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Practitioners and researchers working together in an intervention efficacy study

A fine example of synergy



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Abstract: All too often it is assumed that the differing priorities, values and ethics of practitioners and researchers are irreconcilable. This article describes the long, sometimes difficult and ultimately fruitful process of setting up an evaluation of the efficacy of the bereavement support service offered by Cruse Bereavement Care Scotland (CBCS). CBCS invited researchers from Utrecht University's Centre for Bereavement Research and Intervention to work with them to design and deliver a controlled trial that would compare outcomes for recipients of each of its three modes of 'stepped care' with those of a group of bereaved people receiving no care. The proposal raised a number of major ethical and practical issues, which were successfully resolved through open discussion and negotiation, providing a positive example of practitioner/researcher collaboration in a research endeavour.

Keywords: Evaluation, stepped care, controlled study, ethics, collaboration

Paul Simon is good; Art Garfunkel is good too, but together they are better. Gilbert was good, so was Sullivan, but working together brought out the best of both. Sometimes the whole is indeed more than the sum of its parts. This can even be true in cases where science and clinical practice meet. It may seem unlikely, but it does happen. Not that we see much written about it; instead we just hear about it in passing from our colleagues who talk about why and how the interaction of scientists and caregivers can be valuable and fruitful.

The authors of this paper are all part of what we believe to be just such a whole-that-is-better-than-its-parts phenomenon – a joint venture between Cruse Bereavement Care Scotland (CBCS) and the Centre for Bereavement Research and Intervention (CBRI) at Utrecht University, the Netherlands. We think this kind of collaboration has tremendous potential, in practical and theoretical terms. We are also finding it to be an exciting and enjoyable endeavour (it is still in process), and we hope this article will inspire readers to explore such collaborations themselves.

A science-oriented organisation

When Cruse Bereavement Care Scotland became independent from Cruse Bereavement Care (which provides bereavement support services in England, Wales and Northern Ireland) in April 2001, they were eager to develop their own identity and programmes of bereavement care to fit the Scottish situation and character. These would have to be up to standard with current scientific thinking about and research on grief and bereavement care. CBCS was well-equipped for that job, and they also asked two of the authors (MS and HS), both based at Utrecht University, for advice.

CBCS's basic philosophy is one of 'stepped care' and 'watchful waiting'. Stepped care is a philosophy that reflects the belief that one approach does not suit all; different protocols of intervention are needed, depending on the level of grief and complicating factors. CBCS therefore offers bereaved people one of three levels or modes of intervention, depending on their assessed needs: 'skilled listening', 'advanced listening' and 'counselling'.

The volunteers offering bereavement care undertake a carefully designed training programme to become a skilled listener, advanced listener or counsellor. A crucial step in delivering the new CBCS intervention model was the realignment of CBCS training to meet criteria established by the professional body for counselling and psychotherapy in Scotland (COSCA). These criteria provide an external benchmark for the quality of CBCS training content and delivery. CBCS training courses are validated by COSCA, and volunteers can gain a CBCS/COSCA Certificate in Bereavement Counselling Skills. This is the minimum level of qualification required to become a skilled listener. CBCS also offers a specialist module in Bereavement and Loss, which is designed for practitioners who wish to become CBCS volunteers but who already have qualifications in counselling and counselling skills (eg. a Diploma in Counselling, or the Certificate in Generic Counselling Skills etc).

The second element of the CBCS approach, 'watchful waiting', refers to the practice of not reaching out to bereaved people but establishing an infrastructure that makes it easy for bereaved people to access help if they choose to do so. Critical reviews of grief intervention efficacy studies (eg. Schut *et al*, 2001) have shown that early interventions for bereaved people in general appear to have no measurable benefits for the bereaved person's psychological and psychosocial functioning when initiated by bereavement support organisations. These primary preventive interventions seem only to lead to improvement in functioning when the bereaved person seeks the help themselves (Currier, Neimeyer & Berman, 2008; Schut & Stroebe, 2005).

These findings provided the evidence for the CBCS decision to include watchful waiting in their procedures.

A practice-oriented research group

Utrecht University's Centre for Bereavement Research and Intervention (CBRI) was enthusiastic when CBCS approached them with the proposal that they should conduct an evaluation study of the effectiveness of their new service model. The CBRI team was encouraged by the fact that CBCS's intervention model was based on the latest theoretical insights. Having enjoyed a longstanding and successful loose collaboration for some years, the CBRI team was drawn to the idea of creating a well-designed intervention study together.

Over the last 20 years, CBRI has been involved in a wide range of studies on bereavement, including a substantial number of studies of the efficacy of grief interventions. These studies have often been situated in clinical settings. For researchers, such field studies hold a particular attraction in that they require constant negotiation between the strictures of research methodology and the practical considerations and limitations imposed by the real-life clinical setting (see also Schut & Stroebe, this issue). When both parties have the well-being of the individual client as their top priority, this tension requires the highest standards in study design and every decision must be carefully thought through and rigorously evidenced. A research study with CBCS was thus a challenging prospect, and a significant one, and all to answer what appears on the surface to be such a simple question – does what we offer actually work?

Does it work?

Once the new CBCS service model was fully developed and implemented, it was time to ask the research question: does it work – is it indeed effective? Standard service evaluations tend to focus on actual service provision. Gallagher, Tracey and Millar (2005), for instance, undertook an evaluation of bereavement counselling based on reports of clients following their participation in a service provided by a Cruse branch located in the northwestern region of Northern Ireland. Six weeks after the counselling ended, almost 90% of the clients in the study reported that they experienced their loss less intensely, and between 80% and 90% reported substantial improvements in other aspects of their lives.

However, although such evaluations are tremendously important in improving the quality of care and client satisfaction with the service, they do not necessarily say anything about the effects of the intervention itself. Changes that occur during an intervention are often attributed to the intervention, even though such changes can take place naturally over time. From a research perspective, a well-designed efficacy study has to be able to distinguish natural change from changes caused by the intervention. To do this, it has to be possible to compare people receiving the

intervention with people in a non-intervention control group or a group receiving another treatment. Also needed are pre- and post-intervention assessments of all participants, in order to assess change over time (these are only the very basic requirements; see Kazdin (2008) for more information).

All in all, a well-designed efficacy study involves a great deal of work, and it was clear that CBCS was not in a position to conduct such project alone. Apart from the need for specialist research skills, an evaluation of one's own work has less credibility, especially if the results turn out to be positive. An outside organisation was needed for such a job. Since collaboration with Utrecht University was already established, it seemed natural to explore the possibility of expanding that partnership.

Assessment tool

For the stepped care model adopted by CBCS to function properly, accurate assessment is needed to ensure bereaved people are assigned to the correct intervention mode. The allocation process needs to have clear and reliable criteria and procedures in order to ensure the complexity of need of the bereaved person is appropriately matched to the right level of care.

The assessment process serves a practical purpose in that it optimises care and efficient use of resources. It also serves a scientific purpose pertinent to evaluation. Such a systematic assessment of participants is also necessary to allocate them to the appropriate intervention group (or condition). We therefore needed a psychometrically sound assessment tool. However, such a tool appeared not to exist, and thus it was decided to develop one. A small task force, led by the then CBCS chair John Birrell, was assigned to develop such an instrument.

The resulting assessment tool – the Initial Client Interview (ICI) (Birrell, Stevenson & Schut, 2006) – is partly based on the Inventory of Complicated Grief (ICG) (Prigerson & Jacobs, 2001), and partly on the Clinical Outcomes in Routine Evaluation (CORE) brief outcomes measure (Evans *et al*, 2002).

The ICI combines selected items from the ICG (Prigerson, 2010) with important information that is required by the CBCS ethical guidelines (checking for suicidal ideation, for instance, which, if present, requires specific action to take place) and appreciation of the CBCS volunteers' experience in assessing client needs and problems (the volunteer can add discretionary points to the standard assessment score). The draft version of this instrument was extensively discussed with CBCS volunteers, staff and external advisers and was comprehensively tested by a number of volunteers before the final working version was implemented. An ICI training module has since been developed to ensure that the instrument is used correctly and has high inter-rater reliability, and now CBCS

volunteers receive training from two accredited trainers in using, scoring and interpreting it.

In the context of the evaluation study, the ICI is used for the systematic assessment of clients' grief problems and allocation to the appropriate intervention condition. In the course of the study specific attention will be paid to the validity and reliability of the instrument.

The road show

An essential element in getting the study plan improved, accepted and embraced by CBCS was talking to everybody involved, especially the volunteers. Staff at the CBCS national office were convinced of the value and potential of the study, but the research team was well aware that the volunteers – the practitioners providing bereavement support – needed to be convinced of it too. To conduct such a study in a voluntary organisation without the co-operation of the volunteers would be like cooking without spices and herbs. The volunteers needed to be informed about the plans, and we also needed them to help solve some of the most crucial problems raised by the study.

Our plans still contained numerous flaws. The grassroots of any organisation usually know in detail its procedures, its weak spots, how problems are solved informally and, most importantly, what makes the organisation tick. For all these reasons, a road show was organised – a series of meetings with members of a number of the local CBCS branches in the country.

These get-togethers provided an essential opportunity for exchanging plans, doubts, ideas and points of view. Everybody spoke frankly and openly about the project and all it would entail. The experience illustrated first of all that practitioners and researchers can have stereotypical ideas of each other and each other's work, but that it does not take much effort to change them. For example, the researcher leading the road shows (HS) discovered right at the start that being a bereavement volunteer in a voluntary organisation does not mean that you can't think in terms of research methodology. The bereavement volunteers, for their part, found their presumptions challenged – for instance, the belief that researchers, and most certainly quantitative researchers, put people in boxes and manipulate reality to fit their research requirements. These meetings broke down many barriers to collaboration and laid the ground for the project's success.

The big ethical dilemma

Unavoidably, because of its design, the evaluation study needed a control group of bereaved people who would not receive support. Otherwise, as previously explained, it would be unclear whether any changes in functioning among the bereaved were due to the support from CBCS or

to natural decline in grief. After all, grief is supposed to be a process; it does change.

This would have been less of a problem if we were involving bereaved people who were not asking for help. Then we would not be withholding care from people who wanted help simply for the purposes of the study. However to evaluate the CBCS service we needed people who were asking for help to populate all the conditions – the intervention groups (the evaluation study actually combines three controlled intervention efficacy studies: one for each mode of the CBCS new service model) and the control group. This meant that the bereaved in the control group would have asked for help and would not receive it. This was, of course, unacceptable to CBCS volunteers. How can you refuse somebody who asks for the very kind of help you are trained and your organisation exists to provide?

The road show provided the setting for a series of lively discussions with many strong, insightful and passionate volunteers. And it was they who came up with the solution. CBCS was about to introduce a national telephone number for people to contact the organisation. Since CBCS does not (yet) provide a service across the whole of Scotland, it was to be expected that bereaved people would call to ask for help from those areas where no CBCS service was available. These people could be asked to participate in the study – although that would not be an easy request to make immediately after telling them the help they were seeking was not available.

Thus we can see how research methodology set a standard and created an ethical problem; CBCS practitioners discussed and accepted the need for these scientific conditions, and came up with the solution. In the view of the CBCS executive director, this is a fine example of synergy.

Ideally, in a gold standard research project, participants would be randomly assigned to each intervention group. In our project, for the ethical reasons discussed above, randomisation is not being used and the control group will contain only those living in areas without a CBCS service. This leaves open the possibility of systematic differences between the intervention and control groups. The locations where CBCS is not active tend to be more rural areas, for example, which may of itself have an effect on grief.

This means it will be difficult (although, using scientific techniques, not impossible) to compare the two groups. From a care provision perspective, not being able to meet the needs of the bereaved and yet asking for their participation in a study is also far from ideal. This was nevertheless the only solution that was acceptable to both groups and that would keep the enterprise worthwhile. The rationale behind the decision is the potential for the expansion of CBCS to offer a service in areas where it is currently unavailable if we can scientifically prove its interventions are effective in helping bereaved people.

Another apparent anomaly is the fact that the ICI, the allocation instrument for the different intervention modes, will have to be used in the control condition as well as the intervention conditions. This may seem odd at first sight: why would one need to use an instrument for allocating clients to a condition if no intervention is to take place anyway? The ICI must be conducted in both conditions in order to allow comparisons between the course of grief and other problems among people who receive help and the course of grief among people who receive no intervention, but would have done so if it were available.

Challenges in working together

The operational phase of the project has been running for almost two years now. It turned out to be more difficult to implement the project plans than we had expected, but this had little to do with the different disciplines and professions working together. The main problem turned out to be the international collaboration. It was difficult to obtain funding in Scotland because it was considered a Dutch project, and getting money for the project in the Netherlands was equally complicated because there it was seen as a Scottish project. The project was too small for European funding as it involved only two countries. The problem was eventually solved when Utrecht University decided to finance the project in conjunction with the professorship of one of the authors (MS).

The study required the appointment of a researcher. The PhD position was advertised internationally and a joint CBCS-UU committee appointed the lead author (CN) in 2009 to conduct the study and write her dissertation on it.

One major hurdle remained to be overcome, and that was getting ethical approval for the project. Again, we were in a situation similar to the one we had faced with the funding. The Dutch ethical committees referred us to their Scottish counterparts and the Scottish ethical committees did the same in reverse. This time, after a lot of frustrating hard work, the solution came from Scotland, when the NHS Tayside Research Ethics Committee gave the project the green light towards the end of 2010.

Conclusions

Conclusions can be drawn on two levels, specifically regarding this project and with respect to this kind of research in general.

First, several years have passed since we started thinking about the project and it has not always been easy. However, with the funding in hand and the researcher in post, supervised both by CBCS staff and UU researchers, we are confident that this complicated and delicate project will be a success in some years' time. We hope to be able to report on the results in *Bereavement Care* at a later stage.

Second, researchers and clinicians are often considered to be different breeds with different agendas, value systems and aims. We think that that is incorrect and we like to believe we have proved this to be wrong. The proverbial 'twain' did meet and it did not look or feel like a collision at all; just the opposite. Through open discussion, clear exchange of views, mutual respect and the awareness that we both have the same goal – the best care possible for the bereaved – we have built a fruitful and enjoyable working relationship. This is probably far from unique, but it is rare, and contradicts the myth that practitioners and researchers face each other across an insurmountable gap. We hope this account will inspire others to do something similar. Bereavement care will gain from it. ■

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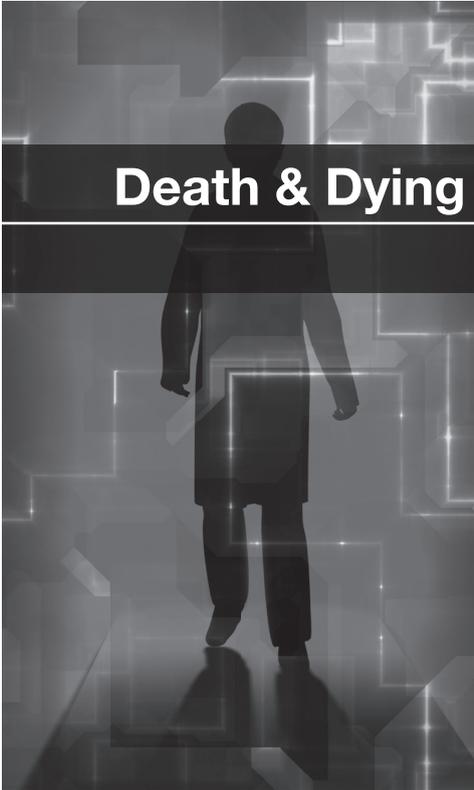
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