

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.