

Survey of bereavement support provided by Australian palliative care services

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Grief is a natural response to the loss of a loved one, and hence expected in families of patients linked to palliative care services. A prolonged or abnormal bereavement process, termed complicated grief, is associated with maladaptive responses to the loss and can lead to physical and psychological morbidity, social dysfunction and increased mortality.¹⁻⁶

The provision of bereavement care is now an established part of modern palliative care. However, the involvement of palliative care services with patients, their families and "significant others" may be relatively short. Median survival times after referral to palliative care units in Australia have been reported for Newcastle (54 days)⁷ and southern Adelaide (47 days).⁸

The prevalence and nature of bereavement programs in palliative care have been studied in the United Kingdom and Japan,⁹⁻¹¹ but not in Australia. This study aimed to determine:

- the prevalence of bereavement programs in Australian palliative care services;
- the staffing of these bereavement programs;
- the types of bereavement support provided; and
- the allocation of bereavement support.

METHODS

A questionnaire with 11 questions relating specifically to the aims of the study was developed. These included whether the service provides bereavement follow-up, the position of the person who acts as coordinator of the bereavement follow-up/program and of the person who performs the follow-up/program, the type of follow-up provided, the length of time to first follow-up contact, who is referred for follow-up, whether bereavement risk assessment is performed, and the nature of the risk assessment. A question about the intention to develop a bereavement service was adapted from a previous study.¹¹

The questionnaire was mailed to all palliative care centres identified in the Australian *Palliative care national directory 2004*.¹² This directory lists and describes Australian palliative care services and other health

ABSTRACT

Objective: To determine the prevalence, staffing, methods, timing and allocation of bereavement programs in Australian palliative care services.

Design: Questionnaire-based postal survey.

Setting and participants: The questionnaire was mailed in January 2007 to all 324 palliative care centres identified from the Australian *Palliative care national directory 2004*.

Results: 236 of the 324 centres responded (73%), and 95% of these undertook bereavement follow-up, with similar prevalence in metropolitan and regional areas. Staff from a range of disciplines were involved in coordinating and delivering these services, with nurses taking on these roles in most regional centres. Common types of bereavement follow-up included individual sessions and visits, telephone contact, letters, anniversary cards and memorial services. Most centres (74%) approached the bereaved within 2 weeks of the death, and 83% of centres offered bereavement support to families or "significant others" of all patients who died under their care. Some form of risk assessment for complicated grief was performed by 69% of participating centres.

Conclusion: Bereavement care is an integral part of Australian palliative care services. Given the multidisciplinary staffing demonstrated, it is important that those coordinating and delivering these programs are adequately trained and supported. There is a need for further research to guide the development of bereavement support practice.

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service units involved in the delivery of palliative care. Centres listed as palliative care services or those that provided palliative care as part of their function were included in the mailout.

The initial mailout was in January 2007, with a second mailout to centres that had not responded after 6 weeks. Returned questionnaires were deidentified, and responses analysed. The Stata statistical software system (StataCorp, College Station, Tex, USA) was used to perform *pr* tests, which examine the equality of proportions using large-sample statistics.

The study was approved by the Hunter New England Human Research Ethics Committee.

RESULTS

The questionnaire was mailed to all 324 palliative care centres identified from the Directory. Completed questionnaires were received from 236 centres (response rate, 73%).

Seventy-two of the participating centres (31%) served metropolitan areas, and 169 served regional areas (72%) (five centres, or 2%, served both metropolitan and regional areas). Of the 88 non-participating centres, one had closed, and another had ceased providing palliative care. Of the remaining

86 non-participating centres, 23 (27%) were metropolitan, and 63 (73%) were regional.

Ninety-five per cent of participating centres (223 of 236) offered some form of bereavement support to families and significant others of palliative care patients. Geographically, prevalence of bereavement support was 96% for metropolitan and 94% for regional palliative care services, with the difference not statistically significant ($P=0.67$). Of the 13 centres that did not provide bereavement support, four indicated that they intended to expand their practice to include such programs in the future. The remaining nine centres did not at that time intend to take on bereavement support.

The position descriptions of the staff responsible for coordinating and for delivering the bereavement support programs are shown in Box 1. The types of bereavement support provided are summarised in Box 2.

Centres were asked to specify the length of time from the death of the patient to the first contact with family and significant others for bereavement support. Seventy-four per cent of centres made contact within 2 weeks of the death (Box 3). This was the case in 69% of metropolitan and 76% of

1 Staff responsible for coordinating and delivering follow-up/programs among centres with bereavement follow-up

Staff description	Coordination of follow-up/program				Delivery of follow-up/program			
	All centres (n = 223)	Metropolitan (n = 64)	Regional (n = 159)	P*	All centres (n = 223)	Metropolitan (n = 64)	Regional (n = 159)	P*
Social worker	57 (26%)	24 (38%)	33 (21%)	0.01	88 (40%)	34 (53%)	54 (34%)	0.01
Nurse	114 (51%)	15 (23%)	99 (62%)	<0.01	160 (72%)	33 (52%)	127 (80%)	<0.01
Pastoral care	24 (11%)	16 (25%)	8 (5%)	<0.01	69 (31%)	34 (53%)	35 (22%)	<0.01
Volunteer	10 (5%)	2 (3%)	8 (5%)	ns	67 (30%)	21 (33%)	46 (29%)	ns
Bereavement coordinator/ counsellor	42 (19%)	15 (23%)	27 (17%)	ns	49 (22%)	18 (28%)	31 (20%)	ns
Psychologist/mental health	5 (2%)	4 (6%)	1 (1%)	ns	8 (4%)	5 (8%)	3 (2%)	ns
Doctor	2 (1%)	1 (2%)	1 (1%)	ns	7 (3%)	3 (5%)	4 (3%)	ns
Memorial committee	2 (1%)	0	2 (1%)	ns	1 (0.4%)	0	1 (1%)	ns
Volunteer coordinator	1 (0.4%)	0	1 (1%)	ns	2 (1%)	0	2 (1%)	ns
Other	3 (1%)	3 (5%)	0	ns	4 (2%)	3 (5%)	1 (1%)	ns

ns = no statistically significant difference ($P > 0.05$). * For comparison of metropolitan and regional centres. ◆

2 Types of bereavement support provided by centres with bereavement follow-up

Type of bereavement support	All centres (n = 223)	Metropolitan centres (n = 64)	Regional centres (n = 159)	P*
Phone call	192 (86%)	61 (95%)	131 (82%)	0.01
Memorial service	148 (66%)	55 (86%)	93 (59%)	<0.01
Group session	69 (31%)	25 (39%)	44 (28%)	ns
Letter	122 (55%)	52 (81%)	70 (44%)	<0.01
Anniversary card	118 (53%)	39 (61%)	79 (50%)	ns
Individual session/visit	187 (84%)	47 (73%)	140 (88%)	0.01
Informal gathering	8 (4%)	2 (3%)	6 (4%)	ns
Information package	10 (5%)	7 (11%)	3 (2%)	ns
Other†	10 (5%)	3 (5%)	7 (4%)	ns

ns = no statistically significant difference ($P > 0.05$). * For comparison of metropolitan and regional centres.
† "Other" included sympathy cards (3 centres), referral to mental health service (4), an educational workshop (1), lending library (1) and commemorative quilting (1). ◆

3 Time from death of patient to first bereavement follow-up contact by centres with bereavement follow-up

Time to first follow-up (weeks)	All centres (n = 223)	Metropolitan centres (n = 64)	Regional centres (n = 159)
≤ 1	124 (56%)	30 (47%)	94 (59%)
> 1 to 2	40 (18%)	14 (22%)	26 (17%)
> 2 to 4	20 (9%)	7 (11%)	13 (8%)
> 4 to 6	23 (10%)	8 (13%)	15 (9%)
> 6	2 (1%)	1 (1%)	1 (1%)
Not specified	14 (6%)	4 (6%)	10 (6%)

regional centres, with the difference not statistically significant ($P = 0.33$).

Most centres (83%) approached those bereaved for all patients who died under their care. The difference between metropolitan (80%) and regional (85%) centres was not statistically significant ($P = 0.35$).

Of the 223 centres that offered bereavement support, 154 (69%) undertook some form of risk assessment for complicated grief. Metropolitan centres were more likely than regional units to include these risk assessments in their management strategies (80% v 65%), representing a statistically significant difference ($P = 0.03$). Of the 154 centres that undertook this risk assessment, a formal bereavement risk assessment tool was used in 57% and 68% of metropolitan and regional centres, respectively, although this difference did not reach statistical significance ($P = 0.18$). The other forms of risk assessment were multidisciplinary team opinion (69% metropolitan and 45% regional, $P < 0.01$), and single staff member opinion (53% metropolitan and 45% regional, $P = 0.34$).

DISCUSSION

Bereavement support to family members and significant others has become recognised as an integral part of the provision of palliative care. To our knowledge, this is the first study to quantify the prevalence, staffing and nature of bereavement support programs in Australian palliative care units and community health services involved in the management of palliative care patients. The

results indicate that Australian services have embraced the importance of bereavement care, with 95% of responding centres having a bereavement support program. This compares well with previous results from the UK and Japan.⁹⁻¹¹ Additionally, both metropolitan and regional areas had similar prevalence of such services.

The response rate for this survey was 73%, suggesting that the data reported are reasonably representative of the status of bereavement support in the Australian palliative care setting. A limitation of the study was the use of the *Palliative care national directory 2004* to identify potential participants, as it may not have included recent changes to services, such as address alterations.

Bereavement support programs were coordinated in most participating centres by staff from a single classification — largely social work, nursing or pastoral care (Box 1). A minority of centres had a specifically designated bereavement coordinator or counsellor. In regional Australia, nursing staff were responsible for the task of coordination in most centres (62%), while, in metropolitan areas, social workers were the most common (38%).

Follow-up for bereavement care was more likely to be shared among various staff disciplines (Box 1). The staff most commonly involved were again social workers, nurses, those from pastoral care, and bereavement coordinators/counsellors. However, volunteers were involved in about a third of both metropolitan and regional services. Again, nurses were involved in 80% of responding centres in regional areas, compared with 52% of responding metropolitan centres.

With only a small proportion of centres employing staff strictly dedicated to bereavement support, the main workload burden for both coordinating and delivering these services falls on staff who are also responsible for other aspects of patient management. Ensuring these staff are armed with adequate training in bereavement issues (given the diversity of staff disciplines involved) and time management skills is thus important to maximise their effectiveness. This work can be emotionally taxing, so staff also need to be supported from this perspective. In regional areas where nurses play a large role in bereavement support, the extended responsibilities beyond pure nursing care need to be taken into account in the health services budget for nursing staff.

As seen in Box 2, the forms of bereavement support offered in Australia are quite

varied, with phone calls, individual sessions and visits, letters and memorial services provided by more than half the responding centres. It should be noted that there is a wide difference in staffing time requirements between the interventions. The timing of first contact in bereavement follow-up was found to be quite early in most centres that provided such programs: contact within 2 weeks of the death was the policy in 69% of metropolitan and 76% of regional centres. There is little evidence to guide decisions on the best interventions or the optimal timing of first contact in a palliative care setting.

This survey showed that 83% of Australian palliative care services with bereavement programs offered these to the families and significant others of all patients who died under their care. The rates were similar for metropolitan and regional areas. The palliative care literature includes no good-quality studies comparing bereavement intervention outcomes for blanket referral of “all-comers” versus high-risk candidates.

Bereavement risk assessment was common, and more so in metropolitan than in regional centres. Roughly two thirds of responding centres used a formal risk assessment tool. Multidisciplinary team and staff member opinion also featured prominently, again to a greater extent in metropolitan services. A possible reason is that metropolitan centres are more likely to have access to a wider and palliative care-dedicated multidisciplinary team compared with regional counterparts. For regional participants, staff may be spread over larger areas and less able to attend regular meetings to discuss cases.

Bereavement care is now a standard part of palliative services in Australia, with very high prevalence in both metropolitan and regional areas. These programs are coordinated and delivered by staff from a variety of disciplines, although nursing staff carry a major load in regional centres. The supports provided are also varied, but there is a high prevalence of personal contact (such as phone calls and visits), which are more time-intensive. Early contact with the bereaved occurs in most centres, and it is common practice to approach the bereaved for all deceased palliative care patients. The lack of clear evidence to guide development and allocation of bereavement programs in palliative care is no doubt partly responsible for the variability in these services. This area of practice requires further collaborative research to improve the service to patients and their families.

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COMPETING INTERESTS

None identified.

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