Letters to the editor

A review by Malcolm Payne of the book *Guidance for Bereavement Needs Assessment in Palliative Care* was published in the last issue (Winter 2008 27[3] 60). Here we publish a response from the authors of the guidance, preceded by the points at issue in the review, a further response from the reviewer, and a commentary from the BC editors.

Editorial comment

We have chosen to publish the debate that followed Malcolm Payne's review of *Guidance for Bereavement Needs Assessment in Palliative Care* because it raises issues of considerable practical and ethical importance. Is it ethical and practical to assess bereavement needs and to provide proactive support to bereaved people? If, as current research indicates, most people neither need nor benefit from traditional forms of bereavement support, whereas there is a minority who both need and will benefit from the right interventions, then some form of systematic assessment would seem to be essential if we are to continue to offer such services. Indeed, it would be a waste of resources to offer services without such an assessment. Malcolm Payne raises important questions about who should make such assessments and how this can be done without stigma and with the full understanding and consent of those to be assessed.

Self-referral has not been shown to be a reliable method of assessment, although it is true that those who refer themselves are better motivated to accept help than those who have not asked for it. The idea that measures of resilience are good because they emphasise positives fails to recognise that low scores of resilience are likely to be just as negative in their implications as high scores on symptoms or distress. Even measures of coping styles are not free of prejudicial implications.

The most powerful predictors of both bereavement need and service benefit that have emerged from recent reviews are indicators of intense and lasting distress (which may result from anger, depression, fear, or grief) in individuals and, sometimes, families. People with such distress may not ask for help, for a number of reasons, but they can usually be recognised without intrusion and most are happy to accept help if it is offered.

The editors would welcome further correspondence on these issues.

CMP

Points from the review

'This … guide is a renewed attempt to construct a tool to identify people needing bereavement services for help at an early stage, claiming a shift in approach from risk to coping styles. However, loss and coping as a conceptual base for bereavement work has been criticised for labelling and individualising grief as a 'risk' to psychological stability just as much as the old risk assessment tools… 'Need' is about people's deficits. Therefore, this bereavement needs assessment still focuses primarily on negatives: people are classified as combinations of overwhelmed, vulnerable or controlled; resilience is the only positive option, perhaps combined with one of the others. This method of assessment continues to raise the same ethical issues as previous tools: ie. that healthcare staff are supposed to observe, often without informed consent, the behaviour of relatives of dying people, who are therefore not patients and may not feel any bereavement need. Inpatient and community hospice staff are busy with care and treatment, and distressed family members may be outside their orbit. Therefore, the ability to make helpful observations on grief behaviour is likely to be patchy… Full implementation of these methods has considerable resource implications… most people die in care homes, or helped by community health services or accident and emergency units, where this guidance does not aim to help and would need considerable adaptation.'

Authors' response

We would argue that Malcolm Payne's review of this publication is misleading in a number of points. He assumes that the guidance is for general use, whereas it was commissioned by the UK umbrella organisation Help the Hospices specifically for palliative care where 'best practice' includes family and bereavement care (WHO, 1990) and where 'distressed family members' are very much within the orbit of care.

Furthermore, UK national policy recommends that family/carer needs should be assessed (NICE, 2004; Department of Health, 2008) and it is common practice for bereavement services to reach out to those whom staff identify as likely to have a more difficult and problematic period of grief, with nearly half using formal assessments such as risk factor checklists (Field *et al,* 2004). This approach sits alongside giving people information and access to bereavement services (Field *et al,* 2004) but recognises that vulnerable people may be less likely to seek support (Stroebe *et al,* 1993; Kissane & Bloch, 2002).

The guidance proposes a conceptual move from recognising 'risk' to understanding different ways of 'coping'. While there are clear challenges in appraising coping, it nevertheless shifts the attention from fixed (mostly external) risk factors to a more dynamic interplay of internal and external factors and collaboration with people in reaching a view of how they are managing their situation. Rather than consisting of four unrelated elements, as Malcolm suggests, Machin's (2009) range of response to loss (RRL) model recognises the dynamic interaction between grief responses and coping. The matrix provides a way of mapping these interacting elements to help staff understand an individual's style of coping and whether they may be more resilient or more vulnerable. The responses of being more overwhelmed or more controlled are not in themselves negative but part of the way grief is expressed, and vulnerability and resilience are part of a spectrum of external and psychological factors. In practice, this approach appears to be a helpful way of tailoring support to the needs of relatives and carers pre-bereavement as well as making decisions about offers of continuing support from a bereavement service. It fits well with the current focus on care standards that sees integration as fundamental to an interdisciplinary approach to assessment.

In his final paragraph, Malcolm looks more widely at bereavement care services. While the guidance does not focus on non-palliative care settings, we should point out that the central concepts, the RRL and the adult attitude to grief scale (AAG), were developed in community settings and have been tested and used in community health settings. The AAG is increasingly used in reactive bereavement services to map individual grief experiences of those who self-refer.

Malcolm is correct in pointing out the considerable resources needed to make decisions about the use of bereavement services in proactive settings. Assessment relies on staff having knowledge and skills to inform their clinical judgements, and on organisations being explicit that assessment is family-focused, whatever approach is adopted. One of our aims in writing the guidance was to raise issues for a more informed debate about what is involved in putting assessment policies into operation. There is a growing demand for tickbox assessment tools and we believe the guidance provides an alternative, more practice-based approach. Currently the guidance is being piloted in three different palliative care settings, using an action research method to develop in-depth understanding of the practicalities of applying the concepts in routine practice. This research will help to clarify the organisational issues to which Malcolm refers and we will share our results and continue the debate. ◼

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Reviewer's response

My review, by which I stand, reflects an alternative conception of bereavement care to that of the authors. Sociological analysis sees grief as a natural human, though not universal, phenomenon, and bereavement as formed by social and cultural expectations (Howarth, 2007). Holloway (2007) expresses disappointment about the focus on intra-psychic processes and emotional response in bereavement care. We need to integrate in bereavement care the idea that most bereaved people are entirely reasonably negotiating a pathway through the social expectations made of them in a new set of social relations and we should avoid labelling them unnecessarily as 'at risk' or 'in need.'

The review points out that the guidance comes from a palliative care background, is published by a hospice infrastructure body, Help the Hospices, and is useful in those settings. A *Bereavement Care* review needs to comment for a wider audience, and I took on the review as someone concerned with bereavement care management and policy, commenting on whether this hospice-focused guidance should be adopted within hospices and more widely.

The documents cited show that bereavement care is supported by government policy as an important service in end-of-life and palliative care, but do not support the aim to assess bereavement needs of relatives of all hospice patients, as the guidance (see flowchart p22) envisages, let alone those in wider populations. Paragraph 12.30 of the NICE guidance on supportive and palliative care (2004) says information provision will be enough for most people. Its evidence review comments: '… individual clinical judgement is currently the most effective way of identifying those at risk, as risk assessment tools cannot be relied upon as a predictor of outcome' (para 12.53). The Department of Health's End of Life Care Strategy (2008) mainly focuses on supporting carers in wider services, not hospices. It proposes that everyone should have access to, but not necessarily be assessed for, bereavement services.

Stroebe, Shut and Strobe's (2007) recent extensive systematic literature review looks at similar categories as the NICE guidance, saying: '… primary prevention may be helpful when the initiative is left to the individual.' This is because positive results are shown mostly in studies where the bereaved person asks for help. Where there is risk, Stroebe *et al* say: '… improvement in assessment of empirically based risk factors are essential for better results to be achieved.'

To achieve this, the guidance proposes assessment by a practitioner caring for the dying patient of known relatives to determine bereavement need prior to referral to a bereavement service. This is 'to inform decision-making so that we can make the best use of our bereavement services and offer the right help to the right people' (p2). However, it forcefully rejects rationing by not giving help to those who ask for it, and encouraging people who refuse services to come back. That covers everybody, so it seems that the only impact on decision-making about targeting services will be the small gain of 'proactively offering services to those considered to be vulnerable' (p15).

The guidance outlines problems with assessment schemes, some mentioned in the review: only selected relatives can be assessed and staff may not have useful information and may not be focused on bereavement during their work in the dying phase.

The guidance covers ethical issues about managing information, but takes for granted that bereaved

people have given consent when they were carers for the use of this instrument because the general philosophy of palliative care is to care for the whole family (p15). Hospices and other services need to be careful about informed consent. Much of the assessment will be based on nurses' recollections of people at a time of great stress in their lives. Even when a carer is interviewed, it may not be transparent that being encouraged to tell their story (the recommended approach) will lead to the information being used to categorise them as some combination of overwhelmed, vulnerable, controlled or (the only clear positive) resilient. The guidance recommends assembling many other documents as part of the assessment. I doubt that service users who chose to exercise their rights of access to the records would feel that they had given informed consent to the collection of this material and the deficit language of the assessment.

The informed consent issue is more important because the evidence is that most people going through the normal social processes of grief and bereavement will not need more than information. It also seems that the needs assessment will not guide decision-making about the service they receive, because they can take or refuse services and this will be accepted. Using, without clear consent, a negatively-phrased instrument requires extremely strong justification of its capacity to discriminate between people to achieve important service outcomes, which we do not have for this or other assessment instruments.

The resource issue is also important. Expending resources on training a high proportion of hospice staff for an occasional assessment role has to be justified. Many health and social care practitioners involved in care for the deceased person will also have useful information untapped by this process, another weakness in a hospice needs assessment.

So my overall view, expressed in the original review, is that it is better to develop well-respected services, put time and resources into really good information and regularly offer the service so that people can actively decide that they want it. When they do, bereavement service practitioners themselves can listen to the story and agree about needs in a therapeutic relationship to which the bereaved person has clearly consented. A transfer of helpful information from staff involved in caring for the dying person is also useful, if the bereaved person agrees. I'm sure they will, but they should be asked because they are not the patient who originally consented to hospice care. All the aims set out in the guidance (p3: Rationale for assessing need) can be met without this assessment stage being interposed between family care in the dying phase and bereavement care afterwards.

I welcome the opportunity of thinking again about this review as a point at which we can all debate how assessment in bereavement care should move forward. ■

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