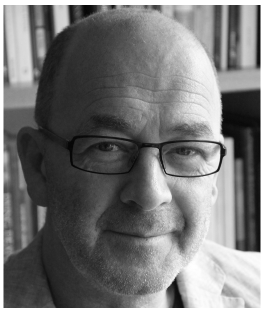
Challenges in evaluating adult bereavement services



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Abstract: Evaluating the effectiveness of bereavement interventions presents major theoretical, ethical and practical challenges. Based on the extensive research experience of the authors, this article outlines some of the key considerations that must be addressed when seeking to demonstrate the effectiveness of an intervention. These include what methods to use, the recruitment of participants, what to measure to demonstrate effectiveness, adapting measures to reflect cultural and other diversities, and how to deal with variables likely to influence the delivery and outcomes of the intervention.

Keywords: Evaluation, efficacy, outcomes, measures, assessment instruments

A shared goal of practitioners and researchers in the field of bereavement is to provide the best care for people who have lost a loved one. Working toward this goal, we face numerous challenges, not least those to do with the basic question: is intervention by caregivers really effective?

Raising this question brings others to the fore. By what standard can we say that care is effective? Do researchers actually know enough about the efficacy of bereavement intervention? Do researchers do enough to disseminate and implement their findings? Do service providers do enough to keep up to date with scientific findings?

At this stage in the development of research into the evaluation of the efficacy of bereavement interventions, it seems timely to take stock, to give consideration to such issues of theoretical and/or practical importance. Our aim here is to describe and discuss some of the main challenges that we have encountered as researchers in this field.

Even before we start, one difficulty arises in defining the range of bereavement care services: what should one include or exclude in evaluating their efficacy? Grief intervention is a broad term, and relevant services cover a wide range of provision, delivered in various forms (eg. face-to-face or through the internet; in groups or individually; by trained professionals or volunteers etc). They include crisis intervention, psychological debriefing (telephone and home visiting services), self-help and peer support groups, hospice care programmes for the bereaved, writing interventions, paraprofessional and professional counselling/therapy, and support from psychologists, social workers, nursing and pastoral staff.

The discussion in this article applies, in principle (as not all services have been scientifically evaluated) to this broad range of organised or institutionalised help. It does not focus on the usefulness of informal help (from family, neighbours, friends etc). Nor does it focus on the special case of intervention for children, although some of our points may be applicable (see also Rolls, this issue). It also excludes interventions not specifically aimed at ameliorating grief (eg. palliative care for the dying patient, which may have positive effects on their survivors too).

Nevertheless, we cover a broad range of interventions, which raises the possibility that some of the challenges we consider may not be equally applicable to all of them. This should be borne in mind when reading this article.

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Conducting efficacy research

One of the initial challenges facing us is whether we really need to establish the efficacy of bereavement intervention at all. It is not unusual for researchers to come up against considerable resistance to this idea. Is such research really part and parcel of the humanitarian offer to help bereaved people in need? After all, these types of support have been in place for years and improvements have been made over time, based on prior experience and the accumulation of knowledge. People firmly believe that these interventions work – is that not sufficient?

But providing support is usually costly not only in financial terms but also in terms of human resources. Related to the last point, to obtain resources for bereavement care, governments and other funding agencies need to be convinced that they are putting their money where it is going to be useful. And it is easier to convince organisations to spend money on care that has been shown to be effective by contemporary scientific standards than on interventions that have to be taken on trust or belief. Another reason is that, without sound evaluation, not only is it not known whether the intervention is effective, but also whether it has harmful side-effects. Therefore, we must question whether it is actually ethical to provide any type of care that has not been proved effective.

If we agree about the need for evaluating intervention efficacy, the next concern is to establish what the intervention can actually be expected to achieve. At the outset, we need to understand that grief intervention cannot take away all the suffering and pain that comes with loss: it is often claimed that grief is the price we have to pay for loving someone. The aim must be more modest: to protect the bereaved from unnecessary consequences of loss. The question immediately becomes more nuanced: what are unnecessary consequences and who suffers these particularly? Who can be helped, under what conditions, and at what point in time following bereavement? These are challenges to which we return later.

Furthermore, if we want to establish whether intervention helps, we need to decide on valid indicators of helpfulness. Caregiving professionals often use their training, experience, intuition and insight to assess when their intervention has been effective. They may be correct in their assessment. However, this alone does not prove that their intervention has brought about the improvement. In Parkes' words (2010, p1): 'Intuition is notoriously fallible, and our clients may find it hard to tell us if we are not much help'. Adaptation takes place naturally over time (cf Bonanno, Wortman & Nesse, 2004); the bereaved person might have improved at the same rate without intervention. Caregivers may also base their judgment on client satisfaction, an indicator frequently mentioned in the context of intervention evaluation. Of course, client satisfaction is important, but satisfaction is not a good gauge of effectiveness.

An illustration may make the above point clearer. Gallagher, Tracey and Millar (2005) have shown that former Cruse clients were very satisfied on a number of important dimensions six weeks after their counselling ended. These bereaved people felt their loss less intensely, experienced fewer physical symptoms and generally felt better. However, their point of reference for their level of distress and grief is earlier in time, closer to the loss, when bereaved people in general would experience higher intensities of such symptoms. How can one know that the improvement has to do with the intervention itself? Again, it could be that they would have improved at the same rate without this help. It could even be that they were actually worse off through the intervention, compared with people who did not receive this intervention.

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The effects of the intervention can only be assessed by comparing these clients with a group of similar bereaved people who have not received Cruse help, at the same points of time in their bereavement. We need then to distinguish carefully between satisfaction with and effectiveness of intervention. In answering the question, 'Does intervention help bereaved people to adjust to their loss?', we need to restrict investigation to the latter. However, we need to keep in mind that, for an intervention to be (shown to be) effective, it is necessary to follow up clients who participate in the whole intervention programme, and clients who are satisfied with the service they are being given are less likely to drop out.

The different viewpoints outlined above can potentially cause conflicts between researchers and practitioners. For example, one emerging challenge for researchers is to help practitioners understand the necessity for studies of effectiveness rather than just satisfaction. This may go against the tradition in counselling and therapy and be greeted with considerable scepticism. Another understandable reluctance that practitioners sometimes express is having their own work evaluated, assuming that the researchers will assess how well they are doing their job, which can be quite threatening. It is important for them to realise that evaluation of the sort necessary to establish the efficacy of bereavement intervention does not involve individual counsellor/therapist assessment and evaluation. Here the focus is on the efficacy of the intervention service in general. But, given this, there is a major challenge for the bereavement intervention organisation itself: those involved need the courage to, so to speak, put their heads on the block and submit their intervention programme to empirical test, which brings with it the risk of it being shown to be ineffective.

These potential difficulties could create barriers between researchers and practitioners, and jeopardise the collaboration that is, in our view, essential for conducting high quality intervention efficacy studies. To set up the best evaluation study, researchers need the insights and experience of the counsellors/therapists who will conduct the intervention (eg. to contribute to the design of the most appropriate instruments of assessment; to jointly administer the research project); they need them to bring their unique '3 C' skills to the enterprise: creativity, critical reflection and communication. The research endeavour cannot and should not be a one-sided assessment by outside researchers imposing their limited perspective on the bereavement service and practitioners.

An example of how the voluntary bereavement support organisation Cruse Bereavement Care Scotland and the University of Utrecht joined forces to overcome some of the above challenges can be found in this issue (see Newsom *et al*, this issue).

The role of research in practice

The collaboration mentioned above can begin with an exchange of information about the design of the study that is to be scientifically evaluated. It should be possible for researchers to use their knowledge base on the efficacy of intervention to guide the design of these programmes and for practitioners to adapt their models of care accordingly, to increase the likelihood of them being (evaluated as) effective. Indeed, considerable consensus has been reached among reviewers of the scientific body of research regarding a major question: for whom is professional intervention effective? Research has shown that intervention is not effective for the bereaved in general, but is effective for those at high risk or for those who are already experiencing complications in their grief (see Currier, Neimeyer & Berman, 2008; Schut *et al*, 2001).

There is also sufficient evidence to show that unsolicited help based on routine referral and delivered shortly after loss is not likely to be effective (Schut, 2010). Using such scientific knowledge when designing the intervention programme might increase the likelihood that an evaluation will show positive outcomes. However, we should not lose sight of the complex ethical issues that adopting such strategies may raise, even if they are scientifically-based. For example, although inreach (the bereaved person seeking help themselves) is associated with better intervention results than outreach (an organisation offering help to the bereaved person), a service that only responds to requests for help may exclude those who are, for various reasons, unable to seek professional support (Walsh *et al*, 2008). Against this argument, we need to consider whether professionals disempower bereaved people if they reach out to them (cf Dyregrov, 2005). Practitioners and researchers need to come together to discuss and find the best solutions to such complex puzzles.

It also needs to be recognised that scientific guidance is not always available. First, there are ongoing controversies among scientists – most noticeably in the current context, between Larson and Hoyt (2007; Hoyt & Larson, 2010) and Neimeyer (2000; Currier, Neimeyer & Berman, 2008), who come to different conclusions about certain aspects concerning the efficacy of bereavement intervention programmes, based on their reviews of the scientific literature. (Their arguments are set out in full in *Bereavement Care* 2010, 29(1).) Such debates may further the scientific enterprise but, naturally, do not convey a clear message to practitioners about the efficacy of intervention.

> To set up the best evaluation study, researchers need the insights and experience of the counsellor/therapists who will conduct the intervention

Second, there are huge gaps in our knowledge. Again in the current context, a relevant example concerns those people who can be regarded as 'at risk' of poor bereavement outcomes. Some factors have been too little researched, although there is a growing body of research identifying risk factors including, among others, circumstances of the death, personal characteristics and coping strategies (Stroebe, Schut & Stroebe, 2007). It would seem relatively easy to use this information to identify at least some appropriate risk groups for intervention, and indeed efforts are currently being made to develop measurement instruments (eg. the matrix described in Relf, Machin & Archer, 2010; the ICI described in Newsom *et al*, this issue).

However, risk factors influence bereavement outcomes in complex ways and they interact with each other. This makes it extremely difficult for researchers to develop and test the quality of screening instruments for allocating bereaved people to risk categories (we return to this discussion in the next section). Given that we need to target people at risk (since they are more likely to benefit from intervention), a well-validated risk factor screening instrument is precisely what is needed for designing and evaluating an intervention. We need to acknowledge the limitations outlined here and work towards improving the knowledge base.

Design and measurement issues

In scientific terms, what is needed to establish the efficacy of a bereavement intervention programme is an investigation using a randomised controlled trial (RCT). This is a study in which people are allocated at random either to receive the intervention (or a number of different interventions) or not to receive any intervention (the control group). Quantitative measures are taken to compare the outcomes of the participants in the intervention with those of the control group.

A main challenge here is the recruitment of bereaved people to participate in such an evaluation study. A substantial minority of bereaved people typically agree to do so, motivated by, for example, the thought that their participation may help other bereaved people in future, or by their willingness to share their experience with 'experts'. Researchers need to consider carefully whether these self-selecting participants are representative of the bereaved in general (are they perhaps the ones most affected by their loss? Or are they the ones who are feeling strong enough to participate in the extra assessment, beyond the intervention that they are receiving?).

An even more difficult issue, one of major ethical relevance, concerns assignment of bereaved people to the non-intervention control group. Can we really refuse to provide intervention to those who want and need it? This brings to the fore the delicate balance of scientific versus clinical interests, and options need to be carefully weighed. One strategy, which is quite often adopted, is to make the control group into a waiting list: those in this group will receive the intervention later, once the evaluation has been completed (for examples, see van der Houwen *et al*, 2010; Wagner, Knaevelsrud & Maercker, 2006).

However, this is difficult to implement, because these bereaved people are likely to be waiting a long time for the intervention. It is essential to include longer-term follow-up investigation of the impact of intervention (Schut, 2010). This is necessary not only to compare speed of adjustment (if the intervention is effective, those receiving it should have lower scores than the control group sooner after bereavement on, for example, acceptance or grief intensity) but also to see whether this relatively swifter improvement is maintained across time. Thus, those in the waiting list control condition would have to wait some months before starting their intervention. This strategy, then, needs careful consideration by all involved in the design of the evaluation.

An additional challenge in developing an evaluation study concerns the inevitable differences in how counsellors apply the intervention programme. Any counselling relationship is a unique interaction between practitioner and client. Practitioners will also provide a specific bereavement programme in different ways, depending both on the individual practitioner and the client. This needs to be taken into account when evaluating outcomes of an intervention. One way to deal with this is to create a systematic account of the main differences in how the programme is applied in routine practice. Such differences can include factual information, such as the number of and length of sessions, but also such issues as the client and counsellor's views of the quality of the therapeutic relationship. Such variables can then later be used to analyse the impact they may have on the outcomes of the intervention.

> We need to find the measures that are most likely to identify improvements due to the intervention. This is no easy task

We have earlier discussed the development of the risk assessment screening instrument for those participating in the intervention (the intake assessment instrument). We also need to decide which additional measures to include in order to be able to assess the impact of the intervention (note, there may be overlap between these two assessment instruments). These are typically administered before the intervention, after it and at follow-up point(s) later in time. What should be included? Which mental and/or physical health indices? A measure of grief intensity? Anxiety, depression or PTSD? Maladaptive coping strategies? Do we need to go beyond health indices to social/work functioning or resilience? Or a clinical assessment using DSM-5 criteria? Or back to basics: evaluating acceptance of the loss, a sense of control, feeling one can cope, loneliness?

We need to find the measures that are most likely to identify improvements due to the intervention. This is no easy task because there are many aspects that need to be taken into account. For example, is an accumulation of symptoms or one overwhelming difficulty (eg. extreme feelings of guilt or anger) a key feature in maladjustment? Furthermore, we need to recognise that 'one size does not fit all': the appropriateness of an assessment tool for diverse subgroups (eg. ethnic minorities) needs to be considered. Also, there may be complications that the assessment instrument does not measure (eg. absence of grief).

In selecting the assessment instruments it also makes sense to focus on those specific aspects of well-being and adaptation that the intervention has been designed to address. For example, if loneliness and social reintegration are major targets for improvement (eg. the client is helped to increase participation in social activities that would reduce loneliness), it would be advisable to include questionnaires addressing loneliness and participation in social activities (which can be compared before and after intervention and with levels for the control group). Again, to devise a sound measurement instrument, researchers can usefully collaborate with those who have designed the protocols and/or are conducting the intervention.

Somewhat conversely, we may also need to target (adapt) the intervention towards those difficulties that research has shown to be good predictors of intervention outcome. For example, research has shown that intensity of grief diminishes as a result of certain kinds of intervention (cf Schut & Stroebe, 2005). We would therefore be well-advised to select intensity of grief as one indicator of the impact of our intervention, and we would choose well-established measures such as the Inventory of Complicated Grief, which has been shown to be a valid and reliable measure for this purpose (Prigerson & Jacobs, 2001).

Concluding comments

This article has covered some of the challenges that are involved in conducting research to evaluate the efficacy of bereavement interventions. We have focused quite narrowly on the challenges that are encountered when setting up and carrying out the research. We have nevertheless had to be selective. Other challenges that we have come across are reported in the contribution by Newsom and colleagues to this issue (eg. the difficulties in obtaining funding for such projects). Still others are beyond the scope of both articles (eg. how to disseminate knowledge and work with the media so that scientific findings about the efficacy of bereavement intervention are correctly reported; quality control, and training counsellors and caregivers).

We have also only touched on broader aspects, such as the important ethical dilemmas involved in testing and providing the best scientifically-based assessments. Nevertheless, within these limitations, we hope we have demonstrated that this kind of research is not easy; that there are many difficult decisions to be considered along the way; that it takes a long time to conduct such research properly and, most of all, in our experience, that it needs close partnership between researchers and practitioners (cf Newsom *et al*, this issue). By bringing together the papers included in this special issue, *Bereavement Care* usefully allows these fundamental messages to be presented for critical appraisal by all those concerned about the well-being of bereaved people. ■

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