



BEREAVEMENT SUPPORT GROUPS:

***Issues in development,
leadership and training***

Report of a project on building
partnerships in developing an
international best practice for responding
to work-related deaths

Volume one

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PREFACE

This report is one of three reports from an Urban Ministry Network (UMN) project, "Building partnerships in developing an international best practice for responding to work-related deaths".

The project was designed to build upon work initiated by UMN in 1990 with the first Ecumenical Memorial Service in Melbourne to remember workers who died from occupational accidents and diseases. Our subsequent involvement in support for families and workers bereaved by work-related death led to the establishment of our Partnerships in Grieving Program. The project explores key partnerships that UMN believes are vital to establishing an international best practice for our PIGP.

The UMN gratefully acknowledges the support of The William Buckland Foundation and the Victorian WorkCover Authority for this project. We are also grateful to the law firm Ryan Carlisle Thomas for their sponsorship in publishing the series of three reports.

There are three components of this report.

The first section of the report is the proceedings from a workshop sponsored by the Bereavement Support Groups Network (BSGN) titled, "What works and what doesn't in bereavement support programs".

UMN was delighted the BSGN accepted our invitation to sponsor this workshop.

The BSGN is a network of a wide range of bereavement support programs, some with more than twenty years experience in grief support to bereaved people. The workshop was designed to promote shared learning and understanding between bereavement support self-help programs. From this process, UMN hoped to learn from the practical wisdom of those who have gone before us in developing bereavement support self-help programs.

The second section is a literature review that has been prepared by Brian Cooper and Cliff Picton from La Trobe University Social Work Department. The literature review addresses "Bereavement support groups and social health: issues in development, leadership and training".

Section three is advice to the Urban Ministry Network from the La Trobe University Social Work Department, based upon their reflections on the workshop proceedings and the literature review.

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“WHAT WORKS AND WHAT DOESN’T IN BEREAVEMENT SUPPORT PROGRAMS”

PROCEEDINGS OF A WORKSHOP SPONSORED BY THE BEREAVEMENT SUPPORT GROUPS NETWORK

Introduction

Chair: John Bottomley (Urban Ministry Network)

Welcome to this workshop on issues for self-help groups for bereaved people. We have brought our diverse experiences to this workshop today, to hear the views of four speakers involved with self-help bereavement support programs, and to have a reflective conversation on the issues around ‘what works and what doesn’t in bereavement support programs’.

Session one: My experience in bereavement self-help - what works and what doesn't in meeting diverse needs.

Michele Roberts (Road Trauma Support Team)

The Road Trauma Support Team employs me, where one of my tasks is to lead a monthly support group for bereaved people. I will focus on my own experiences in leading this group to talk about what works and what doesn’t in meeting the diverse needs of bereaved people.

I will focus my talk about a conversation I had recently with one of the people in the support group. Her name is Glenda.

I was talking to Glenda in the kitchen after one of our monthly support group meetings. I said I can’t figure out whether it’s an honour, a slap in the face, if I’m moved, but I am frequently overwhelmed when I’m in the group. I sometimes have no idea how she and the others can sit through these groups, because for me, as a ‘non-bereaved’ worker, very committed to what I do and very much believing in what I do, it is very overwhelming to take part in these groups. It is a very powerful morning in my life.

So I will talk around these four words - honour, slap, moving, and overwhelmed - to reflect on the experience for some of the people in the group, and my experience too, as a worker running the group.

‘Honour’

It’s an honour for me, but it’s not an honour for other members of that group, to take part in that group. For me, it feels like an honour, in that I sit and witness their courage, their strength, their ability to go beyond themselves, and sit with each other’s pain. It’s an honour that they trust they can come to the group, and they trust me. They trust they can

speaking their stories, and that their stories will be respected and heard. They trust their differences will be appreciated and recognised. I am always very aware that I sit in a very different seat from everyone else in that group.

Participants do honour each other and themselves and they honour each other's experience - by honestly and respectfully listening to each other, and giving so much of themselves. I am overwhelmed by the courage it takes for someone to come for the first time especially, to walk into a room and to come into the group.

They are also honouring people they love by coming to the group. It is a forum for them to remember and to story tell. They talk and laugh as well, talking about the people they loved, and their relationships with them, sometimes ambivalent relationships.

It is an honour to work with, and support people in my role as worker, but it's not an honour for the people that we work with.

'Slap'

For me, participation in the group is a slap in the face in the sense of being a reality check. I always experience the group as that. For one Saturday morning a month it's like someone turns bright lights on and you see the world and these people's sorrow and your own lack of sorrow too. It is sometimes like a wake-up call.

But I also experience that this is their reality day in, day out. So once a month I have this experience - but then I get to go home. But they live with this reality all the time. It is important for me to remember this as a worker.

It is also a slap in the face for me to see the length of grief, and to see the depth of continuing bonds. I see how long and hard and exhausting grief is for people, but also see how powerful and loving their continuing bonds are with their loved ones, too.

I see and learn about the reality of family and friends, and why grieving people in their daily lives get silenced and need the group to come and talk to. They're not often given the opportunity to express themselves with their family and friends. Continuously people talk about being silenced. They are asked, 'how long are you going to drag this on for?' Family and friends seem to be saying 'your grief is hard for me to see and I don't want to see it.' That is a slap in the face for the grieving people, too.

It is also a reminder and a reality check about the process and depth of grief and growth. I learned these connections from this group.

'Moving'

Some of people's stories are so moving. For example, one of the women in the group had a stroke recently. Now she catches the train and walks all the way to the station and from the station to come to the group every month. I always offer to arrange transport for her - but it is very important to her to do this on her own, to bring herself to this group. People around her tell her 'you can't, you can hardly walk', but she struggles her way to the group.

One of my favourite stories is from Glenda who has had people say to her 'you are carrying too much baggage - you are carrying your family around with you'. She can come to the group and demonstrate to us that if it's her family, then it's 'Louis Vitton Luggage' - the most expensive, the best luggage you can buy. It's her opportunity to share her 'Louis Vitton Luggage' with us.

In the group, it's very moving when people hear about other's experience and say things like 'well I'm so glad - at least I didn't see it on television before the police made it to my door'. There's always somebody in the group who did have that experience.

'Overwhelmed'

It is overwhelming for all members of the group, but it's certainly overwhelming for me. It is overwhelming to think that people wait all month for the group. One member puts it this way - she can survive for two weeks of the months because she's just been to the group, and for the other two weeks she can just make it because she knows she's going back to the group.

I know that in this group I facilitate, I'm doing my job best when I sit back and 'do nothing'. I visualise my role as cushioning the edges. I sit 'on the outside' but if there is anyone feeling unsafe, or needs to leave, or if the group sits with silence and I sense that it's an uncomfortable silence with people, then I have a role. But I am doing my job well when I am doing nothing at all. Then it's self-help, they're helping each other. I don't play that helping role - they do that for each other.

Mary Hansen (The Compassionate Friends)

I have been a support group leader with The Compassionate Friends for over ten years. My presentation will focus on the two main questions - 'what are the diverse needs of people who come to these groups?' and, 'what works and what doesn't?'

(a) Diverse Needs

First, men and women may grieve differently. To illustrate this point I quote from the Journal of Family Therapy, 1996. "Support strategies must take into account the evidence of distinctive differences in ways in which men and women grieve." For example, in a still birth support group, an elderly lady was asked if she had mistakenly entered the wrong room when she arrived at the support group. She replied 'Sixty-one years ago I delivered a still born baby. At the time, my husband said 'I've buried him, I never want to hear you mention it again.' Four months ago, my husband died. So I'm here, to talk about my little boy.'

This story illustrates one important point which relates to the different ways men and women may express their grief, but it also points to the need for people to grieve in a time-frame that is appropriate for them and their circumstances.

For example, I have taken phone calls with The Compassionate Friends for many years and one still sticks in my mind. The woman rang and asked 'Is there a support group for me?' I asked her whether she was a bereaved parent and she said 'Yes, twenty-five years ago my baby was still born - is there a support group for me?' I said 'Yes, we are here for

bereaved parents.’ She said ‘No - it’s been twenty-five years - you don’t understand - I should be over it - how can I get help?’ and I said ‘That’s what we’re here for’. She burst into tears and said ‘They never let me hold him.’ And that was all she needed to say.

The general point is that as a support group leader, one should never make assumptions about people who come into the group. So - what are some of the participants’ diverse needs?

- Concerns around the manner of the death, the need to share issues around the fact of the death, the need to share the death of one’s child.
- The need to accept that children die, including adult children, and all the feelings that go with that - the helplessness, the lack of control, and the guilt related to feelings that parents should be able to look after their child even if their child is twenty-five. There is also general and specific guilt relating to the manner of the death.
- The need to redefine one-self - am I still a parent? Is this a new role? How do I approach it, deal with it? What are other positions in the family now? A lot of bereaved people have to try to re-define themselves within their family.
- The need to question and seek answers from anybody that will listen - the why? why?
- The need to have feelings validated, no cliches, no advice, only acceptance that ‘this is how I feel’. People need acceptance and validation about how they feel.
- The need to survive, and how to survive, and the need to provide a model for survival, the need not to feel totally vulnerable in relation to other children, other brothers and sisters.

Within a support group, there are also needs of the group leaders themselves for support, and not to have to do it alone. Some of these needs are -

- To have confidence in their abilities.
- To come to a position of ‘comfortableness’ with the grief you are asked to face over and over again - other people’s grief, layered on top of your own. This is one reason why training is so very important.
- The confidence to be able to say to oneself ‘I can’t fix this’ (particularly if you are ‘a fixer’) and to understand that people don’t expect you to fix it - it’s not fixable, just to walk beside people in their journey through grief and to feel OK about that.

(b) In relation to support groups, what works and what doesn’t?

It can be difficult to specify what works and what doesn’t, partly because of the diversity of needs of people in the group. What works for some people won’t necessarily work for others. But what generally works is:

- Validation of feelings, validation of the person.
- Empathy, and sympathy too, even though ‘sympathy’ is currently an unfashionable concept.
- Leadership and control - when you are a group leader you do need to have some control.
- Some form of structure is necessary - for example regularity of venue and time.

What doesn’t work, in my experience is:

- Advice, cliches.
- Comparisons with other grief or losses.
- Uncertainty about the group - for example when and where it will be meeting.

In The Compassionate Friends, a feature which works for some and not for others is the open-ended nature of the group, where bereaved people can come and go as they wish. There will be a group meeting every month at the times advertised, and attendance will fluctuate a lot. People may come for a few months, stay away, and come back again. Some only come to one meeting. But the meeting will always be held irrespective of how many people come.

What works for me as a leader?

- Trusting people to find their own paths of resolution.
- Giving people options for levels of involvement that they need and will utilise for themselves.
- Listening, hearing the pain of others - this is powerful, and important.
- Modeling hope that there is a life after the death.
- Laughter, although this can be a problem for some people in the group.
- Tears, although this, too, can be a problem, as some people may not handle the tears of others very well and want to rush in to give them a tissue.
- Hearing the pain of others, especially the pain of the newly bereaved (a person who hasn't been to a group before). Hearing the pain of others can be very difficult for the new person and it is hard to know how they can be prepared for what they will hear.
- Saying at the end of the group 'don't take other people's grief home - you have enough of your own'

I would like to conclude my presentation by taking some points from a letter sent by a grateful parent who lost one of her children, and wrote a long letter to The Compassionate Friends to express what the group had meant to her. She came from Anglesea to a group meeting in Canterbury, and it took three tries before they were able to actually gather the courage to walk through the door.

'Our family of three now, instead of four, made several attempts to attend The Compassionate Friends meetings. We finally made it last Tuesday night. Coming up from Anglesea, twenty minutes past Geelong, we had plenty of time to back out, pick a fight, sabotage the event. There were fantasies as to how it was going to be for us. How I imagined it would be, and how it really was, were very different. Once in there, and there was no great emotional welcome or fuss as I had thought, I felt comfortable. I knew I was in the right place. People were warm, receptive and responsive. But it was very natural, and very normal. My Simone, thirty-one years old, had died September 1999. I had not felt natural or normal since that fatal day. So I couldn't believe anyone else could, and would, feel normal. The opening response told me they truly knew this journey. 'We are not glad you are here' they said 'but we are glad you found us.' So the gentle and gracious compassionate procedure unfolded. I felt better and better. Caught between being in my new niche, with others like me. Should I really be here, or just put it behind me? I began to understand the magnitude of my loss in the eyes of others. Yes, you have hit a wall, big time. Getting back up is a huge process, and needs support.'

Workshop Conversation: Session one

Both Michelle and Mary's contributions make it clear that we are dealing with both reflection and very personal experiences. Your silence and attentiveness to both their contributions indicate something of the sacred quality of the ground on which we are

walking with this discussion. But I would like to invite you to ‘take your shoes off’ and tread on that sacred ground. Tread gently with each other, but nevertheless explore at whatever depth you wish, using Michele and Mary’s presentations as a model for reflecting at depth.

You are invited to identify in your own reflection any echo or resonance with Mary’s or Michelle’s reflections - that is, to identify some of the things that you’ve heard that are important in your own work as a way of starting the conversation.

Public remembrance of personal loss

Michele said ‘we honour each other’ and I realise that’s what we’ll be doing next Saturday. Next Saturday is the first anniversary of one of our parent’s son’s suicide, and she wants us to come over and watch the video of the funeral. It won’t be easy, but we’re going to do it. We’re taking food over and we’ll have lunch and watch the video with her.

We send anniversary cards. I had a client who, last year, told me that this was the only card she had received.

Some personal impacts of professional involvement in bereavement support groups

I am not a bereaved parent. I work as an outreach worker with TCF and the word ‘honour’ is the word I would use too about attending the group. Each time I am ‘blown away’ by the power of the group and the self-help process. And it is not an honour for them. But last week I was at a group in Geelong and there was the laughter and the sadness, and swearing, and people told their stories. At the end I said, ‘you’re all bloody amazing!’ and they looked at me. I said ‘the power of the energy in this room is something that I as an outsider can see and can give you accolades for’. It is such an honour to be part of that process even if it’s being on the outside of it, to be present in that space.

I’ve been working for about five years with bereaved parents. For me it’s been an affirmation of my humanness, in being with people in a real human way. And also we have the luxury of being involved and in contact with other people who take the time to be human. It is true that people are prevented from talking about their bereavement and their grief experience. We have that luxury to be involved, to be real ourselves.

Affirming diversity in grief responses, developing flexibility in organisational responses

It is important we understand that everyone in the family will grieve in different ways and at different times. We mustn’t expect too much of each other, and if we know that, it can help us understand.

In reflection on the story of the woman who came three times before she actually came through the doors - I find that happens often. I have a list of people that I ring every month, and remind them of the date of the group. Many of them never come, and perhaps

never will, but they always want me to ring again and remind them. I invite them to come but I also give them permission not to come if it's too hard.

Part of it is knowing that somebody is concerned about them and somebody cares about them. Even though they don't come, they are still worthwhile, and are acknowledged. This is an important part of our work - even though people don't participate in our activities, they know they are welcome, and people do care.

I would like to mention the diverse ways people could meet up with others. It doesn't have to be from meeting in formal groups, but by making opportunities for people to meet in a whole range of different ways that are suitable for them. We have drop-in groups, formal structured groups, and a father's group. We also try to have other opportunities for people to get together if they don't want to actually attend a group but would value the chance to meet others through other activities - for example, write a booklet, the gardening group, the sticky bun group. I think there are diverse ways. Self-help doesn't have to have one model.

There are a lot of examples of ways within a formalised group - it could be going to someone's house, a walking group, a lunchtime group, the ACORN foundation (building, fund-raising). People will take what they want from an organisation, e.g. writing letters or using the telephone. This is therapy in itself. Others might just want to get the newsletter.

We've got a recruitment campaign for volunteers to work in the centre, and many of them volunteer because they feel they can't go to a group. But even doing administrative work or something similar they get to know a network of people. Volunteering is not just about supporting the organisation - it is of value to the person himself or herself - the feeling of giving back and receiving.

I like the notion of having an organisation that's very open to a wide range of roles for people, whatever is going to suit them. This means sustaining flexibility in the organisation so that people can use their talents. There needs to be opportunities for joining in and meeting others. We need to avoid structures that say 'sorry, we can't fit you in', implying that they will have to go somewhere else. That level of flexibility is a characteristic of the support groups network, and it is precious. There is always a push towards getting 'neatened up' and putting people into neat boxes, and keeping things 'clear'. Often that flexibility and sharing is precious and people feel they are joining back into the community and contributing when they are at their worst. That is a marvelous thing.

We are recruiting at the moment for the Road Trauma Support Team. We are trying to work out who are going to be our volunteers. We have a selection procedure to work out which of these are going to be pretty useful volunteers for us and our clients, and which are going to be clients in their own right who will need a lot of extra work from us. It is interesting to hear about the different levels of work that other groups can offer volunteers when you have flexible structures. The discussion focuses attention on the sort of organisation that we are. Do we want to recruit people who are good at volunteering and support? What do we do with the people who aren't quite at that point, and who don't meet our criteria now, who can't yet provide a hope path for others? How

do we assess the amount of work it will take for us to keep them and help them develop?
It's a tight line.

The broader the organisation is, the more roles are available. When your customer base is tighter, that's more difficult. KOKAAS is very tight. It is for people affected in one particular way. There are not a lot of roles in our organisation. Anyone is welcome to start a group, but there are no libraries to maintain, no phones to man. It's a pity, but there is not a wide base of facilities. Road trauma is also the same.

I have been caught out with this many times. If you've got paid staff, no matter what their time fraction, there is a danger of underestimating the skills of volunteers and what their skills are. We have one volunteer who is doing a remarkable project for us. They are doing a sensational job. Normally I would have thought 'I can't give that to a volunteer' but one has to think more broadly, not thinking 'we've got paid staff to do that'. Volunteers can work very competently if they want to take on some of those roles, or expand the organisation. There is enormous value for the volunteers in doing work they find satisfying. It's important not to underestimate what volunteers can do and can't do. They can do anything if they have the skill and the desire to do it.

Learning and growing in a bereavement support program

I've also noticed that people model grief in the group. People in the group see how others grieve, and how they express themselves. That can provide a model for them. They might leave with new knowledge about themselves or others. 'Maybe that's why my husband does this, or why my daughter does that' because they have a chance to explore those reactions outside of their own family as well.

One of the things I have noticed is the sense of hope that people get from meeting other people who are further along the way. I am from SIDS. One of the people at one of our morning tea meetings - a woman who had lost her baby a number of years ago now - came up and said, 'you know, I'm really ready now to do something to help other people'. She said 'Lesley, you were my saving grace, or my light'. She just met and knew me from the drop-in mornings. This woman came irregularly to the morning teas. She wasn't one of those people who came to every meeting religiously, because she was really consumed by her grief. I think the effort to get there was too much, even though she wanted to come. It was nice to know that I had been able to offer just a bit of hope to someone.

You can't underestimate how much help people get from even a small interaction. It can be quite a small interaction. Then four years later, that can be the 'thing' that, when a person looks back, she might reflect on as being the most important thing that I did - being there that day. That's important - the reason Lesley was so helpful is because of who she was, and what she had been through herself. That's the irreplaceable thing about self-help.

Often a human presence is all that we really need - a human presence.

I'd like a dollar for every time I've heard someone say 'thank God I'm not going mad - other people have these thoughts and feelings - feelings of going insane'. Sometimes

that's all a person needs from us. It's enough - because sometimes they feel they are going insane.

As a bereaved parent I came to TCF 18 months ago. I was almost relearning skills that had got lost in the period of grief, and gaining memory retention. For example, we were talking about what we had lost and one woman from TCF told me that she would just like to learn to spell again! During the grieving process some of these skills are lost along with confidence in the world around us. In the last eighteen months I have started to relearn skills that just got lost.

Attitudes and structures that inhibit healthy grieving

There is a huge expectation that 'you will get over it'. A woman's boyfriend died, and the expectation is from her family and friends that 'you had broken up with him - come on!'. But she had spent four years travelling overseas with this man. Then at another level, her fear is that she won't get over it, and by going into the group she is going to be 'stuck'. She fears being exposed to everyone else's grief, and her fear is 'how will I contain that for myself in talking that through?'

People get told 'you should be over it'. Yet at another level, a person is not a computer screen - you can't just push the 'delete' button. They are still very much in your heart and in your mind and they will be with you until you die. Being able to say that to a bereaved person can be very useful and very helpful, especially when a person is being urged to 'get on with things', 'get over it', 'get another partner', 'have another child' - all these cliches!

Stephanie Dowrick talks about not 'getting over' but 'getting on', and I like that, because I will never get over it. Other people can talk about their children - why can't I talk about my son?

The professional and/or leadership role in self-help support

Sometimes the bereaved person needs to know that there is someone who can help 'contain' his or her emotional stuff. Even though they are sharing it, it's good to have a facilitator just on the outskirts so that if things get awkward or too awful we know we can turn to them. That's an important thing in these groups.

With the volunteer selection process at Griefline there is always an obligation to support people for some time after their selection. And people do help in different ways. We have some working in the office. People can support us in very different ways.

In the selection process for volunteers, we find some people are unable to have a role in the organisation. When you think about the support you end up giving them, it is plain counselling. You might counsel them, set them on a road, and never see them again. But you've actually got them at their most vulnerable time, and you just can't let them go off on their own as volunteers. So there's not always a role - no matter what you can offer. They simply need support.

You have to think about how to support them into the best possible position. The point is that they make contact with us. Sometimes we underestimate people's ability rather than

overestimate it. There's always going to be a need to take it person by person and not make assumptions about them.

Summary

Participants offered the following summary of the first workshop session:

- Organisations need diversity and flexibility to provide all sorts of experiences for people.
- Trust that people will access whatever service that is right for them.
- Honouring the different levels at which people come into the organisation.
- Depth of respect for the experiences of people - not stepping back from that depth of respect sets you on a different path.
- Patience is very important. Reflecting on my experience of working in a support group and planning support groups, I used to think that if you build it people would come. That's not actually the case. They are hard work, and require a lot of patience. People don't flock to them. Some people do come and get a lot from them, but an awful lot of people don't as well. Agencies need patience.
- There are particular issues in country areas. Some groups in country areas find it hard when, for example only one person comes. You need to reassure group facilitators that if only one person comes it is really important for that person.
- When a support group is established people have to know that it's going to be there for a long time - tomorrow, next year, and in twenty years. In twenty years I'll still be here and I'll still want to be involved in a group because that's the opportunity I get to speak about my child. Also some of the people who have been helped by those groups, as they grow, will want to return something to it. The support group has to have a vision to create something much bigger than what they first establish. This vision needs to focus beyond today or tomorrow, or while there's funding.
- Jo and I assist with a group in Malvern. From a professionally trained person's view I think I started doing this too early. I probably wasn't 'ready'. But personally it was great for me, and I don't think I've ruined anybody's life.

Session two: My experience of professional and self-help collaboration - what works and what doesn't in bereavement support programs.

Lesley Jones (Sudden Infant Death Research Foundation)

My involvement as a volunteer in SIDS is probably a way for me to put back things that I got from there. We talked before about people being volunteers and paid staff. Jo and I both do the after hours service, which is paid work. I don't want to be paid for it because it's really important to me to do that work. It's something that I really need to do and I don't want to be paid for it.

We talked about remembering, telling stories, and honouring. These are all part of being involved in the group that we run once a month. I spoke earlier about a lady who said it was great I was there four years ago when she really needed someone. I don't really know what I did for her. Obviously just being there, and being a bit further down the

track a distance, gave her an opportunity to know that that can happen for her. They could see that somehow they will still go on and hopefully they will smile, and the pain won't be there all the time. But I don't always feel a great example because I still struggle, even twelve years down the track. I don't have the pain that I had then, but I still struggle. I have the lack of being able to spell, the lack of being able to put my mind to something. I still struggle with that all those years later.

What we do means we are confronting other people's grief, things that I would never have thought about before. We have people at SIDS whose children have died from other causes, but they are sudden and unexpected deaths. This can be quite confronting. These are things I never had to think about before. For example, often I see my children go off swimming with the family, and I can't help thinking 'I hope they don't drown'. I don't know if these thoughts come from the people I am in contact with, or whether it's a natural parenting thing.

But this type of confusion is in your life forever. I am not sure whether it's because of what I do, or every parent has these thoughts. I feel like my life is confusing, and my life is confusing for everybody. I have two children, 11 and 15. Louise often says to me 'Mum - (she was born after Brendan died) - am I the second or the third child in our family? So she's confused about her life. So the confusion goes on and on, and I think it will go on forever. I try to convey this to people that my life will always be confusing. I will always have his memories and I will always be confused about even that, about the best way to remember him.

We have a lot of people come that are very creative. I often think 'I wish I could do something like that'. My children even say to me now, 'Mum, why don't we make a quilt for Brendan?' and I don't want to, and also I couldn't! You're always faced with this on-going attack on yourself.

My experience has brought me a lot of personal development and great understanding. I don't think I appreciated or understood what death could mean to a family until now. I suppose it's my own experience that's brought that on, but being given the opportunity by the SIDS Foundation to be involved, even though I may not have been ready initially, has helped me a lot personally. I'm very thankful for that.

What we offer is a combination of self-help and trained professionals. I needed that in those very early months. I didn't really want to go into a counselling session because I had a preconceived idea of what that was. I basically didn't think a 'shrink' would be able to help me. I didn't understand what a trained professional meant, but when I went to the groups I had an incredible need to know about clinical things that happened to Brendan. I found I could get that help from the people there. They could tell me what happened to him after he died, and what happened in the autopsy. I even wondered about how his body would be in the months after and these people could tell me. You won't really get all that information out of a self-help group. Those experiences were good for me. We had people who helped families. Now we've got families whose child has died under circumstances that involve the courts, such as homicides. The families are going through court proceedings and they need help and advice. They find it good to be able to talk together and the people from SIDS can help them a lot. They get a lot out of that.

What works is what works for an individual person. I tried to list these things myself, but what works is what works - and what works today may not necessarily work tomorrow. I say to people 'don't even try to analyse it'. A person might say 'today I feel good if I get up at 9 but tomorrow if I get up at 10'. I think you've just got to go with the flow. In some of our groups we've had people that have been together, coming regularly. They develop quite a relationship with each other. They have very like reasons for being there. Their children have died under the same circumstances. I try not to do very much in the groups. They work best when people do it themselves. But I am more aware now of the new person who comes in. The other people have developed quite a relationship and have very strong bonds. It's important to be aware of the new people who are coming in. If they keep coming they will 'fit' to the group just as much as everybody else. But you do have 'the very new' and the long-timers. They each have their own path of development, and where they're at, so you need to take into account what's happening for them.

It's natural that people who get a lot out of a group and who attend regularly, will in time want to give something back. That's got to be part of the group - the opportunity to give something back.

Their needs won't go away after six weeks or six months, or six years. It's important the group is there for the long haul. There needs to be a space for people to do whatever they want to do without others questioning them. I know it's important that you have certain skills in the group, but I'm sure there's a spot for everybody.

Geraldine Paine (Outreach Grief Services)

In a recent autumn edition of the journal Grief Matters, there was an article that clearly addressed building relationships between loss and grief self-help organisations and health professionals. Denis Klaus says that self help and professional help are two means to the same ends. At Outreach, self-help groups work alongside our professional staff in ways that are complementary to each other.

The professionals sit to one side and observe but are also 'being there' when it's appropriate to be there.

I will describe the different groups we run at Outreach Grief Services. There is the younger bereaved partners program, and hand in hand with that is the children's group facilitated by trained volunteers. Our Good Grief program is a peer support program for adolescents who have lost a parent or other relative.

The younger bereaved partners program has changed significantly over the eight years it has been operating. In the early days, we would invite people who were newly bereaved. Some were in counselling, some weren't. That needs to be respected. For some people, having individual counselling can be very useful. For others, having contact with people who have had a similar experience is very useful too. What is important to each person needs to be taken into consideration. In the early stages we used to invite the newly bereaved person to a support group meeting on a monthly basis. We had a group of volunteers who were trained in grief and loss. Some had the experience of losing a partner, some didn't. Our first evaluation feedback from participants told us they felt awkward there were people sitting in who hadn't had that experience. The volunteers

were making cups of coffee and tea, but some in the group felt they were a bit invasive. There was a sense of ‘what right did they have being there?’ We changed this so the volunteers would meet and greet the participants, but not be part of the meeting.

The program evolved to where it was facilitated by a staff member. Our staff member involved with the program had a bereavement of her own some years prior. That gave validation and credibility to the program. Now she sits to one side. In the main, people who have had a partner die and are some way down the track in their bereavement facilitate each group. The group now comes together. They break into smaller groups that are facilitated by one of the facilitators.

There’s a need to give back to a group when you’ve received something from the group. Participants sense they are reasonably OK in their grief. It doesn’t mean they are not going to have triggers or hear a similar story that’s going to make them think about their own experience. But hopefully they have developed the facility to deal with that in supervision or outside the group.

In our evaluation we became aware there were people who were newly married in the group who had a partner die, but had no children. They were with a group of surviving parents talking about child caring and parenting issues. These people didn’t have the opportunity to have a child. Now groups are broken up into those that are bereaved but don’t have children, and those that do have children. This is an open group that meets on a monthly basis. We also have a six week program which is a closed group called ‘crossings’. We have a ten-hour workshop that’s run yearly.

After someone has attended six times, we send them an evaluation form. We ask them how things are going, so there is a sense of their purpose in coming. We ask whether the group is still meeting their needs. Often there will be a suggestion very gently put ‘would you benefit from coming to one of the closed groups or the ten hour workshop?’

The ‘Good Grief’ program runs similarly. It is a monthly program. The young folk running it have themselves been bereaved, and are further down the track with their grief. ‘Stepping Stones’ is a six week program facilitated by one of our staff members. Training is built into all these programs, so on a fortnightly basis the facilitators will be attending training.

Our experience is that professionals and self-help groups complement each other. They run alongside each other. For some it is their ability to go to groups. Other find they need the opportunity to go somewhere where they don’t feel they are burdening friends and family members, but have a safe environment. Some like the opportunity to come to professional counselling. Everyone comes and is debriefed on an individual basis. We give people choices as to how best support and meet their needs.

Workshop conversation: Session two

Evaluation

I like the idea of sending out a questionnaire to people after they have attended six meetings. How does this work?

It is usually done in an informal way. People are invited to take the questionnaire and reflect on the benefits of the group. Any feedback they can offer as to how the group can run is invited. We give people the opportunity to name what their needs are, and how the facilitator is meeting people's needs. The ten hour workshop came out of this type of evaluation. People with children were finding the six week program difficult having to get babysitters. The new program on a Friday night and a Saturday means that perhaps grandparents can mind the children. It helps us give people choices to meet their needs in a practical way.

The evaluation process has also drawn our attention to topics people wish to discuss. Four times a year we have guest speakers that come in. It may be around, for example, 'when is it appropriate to start forming new relationships?' For a lot of people who are bereaved, there is a real awkwardness. They think it's now three or four years down the track and feel attracted to a person. They may feel awkward about what their family will say and what the children will think. The question for us is how do we support and help people who are forming new relationships? Other speakers have included financial issues, such as wills, organising finances and taxation, practical things, parenting. These topics often come out of the evaluation process.

The group setting

We have people with special needs come to The Compassionate Friends. They might have a wheelchair for instance, so they can't be upstairs. We have a lot of children and they need to be safe, so downstairs isn't always necessarily appropriate either. So that's becoming an issue in the group. We want parents (usually mothers in the morning group) to have time to talk, and know their children are safe. Physical things are an issue that you may need to look at all the time, not just when you set up the group.

How people move from participant to volunteer

It was mentioned SIDS embodies the idea that people can give back to the group, and that's a natural part of the group process. How does this happen?

A lot of the people who are here today are now involved because of personal involvement in the beginning. It's something that you grow to. People go through the stage and one day they wake up and think, 'now I'd like to do that - that would be something I'd really like to do'. Usually they come up at odd times. A woman came in last Friday for Red Nose Day. She had been thinking about it at home, and said, 'it's four years since my son died. I can't talk about it with my family - they tell me to get over it, move on'. She loves the environment, and wants to have the opportunity to talk about her son forever. And they feel that by giving something they can take something forever. Certainly I feel if I do a little bit I can be here forever and get that reward.

You have to have flexibility and be thinking about the group. As group leaders Anne and I will often say to each other, 'gee that one's got potential'. We are always looking for people to join the support team, to do the 'meeting and greeting' beforehand, and to think about if she could become a group leader.

It's something for the workers to do, rather than the volunteers. Anne's brilliant at that. We volunteers are in a luxury situation. We have these people that look after us all the time. They're always out there doing things for us. We are very fortunate.

I think it requires flexibility to encourage people to do what they can do. We have a young couple who would not even think about running a group because (a) they're not so far down the track, and (b) it's not been proposed to them. But they come along and set up biscuits and tea etc. They naturally do the 'meeting and greeting'. So you encourage that. One day they might lead a group.

When our son died, I never had the opportunity to explore different avenues with funerals. That has been an issue for me. I was bogged down by it. So I wrote it down on paper and we developed a brochure. I would never have done this by myself, but one of the workers suggested this.

With the funeral brochure, the important thing was you telling your story to a group of people who were right with you at the time and were motivated to pick up the issue. Volunteers come because they want to put something back - so it is important for an organisation to be able to offer that opportunity in any form.

We volunteers make the coffees. The people come to the group to get out of it what they can, for that session. When they decide they're going to become more involved, it's not decided in a group session. It's done outside of it. It may be when they're talking to you, or something like that. Certainly our support group doesn't get involved with those sorts of decisions. They really come for the contact with the other parents. For our people, their energy is totally involved in the group, and really nothing else.

It is hard to turn up and become a volunteer. It is hard to put your name forward, but sometimes that provides the framework for the new direction of your life as a grieving person. You will examine some issues in your life, and perhaps the people around you. By volunteering and going to groups a framework develops for that new direction. You surround yourself with new people when you go in on your day. You make new friends who become part of that new direction.

Volunteers and bereaved parents actually employed by the Foundation have come into our support group, and usually end up as absorbed in the conversation as the people who are there as participants. That's what the group is there for.

One of our selection criteria is that if someone themselves has been bereaved, they need to work through some of their grief. Twelve months is the minimum time from the date of the death for becoming a volunteer.

We are meeting mothers who are 18, 20 - under half our age, certainly struggling with issues that we never struggled with. When I step back I think 'well if we weren't doing it, the support may not happen'. They're better off with us, than no-one. That's basically what it boils down to. We struggle with issues of single mums, mums that have had all types of abuse, and things I've never had to deal with in my life before. I often say to Anne 'I don't know if I'm the right person'. Then I come back to what we always say. The fact that we have had a child die makes us the right person. I try not to get to any other level other than that.

Training volunteers

We reviewed what our parents thought of our training. We asked experienced supporters what they thought they really needed to have in the parents' supporters training program. And they all said they wanted theoretical content. We need to know about grief, trauma, and what self-help is. But overwhelmingly they wanted to talk with other people who had done it. They wanted to know how it is for you, how it impacts on you personally, and how do you do it. What are the issues that you are confronted with and take on if you are in a support role? So, in our training we try to provide some theory and a range of practical things.

The practical things are important to me. One thing that's been most useful to me is the protocols that have been developed. I know what happened to our son when he died of SIDS, but it's always changing and that's what people want to know - 'what happened when he died?' 'What happened when he went to the coroners and had to stay there 24 hours,?' Parents want to know all of those very practical issues. The protocols that you put out are really helpful because I could answer some of their very basic questions.

We are giving some of the theory to parents by talking with other parents who have done it. Then we ask them to write their experience and connect it up with the theory so they get that integration of experience.

At Outreach we offer a Friday evening and Saturday initial training. It's a combination of theory and practical. We have someone come in to teach facilitation skills. We use role-play. We also have a night for volunteers who have been involved in facilitating a group to give them feedback about what we experienced and what it was like for them. We offer on-going training, so prior to the monthly meeting there would be a planning meeting with the Good Grief program. With the younger bereaved partners, that takes place after the actual evening because of practical reasons. We have built supervision into all our training, so each group has supervision. This normally happens after the group, on the same evening. There's always a staff member they can have supervision with, but usually that's built into the training. We also offer education and training for both professionals and for our volunteers to attend too.

In the road trauma support team, we offer training that covers a range of areas such as how the TAC works, what happens in an emergency, hospitals, issues of loss and grief around injury and rehabilitation, loss and grief and bereavement, understanding trauma, and post traumatic stress. We have a number of on-going meetings that are personal and professional development meetings for volunteers. We arrange guest speakers and provide a chance to talk about how they are going with their clients. They can compare notes, and ask each other 'how you deal with this?', or 'what you did about that?' We run some ongoing counselling skills training. What they often say is the two weekends training has put their own experience into a framework where they can understand what is happening to them more clearly. That is a huge benefit. They can go out and help others, which is a thing they really need to do.

I like that word 'companion'. We have to be so careful with people who have just been diagnosed with something not to frighten them. We have to slot into the stage they're at, and be there with them, and walk alongside them.

With volunteers, there needs to be a balance between theory and on the job training. For example, with telephone support the training is practically based. After people have sessions in the centre so that they know the theory, they put it into practice immediately after. Then they talk to someone on how that particular phone call went. It's very important to put into practice what you've learned straight away, and know that someone else is there if they are needed.

I've had experience of training at The Compassionate Friends from both sides - doing the training as a telephone person, and as a group leader. I did telephone answering many years ago before we really formalised the program. Then I did the training and felt, 'god, I know nothing'. You realise your lack of skills, but good training will take you through all that and hopefully you will come out the other end a better listener.

What I learned through the training was to be confident to say 'I cannot fix this' and that's OK.

It's very different from running a group - giving support in a group. There is nothing the same. Facilitating a group is like juggling - so many balls in the air at the same time.

Summary by participants of the critical issues about professional and self-help collaboration for bereavement support

- Selection of volunteers- the more effort you put into this the less trouble you will have down the track.
- The importance of the support you get from the people that back you up. I couldn't do the after hours service if I didn't know I had my back-up. It's like the support groups. I know I have the support of good people who would come at any time, and that's really what allows me to do what I do. I couldn't do it on my own if I didn't know that there were people there I could call on.
- The professionals and self-help participants working together is one of the key things. Professionals can back up the people who do the self-help work. It can be hard to remember the theory side of things, particularly if you are lacking that concentration. I know that I don't pick up everything, even though I am getting that theory at some level, but I don't learn it thoroughly because of the concentration issue.
- People need to have the opportunity to debrief, especially if you have had a difficult phone call. At Outreach we now take it in turns to do intake. There are times when you get off the phone when, for example there has been a series of suicides in a family within two years, and you are saying 'help'. In setting your own boundaries it's helpful having someone you can actually have good supervision or debrief with.
- We need to evaluate training programs regularly. If you are still doing the same training you were doing ten years ago then there's something wrong in your organisation.
- We need to validate volunteers and their work. This includes validating their personal experience, but balancing that with validating when their personal experience makes it too hard to continue in the role as a volunteer. This may mean validating them withdrawing from the role as well
- Learning to balance the role of group leader with the needs of the group.
- Containment of the personal experience of the volunteer is also important. Sometimes there has been feedback from a bereaved person that there are organisations where the

person on the other end of the phone has been prescriptive about what they should and shouldn't do. There needs to be something in volunteers' training about validating their own experience and how it can inform the support they can give, while also emphasising how everybody grieves in a different way, their own way. Sometimes the regrets of the people who are volunteering can get in the way of the people they are trying to support.

- My experience from doing support training is two things were important. One is the self-care aspect for a volunteer, because unless you can look after yourself you can't possibly care for someone else. Also I rarely bring up my own grief issue unless I'm specifically asked. It's important not to bring your own stuff into it unless you're invited to.
- How do you encourage people who are 'anti training'? We say there is an expectation they will attend the initial training as part of their volunteer commitment. We also expect they will avail themselves of the opportunity to do on-going training. We offer that outside of the formal training. We can't let volunteers loose on other bereaved people. We need to set some boundaries so we can feel safe in this situation.
- We have a written contract with volunteers and we let them know what we are going to offer them, and they sign it.
- I've done training because it's been offered to me. I still need a lot of help not only with the groups, but to get through my life. It is not a decision I want to make about what training I need. I don't know what this might be as it is not part of my 'work life'. I can't identify my own training needs - this is not my area of skill. The professional people are better at this.

Closing reflection

John Bottomley (Urban Ministry Network)

It has been very interesting to have more than one person from the same organisation come and talk about their organisation in front of a large audience! It's a gift that you've brought to the workshop to be able to talk out of your different memories and experiences, often of the same event, but remembered differently. This has enriched our understanding of what goes on in organisations. There is not a monolithic view of what each organisation actually is, but within each organisation there is a very rich range of experiences.

In view of the discussions the Bereavement Support Groups Network has had about accreditation, this discussion has been quite solid and substantial, underpinning the move in that direction.

Having joined the Bereavement Support Groups Network in the last twelve months, this experience has given the UMN a wonderful opportunity to host the BSGN for the first time. To have such a large number of people attend and express interest in this issue suggests that one of the functions of the BSGN in the future will be to continue creating opportunities for reflection.

Two things I would draw attention to. First, this particular network is in a sense a prophetic group that lives between two worlds. There's a world where death is in fact denied. People spoke about the silence around death. It is a world where many find their humanity denied by this oppressive silence.

There is also the world this network is creating. This is a world that allows people to tread in the sacred space of the real depth of humanity, where death and life are both present realities and we taste their depths of pain and joy. A number of you gave testimony to the value of the shared experience of self-help at the points of pain and of joy. This experience is very important in shaping a new world, a new type of community that allows that humanity to be lived out.

The meeting spoke earlier about the diversity of needs, and the importance of flexibility of response. But this second session has made it very clear that flexibility is actually won at the cost of organisation. There is tremendous energy that goes into being structured and organised and thoughtful. Flexibility is not the same as looseness or no structure. Underneath all the sharing has been a real concern for order in the midst of chaos and how that is achieved.

People have talked about the time commitment in their work. If we are on about social transformation as well as personal support, that is a long haul. Not only is the personal healing a long haul, but the changes in society that allow grief to be more honestly lived out is a big challenge to our culture. Along side that commitment of time there is a commitment to honouring boundaries so that people know who they are and where they are in that journey.

Training and supervision is that which nurtures people in their journey. There is a patience of commitment to the journey, and a commitment to being properly resourced. This means knowing that you need watering holes or oases along the way. This network is one of those nurturing places and is part of its ongoing value.

A number of people expressed their gratitude that, while not actually wishing to be in the work they're in, nevertheless have a profound sense of gratitude for discovering a dimension to life that has been both nurturing and sustaining. That sense of gratitude cuts across boundaries between being bereaved and being a professional. In the gratitude that people spoke about there seemed to be a collapsing a boundaries and a real sense of common purpose. Finally, I wish to express my gratitude for your participation today. What you've given to our agency's reflections in this area is greatly valued.

BEREAVEMENT SUPPORT GROUPS AND SOCIAL HEALTH

Issues in development, leadership and training

Introduction

The first part of this report reviews the national and international literature on 'what works best' in bereavement support groups, with particular emphasis on issues of development, leadership and training. This report has been prepared by the Urban Ministry Network (UMN) in order to assist in the development of mutual support groups for the bereaved as part of the Partnerships in Grieving program.

Growth of Bereavement Support Groups

It is widely recognised that many people have difficulty adjusting to the death of someone close and are at risk of experiencing a variety of psychological sequelae, including depression, anxiety, reduced self-esteem, guilt and feelings of isolation (Jacobs et al 1989; Raphael 1984; Stroebe et al 1993; Worden 1991). Although most people are able to progressively resolve their grief, a significant minority are at risk of complicated outcomes characterised by high rates of depression, anxiety, grief symptomatology (Middleton 1998; Worden 1991).

Caring for the bereaved requires a range of interventions, from self-help or mutual aid groups, to counselling and therapy programs. The recognition and validation of personal experience as a medium for promoting growth in groups of people with some common experiences has added a powerful tool to the range of interventions available to support the bereaved. The past three decades have seen a dramatic increase in the phenomenon of the support group as a means of providing support to those who are bereaved (Stroebe et al 1993; Raphael 1984). Support groups are now seen to be a part of the continuum from the direct management and direction of professionals to a variety of intermediate models including the autonomous group managed by its members, and a group facilitated by a professional.

Origins

Support group development stems from a range of sources. Sometimes lack of professional interest or absence of resources for a particular activity threw people back on their own initiative. Particularly at times of scarcity of professional availability, and in recognition of unmet need, the power of group processes was recognised as a means of providing mutual support and promoting personal growth and change. Many self-help or mutual aid groups arise as a result of deficiencies in the mainstream or formal health and welfare service system.

Self-help groups tend to arise when there are meaningful and recognised needs among people that are not being met by existing institutions. Self-help groups provide alternative pathways to existing services that are not available in an adequate form to meet certain people's needs. As such, they provide valuable additional resources which may be more accessible than those provided by more conventional service delivery systems.

Benefits of Group Work with the Bereaved

The value of group interventions in facilitating positive bereavement outcomes has received considerable attention in the international literature. Group interventions, in general, are reported to be an efficient and effective means of imparting information, providing support to those who are isolated and enable participants to enhance their coping capacities (Toseland and Sipoin 1986; Yalom 1975). Bereavement support groups provide people with a caring and supportive environment in which people can share their grief with others who have similar experiences and who seek relief for their distress and feelings of isolation (Hopmeyer and Werk 1994; Levy and Derby 1992; Raphael 1984; Schwab 1996). As Oliviere et al (1998) have noted:

Groups can help promote people to feel less lonely and isolated; they offer opportunities for mutual support and problem-solving, a safe place to express feelings and ideas, feedback on behaviour and improved self-esteem through the opportunity to give support as well as to receive it. (p 71).

Previous research (Johnson and Johnson 1987; Lieberman et al 1968; Humphrey and Zimpfer 1996; Yalom 1985) suggests that group interventions achieve their positive outcomes by generating a sense of community, belonging, mutual support and acceptance that eases the pain associated with bereavement. Groups provide an environment in which participants may experience previously distressing feelings with a new sense of acceptance. Groups also provide the constructive peer relationships needed for healthy social and cognitive development (Johnson 1980). Evidence certainly suggests that the participants strongly value the informal social support and friendship offered by support groups.

Professional Use of Bereavement Support Groups

Despite the many apparent advantages to support groups, Oliviere et al (1998) suggest that group work is often not used enough in the field of bereavement. One reason may be professional suspicion of the 'curative' or therapeutic value of group interventions, particularly groups run by lay-people. Writing in the more general field of mental health, Salzer et al (1996) note that 'consumer-owned' self-help groups are typically less valued by those working in formal services and that interventions with less professional involvement are perceived as less effective. Alternatively, group interventions may be perceived by professionals as 'daunting, something beyond their time, resources or experience' (Oliviere et al 1998, p 72). Whichever is the case, it is important to review the evidence on 'what works best' in effective group work with the bereaved. To this end, it is therefore timely to examine factors that promote positive outcomes in bereavement support groups. It is to this issue that we shall now turn.

What Works Best in Bereavement Support Groups?

Having established the benefits of support groups, it is worth considering what factors promote optimal outcomes in effective bereavement support groups. The literature suggests that the following six factors can be identified:

1. Who to offer bereavement support.
2. The value of early intervention.

3. The importance of group leadership.
4. The importance of training and the role of professional support.
5. The value of structured, closed-ended support groups.
6. Group method: the value of emotional support.

Who to Offer Bereavement Support

An important issue is who to offer bereavement support. The available evidence points to the following three points on who benefits from group work:

1. Group support is particularly useful for those without adequate support from family and friends, including bereaved people who do not find others who have suffered a similar loss in their social support network (Parkes 1980; Schwab 1996).
2. Group support may be most helpful to the most distressed, those with greater psychological morbidity or otherwise identified as being at risk (Parkes 1980).
3. Notwithstanding the above, it is generally accepted to exclude participants with serious 'pathology' or maladaptive behaviours. These people are likely to require the intervention of a professional grief counsellor/therapist (Raphael 1984; Worden 1991).

As Parkes (1980) concluded in this review on the effectiveness of bereavement counselling:

Services are most beneficial, among bereaved people who perceive their families are unsupportive, or who, for other reasons, are thought to be at special risk. (p 9)

The Value of Early Intervention

An important issue is when to offer bereavement support (Worden 1991). Clearly, the provision of support at appropriate times is an important aspect of bereavement service provision. However, very few studies have examined the most appropriate time at which group involvement should be offered. On the one hand, it is commonly assumed that interventions should be applied within the first six months of bereavement, as it is in the early stages after the death where people are most in distress and at risk of detrimental outcomes (Lund and Casterta 1998). On the other hand, it could be argued that bereavement support offered too early after the death is less likely to be effective as the bereaved person is still in a state of 'shock'. Worden (1991) argued that it is important not to include people where loss is six weeks or earlier, as they are less likely to be ready for a group experience. In a recent study of bereaved people who had participated in professionally led support groups, it was found that participants said they joined the groups at what they felt was the right time - at the time they needed it - whether this was in the first few weeks, months, or for some, years after the death (Picton et al in press). Although the idea that support in the early weeks of bereavement was limited in value was voiced by some participants, others said they benefited from group support within the first three months after the death, particularly for those without adequate family support and the most distressed. These findings suggest that a case could be made for early intervention providing support to those most at risk of negative bereavement

outcomes. Just as we acknowledge that people grieve in different ways, perhaps we should be more ready to reach out and offer group support as early as possible.

The Importance of Group Leadership

Group processes are often described as powerful and potentially threatening (Gottschalk 1966). Although this is not clearly supported by research evidence, it is clear that responsible management will tend to result in optimally beneficial outcomes. This is often linked to the issue of group leadership. Members of support groups often value the importance of group leadership. For example, Thuen (1995) found that participants' satisfaction with support groups is strongly related to the structural characteristics of the group, particularly how the group is led.

One of the most controversial debates within the wider 'self-help' movement concerns the nature of group leadership, particularly the role of professionals in running support groups (Block and Llewelyn 1987). Much has been made of the pros and cons of peer-led support groups versus groups led by professionals. Although it is often argued that support groups which are professionally led are intrinsically different from peer-led, self-help groups (Matthew et al 1999), there is a paucity of research which has assessed the role and impact of professional involvement in bereavement support groups.

Peer-led support groups are common in the wider self-help movement. By definition, these groups are:

sanctioned, structured, and controlled by group members so that the provision of help relies primarily on member's skills, knowledge and concern - not on outside professionals (Hinrichsen et al. 1985, p 66).

An example of this type of group is one run only by bereaved individuals. Certainly, there is some evidence to suggest that autonomous 'self-help' groups are a useful resource in bereavement support (Lieberman 1993; Parkes 1987). In reality, the dichotomous view which compares 'peer-led' and 'professionally-run' support groups is simplistic and artificial (Matthew et al 1999). Most bereavement support groups have some form of professional involvement and the existing models of group leadership reflect this. For example, Compassionate Friends is a general outreach 'self-help' group for bereaved parents and usually functions with a backup of professional support (Klass 1984; Raphael 1984). Although various leadership models have been used including single or co-leadership, professional leadership, or even facilitation shared between a professional and a bereaved person (Oliviere et al 1998, Stroebe et al 1993), there is little empirical evidence to suggest that any one model of group leadership is necessarily more effective than another.

Training of Group Facilitators and the Role of Professional Support

Within the self-help movement, there has been some resistance to the idea of trained leaders, presumably because they are seen as representing autocratic or hierarchical group structures. However, Block and Llewelyn (1987, p 257) have argued that:

without responsible feedback and guidance, the group could become a negative experience for the membership. A trained leader is seen as necessary to prevent

this occurring by fulfilling certain functions, such as preventing any individuals or clique dominating the group, ensuring that decisions are reached, and making sure that all interests are equally represented.

With appropriate training and professional support, there is evidence to suggest that peer facilitators can be as effective as professionals. For example, Parkes (1980) suggested that it takes time, as much as a year, for volunteers to develop skills to work competently with the bereaved and 'thereafter many volunteer counsellors come to rival professionals'. The crucial variable is the degree of professional support and training provided to lay leaders. As Parkes (1980) has noted, the 'value of services that lack the support of trained and experienced members of the care-giving professions, remains to be established' (p 6).

What, then, are the necessary leadership skills that enable groups to work effectively? At the most general level, clear understanding of roles in groups is necessary for the promotion of positive outcomes. This includes the maintenance of boundaries and providing a sense of safety and continuity for participants (Johnson and Johnson 1987). Professionals also have an important role in session debriefing and external supervision of group facilitators (Oliviere et al 1998).

More specifically, leadership of groups in bereavement requires a number of qualities: understanding the special powers of group experiences, understanding the factors in the groups that promote participant growth and change, understanding the goals of the group and the ability to perform competently a set of skills needed to facilitate the group. Oliviere et al (1998) noted the importance of strong boundary management in group work, given the powerful and often painful emotions surrounding loss and death.

In addition to training in effective group processes and intervention skills, facilitators require knowledge of bereavement patterns and dynamics. Raphael (1984) noted that knowledge of bereavement processes and grief responses is critical for group leaders, as is training in the skills required to address them. However, Raphael (1984) goes on to note that:

The core attribute, however, of anyone offering support to the bereaved is the capacity for empathy. This brings special difficulties for the counsellor, since empathy with the bereaved in their encounters with loss and death touches off in each one of us the most personal of terrors. We all have to learn to live with loss, but the person who works in this sphere must confront it every day. (p 401)

The Value of Structured, Closed-Ended Groups

Like other mutual aid groups, bereavement support groups display considerable variation in the extent to which they are structured and open or closed-ended. Groups may be closed-ended, in which case they exist for a limited period of time and people enter and leave the group at the same time (Worden 1991). Others are open-ended which means there is no definite termination or fixed membership - people come and go as the group fulfils the needs of members. There are pros and cons for each group type. Open-ended and unstructured support groups offer participants the opportunity to attend when they want and are able to. Within the fields of bereavement it has been suggested that members of open-ended groups may find it difficult to express their feelings about loss

and death (Oliviere et al 1998). Although there is little reliable data on the efficacy of different group types, structured, closed-ended group work may provide a greater opportunity to define membership and thus give participants the safety of a closed environment in which emotional releases of powerful and distressing feelings can occur (Oliviere et al 1998).

Group Method: The Value of Emotional Support

In order to meet the needs of participants, support groups may perform many functions. Worden (1991) suggests there are three main types of groups:

1. Educational or information provision.
2. Social support and friendship.
3. Emotional support.

Of course, any given group may perform one or more of these functions. Although there is little evidence on efficacy, Worden (1991) asserted that the most valuable group is one set up for emotional support. These groups provide the empathy that members need to feel toward each other, with the sharing of distress with 'someone else who had been through the same thing' (Raphael 1984). The group support, particularly if in a closed group, enables participants to understand and normalise their grief through the sharing of experiences in a safe and supportive environment.

Summary

Previous research indicates there are many benefits to bereavement support groups. Perhaps the most pertinent of these is the 'empowerment' of participants. Bereavement support groups offer:

particularly potent opportunities to return power and control to the members rather than the 'professional leaders' (Oliviere et al 1998, p 71).

The evidence, however, does not strongly support the case for autonomous 'self-help' groups with professional intervention. Given the involvement of professionals in most support groups, 'the case for self-help without professional backing must therefore be regarded as unproved' (Parkes 1980).

In summary, what are the factors that 'work best' in bereavement support groups? The following is an attempt to summarise the available evidence. Bereavement support groups are probably most effective when they are professionally supported with appropriate models of leadership and training of facilitators. Structured, closed-ended groups offering emotional support at appropriate times throughout the process of mourning to those who are most distressed and isolated appear to be capable of producing positive outcomes and thereby attenuating the negative effects of bereavement. In conclusion, Raphael (1984) has summarised the existing body of knowledge:

Those organisations that offer counselling and emotional support, over and above their friendship and sharing of feelings, make a very significant contribution to the care of the bereaved. They are best able to fulfil this function when the

helping members are well trained and backed by ongoing professional support from those skilled in the area of bereavement. (p 398)

RECOMMENDATIONS TO UMN FOR THE PARTNERSHIPS IN GRIEVING PROGRAM

1. Conduct closed end support programs over an agreed number of sessions rather than an open ended support group.
2. Use appropriately qualified leaders for support programs.
3. There is considerable value in training volunteers who have experienced loss for support and program leadership roles.
4. The training of volunteers needs to focus on integrating their experience of loss and grief with their provision of support for other bereaved people.
5. Professional staff and volunteers dealing with grief and loss of bereaved people need regular professional supervision.
6. The PIGP needs to sustain a range of support options, including support programs, one-on-one counselling, remembrance of anniversaries, and regular newsletters.

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