Family caregivers' perspectives on the purpose and value of palliative bereavement services

Kate Jurgens, PhD, Professor David Currow and Professor Jennifer Tieman



BACKGROUND

Family caregivers and friends provide the majority of end-of-life care for most patients. Provision of bereavement information and support is an expected function of specialist palliative care services. However, the impacts of bereavement services is not well understood. Bereavement services are often described as providing universal interventions regardless of the need, though the assertion lacks evidence.

RESEARCH QUESTION

- To assess the preferences for, and impact of, service-initiated contact and subsequent use of support.
- Self-reported data was also gathered on preparedness, impact of support, adjustment, and signs of problems moving forward.

METHODS:

Data were gathered from a consecutive sample of bereaved caregivers (224/1057) from an Australian specialist palliative site using a purpose-designed, self-administered questionnaire.

• Current adjustment was self-reported using the Prolonged Grief tool, PG-13.

Analysis:

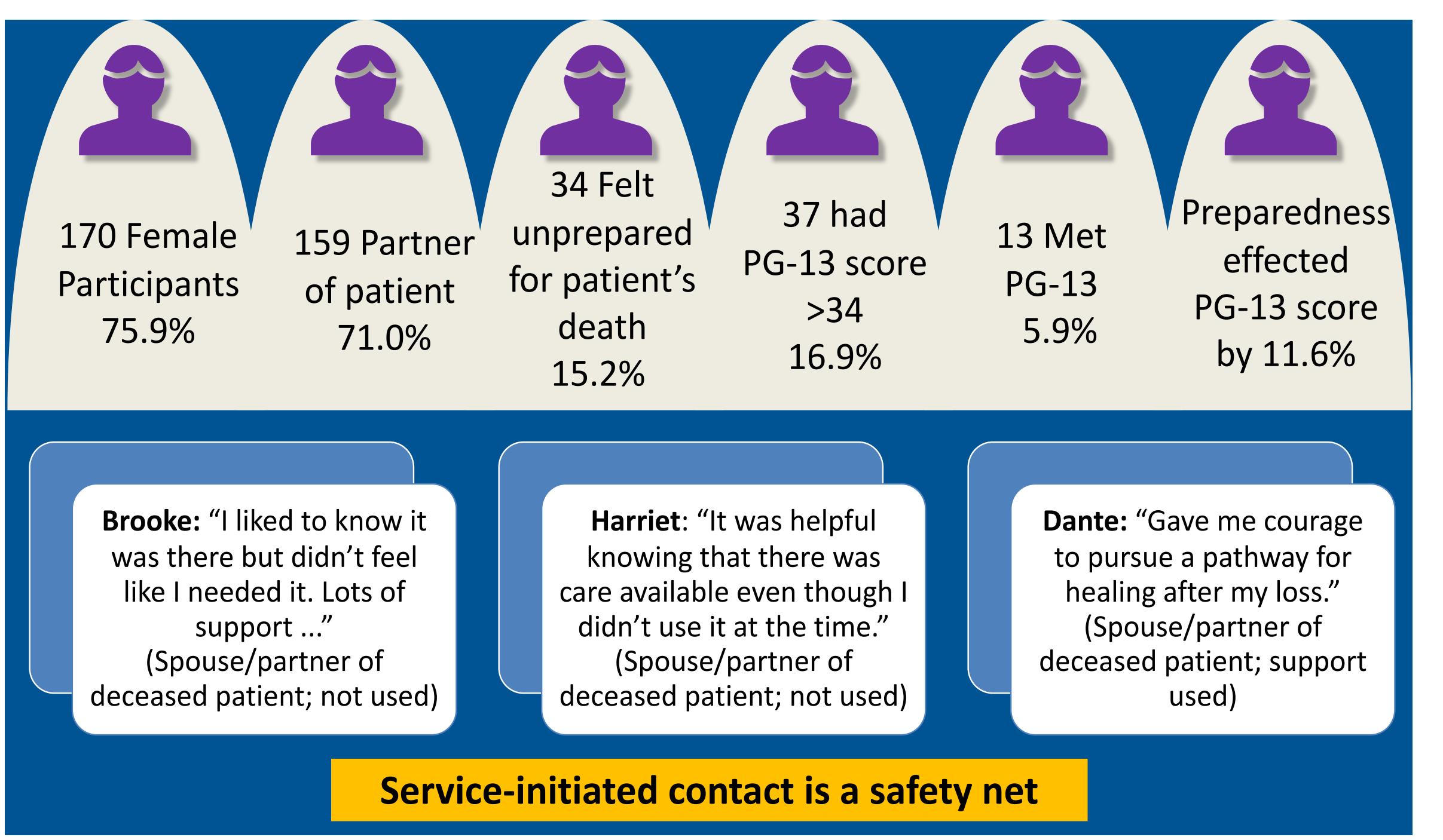
• Inductive thematic analysis was chosen to enable themes to emerge from the data

DISCUSSION

Implications:

- Palliative bereavement services should provide information on pathways to support to reduce the burden on bereaved caregivers when assistance is needed.
- Evidence is presented which challenges the literature about services undertaking grief interventions regardless of need.
- Researchers and clinicians need to work in partnership to develop more precise information on the aims and purpose of palliative bereavement services.

RESULTS: 224 Participants



- Service-initiated contact was a safety net due to informing people the service was there if required.
- Influence of service-led bereavement contact was tested which found that minimal 'influence' on the decision to access grief services unless it was needed
- Barriers to use of bereavement support were identified by some, relating to time to access, trust of services, or the disruptive nature of grief.
- Analyses of PG-13 self-reported scores reinforced the importance of caregivers sense of preparedness for the patient's death.
- A multiple regression model confirmed that feeling only somewhat prepared or not at all prepared was significant predictor of greater intensity and frequency of grief symptoms.