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

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

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 pre-bereavement, 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.

BACKGROUND

Two of the most stressful human experiences are caring for a person with a terminal illness and the death of that person. As the majority of deaths worldwide are currently caused by life limiting illnesses with a significant proportion of these deaths occurring in old age, the investigation of the situation of bereaved family caregivers following caregiving during the end-of-life phase of illness has not received enough attention (1).

There is evidence to suggest that family caregivers who have cared for a relative/friend throughout a life-limiting illness are adversely affected during bereavement due to their caregiving role (2-5). Nielsen et al (6) reported that severe grief and depressive symptoms already existing before the patient's death strongly predicted complicated grief and post-loss depressive symptoms. They also found that the levels of grief and depressive symptoms were higher during caregiving than six months after the loss.

Studies have reported that reducing the burden of caregiving can prevent post-death psychiatric morbidity (3, 4), and that caregivers' limited preparedness for the impending death was associated with increased complicated grief, depression and anxiety (7, 8). It has been suggested that surviving spouses of people admitted to a hospice have lower mortality compared to those whose spouses are not, due to hospice services preparing the family for the imminent death (9). The extent to which caregivers are prepared or ready for the death of their family member comprises several dimensions: clinical, practical, psychosocial and spiritual (10). Communication between caregivers and health care professionals is crucial to aid preparedness in all these dimensions (7, 8).

Other factors that may also impact on post-bereavement outcomes of family caregivers are the location of death, the fulfilment of the patient's or caregiver's preferred place of death, or the perception that the place of death had been the right place according to the bereaved family caregivers (11-14), though the evidence is conflicting. The importance of meeting the patient and family preferences has been reported to have a strong impact on the actual place of death (12).

As family caregivers experience support needs in a number of the mentioned dimensions, it has been challenging to find accessible and acceptable interventions that address the range of needs (15). The Carer Support Needs Assessment Tool (CSNAT) is an evidence-based and validated tool for the comprehensive assessment of caregivers' support needs in all the domains of end of life care, and it is delivered through a person-centred approach that is led by the caregiver but facilitated by the health professional (16-18). The CSNAT is structured around 14 broad support domains which fall into two distinct groupings: support that enables the family caregiver to care for the care recipient at home (7 domains); and direct support for the family caregiver in their caring role (7 domains). The CSNAT Approach provides an opportunity to open up a conversation with caregivers, to understand their individual support needs and the support they would find helpful. The CSNAT intervention comprises the tool integrated into the person-centred approach (16).

Two trials of the CSNAT intervention were conducted in Australia, one in a community palliative care setting (described in Box 1) and one in a hospital setting. Results showed a significant reduction in caregiver strain during the caregiving period in community palliative

care (19) and family caregivers of older people discharged home from hospital were significantly more prepared to provide care and reported reduced caregiver strain and distress compared to family caregivers in a control group (20). The trial of the CSNAT within palliative home care in the UK (21) found a small reduction in early grief, improvements in mental and physical health post-bereavement and in the probability of death at home.

Box 1: Brief description of the Australian CSNAT trial in community palliative care

The overall aim of this trial was to investigate the extent to which a carer assessment tool of support needs in end of life home care improves perceived support, carers' psychological and physical wellbeing, caregiver workload, grief and the likelihood of the patients achieving their preferred place of death, hence spanning the pre and post bereavement phases.

A stepped wedge cluster design was used to trial the CSNAT intervention in three bases of the palliative care service in Western Australia, 2012-14. The outcome measures for the intervention and control groups, at the pre-bereavement phase, were caregiver strain and distress as measured by the Family Appraisal of Caregiving Questionnaire (FACQ-PC) (22), caregiver mental and physical health as measured by SF-12v2 (23), and caregiver workload as measured by extent of caregiver assistance with activities of daily living, at baseline and follow up. Total recruitment was 620. There was 45% attrition for each group between baseline and follow-up mainly due to patient deaths resulting in 322 caregivers completing the study (233 in the intervention group and 89 in the control group). At follow-up, the intervention group showed significant reduction in caregiver strain relative to controls, $p=0.018$, $d=0.348$ (95%CI 0.25 to 0.41). Priority support needs identified by caregivers included knowing what to expect in the future, having time for yourself in the day and dealing with your feelings and worries. The detailed description of the intervention and methodology of the pre-bereavement phase is described in Aoun et al (19). There was also positive feedback on using the CSNAT from family caregivers (24) and nurses (25).

Brief description of the intervention

The CSNAT intervention consisted of at least two visits from nurses to caregivers, 2 to 3 weeks apart, where nurses incorporated the CSNAT into a practitioner facilitated but caregiver-led approach to needs assessment and support. Family caregivers identified domains where they needed more support. This was accomplished by the CSNAT being either self-completed by the family caregiver or completed jointly with the nurse. Then a conversation took place to determine individual needs and the caregiver's priorities were discussed with the nurse to agree on actions/solutions and a shared action plan. The control group received 'standard practice' which consisted of the staff meeting with the caregiver during the client visit and discussing caregiver needs on an informal and ad-hoc basis that was not documented.

This article reports on the second phase of the Australian community palliative care trial (described in Box 1), the follow-up at the post-bereavement phase.

OBJECTIVES

This study investigates the extent to which using the 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.

METHODS

The study was approved by the University Human Research Ethics Committee (HR 24/2011) and the Service Human Research Ethics Committee (EC App 068). All caregiver participants provided written informed consent to participate in this study and the two ethics committees approved this consent procedure.

Data Collection (the caregiver survey)

All family caregivers who completed the pre-bereavement phase (n=322) were invited to take part in a caregiver survey by telephone 4-6 months post-bereavement (2015).

Demographic information was already available from the pre-bereavement phase of the study. Both intervention and control groups completed the following primary and secondary outcome measures at post-bereavement:

The primary outcome measure was the perceived adequacy of support provided for the caregiver during end of life care which was measured using the fourteen questions of the CSNAT domains, revised to the format 'Did you need more support with' (responses: 1=no; 2=a little more; 3=quite a bit more; 4=very much more). These scores were summarised for the analysis. The two main groupings of the CSNAT were each summarised and analysed separately: The seven domains enabling the caregiver to care for the patient (CSNAT Enabling Support domains) and the seven domains providing more direct support for the caregiver's health and well-being (CSNAT Direct Support domains).

An additional set consisted of three general questions on whether caregivers had been asked about their support needs, whether they felt their needs had been listened to, and whether there were concerns they had been unable to discuss (responses: 1=always, 2=usually, 3=sometimes, 4=never).

There were three secondary outcome measures:

1- Level of grief in bereavement was measured using the Texas Revised Inventory of Grief (TRIG) (26). This is a Likert-type measure in two parts. Part 1, comprising eight items, measures initial grief at the time of death (TRIG initial). Part 2, with 13 items, assesses present grief (TRIG present). It has an internal consistency of 0.77 (Part 1) and 0.86 (Part 2) and a reliability of 0.74 (Part 1) and 0.88 (Part 2). A higher grief score indicates a worse bereavement outcome.

2- Mental and physical well-being was measured using the SF-12v2 (23). The SF-12v2 consists of 12 questions relating to: physical health problems, bodily pain, general health perceptions, vitality (energy/fatigue), social functioning, role limitations and general mental health (psychological distress and psychological well-being). Reliability estimates range from 0.93 to 0.95. The analysis was undertaken for two scores: the Mental Component Score (SF12-MCS) and the Physical Component Score (SF12-PCS) (23). A higher physical or mental health score indicates a better outcome.

3- A measure of achievement of the preferred place of death was obtained by asking whether the actual place of death (home, hospice, hospital, nursing/ residential home, other) was the preferred option for the patient (according to the family caregiver, with responses yes, no, not discussed) or the preferred option for the family caregiver. The three questions were: "Where was the place of death of your loved one?"; "Was that the preferred place of death for your loved one?"; "Was that *your* preferred place of death for your loved one?" A congruence analysis was undertaken between actual and preferred place of death for each group.

Statistical analyses

Analysis of the trial was on a per protocol basis. Continuous variables were reported as means and standard deviations and categorical variables as frequencies and proportions. Differences between groups for continuous variables was determined using independent t test, and categorical data using chi square or fishers exact test (when expected cell counts <5).

Congruence between preferred and actual place of death was computed as the number of patients who died in their preferred locations divided by all patients/caregivers with preferences. A difference in proportions was determined using Chi square or Fishers exact test.

The primary and secondary outcomes were examined using mixed models accounting for the clusters at the three service bases. Linear mixed models were used for the continuous data, except for the CSNAT outcomes (direct support, enabling and total) where Tobit regression was used due to the floor effect. For questions with ordinal responses, ordered logistic regression was used producing proportional odds ratios. For binary data (yes/no) logistics regression was used producing odds ratios. For all models, unadjusted and adjusted analysis were produced with the control group coded as 0 and the intervention group as 1. Models were adjusted for cluster effect, age of caregiver, gender of caregiver, time since death, diagnosis of patient, relationship to care recipient (spouse, child, other) and length of palliative care. For the primary outcome, CSNAT, cohen's d was calculated for statistically significant findings.

All data was analysed using Stata 14.1 (27). Statistical significance was considered $p < 0.05$.

RESULTS

Two thirds of participants in the pre-bereavement phase completed the post-bereavement phase of the study (212 out of 322) (Figure 1). Reasons for attrition in the intervention group comprised: 28 (12%) patients were still alive at the end date of the project, 9 caregivers (4%) declined to participate and 45 (19%) could not be contacted after three attempts or their phone line was disconnected. Reasons for attrition were similar for the control group: 4 patients were still alive (5%), 2 caregivers declined (2%) and 22 were not contactable (25%) (Figure 1).

[Figure 1 about here]

Table 1 shows the characteristics of family caregivers who participated in the post-bereavement study (T3) compared to the larger sample of caregivers who participated in the pre-bereavement study (T2). The two groups did not differ on any characteristics.

The only detected difference between the intervention and control groups at the post-bereavement phase (Table 1) was the higher proportion of ‘non-cancer’ diagnoses in the control group and the longer period of palliative care, which is similar to the profile at the pre-bereavement phase reported in Aoun et al (19).

[Table 1 about here]

Both groups, when asked in which areas they would have liked more help and support for themselves, predominantly reported “having time to yourself in the day”, followed by “knowing what to expect in the future” (Figure 2). The unmet needs of the control group were more pronounced than the intervention group in most domains. In particular, the two areas in the enabling care grouping with significant differences (greater unmet need for the control group compared to the intervention group) were “understanding your relative’s illness” ($p=0.026$) and “knowing who to contact if concerned” ($p=0.028$).

[Figure 2 about here]

The summary statistics for the primary and secondary outcomes are shown in Table 2. Lower mean scores are noted for the intervention group on the CSNAT (enabling, direct and total), indicating lower unmet need. Similar distribution of responses was seen for ‘feeling listened to’ and ‘being asked about support needs’. There was a greater proportion of caregivers in the intervention group who felt that ‘sometimes’ they were unable to discuss their concerns. The regression analysis supported this finding with a reduced odds of being able to discuss concerns (OR 0.30: 95% CI 0.1 to 0.5, $p<0.001$) (Table 3). Responses to the question :”Which support needs were you unable to discuss with the nurses and why was this?” revealed that the majority of the family caregivers with the “sometimes” response (69%) was reporting constraint due to the presence of the care recipient, be it mother, father, sister and mainly husband. The following caregiver’s comment describes this situation: *“Difficult to bring up when he was in the room. I would phone the nurses later and I would email his doctor” (ID 109).*

[Table 2 about here]

Table 3 outlines the unadjusted and adjusted analysis for primary and secondary outcomes. The CSNAT enabling and total scores demonstrated statistically significant differences between the groups. The intervention group scored on average 2.2 points (95% CI: -2.9, -1.4) less on the CSNAT enabling domains compared to the controls, indicating lower unmet need with a moderate effect size (Cohen’s $d=0.43$). For the CSNAT total score, the intervention group scored on average 2.9 points (95% CI: -3.7, -2.1) less compared to the control, with a small to moderate effect size (Cohen’s $d = 0.33$). There was no difference between the two groups in the direct support grouping. There were no significant differences in the initial and present grief levels or for MCS and PCS scores for the two groups.

[Table 3 about here]

Table 4 presents the actual and preferred place of death for the patient (according to their family caregiver) and the caregiver preferred place of death for their care recipients. The actual place of death did not significantly differ between the two groups, though more of the intervention group died at home (55.9%) compared to 48.3% in the control group. Congruence between patients' preferred and actual place of death as reported by their caregiver was 79.6% for the intervention group compared to 63.3% for the control group, meaning that significantly more in the intervention group could achieve their preferred place of death ($p=0.034$). There was no significant difference in such congruence for family caregivers. The preferred place of death was agreed upon more often between patient and caregiver in the intervention group compared to the control (93.8% vs 83.0% respectively, $p=0.020$). A small number of respondents did not complete the questions on preferences, either because they were distressed or because the caregivers did not know of their care recipients' preferences. There was a significant difference in the bereavement period (time since death) between the two groups (a mean difference of 2.8 weeks) with controls having had a longer time since death.

[Table 4 about here]

DISCUSSION

A considerable proportion of family caregivers who completed the intervention pre-bereavement responded to the post-bereavement survey (66%) with the attrition rate being mainly due to patients not having died before the end of the project (10%), and also due to caregivers being uncontactable (some with disconnected phone lines) having moved on or moved away after the death (21%). However, very few caregivers declined to participate (3%). This good response rate is consistent with the one obtained for the feedback interview at the pre-bereavement phase of the study (24). On the whole, the total sample and the intervention and control groups at post bereavement were representative of the pre-bereavement total sample and its two groups. It is worth noting that the interview style used pre and post bereavement in this study may have contributed to the good response rate by facilitating the creation of relationships between participants and the research nurse that fostered respect, trust, and concern, such advantages being reported in the literature (28, 29).

The majority of the intervention effect estimates on outcomes (7 out of 10) were in a favourable direction even though not always reaching statistical significance (Table 3). There was a significant difference in perception of support needs being better met for the intervention group (CSNAT total) and more particularly for domains in the enabling care grouping ($p<0.001$, $d=0.43$) which means the support that enables the family caregiver to care for the patient at home, rather than the more direct personal support for the caregiver. Within the enabling care grouping, three items were particularly better achieved for the intervention group "understanding your relative's illness" ($p=0.026$), "knowing who to contact if concerned" ($p=0.028$) and to a lesser extent "managing your relative's symptoms" ($p=0.052$). Reducing such uncertainty by targeting the specific support and information needs of caregivers through open and frequent communication with their health care

provider (as afforded by the CSNAT Approach) is reported to allow family caregivers to more fully prepare for the death (7,8). The finding that more of the intervention group felt that “sometimes” they could not discuss their concerns with the nurses, albeit because they felt they did not want to discuss them in the presence of their care recipients, is a reflection of the more comprehensive nature of the CSNAT compared to standard practice. The CSNAT identified the legitimate caregiver concerns and encouraged the discussion but not all caregivers wished to conduct the discussion in front of the patient. This raises a training issue for practitioners where it may be necessary to give caregivers the option of completing the CSNAT on their own and then make a separate contact to have the CSNAT conversation with them.

The fact that the intervention group reported that more of their needs have been met is consistent with them experiencing less strain than the control group during the pre-bereavement period (19). The fact that this support was significant in the enabling care grouping of the CSNAT is also in line with the nurses’ feedback during the caregiving period (25), where a higher percentage of nurses (77%) indicated that ‘enabling care’ was within the service’s capacity, whereas a lesser proportion of nurses (56%) felt they could action ‘direct’ personal support for the caregivers themselves. The authors explained that this difference in nurses’ responses may be due to the existing and necessary focus of service providers’ resources on patient care delivery and support that the service routinely provides (25). While it is an important finding that caregivers felt supported delivering care to their relative, nevertheless it is an indication that the service focus has not shifted enough towards the direct support needs of the caregivers. It may also be the case that the nurses saw the enabling domains as delivering their usual patient-focussed care (equipment, medications....) but they did not distinguish between the needs of the caregivers within these domains and those of the patients.

In both groups, nearly one half or more died at home, and in particular this was 55.9% for the intervention group, which is consistent with the palliative care service proportion of home deaths, reported as 56.8% for people who have family caregivers (30). More patients in the intervention group, compared to the control group, achieved their preference for place of death according to their family caregivers (79.6% vs 63.3%, $p=0.034$). This congruence rate is at the upper end of those reported in the literature 30-90% (31). However, home may not be the ideal or the preferred location for dying for many patients (14, 32). Aoun and Skett emphasized that “the ability to die in the place of choice needs to be looked at as a possible indicator of meeting patient needs or as a quality measure in end-of life care” (32, p.534).

One proposed explanation put forward for the high agreement rates between patients’ and caregivers’ preference about the place of death is that they could be due to the opportunity of the conversation that CSNAT has systematically provided. Nurses have mentioned undertaking discussions with caregivers which consisted of “what to expect as [client’s] condition deteriorates and death nears”, and “long talk about end of life care/dying at home” (19, p.11). This may have prepared caregivers for the imminent death, a concept being emphasized in the literature as protective against adverse outcomes in the post bereavement period (7, 8, 10). The importance of early conversations about preferences for place of death involving patients and their families in order to achieve the preferred place has been highlighted in the literature (12).

There was also a significant greater agreement in the intervention group between the caregivers and their care recipients on the preferred place of death (93.8% vs 83%, $p=0.02$) in this study. Grande & Ewing (33) reported that death in the preferred location was more likely if the patient and caregiver agreed. Therefore a higher likelihood of dying in place of preference in the intervention arm may be a result of higher level of agreement, rather than perhaps the intervention itself.

The post-bereavement outcomes differed between this study and the UK post-bereavement study (21). The UK study reported a small reduction in early grief, improvements in mental and physical health and probability of death at home, but no indication that the intervention group was more likely to feel their needs had been met. The UK trial also had a considerably larger sample size ($n=681$) and therefore higher statistical power than in our study. However, the authors stated that the low implementation rate of the CSNAT by the services during the caregiving phase and subsequently the low response rate by bereaved caregivers to the postal surveys have reduced the potential of the intervention to make an impact (21). Also the use of intention-to-treat analysis, where not all participants received the intervention, may have diluted the intervention effect.

Though not significant, the differences in the SF-12 scores of MCS and PCS in our study were consistent with the pre-bereavement profiles, where the control group had better mental scores, and the intervention group had better physical scores (19). Compared to the UK study, this group had similar PCS scores but better MCS scores (21), perhaps meaning that their mental health was less compromised. In this study, the intervention had no impact on grief, but this study group had lower initial and present grief levels than the UK group, possibly due to their better mental health impacting positively on their grief. Garrido et al (34) have shown that, among other outcomes, better quality of death and better caregiver mental health before the patient's death were predictors of improved caregiver bereavement adjustment.

The fact that Nielsen et al (6) found that the levels of grief and depressive symptoms were higher during caregiving than six months after the loss, and the fact that our study found that caregivers experienced less strain pre-death due to the intervention (19), and that at post-death they felt their needs have been met and achieved the patient preferred place of death, reinforces the need for palliative care services to take action during the pre-bereavement period to effectively support family caregivers. Yet the 'window of opportunity' for contact with caregivers to assess their grief and bereavement needs while heading to the care recipient's impending death is still not well utilised in the palliative care system (35). Seizing this opportunity pre-bereavement is even more crucial that the latest findings from the Australian bereavement support survey showed that just half of the bereaved had a follow up contact from the palliative care services at 3-6 weeks, and only a quarter had a follow-up at 6 months, and that the blanket approach to bereavement support adopted by the services was deemed unhelpful (36). While in general, there is a lack of evidence which could guide pre-death risk identification and interventions that could benefit informal caregivers before and after the death of their care recipient (35), the results from this study provide the evidence that the CSNAT intervention has a positive impact on family caregivers post-bereavement.

Limitations

The main analysis in this study was based on per protocol analysis, in line with the pre-bereavement trial. Per protocol analyses may have boosted the likelihood that the intervention had an effect as it only included those who actually received the intervention. However, statistical comparisons were undertaken for participants who withdrew from the intervention and the control groups and there were no significant differences with those who completed the study. Table 1 demonstrates that the characteristics of family caregivers were similar in the two phases and there were no characteristics that appeared to influence withdrawal.

Restricting the time since death to 4-6 months for the post-bereavement interviews reduces the likelihood of recall bias and has produced adequate response rates as reported in the literature (21, 37). May be a longer term follow-up of six months or more could have captured those who developed complicated grief and thus produced more group differences. However, it is likely that the sample size would have been much smaller with lower statistical power to show such group differences.

Another limitation is that all the preferences for place of death have come from caregiver interviews collected post bereavement. Certainly a prospective measure would have been better to elicit preferences that are provided directly by the patient rather than by proxy from the caregiver. However the end result is about the caregiver feeling good about the patient achieving what they have thought would be their preference.

As reported in the pre-bereavement phase of the study (19), the issue of unbalanced groups ultimately is an inherent limitation of the stepped-wedge design; however, the generalized linear mixed modelling (GLMM) used to examine the efficacy of the CSNAT intervention is generally robust to unbalanced groups. Relatedly, the intervention and control groups in both the pre and post bereavement phases were found significantly different on a number of baseline characteristics. While analyses were adjusted for these differences, other potential underlying biases cannot be completely ruled out.

Conclusions

The positive supportive outcomes from the CSNAT trials demonstrated the benefits gained by both family caregivers and health care providers in engaging caregivers in early and direct assessment of their support needs pre-bereavement. Therefore, there is a need for palliative care services to consider the continuum of the pre and post bereavement phases, the predictors of bereavement outcome among caregivers during caregiving, and to develop strategies that assist caregivers in feeling more prepared for the death and their bereavement. However, all this will not be achieved until services are funded to enable them to fully adhere to their remit or ethos of being there for the family caregivers as well as the patients and thus be able to incorporate systematic assessment and support of family caregivers.

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REFERENCES

1. Stroebe M, Boerner K. Caregiving and bereavement research: Bridges over the gap. *Palliat Med.* 2015;29(7):574-6.
2. Aoun SM, Kristjanson LJ, Currow DC, Hudson PL. Caregiving for the terminally ill: at what cost? *Palliat Med.* 2005;19(7):551-5.
3. Boerner K, Schulz R. Caregiving, bereavement and complicated grief. *Bereavement care : for all those who help the bereaved.* 2009;28(3):10-3.
4. Guldin MB, Vedsted P, Zachariae R, Olesen F, Jensen AB. Complicated grief and need for professional support in family caregivers of cancer patients in palliative care: a longitudinal cohort study. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer.* 2012;20(8):1679-85.
5. Schulz R, Boerner K, Shear K, Zhang S, Gitlin LN. Predictors of complicated grief among dementia caregivers: a prospective study of bereavement. *The American journal of geriatric psychiatry : official journal of the American Association for Geriatric Psychiatry.* 2006;14(8):650-8.
6. Nielsen MK, Neergaard MA, Jensen AB, et al. Predictors of Complicated Grief and Depression in Bereaved Caregivers: A Nationwide Prospective Cohort Study. *Journal of pain and symptom management.* 2017;53(3):540-50.
7. Hebert RS, Prigerson HG, Schulz R, Arnold RM. Preparing caregivers for the death of a loved one: a theoretical framework and suggestions for future research. *Journal of palliative medicine.* 2006;9(5):1164-71.
8. Hebert RS, Schulz R, Copeland VC, Arnold RM. Preparing family caregivers for death and bereavement. *Insights from caregivers of terminally ill patients. Journal of pain and symptom management.* 2009;37(1):3-12.
9. Christakis NA, Iwashyna TJ. The health impact of health care on families: a matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses. *Social science & medicine (1982).* 2003;57(3):465-75.
10. Steinhauser KE, Christakis NA, Clipp EC, et al. Preparing for the end of life: preferences of patients, families, physicians, and other care providers. *Journal of pain and symptom management.* 2001;22(3):727-37.
11. Addington-Hall J, Karlsen S. Do home deaths increase distress in bereavement? *Palliat Med.* 2000;14(2):161-2.
12. Gomes B, Calanzani N, Koffman J, Higginson IJ. Is dying in hospital better than home in incurable cancer and what factors influence this? A population-based study. *BMC medicine.* 2015;13:235.
13. Grande GE, Ewing G, National Forum for Hospice at Home. Informal carer bereavement outcome: relation to quality of end of life support and achievement of preferred place of death. *Palliat Med.* 2009;23(3):248-56.
14. Pollock K. Is home always the best and preferred place of death? *BMJ.* 2015;351:h4855.

15. Harrop E, Byrne A, Nelson A. "It's alright to ask for help": findings from a qualitative study exploring the information and support needs of family carers at the end of life. *BMC palliative care*. 2014;13(22):22.
16. Ewing G, Austin L, Diffin J, Grande G. Developing a person-centred approach to carer assessment and support. *British journal of community nursing*. 2015;20(12):580-4.
17. Ewing G, Grande G, National Association for Hospice at H. Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: a qualitative study. *Palliat Med*. 2013;27(3):244-56.
18. Ewing G, Brundle C, Payne S, Grande G, National Association for Hospice at H. The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: a validation study. *Journal of pain and symptom management*. 2013;46(3):395-405.
19. Aoun SM, Grande G, Howting D, et al. The impact of the carer support needs assessment tool (CSNAT) in community palliative care using a stepped wedge cluster trial. *PLOS ONE*. 2015;10(4):e0123012.
20. Toye C, Parsons R, Slatyer S, et al. Outcomes for family carers of a nurse-delivered hospital discharge intervention for older people (the Further Enabling Care at Home Program): Single blind randomised controlled trial. *International journal of nursing studies*. 2016;64:32-41.
21. Grande GE, Austin L, Ewing G, O'Leary N, Roberts C. Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: a stepped wedge cluster trial. *BMJ supportive & palliative care*. 2017;7(3):326-34.
22. Cooper B, Kinsella GJ, Picton C. Development and initial validation of a family appraisal of caregiving questionnaire for palliative care. *Psycho-oncology*. 2006;15(7):613-22.
23. Sanderson K, Andrews G. The SF-12 in the Australian population: cross-validation of item selection. *Aust N Z J Public Health*. 2002;26(4):343-5.
24. Aoun S, Deas K, Toye C, et al. Supporting family caregivers to identify their own needs in end-of-life care: Qualitative findings from a stepped wedge cluster trial. *Palliat Med*. 2015;29(6):508-17.
25. Aoun S, Toye C, Deas K, et al. Enabling a family caregiver-led assessment of support needs in home-based palliative care: Potential translation into practice. *Palliat Med*. 2015;29(10):929-38.
26. Faschingbauer T, Zisook S, DeVaul R. The Texas Revised Inventory of Grief. In: Zisook S, editor. *Biopsychosocial Aspects of Bereavement*. Washington, DC: American Psychiatric Press; 1987. p. 110-24.
27. StataCorp. *Stata Statistical Software: Release 14*. College Station, TX: StataCorp LP.; 2015.
28. Aoun S, Slatyer S, Deas K, Nikolaichuk C. Family Caregiver Participation in Palliative Care Research: Challenging the Myth. *Journal of pain and symptom management*. 2017;53(5):851-61.
29. Steinhauer KE, Clipp EC, Hays JC, et al. Identifying, recruiting, and retaining seriously-ill patients and their caregivers in longitudinal research. *Palliat Med*. 2006;20(8):745-54.
30. Aoun S, Kristjanson LJ, Currow D, et al. Terminally-ill people living alone without a caregiver: an Australian national scoping study of palliative care needs. *Palliat Med*. 2007;21(1):29-34.

31. Bell CL, Somogyi-Zalud E, Masaki KH. Methodological review: measured and reported congruence between preferred and actual place of death. *Palliat Med.* 2009;23(6):482-90.
32. Aoun SM, Skett K. A longitudinal study of end-of-life preferences of terminally-ill people who live alone. *Health Soc Care Community.* 2013;21(5):530-5.
33. Grande G, Ewing G. Death at home unlikely if informal carers prefer otherwise: implications for policy. *Palliat Med.* 2008;22(8):971-2.
34. Garrido MM, Prigerson HG. The end-of-life experience: modifiable predictors of caregivers' bereavement adjustment. *Cancer.* 2014;120(6):918-25.
35. Sealey M, O'Connor M, Aoun SM, Breen LJ. Exploring barriers to assessment of bereavement risk in palliative care: perspectives of key stakeholders. *BMC palliative care.* 2015;14(49):49.
36. Aoun S, Rumbold B, Howting D, Bolleter A, Breen L. Bereavement support for family caregivers: The gap between guidelines and practice in palliative care. *PLOS ONE.* In press.
37. Gomes B, McCrone P, Hall S, Koffman J, Higginson IJ. Variations in the quality and costs of end-of-life care, preferences and palliative outcomes for cancer patients by place of death: the QUALYCARE study. *BMC Cancer.* 2010;10:400.

Table 1: Comparison of characteristics of family caregivers who participated in the CSNAT pre- and post-bereavement phases.

Caregiver profile	Pre bereavement T2			Post bereavement T3			Total pre bereavement	Total post bereavement	p value * T2 vs T3	
	Intervention n (%)	Control n (%)	p value*	Intervention n (%)	Control n (%)	p value*	T2	T3		
Total	n=233	n=89		n=152	n=60		n=322	n=212		
Age	Mean (SD)	62.1 (0.8)	65.5 (1.4)	0.030 ^T	63.7 (11.8)	67.1 (11.7)	0.063 ^T	63 (12.7)	64.6 (11.8)	0.144 ^T
Gender	Male	69 (29.6)	18 (20.2)	0.090	42 (27.6)	10 (16.7)	0.095	87 (27)	52 (24.5)	0.521
	Female	164 (70.4)	71 (79.8)		110 (72.4)	50 (83.3)		235 (73)	160 (75.5)	
Marital status	Never married	13 (5.6)	2 (2.2)	0.217 ^F	8 (5.3)	1 (1.7)	0.190 ^F	15 (4.7)	9 (4.2)	0.881
	Widowed	7 (3.0)	2 (2.2)		6 (3.9)	2 (3.3)		9 (2.8)	8 (3.8)	
	Divorced/ Separated	11 (4.7)	9 (10.1)		5 (3.3)	6 (10.0)		20 (6.2)	11 (5.2)	
	Married/ Defacto	202 (86.7)	76 (85.4)		133 (87.5)	51 (85.0)		278 (86.3)	184 (86.8)	
Education	No formal education	1 (0.4)	0 (0)	0.689 ^F	1 (0.7)	0 (0)	0.322 ^F	1 (0.3)	0 (0)	0.654 ^F
	Primary	5 (2.1)	1 (1.1)		5 (3.3)	1 (1.7)		6 (1.9)	7 (3.3)	
	Secondary	133 (57.1)	57 (64.0)		85 (55.9)	41 (68.3)		190 (59)	126 (59.4)	
	Tertiary/ Trade	94 (40.3)	31 (34.8)		61 (40.1)	18 (30)		125 (38.8)	79 (37.3)	
Culture	Australian	12 (5.4)	60 (67.4)	0.103	91 (59.9)	40 (66.7)	0.231 ^F	189 (58.7)	131 (61.8)	0.775
	Other English speaking	66 (28.3)	21 (23.6)		37 (24.3)	16 (26.7)		87 (27)	53 (25)	
	Non-English speaking	38 (16.3)	8 (9.0)		24 (15.8)	4 (6.7)		46 (14.3)	28 (13.2)	
Relationship to care recipient	Spouse	15 (6.4)	63 (70.8)	0.644 ^F	102 (67.8)	43 (70)	0.545 ^F	220 (68.3)	145 (68.4)	0.979 ^F
	Parent	4 (1.7)	3 (3.4)		2 (1.3)	2 (3.3)		7 (2.2)	4 (1.9)	
	Child	52 (22.3)	16 (18.0)		37 (24.3)	11 (18.3)		68 (21.1)	48 (22.6)	
	Sibling	5 (2.2)	3 (3.4)		2 (1.3)	2 (3.3)		8 (2.5)	4 (1.9)	
	Other	15 (6.4)	4 (4.5)		8 (5.3)	3 (5)		19 (5.9)	11 (5.2)	
Diagnosis	Cancer	17 (7.5)	66 (74.2)	0.026	109 (71.7)	43 (71.7)	0.028 ^F	241 (74.8)	152 (71.7)	0.713
	Cancer & non-cancer	39 (16.7)	8 (9.0)		29 (19.1)	5 (8.3)		47 (14.6)	34 (16)	
	Non-cancer	19 (8.2)	15 (16.8)		14 (9.2)	12 (20)		34 (10.6)	26 (12.3)	
Length of palliative care in months,	Mean (SD)	2.9 (0.3)	6.0 (0.88)	<0.001 ^T	3 (4.5)	6.3 (9.7)	0.001 ^T	3.8 (-5.8)	3.9 (-6.6)	0.854 ^T

*Chi-squared unless otherwise specified. T, t-test of means; F, Fishers exact test.

Table 2: Summary data for post-bereavement outcomes (T3)

Variables	Intervention		Control	
	total n	mean (SD)	total n	mean (SD)
CSNAT Enabling domains	147	7.6 (1.3)	56	8.5 (3.2)
CSNAT Direct Support domains	147	7.9 (1.8)	56	8.4 (3.3)
All CSNAT domains (Total)	147	15.6 (2.7)	56	16.9 (6.4)
TRIG initial	147	20.6 (7.9)	58	18.6 (6.4)
TRIG present	148	42.8 (10.5)	56	42.1 (11.5)
SF-12 MCS	151	47.0 (10.5)	60	49.3 (10.9)
SF-12 PCS	151	50.6 (10.2)	60	48.7 (10.3)
Perceived adequacy of support	total n	n (%)	total n	n (%)
Nurses asked about your support needs				
never	149	2 (1.3)	56	1 (1.8)
sometimes		19 (12.8)		8 (14.3)
usually		30 (20.1)		11 (19.6)
always		97 (65.1)		34 (60.7)
don't know		1 (0.7)		2 (3.6)
Nurses listened to any concerns you had				
never	149	0 (0)	54	1 (1.8)
sometimes		10 (6.7)		4 (7.4)
usually		20 (13.4)		8 (14.8)
always		119 (79.9)		41 (75.9)
don't know		0 (0)		0 (0)
Unable to discuss any concerns with nurses				
always	149	3 (2.0)	56	2 (3.6)
usually		1 (0.7)		0 (0)
sometimes		16 (10.7)		1 (1.8)
never		126 (84.6)		53 (94.6)
don't know		3 (2.0)		0 (0)

Table 3: Estimate of effect of intervention in the post-bereavement phase (control=0, intervention=1)

Variable	Unadjusted Analysis		Adjusted Analysis		Favourable result
	Intervention Effect unadjusted difference (95% confidence intervals)	p value	Intervention Effect adjusted difference* (95% confidence intervals)	p-value	
Estimate of effect of intervention from linear mixed effects models, accounting for cluster effect of base. Intervention effect indicates differences in scores between the control and intervention groups (control=0, intervention=1)					
CSNAT Enabling Support domains ¹⁰	-2.2 (-3.3, -1.2)	<0.001	-2.2 (-2.9, -1.4)	<0.001	<0
CSNAT Direct Support domains ¹⁰	-0.9 (-2.3, 0.5)	0.228	-0.8 (-0.1, 0.04)	0.372	<0
All CSNAT domains (Total) ¹⁰	-2.8 (-3.4, 2.3)	<0.001	-2.9 (-3.7, -2.1)	<0.001	<0
TRIG initial	2.0 (-0.3, 4.3)	0.085	1.2 (-1.2, 3.7)	0.325	<0
TRIG present	0.8 (-2.4, 4.1)	0.615	-0.6 (-4.1, 2.8)	0.713	<0
SF-12 MCS	-2.4 (-5.1, 0.8)	0.146	-1.7 (-5.1, 1.7)	0.319	>0
SF-12 PCS	1.9 (-1.1, 5.0)	0.212	1.3 (-2.0, 4.5)	0.451	>0
Perceived Adequacy of Support. Estimate of effect of intervention (proportional OR) on ordinal response outcomes					
Nurses asked about your support needs	1.2 (0.8, 1.6)	0.689	1.0 (0.4, 2.4)	0.970	>1
Nurses listened to any concerns you had	1.3 (0.9, 1.8)	0.174	1.1 (0.6, 1.9)	0.829	>1
Unable to discuss any concerns with nurses	0.4 (0.2, 0.6)	<0.001	0.3 (0.1, 0.5)	<0.001	>1

* Mixed-effects models provided estimates of the mean adjusted difference. Adjusted for cluster effect, age of caregiver, gender of caregiver, time since death, diagnosis of patient, relationship to cared person (spouse, child, other) and length of palliative care.

¹⁰ Tobit regression used for CSNAT due to floor effects.

Intracluster correlation (ICC) for the bases (clusters) were essentially zero meaning that there was no correlation of outcome within each base.

Cohen's d=0.33 (0.02, 0.64) for CSNAT Total, and Cohen's d=0.43 (0.12, 0.74) for CSNAT Enabling Support.

Table 4: Comparison in actual and preferred place of death between the two groups

		Intervention n=152		Control n=60		Two group comparison, p-value*
		n	%	n	%	
Bereavement period (Time since death in weeks)	Mean (SD)	23.5	(8.2)	26.3	(8.2)	0.032^T
Actual place of death	Home	85	55.9	29	48.3	0.318 0.322 ^{F1}
	Hospital	15	9.9	8	13.3	
	Hospice	43	28.3	22	36.7	
	Nursing home	8	5.2	1	1.7	
	Other	1	0.7	0	0	
Actual place of death (Recoded)	Home	85	55.9	29	48.3	0.318
	Elsewhere	67	44.1	31	51.7	
Achievement of preference for place of death (<i>patient preference is reported by caregiver</i>)	Patient preference vs actual					0.034
	Achieved	121	79.6	38	63.3	
	Not achieved	24	15.8	15	25.0	
	Too distressed/not discussed	7	4.6	7	11.7	
	Caregiver preference vs actual					0.110
	Achieved	125	82.2	46	76.7	
	Not achieved	24	15.8	9	15.0	
	Too distressed/not discussed	3	2.0	5	8.3	
	Patient preference vs Caregiver preference					0.020
	Agreed	136	93.8	44	83.0	
	Disagreed	9	6.2	9	17.0	

*Chi-squared unless otherwise specified. T, t-test of means. F1, Fishers exact test using the four groupings of Home/Hospital/Hospice/all-others.

Congruence analysis based on data for preferred location for 198 patients and 204 caregivers

Figure 1: Flowchart of participants between the pre-bereavement and post-bereavement phases

Figure 2: Comparison of unmet support needs for the intervention and control groups at the post-bereavement phase

(More help needed classified as a response of “A little more”, “Quite a bit more” or “Very much more”)

ACCEPTED MANUSCRIPT



