

Conclusion

If you are considering implementing a web-based survey and are worried about validity (compared to paper-based surveys) I have some simple advice for you: relax. There is little evidence that the simple fact that your questionnaire form is displayed on a computer and that respondent must manipulate a keyboard and/or mouse in order to respond will systematically bias the responses. In the cases where a difference has been detected, very few authors have identified empirically testable hypotheses for why that might be so. (Some have, but have not proceeded to test them.)

That doesn't mean that you can relax about everything, of course. You still have to worry about all the things a questionnaire designer normally worries about. In particular, if your research question is important to you, you still need to test your instrument before deploying it, and in particular consider doing 'cognitive interviews', i.e. asking people to tell you what's running through their mind while they're filling out the form.

Finally, consider reading the 'Bible' of questionnaire survey research: *Internet, Mail and Mixed-Mode Surveys*, by Don Dillman and colleagues.⁴ There are many, many books on this topic, but this is the best one I've read, and previous editions seem to be the most widely cited. If you can read nothing else on this topic, read this.

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A public health approach to bereavement support services in palliative care

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The philosophy of palliative care emphasises support for the patient during illness and support for family carers before and after the patient's death. Palliative care services provide the most comprehensive strategy for bereavement support in our community. Most Australian palliative care services offer bereavement support services, often regardless of risk or need.^{1,2} However, the majority of bereaved people manage their grief with the support of family, friends and neighbours and it is only a small proportion, about 10 to 20%, who experience persistent psychiatric difficulties, including Prolonged Grief Disorder (previously known as Complicated Grief Disorder), and who benefit from professional intervention.³ As such, there is a need to question current models of bereavement support, which have a tendency to pathologise grief by implying a need for psychological or psychiatric interventions for all bereavement in palliative care. We argue that the application of a public health perspective to bereavement in palliative care provides a systematic and evidence-based framework for meeting the needs of bereaved family carers while reducing economic and staffing constraints on palliative care services.

The public health literature typically identifies three levels of intervention that target different populations – universal (for the whole population of interest), selective (for groups at high risk) and indicated (for people showing signs of disorder). Similarly, in bereavement care generally, preventive interventions for bereavement may be divided into three target groups: primary – targeting all bereaved people; secondary – targeting people at risk of complications of bereavement; and tertiary – targeting people with complicated grief.⁴

These levels of intervention are supported empirically by a critical review of bereavement efficacy evaluation studies⁵ and a meta-analysis of 61 outcome studies indicating that bereavement interventions for those with 'normal' grief tend to be ineffective, unnecessary and even harmful.⁶ Recent empirical studies demonstrate support for targeted interventions for people who meet the criteria for Prolonged Grief Disorder.^{7,8} To assume that grief always merits a professional response may be to introduce iatrogenic effects and marginalise the support available to them through their local community. From our perspective, the restriction of specialist and

non-specialist intervention is not short-changing people because of scarce resources, rather it would provide best-practice care that is likely to be more readily accessible. However, the literature also reveals that health and social care interventions are effective when targeted to those who need them such as griever with higher levels of distress, including those who need specialist interventions for clinical symptomatology such as Prolonged Grief Disorder. Providing high-quality bereavement care to those with complex needs and those at risk of complex needs may prevent further pathology and significantly reduce use of health services, particularly visits to general practitioners for fatigue, immune suppression, sleep disturbances and mental health issues⁹.

UK palliative care bereavement services

The National Institute for Clinical Excellence¹⁰ (NICE) in the United Kingdom proposed a similar three-tiered approach to bereavement in palliative care according to the needs of carers and families (Table 1). Based on cancer or expected deaths, the model advocates that all the bereaved people should have access to information about bereavement and relevant available supports (Component 1). The information would be delivered by the palliative care service involved in the care of the patient and family, with much of the support coming from the bereaved person's social networks, including compassionate family and friends. Just over one-third would in addition need more formal opportunities to consider their loss (Component 2). This component would be provided by non-specialist social and therapeutic support such as volunteer bereavement workers, bereavement mutual-help groups, and faith-based and other community groups. A smaller proportion, 10 to 12%, would need specialist intervention such as counselling, mental health services, bereavement services, or psychotherapy (Component 3) to supplement Components 1 and 2, or because these levels of support are not available to them. For some people, Component 3 may be required while Components 1 and 2 are mobilised. Referral pathways must be available between components as needs change and emerge.

Results from an audit of bereavement support provided to carers in a UK hospice provide empirical support for the three-tiered approach outlined in the NICE and public health models. The Sobell House hospice in Oxford, UK, analysed retrospective data on risk assessment and type of support provided for its bereaved carers between 1989 and 2002¹¹ (Table 1). Of 4,903 referrals, 54% did not access additional support, 33% accessed trained volunteers, and 9%

accessed bereavement staff and other professionals (missing data comprised the remaining 4%).

The way forward

A public health approach to bereavement services in palliative care offers the foundation for determining the types of bereavement services and supports offered to carers and families, depending on their needs and risk factors. It is clear that offering professional support to all bereaved people is unlikely to be effective, let alone affordable, and that it can be counter-productive for those not in the high-need group. For instance, unnecessary intervention may disrupt the natural course of grieving and the presence of interventions could trigger a loss of social support if friends and family withdraw from the bereaved as a result of their receipt of professional services.⁴

In proposing a public health approach to the provision of bereavement supports and services in palliative care, we are guided by the dual imperative of meeting the needs of bereaved carers and family members while remaining cost-effective. Importantly, the model provides an evidence-base for the allocation of appropriate resources in meeting the needs of carers, as currently there is a lack of clear evidence to guide development and allocation of bereavement programs in palliative care.¹ This point is emphasised in recent Australian clinical practice guidelines for bereavement support in palliative care.¹² The Commonwealth Department of Health and Ageing in Australia (and similar funding bodies elsewhere) has a finite pool of funding to spend on bereavement care so determining who should benefit from the three groups of bereaved people identified in the model in Table 1, and how they should be serviced is of utmost importance for equitable resource allocation.

A public health model to bereavement care suggests that all hospice and palliative care services should offer Component 1 to all families, regardless of whether the patient dies at home, hospice or hospital, but reserve access to Components 2 and 3 according to identified need. Furthermore, all members of the palliative care team would benefit from training to recognise need and be able to refer appropriately to services offering Components 2 and 3.

To move forward with a public health model of bereavement support in palliative care we need to work in partnership with primary care health professionals. General practitioners (GPs) play a vital role in the care of bereaved people,^{13,14} with 75% of GPs in Australia reporting engagement in palliative care and regularly seeing

Table 1: A three-tiered model of bereavement care.

Level of Public Health Interventions	NICE Components	Type of Support	Support provided by	Target Population and Level of Support Needed	Proportions Bereaved (Sobell House Hospice in UK, 1989-2002)
Universal	1	Information about bereavement and relevant supports	Family and friends (information supplied by health and social care professionals)	All bereaved (normal grief) Low level of need	54%
Selective or Targeted	2	Non-specialist support	Trained volunteers, mutual-help groups, community supports	Those at-risk of developing complex needs Medium level of need	33%
Indicated	3	Professional specialist interventions	Mental health services, bereavement services, or psychotherapy	Those with complex needs High level of need	9%

family caregivers as patients¹⁵ (for comparison, between 66%¹⁶ and 80%¹⁷ of GPs in the UK offer bereavement support). There have also been calls for more involvement of community pharmacists in the palliative care team.¹⁸ Both GPs and community pharmacists, however, have expressed a need for further education and information on the psychosocial aspects of palliative care, particularly after bereavement.^{19,20} A public health approach to bereavement support in palliative care requires partnerships between palliative care services and primary care practitioners, and also strong links with community groups and services. Drawing and building upon community resources already in existence such as mutual-help support groups, volunteers, and community workers²¹ will ensure that initiatives are cost effective and sustainable.

For referral partnerships to materialise, GPs need to be aware of community resources and those resources must be able to demonstrate their credibility and appropriateness to receive referrals. As an example in Australia, the capacity to keep up-to-date with the availability and credibility of referral resources could be managed by the Divisions of General Practice. If GPs are able to attend to bereavement directly, through appropriate responses and referrals outlined in the public health approach, we would expect to see fewer consultations that arise from somatised loss. Hence, what is proposed is reorienting or redistributing current resources rather than necessitating new costs.

A further strength of the model, with its focus on community partnerships, is its application to bereavement for conditions not receiving palliative care, such as some non-cancer conditions or unexpected deaths. It is possible that the bereavement support needs in palliative care are different to other bereavement support needs. There are indications that proportions of bereaved people with complex needs are somewhat higher following bereavement from suicide²² and neurodegenerative disorders.²³ Widening the scope of bereavement care may require additional resources, at least initially, although even in the short-term the model facilitates the targeted use of current resources without relying on an increase in funds and staff.

It is imperative that we move forward with a robust program of research to ascertain the proportions of bereaved people in Australia in need of the three components of support (information and compassion; non-specialised support; and specialist intervention) so that a range of community-based programs meeting the needs of bereaved people can be developed, offered and evaluated. We need research that bridges the gap between research and practice. Two critical issues are the need for valid and reliable assessment of bereavement support needs²⁴ and the ability to evaluate bereavement interventions²⁵ so that palliative care services are confident in offering the appropriate supports to bereaved family members, relative to need.

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