A qualitative investigation of effectiveness and limitations of telephone bereavement support service in rural and remote NSW.

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Executive Summary

While grief is a normal and unique emotional response to loss, bereavement is the period of time where people grieve (Kaunonen et al 2000). Support during bereavement is considered an integral component of comprehensive palliative care (Palliative Care Australia, 2004) and yet, while the experience of grief is universal, providing equitable access and support in rural and remote regions is a major challenge for health services. Support needs of bereaved people vary significantly and there is considerable debate regarding what is the best evidenced based support model, what should be offered and by whom (Milberg et al 2008), (Roberts and McGilloway, 2008).

Jordon and Neimeyer (2003) and Schut and Stroebe (2005) suggest that providing formal bereavement support can be unhelpful and even potentially harmful as uncomplicated grief is probably self limiting and most people will adequately cope with their loss with the support of their family and friends. They claim that efforts should be concentrated on identifying and targeting support for those people at risk of complicated bereavement. On the other hand the National Institute of Clinical Excellence (NICE) (2004) recommends a three tier support model. Tier one clients require no formal support, tier two clients are adequately supported by a nurse or trained volunteer and a small group of people will require tier three support of professional counselling to meet complex bereavement support needs.

This qualitative study investigates telephone bereavement support provided by a trained palliative care volunteer based in the regional city of Dubbo and servicing rural and remote regions of north western New South Wales. The study looks to examine whether a bereaved person, assessed as likely to experience an uncomplicated bereavement following a significant death, found the support helpful and what its limitations were. Recently bereaved

people were identified from the palliative care data base and recruited to participate in a semi-structured recorded interview with the researcher. Data from nine interviews plus one letter of response were analysed using a thematic approach to research methodology. This study further provided valuable data to inform discussion on the effectiveness of the currently used model of bereavement support and the implications for future service delivery. It has also highlighted the need to assess and improve the services capacity to identify and support the minority of bereaved people who may experience a more complicated grief response.

Findings from this study support the provision of telephone bereavement support by a trained volunteer in relation to;

- Normalising of grief responses through a process of validation that grief is an individual and unique response to a loss,
- Normalisation of grief by receiving support from an 'ordinary lay' person who has an understanding of nature of grief,
- Providing a conduit of reliable, convenient support and continuing care from the Palliative Care Service during a period of adjustment to a significant death,
- Improving bereavement support for people challenged by geographical, financial and social access to the bereavement coordination site,
- Providing independent support outside that offered by family, friends, social and spiritual networks,
- Providing a degree of anonymity and confidentiality that facilitates a greater expression of emotions through the use of a telephone,
- Increasing awareness and identification of those bereaved in need of referral for professional support.

Two distinct limiting factors were identified:

- A sense that receiving support by telephone may inhibit the level of disclosure,
- Support by telephone may limit the comfort gained by a physical presence.

This study has confirmed that not all people will require bereavement support from Palliative Care services. It has also provided the opportunity to review and create practice changes to the current model of bereavement support by implementing;

- A bereavement information package be made available to all bereaved people early in their bereavement and independent of whether they receive telephone bereavement support,
- A formalisation of bereavement risk discussion in multidisciplinary patient care planning meetings in order to assist in the identification of those most at risk of a complicated grief response in order to secure timely and appropriate bereavement follow up,
- Trial the use of a recognised Bereavement Risk Assessment tool to further identify those people most at risk of complicated bereavement,
- Offer bereaved people the option of either face to face, telephone support or both but in consultation with the service providers,
- Bereavement education and training be made available for all health staff involved in the provision of palliative care and bereavement support,
- Clinical supervision is provided on a regular basis.

This study highlights the complexity of providing bereavement support in rural and remote regions and supports current literature suggesting that there is no single best practice model of bereavement support.