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 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.

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. Uninvariant 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.

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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