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Title: Identifying systems barriers that may prevent bereavement service access to bereaved carers: a report from an Australian specialist palliative care service.

Running Head: Carer bereavement access

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Summary of Relevance

Problem

Bereavement support and follow-up in palliative care is an essential service for the recently bereaved. However, current bereavement follow-up practices within specialist palliative care services vary widely. While most bereavement follow-up is provided by registered nurses and/or bereavement counsellors, their ability to provide this service is dependent upon them being able to contact the decedent's next of kin. Barriers at a systems level linking bereavement services to bereaved next of kin may be occurring, further hindering timely access to bereavement support.

What is Already Known

A number of factors impact on the delivery of bereavement services including limited personnel, time, funding and infrastructure resources.

What this Paper Adds

This study identified a number of system level barriers that prevent palliative care services from providing bereavement support resources and service contact details for the recently bereaved.

In keeping with a public health bereavement model, there are opportunities for nurses to play a more active role in providing bereavement information and support at the time of the patient's death and to ensure that families and next-of-kin are aware of where they can access future bereavement support should they require it.

Introduction:

Palliative care services offer bereavement support to family and friends in the anticipation, death and subsequent adjustment to living following the death of a significant other (Christ, Bonanno, Malkinson, & Rubin, 2003). Palliative care nurses and other members of the professional care team provide invaluable, informal support to a patient's family, both before and immediately after the patient's death. This is an important contributor to the family's experience of bereavement, and the continuity between pre-bereavement and bereavement support (Milberg, Olsson, Jakobsson, Olsson, & Friedrichsen, 2008). Following the death of a patient, bereavement follow-up services have been shown to impact positively on grieving relatives' post-death adjustment, providing an opportunity for relatives to discuss the deceased, the illness and care provided, their own grief and other feelings arising from the illness and death of the patient; and for staff to assess the need for further support (Kaunonen, Tarkka, Laippala, & Paunonen-Ilmonen, 2000; Milberg et al., 2008). The World Health Organization (2003) considers bereavement support and follow-up to be integral elements that ought to be offered by all palliative care services. In Australia, 95% of all specialist palliative care services provide some form of bereavement follow-up service (Mather, Good, Cavenagh, & Ravenscroft, 2008). Most bereavement follow-up consists of written bereavement information and/or telephone support with a small number providing one-on-one counselling and/or group therapy (O'Connor, Abbott, Payne, & Demmer, 2009). In the context of specialist palliative care, the first bereavement contact usually occurs within two weeks of the patient's death (Mather et al., 2008).

The format and content of current bereavement follow-up practices vary widely both across and within cancer and palliative care services, with no gold standard approach identified (Collins-Tracey et al., 2009). Services are also often reluctant to contact grieving relatives if they did not know the deceased very well (Bromberg & Higginson, 1996). There is also some uncertainty about the ethical and legal status of providing bereavement support to next-of-kin, if they are not registered as service clients, and a perception that people most in need of bereavement counselling are not always contacted (Collins-Tracey et al., 2009). All of these factors, plus limited personnel, time, funding, and infrastructure resources, impact on the delivery of bereavement services (Collins-Tracey et al., 2009;

Mather et al., 2008; Remedios, Thomas, & Hudson, 2011). An added complexity may occur at a systems level, linking bereavement services with bereaved carers, to provide relevant information about existing services.

Aim

The aim of this retrospective medical audit was to map how one specialist palliative care service ('service') in New South Wales (NSW) Australia linked bereavement services to bereaved carers.

Method

Study design

Process mapping within one specialist palliative care service was undertaken to identify the systems that link bereavement services with nominated bereaved carers. A retrospective audit was undertaken of the services' three electronic and three paper-based data repositories containing next-of-kin information required for bereavement follow-up.

Ethics

Ethical and research governance approval for this study was granted by the relevant hospital Human Research Ethics Committee.

Setting

The study was undertaken in one specialist palliative care service in a large Australian capital city providing community and inpatient palliative care to more than 1200 patients annually. This palliative care service is part of a larger health service consisting of a co-located major public and smaller private hospital. A designated service coordinates bereavement follow-up across the campus while the Pastoral Care Team conducts a quarterly campus Memorial Service. Both services initiate written contact with the palliative care decedent's next-of-kin, based on the information provided by the specialist team at the time of the patient's death. In accordance with service policy, next-of-kin are to be linked with bereavement services. This contact is initially via letter or, if no postal address is

available, then via a home phone. An overview of the bereavement and pastoral care referral and follow-up process is summarised in Box 1.

Box 1: Overview of Bereavement Follow-Up Process

Service	Timeline	Process
Palliative Care Team	Within 7 days	The palliative care team identifies who requires bereavement follow-up at the multi-disciplinary team meeting.
Bereavement Services	Within 7 days	During the multi-disciplinary team meeting Bereavement Services staff add relevant patient and next of kin contact details onto the Patient Information Form.
	Within 4-6 weeks	Send standard letter plus Bereavement Services information pamphlet sent to next-of-kin nominated on the Bereavement Follow-up Form.
Pastoral Care	Within 8 weeks	Send Memorial Service invitation to next-of-kin nominated on the Bereavement Follow-up Form.

Data collection

The electronic (n=3) and paper-based (n=3) records of consecutive patients (N=60) who died in the community (n=20), and within the two inpatient units at the service (n=40), during a three month period in 2010, were audited. It is generally accepted that an audit of 60 patient records is sufficient to provide helpful insights into the strengths and weaknesses of a process or clinical practice (NSW Health, 2002).

A case report form was designed specifically to identify documented evidence of: i) identification of all next-of-kin documented as requiring bereavement follow-up; and ii) their contact details (name, relationship to decedent, phone and address). As there was scope within this service for one or two people to be nominated as the patient's legal next of kin, and for multiple people to be sent information about bereavement services, the case report form was designed to capture this information. The term decedent's 'next-of-kin' refers, in its broadest sense, to any person listed as the

next-of-kin or 'person to be notified' or 'person responsible' which encompasses at least one of the following relationships with the deceased: spouse (e.g. husband, wife, partner); blood relative (e.g. children, sibling); 'person(s) responsible' (NSW Guardianship Tribunal, 2007), or significant other (e.g. friend).

Prior to commencing the study, a small sample of decedents' (n=8) medical and bereavement service records were audited to assess the feasibility of the case report form and data definitions, allowing for refinement of the final extraction tool. An experienced researcher (MP) extracted all of the data from the electronic and paper data repositories in accordance with the audit protocol, adhering to the inclusion/exclusion criteria.

Data analysis

The captured data was entered onto the case report form and a formal monitoring of coding was implemented utilising a uniform approach to ensure inter-rater reliability. The data was entered into SPSS V.17. The Chi-Square test with Yates correction to account for the small sample was used to determine significant differences in proportions between several categories, while Fishers test was used for binary groups with a sample of less than 5. The Spearman statistic was used to determine correlations. Most outcomes are reported using descriptive statistics and *p* values are provided where appropriate.

Results:

Demographics

More than half (58%, n=35) of the audit sample (N=60) was composed of male decedents aged 73 years ($SD \pm 13.3$), with a primary diagnosis of cancer (80%, n=48). Three quarters (n=45) were aged over 64 years and died as a result of advanced cancer. Nearly all decedents (97%, n=58) had a nominated next-of-kin. The majority who died in the specialist inpatient setting (83%, n=50) had only one hospice admission and half (n=25) had also been cared for by the community team at home. The mean length of admission for decedents who died in the hospice was 16 days ($SD \pm 27$). The majority

of decedents who died at home (80%, n=48) had no inpatient palliative care unit admission, and were admitted to the community service on average 185 days ($SD \pm 233$) before death (Table 1).

Table 1: Inpatient and community decedent demographics and length of admission

Sample (N=60)		Inpatient decedents (n=40)		Community decedents (n=20)	
		n (%)		n (%)	
Gender	Male	21 (53)		10 (50)	
	Female	19 (47)		10 (50)	
Age in years	Mean (SD)	71.2 (± 13.8)		72.4 (± 13.8)	
Primary diagnosis	Cancer	32 (80)		13 (65)	
	Other	8 (21)		4 (20)	
Number of hospice admissions	0	N/A		16 (80)	
	1	33 (83)		3 (15)	
	>1	7 (18)		1 (5)	
Length of hospice admission (days)	Time from service admission to death (days)	Range	<1* – 609	2 – 862	
		Mean (SD)	75 (121)	185 (233)	
	Time from last inpatient admission to death (days)	Range	<1* – 162	N/A	
		Mean (SD)	16 (27)	N/A	

* One patient died on the day of admission.

Bereavement follow-up information

Bereavement service records were located for 80% (n=48) of all decedents, with records significantly more likely to be missing for community patients compared to inpatients (45% vs. 8%, $p=0.001$).

The date of death was missing in the information provided to Bereavement Services for over a quarter (28%, n=11) of inpatients. The mean length of time from the decedent's death until bereavement follow-up was 63 days ($SD \pm 19.6$). The most common form of follow-up was the provision of bereavement information and service contact details (85%, n=51) being posted to the decedent's nominated next-of-kin.

Across all data repositories, next-of-kin name, address and home phone number was correctly captured for a greater proportion of inpatients compared to community patients (80% vs. 65%). The electronic palliative care system contained the most accurate and complete next-of-kin information

Table 2: Documented next-of-kin and contact details: inpatient and community data repositories

		Electronic Data Repositories		Paper Data Repositories		
		Inpatient databases (a) and (b)	Palliative Care System	Admission Front Sheet	Nursing Admission Assessment (n=20) [†]	Patient Information Form
		N (%)	N (%)	N (%)	N (%)	N (%)
Completeness of NOK details	Inpatient	7 (18)	28 (70)	21 (52)	16 (80)	24 (60)
	Community	*	13 (65)	*	*	*
NOK - Relationship to patient	Inpatient	7 (18)	39 (98)	27 (68)	17 (85)	40 (100)
	Community	*	19 (95)	*	*	*
NOK - Address	Inpatient	35 (88)	28 (70)	25 (63)	‡	23 (57)
	Community	*	15 (75)	*	*	*
NOK - Phone	Inpatient	37 (93)	38 (95)	25 (63)	15 (75)	38 (95)
	Community	*	15 (75)	*	*	*

(a) NSW Health Database; (b) Organizational Inpatient Database; * Not applicable – repository not used in community service; [†] Nursing Admission Form had designated space for recording five NOK names and phone numbers, but is only used on one ward (n=20). [‡] No space for recording of NOK address in the Nursing Admission Assessment Form.

across both care settings: inpatients (70%) and community patients (65%) (Table 2). Only 10% (n=6) of decedents had complete contact details for next-of-kin (name, relationship, and contact address and phone number) captured across all data repositories. The accuracy and completeness of inpatient next-of-kin contact details in the six data repositories ranged from 18-80%, with the most complete and accurate source of next-of-kin information contained within the Nursing Admission Sheet (80%), compared to 18% in the main electronic inpatient databases. Nearly a fifth (18%, n=7) of inpatient decedents had incorrect next-of-kin details entered into the main electronic inpatient databases. A quarter of these errors (n=10) related to the patient's name, address and phone number being entered as that of the next-of-kin. This error was more frequent for decedents without a spouse, who lived alone, and/or who had no next-of-kin. Contact addresses were missing for a quarter (n=5) of the community decedents' nominated next-of-kin (Table 2).

People identified to be provided with bereavement information and service contact details

Bereavement information and service contact details were provided to a larger proportion of inpatient compared to community decedents' next-of-kin (89% vs. 64%). A total of 126 next-of-kin were identified by the palliative care services to be contacted by bereavement services. Just over half 54% (n=68) of these next-of-kin were contacted. The number of next-of-kin to be contacted ranged from one to five per decedent, with 81% of decedents having at least two next-of-kin identified for bereavement service contact. Adult children (65%, n=) were the people most frequently identified for bereavement follow-up. However, as a proportion of those listed for bereavement follow-up, spouses were more likely to have been contacted than adult children or other family members (84% vs. <75). Most decedents (83%, n=) had at least one of their nominated next-of-kin provided with bereavement information and service details.

The main reason why nominated next-of-kin were not provided with bereavement information was due to incomplete or missing contact details (n=57, 75%). A significant relationship between the completeness of the patient information form (inpatients only) and Bereavement Services having the contact address and home phone number of inpatient decedent's next-of-kin identified for follow-up was also identified, $r(36) = 9.3, p = 0.002$.

Discussion:

This bereavement process mapping study, conducted within one specialist palliative care service in metropolitan Sydney, Australia, has identified a number of missing data items and system barriers that prevent bereavement services from providing important bereavement support literature and service contact details for the recently bereaved. The most notable barriers related to missing next-of-kin contact details and a failure to consistently document essential next-of-kin contact details in a specific location. The proportion of bereaved next-of-kin not contacted as a result of incomplete contact details is greater than that reported in an international bereavement study (Milberg et al., 2008). Inaccurate or incomplete next-of-kin information makes it difficult, if not impossible, to provide bereavement information (Milberg et al., 2008). The proportion of people not provided with bereavement information was greatest for community decedents' next of kin. This is despite community decedents having their details captured in one electronic data repository, being known to the palliative care team for a longer period of time than inpatients, and being more likely to have had an admission to the inpatient palliative care unit. In part, this speaks to the dynamics of community palliative care, where the driver for capturing next-of-kin details is to identify the primary care-giver and emergency contact person as opposed to planning for their eventual bereavement care.

In the inpatient setting, having numerous data repositories holding next-of-kin information, added to the complexity of ensuring that the essential contact details were accurately captured, transposed and/or documented. Completing the next-of-kin information fields in various forms is predominately the responsibility of clerical staff and registered nurses. Given that nurses already spend approximately a tenth of their time charting information (McEvoy, 2000), manually duplicating next-of-kin details across numerous information systems adds to the administrative burden, detracts from the provision of hands-on care and increases the probability that this essential contact information will be incomplete or incorrect (Baker, Bodner, & Allman, 2003; McEvoy, 2000). Failure to nominate one data repository for capturing all essential next-of-kin contact information increases the likelihood that some of these details will be missed or inaccurately transcribed from one repository to another.

This process mapping exercise also identified a default setting in the main electronic information repository which automatically populates 'blank' next-of-kin fields in the electronic patient record system with the patient's name and contact details. Once populated the fields containing incorrect next-of-kin contact details are replicated across into the other electronic data repositories, perpetuating the error. These next of kin details appear to be rarely rechecked when the patient is readmitted.

Within the paper-based information repositories (forms within the paper medical records) there is limited space to document individual next-of-kin contact details. This limits the degree to which clinicians can routinely capture all of the necessary information required for prospectively managing timely contact with next-of-kin whilst the patient is alive, as well as capturing the necessary information for bereavement contact at a later date. When the patient is alive, the team's focus is likely to be on ensuring that they have access to all relevant next-of-kin name(s) and phone number(s), should they need to contact them urgently should there be a change in the patient's condition, with scant attention paid to the need for full postal and phone details essential for bereavement contact at a later date.

Similar to other studies, the decedent's adult children were most frequently identified for follow-up, but spouses were more likely to actually have been followed-up as a proportion of all those listed (Remedios et al., 2011). In our study, adult children were less likely to have been contacted, primarily because, unlike a spouse, their contact details were often not adequately captured in any of the information repositories. As all initial contact for bereavement follow-up is by written correspondence, if a contact address is unavailable, the Bereavement Service will endeavor to make phone contact via a landline during office hours. A reliance on written correspondence as the preferred mode of communication with decedent's next of kin may explain why the rate of bereavement contact provided in our study was lower than that reported by five large UK palliative care teams (56% vs. 67%). In the UK study, initial contact for follow up was predominantly via a visit (50%) or by phone (45%) and not by written correspondence (Bromberg & Higginson, 1996). The degree to which the local policy of not contacting next-of-kin via a mobile phone impacts on bereavement contact is not known, and worthy of further exploration especially in a digital era when

few people are electing to maintain a home phone line. If next-of-kin are employed or have other daytime commitments their chances of being at home when Bereavement Services call is also more limited.

A UK specialist palliative care service bereavement audit (n=4903) of referrals between 1989-2002, identified only 4% of next-of-kin were not contacted due to missing data (Relf & Lines, 2005). In our study, the majority of next-of-kin were provided with bereavement information within three months of the patient's death, which is in keeping with the UK public health bereavement model (National Institute for Health Clinical Excellence, 2004).

Implications for practice

To our knowledge there have been no studies that have assessed the systems that link bereavement services with bereaved carers. This bereavement process mapping exercise has identified a number of factors that impact on the capacity of health care organisation services to deliver an effective and equitable service to bereaved next-of-kin. The ability of palliative care services to link next-of-kin to bereavement services is dependent upon the provision of accurate and relevant next-of-kin contact details, particularly names, postal addresses, phone numbers, as well as information about their relationship with the deceased and the decedent's date of death. Providing bereavement service is particularly challenging when these essential details are missing from most forms and when no single form was consistently used to record these details. In addition, the inaccuracy of contact information could impact on opportunities for bereaved carers to be contacted about future palliative care research studies. However, some of these systems factors could be overcome if nurses' ensured that all decedents family and/or next-of-kin were provided with appropriate bereavement information, including where to access additional support, at the time of the patient's death or shortly thereafter. Nursing input at this time is a central element of a public health bereavement model.

Strengths and limitations

The single participating service and small sample size limits the interpretation and the generalisability of these findings. However, it highlights the assumption that bereavement contact details are

accurately recorded in patient records. The process mapping methodology adopted in this study may be useful to other palliative care services who wish to identify the strengths and gaps in their linkage with bereavement services. Addressing identified weaknesses and building upon the strengths will help specialist palliative care services to optimise the use of limited resources.

Conclusion

Having access to a designated bereavement service can ensure that bereaved next-of-kin are routinely contacted within three months of their loss. However, the effectiveness of any type of bereavement service is dependent upon the nurses and/or bereavement counsellors having access to all relevant next of kin information. Even within specialist palliative care services, where there is a designated service providing bereavement follow-up, there are numerous opportunities to refine and strengthen existing processes to ensure that the next-of-kin who need bereavement support are provided with timely access to this service. Nurses have a key role to play in ensuring timely bereavement support and care, which can commence from the time of the patients of death.

Without undertaking an audit of this magnitude, it is quite likely that many specialist palliative care services would be unaware of the many barriers largely related to data repository systems that may be inadvertently impacting adversely on the provision of bereavement support follow-up. Therefore, specialist palliative care services are encouraged to undertake a similar audit to identify and address any identified deficiencies.

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