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

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### ABSTRACT

**Background:** Bereavement follow up is an integral element of palliative care. However, little is known about the systems that link bereavement services with bereaved carers.

**Aim:** To map how effectively a specialist palliative care service linked bereavement service to bereaved carers.

**Methodology:** A retrospective medical audit, using process mapping was undertaken within one Australian specialist palliative care service to identify the systems that linked bereavement services to a consecutive cohort of palliative care decedents (n=60) next of kin.

**Results:** Bereavement records were located for 80% of decedents. Nearly all (98%) had a nominated next of kin, with just over half (54%) of those nominated contacted by bereavement services. Incomplete or missing contact details was the main reason (75%) that the bereavement service was unable to contact the decedents' next of kin.

**Conclusion:** Having access to a designated bereavement service can ensure that bereaved next of kin are contacted routinely and in a timely way. However the effectiveness of this type of service is dependent upon the bereavement service having access to all relevant contact information. There are numerous opportunities to refine and strengthen the recording of palliative care next of kin details to optimize follow up.

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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 link-

ing 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

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death and to ensure that families and next of kin are aware of where they can access future bereavement support should they require it.

**1. 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 et al., 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.

**2. 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.

**3. Method**

*3.1. 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 service's three electronic and three paper-based data repositories containing next of kin information required for bereavement follow-up.

**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.  |

*3.2. Ethics*

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

*3.3. 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.

*3.4. 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

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