' (24%) levels of vulnerability in grief, and support needs were high/fairly high in six psycho-emotional domains (51% to 62%). COVID-19 deaths were associated with higher levels of bereavement problems ( $p < 0.05$ ), grief vulnerability ( $p < 0.05$ ) and support needs ( $P < 0.001$ ) compared to other causes of death. 21% of those with 'severe' vulnerability were accessing individual counselling, compared with 23% overall. Barriers to accessing professional support included long waiting lists, lack of appropriate support, feeling uncomfortable asking for/not knowing how to access help. 41% reported difficulties getting support from family/friends.

**Conclusions** People bereaved during the pandemic experience exceptionally difficult circumstances at the end of life and during bereavement, including unmet needs for social and professional support. We recommend improved communication with families at the end of life, enabling contact with patients as far as possible, and better support after a death. This includes increased information about and investment in bereavement support services as well as flexible 'support bubble' arrangements for the recently bereaved.

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### 7 SECONDARY DATA ANALYSIS OF THE EFFECT OF ADULT HOME-BASED HOSPICE SERVICES ON PLACE OF DEATH FOR PATIENTS WITH TERMINAL ILLNESSES IN EGYPT

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**Background** 80% of the 60 million individuals experiencing preventable severe health-related suffering live in Low-and Middle-Income Countries (LMICs) where there are limited resources, and few hospice and palliative care services to alleviate the suffering of patients. In many countries, especially with poorer public facing health services, and cost sharing, being cared for and dying at home is important. There is limited research on how models such as home-based services may support hospice and palliative care delivery in already burdened health care systems.

**Methods** A sample of  $n=526$  patients with terminal illnesses who received home-based hospice services from Hospice Egypt between 2010 to June 2020 were identified. The data set included patient demographics, health, social-financial, and home service variables. Data on costs incurred during service provision was collected in a sub sample of  $n = 287$  patients receiving care between 2017 to 2020. Secondary data was analysed using descriptive statistics. Univariate regression were performed to explore the association between variables and the odds of dying at home. Cost analysis with a bottom-up approach and from the viewpoint of the service provider was performed.

**Results** Among 526 patients with terminal illnesses receiving home-based hospice services, the majority died at home 427 (81.2%) compared to 98 (18.6%) who died at the hospital. The univariate logistic regression showed that more visits, and longer duration of services were statistically significant in increasing odds of dying at home OR 1.81 (95%CI 1.11 - 2.95) and OR 1.59 (95%CI 1.11 - 2.28) respectively. Overdue debts were a major contributor accounting for 30 percent of total average costs per patient.

**Conclusion** Home-based services may support the preference of dying at home in Egypt. Further analysis, by matching the sample to control is needed to understand different factors associated with place of death and cost saving.

### 8 DEVELOPING A CASEMIX CLASSIFICATION FOR SPECIALIST PALLIATIVE CARE: A MULTI-CENTRE COHORT STUDY TO DEVELOP A PATIENT-SPECIFIC PREDICTION MODEL FOR THE COST OF SPECIALIST PALLIATIVE CARE USING CLASSIFICATION AND REGRESSION TREE ANALYSIS

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**Background** There is wide inequity in specialist palliative care provision across settings. The absence of any standard way to group by case complexity is a barrier to addressing these inequities.

**Aim** We therefore aimed to develop a casemix classification for UK specialist palliative care across settings, by identifying/grouping patient-level attributes at the start of an episode of care that predict costs of care provision within that episode.

**Design** Cohort study with prospective collection of patient demographic and clinical variables, potential complexity and casemix criteria, and patient-level resource use.

**Results** 2,469 participants were recruited (mean age 71.6, 51% male, 75% with cancer), receiving 2,968 episodes of care, from 14 specialist palliative organisations across England. Episodes of care lasted: median (range) 8 days (1–402) in hospital advisory palliative care, 12 days (1–140) in inpatient palliative units, 30 days (1–313) in community palliative care. Median cost per day (interquartile range) were: £56 (£31–100) in hospital advisory, £365 (£176–£698) within inpatient, and £21 (£6–£49) in community care. Seven hospital advisory, six inpatient, six community casemix classes for specialist palliative care, based on seven casemix variables (pain, other physical symptoms, psychological symptoms, functional status, palliative Phase of Illness, living alone, and family distress) predict per-diem costs.

**Conclusion** The casemix classes show cost weight variations by up to 60% (in hospital advisory palliative care), up to 4.5-fold (in inpatient hospices), and approaching 3-fold (in community palliative care). The proposed casemix classification helps to understand these variations systematically and at scale; for practice, policy (including funding), and research, to help address inequities and provide fair, equitable and transparent palliative care to all who need it.

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## 9 DEMONSTRATING THE IMPACT OF PALLIATIVE CARE: A SECONDARY ANALYSIS OF ROUTINELY-COLLECTED PERSON-CENTRED OUTCOMES DATA AMONG PATIENTS RECEIVING COMMUNITY PALLIATIVE CARE

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**Background** The aim of this study is to describe the characteristics of patients receiving community palliative care and the impact of community palliative care on their symptoms and concerns using routinely-collected patient-level outcomes data.

**Methods** Secondary analysis of routinely-collected clinical and outcomes data (patients' demographics, episodes of care, palliative Phase of Illness, and symptoms/concerns using the Integrated Palliative care Outcome Scale; IPOS) from all patients cared for in the community by one hospice, between June - November 2019. We described the characteristic of patients, their episode of care, and their Phase of Illness at first contact with the community service. We compared

community patients based on their episode outcome (alive versus died, at end of episode) and the impact of community palliative care over the first Phase of Illness. Caldicott Guardian approval was received for analysis of this anonymized data.

**Results** 881 patients received 916 complete episodes of community-based palliative care between June–November 2019. For 916 episodes of care, the median age of community patients was 79 years with IQR (69 “ 87); 66% had cancer. Palliative Phase of Illness was stable (17%), unstable (28%), deteriorating (41%) and dying (14%) at the start of episode of care. By the first Phase change; mean ‘pain’ score reduced from 1.3 to 1.2 (30% of 158 patients with moderate/severe/overwhelming pain improved); mean ‘breathlessness’ score reduced from 0.8 to 0.7, (with 39% of 87 patients with moderate/severe/overwhelming breathlessness improved); mean ‘anxiety’ score reduced from 1.2 to 1.0 (with 31% of 84 patients with moderate/severe/overwhelming anxiety improved); and mean ‘feeling depressed’ score reduced from 0.7 to 0.6 (with 42% of 45 patients with moderate/severe/overwhelming depressed mood improved).

**Conclusions** This analysis demonstrates, for the first time in the UK, how community palliative care teams can systematically use routinely-collected outcomes data to demonstrate the positive impact of the care they provide.

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### 10 ENGAGING YOUNG PEOPLE IN KEY ISSUES SURROUNDING END OF LIFE CARE THROUGH THE DEVELOPMENT OF CURRICULUM RESOURCES FOR SECONDARY SCHOOLS

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**Introduction** The Ambitions for Palliative and End of Life Care Partnership (2015) established a national framework with six ambitions, one of which recognises the importance of engaging local communities including schools. Over the past two years, Gateshead NHS Foundation Trust has established a schools engagement project which involves all local secondary schools. This project demonstrated the value of listening to young people and thus providing an opportunity for them to share their understanding and experiences. The second phase of the project then sought to address gaps in understanding identified through the development of a resource that could be embedded into the personal development curriculum of any school wishing to engage with this important subject.

**Methods** Initial meetings with senior leaders in partner schools were used for information gathering about what is currently taught in relation to this area and the broader personal development curriculum. An assessment of possible curriculum content and an outline proposal was developed by the Specialist Palliative Care Team in collaboration with one of the link schools. This school also agreed to participate in a delivery pilot of these materials as well as shape the resources to ensure that they were age appropriate and aligned to the broader aims of the personal development curriculum.