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The impact of supporting family caregivers pre-bereavement on outcomes postbereavement: Adequacy of end of life support and achievement of preferred place of death

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ABSTRACT

Objectives: This study investigated the extent to which using the Carer Support Needs Assessment Tool (CSNAT) intervention during the caregiving period has affected bereaved family caregivers' perceptions of adequacy of support, their grief and wellbeing and achievement of their preferred place of death.

Method: All family caregivers who participated in a stepped wedge cluster trial of the CSNAT intervention in Western Australia (2012-14) and completed the pre-bereavement study (n=322) were invited to take part in a caregiver survey by telephone 4-6 months post-bereavement (2015). The survey measured the adequacy of end of life support, the level of grief, the current physical and mental health, and the achievement of the preferred place of death.

Results: The response rate was 66% (152, intervention; 60 control). The intervention group perceived their pre-bereavement support needs had been adequately met to a significantly greater extent than the control group (d=0.43, p<0.001) and that patients have achieved their preferred place of death more often according to their caregivers (79.6% vs 63.6%, p=0.034). There was also a greater agreement on the preferred place of death between patients and their caregivers in the intervention group (p=0.02).

Conclusions: The results from this study provide evidence that the CSNAT intervention has a positive impact on perceived adequacy of support of bereaved family caregivers and achievement of preferred place of death according to caregivers. The benefits gained by caregivers in being engaged in early and direct assessment of their support needs prebereavement, reinforces the need for palliative care services to effectively support caregivers well before the patient's death.

Keywords: CSNAT; Family caregivers; pre-bereavement; post-bereavement; place of death; grief; wellbeing; support needs.

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