



“Untold Distress” - Experiences of people bereaved by epilepsy death during the COVID-19 pandemic

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Background

How people respond to the sudden death of a family-member or friend with epilepsy is highly diverse both between individuals and within individuals over the course of their lives.

Similarly, the coping mechanisms people draw upon to help them manage their grief are highly individualistic and multi-faceted, influenced by both formal and informal support structures.

The COVID-19 pandemic has impacted upon all of us but the disruption on those bereaved by epilepsy, whose grief-management can be inextricably linked to the very things that have been disturbed, is far less well understood.

Purpose

This study investigates the experiences of people bereaved by epilepsy during the COVID-19 pandemic.

In particular, we seek to explore, and understand, those consistent themes that have adversely affected the well-being of the epilepsy-bereaved at this time.

Methods and Participation

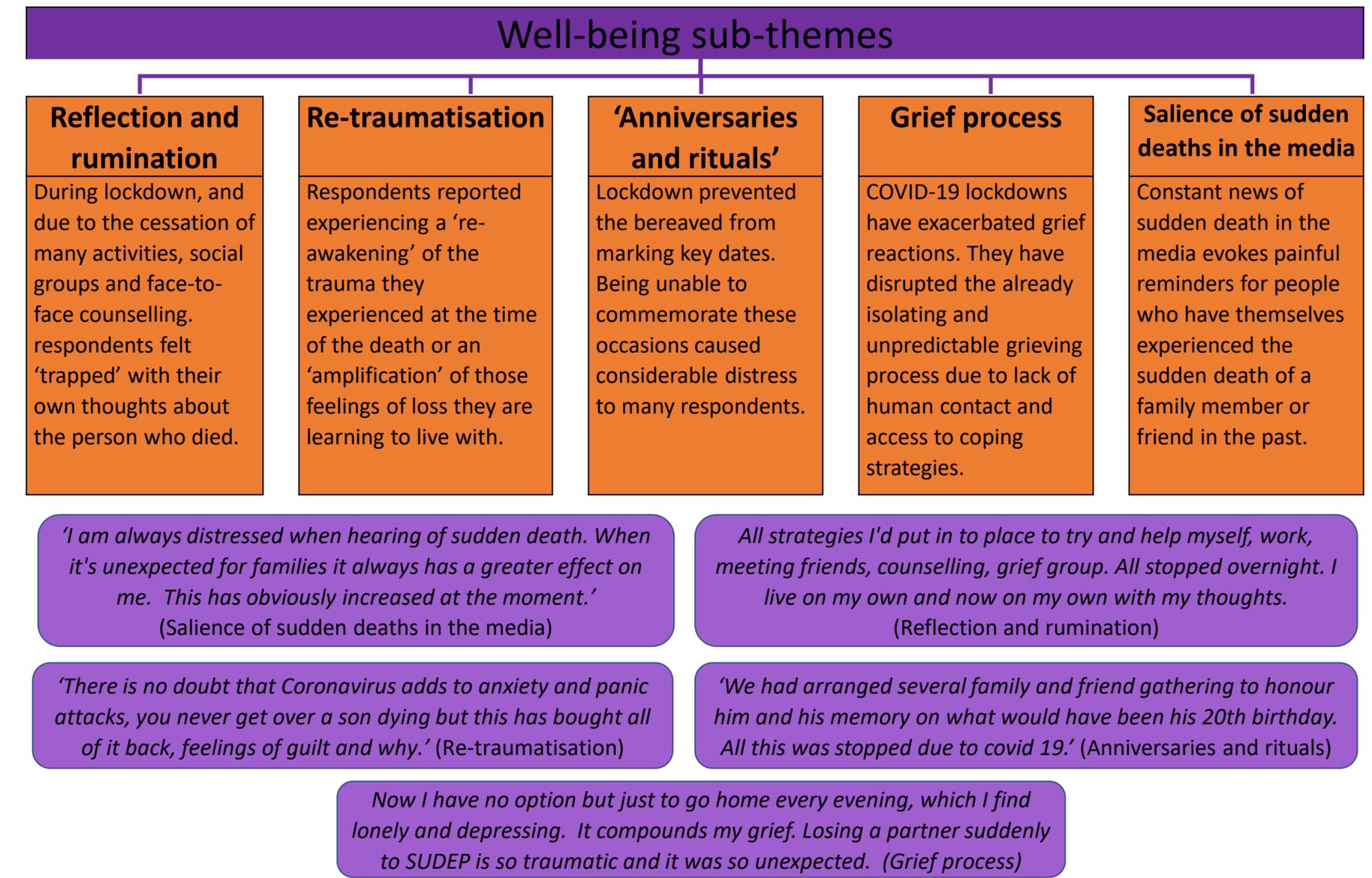
A qualitative approach with responses to open-ended questions provided by 78 people bereaved by epilepsy [via an online survey](#).

Respondent demographics

- 59% parent, 17% son/daughter, 12% spouse/partner
- Mean age 56.7 (low=22, high=87)
- 76% England (25% Midlands, 24% Greater London, 10% North-East, 10% South-West, 8% North-East), 11% Scotland, 7% Wales, 6% Ireland.

Data Analysis

Inductive thematic analysis was conducted independently by three researchers and was analysed collaboratively for consistent themes. The following five sub-themes came out from the data in relation to the main theme ‘Well-being’.



Conclusions

The pandemic has restricted people bereaved by epilepsy being able to utilize the daily strategies that would normally be protective and helpful in pre-pandemic times. Human connection and physical presence are crucial, and the restrictions have removed support and distraction whilst people have been bombarded with news of death and illness daily.

Whilst NICE guidelines recommend clinicians offer condolence, a meeting, and signposting to [SUDEP Action](#), many people do not experience this. Indirectly the pandemic has made these communications more difficult still. Those bereaved by epilepsy will carry their grief with them for the rest of their lives, but health professionals and specialist patient organisations can play a significant role in assisting them to access the support and help they need.