

# Abstracts

## Denise Brady

Librarian

St Christopher's Hospice, London

d.brady@stchristophers.org

### Participants with prolonged grief – how do they benefit from grief group participation?

Johnsen I, Dyregrov A, Dyregrov K. (2012). *Omega* 65(2) 87–105

This article is based on the findings of a Norwegian study that examined the experiences of people attending bereavement support groups. Questionnaires were completed by 262 participants. One asked about socio-demographic details, information about their loss and participants' satisfaction with the group. The second questionnaire asked participants to complete the PGD-13 (PGD) – a diagnostic tool for prolonged grief disorder. This tool is divided into five criteria and all must be met before a diagnosis of prolonged grief can be made.

Many of the sample experienced some of the criteria associated with PGD. However, 22 (9%) fulfilled all the criteria for PGD. Most were women (though this was almost the same proportion as the full number of participants) and most were in their late 50s (and the average age of all participants was between 50 and 59). So the demographic difference between the two groups was not large. The majority in the PGD group had lost children and the cause of death was suicide or other unexpected deaths. Six of this sub-group were related to each other which means that 25% of the sub-group had, presumably suffered the same bereavement.

Overall, participants were satisfied with the intervention. However, those who fulfilled the criteria for PGD indicated that the group had a less positive effect on their life quality than those who did not. There were also more in this group who said it had some negative effect. In addition, those who expressed overall satisfaction with the group were slightly more positive about their experience than in the non-PGD group.

It is interesting that the authors were able to identify differences in satisfaction in those who fulfilled all the criteria for PGD. They recognise and discuss the limitations of their research. They speculate that being part of a grief group may exacerbate the exact problems that constitute PGD as the group may allow too much rumination on grief. They consider that it may well be that this group need a different, probably more structured, type of intervention. Yet one could also speculate it is possible that all participants would benefit from a more structured approach but that the PGD group would benefit more from this. This might be an interesting follow-up study as so many of the group matched some criteria related to prolonged grief disorder. ■

### Facing the challenge of adapting to a life 'alone' in old age: the influence of losses

Kirkevold M, Moyle W, Wilkinson C, Meyer J, Hauge S (2013). *Journal of Advanced Nursing* 69(2) 394–403

This collaborative qualitative research was based on interviews with 78 people aged over 65 in three countries (Norway, England and Australia). They lived in a mixture of retirement villages, care homes and in private homes. 67 lived on their own and 11 lived with a partner. It is not clear how many were widowed or had never been married, nor how many had severe physical difficulties. The original purpose was to find out about loneliness in old age and about 50% described themselves as 'lonely' and 50% as 'not lonely'. The stigma of loneliness is discussed as are the limitations of the research.

However the most interesting finding is that so many of the interviews dealt with losses and accumulated losses. In addition, those who said they were 'lonely' versus those who said they were 'not lonely' differed significantly in how they coped with these losses. These different ways of coping are described in four ways:

- accepting losses versus being overpowered by losses
- staying committed to activities versus feeling unable to do this
- creating a meaningful life in one's company versus a life alone being regarded as an empty one
- staying connected with people versus being isolated from people.

A public health approach to helping them is briefly described. Some ideas from the suggestions, however, could be relevant to helping bereaved people, especially older people. ■

### A qualitative evaluation of the provision of bereavement care accessed by service users living in a health and social care trust area in Northern Ireland

Montgomery L, Campbell A (2012). *Journal of Social Work and End of Life Care* 8(2) 165–181

This study aimed to evaluate the bereavement care offered to individuals living in one Health and Social Care Trust in Northern Ireland through the lens of a number of health professionals

involved in this area of work. Those interviewed were

- a) seven staff members from statutory agencies and
- b) nine staff from voluntary agencies.

All provided services related to losses before an anticipated death and/or provided support to bereaved people.

The results indicated that all the respondents felt that bereavement care was an important part of their role, even if it was not always the major part. They considered people would seek support if:

- a) they had experienced a traumatic bereavement
- b) they were isolated with poor family support or there was family conflict
- c) if they had a 'vulnerable' personality
- d) they had experienced support from health professionals before the death of their loved one.

They seemed to self-refer when they were 'struggling to do the ordinary basic things'. They also experienced a variety of emotions eg 'fears about their mental health, anger, shock and guilt'.

Participants in the research thought their 'goal is to help them lead as full a life as possible with a connection with the person who has died ...'. Support was offered in a largely unstructured person-centred way. Overall, bereavement care was not seen as an integral part of service provision and only one interviewee used a risk assessment tool. Referral appeared to be ad hoc and arbitrary even though those interviewed recognised bereavement as an important aspect of care and statutory and voluntary services worked well together in this informal way.

The authors make various recommendations. There needs to be greater agreement on what constitutes bereavement care and guidelines on who should offer support. Protocols of practices also need to be developed. Currently there appeared to be no leadership to enable a coordinated provision of standards of service.

Interestingly, people were regarded as outside the scope of this service if they had mental health needs associated with their bereavement. ■

### The Australian Centre for Grief and Bereavement: the interface of bereavement education, research and counselling

Hall C (2012). *Grief Matters* 15(3) 58–63

As a possible model of bereavement service provision which might help those involved in bereavement services provision in such places as the Health and Social Care Trust mentioned above, this article could prove useful.

It describes the work of the Australian Centre for Grief and Bereavement – how it grew out of an increasing interest in the

public health movement and how it coordinates bereavement care in the province of Victoria in Australia. The authors describe public education, community support for bereaved people, more intensive training to help people who have more complex needs, and research to underpin the service provision. It is one of a series of articles in this issue of *Grief Matters* that informs readers about the development of a range of bereavement services in different countries, including Cruse Bereavement Care. ■

### When grieving adults support grieving children: tensions in a peer support bereavement group programme

Baughner J E, McIntyre M, House C, Mawhinney M, O'Brien B, Reagan A J (2012). *Mortality* 17(3) 176–299

This study is of a children's bereavement service somewhere in the United States. It is based on interviews with 20 volunteers (former volunteers as well as current volunteers) who worked at the centre, as well as two staff members. The service is based on the 'peer support' model. This seeks to normalise the experiences of bereaved children, mainly through group work. You might think that the article would be about how the volunteers relate to the children and any tensions on how to go about this: in fact it is almost exclusively about the volunteers themselves, the fact they are motivated to volunteer because of their own experience of loss – and their supervision which is based on the overarching theme and aim of the centre 'learning to talk about grief' – not, apparently the grief of the children but their own personal experience of losses. With regard to supervision, for every one and a half hours spent facilitating bereavement groups, volunteers are required to participate in two hours of group supervision. This occurs before and after their volunteering face-to-face time. Some volunteers found this enormously helpful while others found it constraining and inappropriate.

The article makes the point that 'talking about grief' is often regarded as inappropriate for helping young people. The children do have access to play materials and activities but there seems to be an implicit assumption that talking is the best therapy. Yet when discussing this in more detail, it is obvious that that in this small group of volunteers, there is a range of opinion from a rather disparaging remark 'you don't get a lot of incredible insights from these little kids' to 'it was wonderful to watch ... through the role of play, they ... express a lot'.

The authors highlight a kind of 'social policing' that takes place in many areas of the centre and suggest some other supervision models that would be more appropriate. For instance it seemed acceptable to impose ideas on clients that come from professional training but not if they derive from one's own culture or personal experience. They point out the limitations of their research as well as the fact it can draw no conclusions about the quality of the service, based on these interviews. ■

## Narratives of neonatal intensive care unit nurses: experience with end-of-life care

Lindsay G, Cross N, Ives-Baine (2012). *Illness Crisis and Loss* 20(3) 239–253

This article is essentially about the unique stresses of looking after recently born babies that are in danger of death.

This details research (mainly through the recording of views expressed by a small group of nurses in two focus groups followed up by individual interviews), of how nurses have to deal with a range of complex communication, ethical and practical issues as they see the life of a baby fading away. Frequently in a very short time frame, the nurses have to deal with these as they relate to the baby, the parents, the medical team, and their own sadness and loss at what is happening.

The authors went on to hold group sessions with other paediatric neonatal nurse from intensive care that 'uncovered information that helped to illuminate the meaning of their present situation, anticipated future practice and stimulated new insights that led to clarity of practice'. They elicited the process of how nurses develop their practice and the, often emotional, difficulties they faced. They identified an organisational need for education for these nurses and followed up with courses to further develop the nurses' practice as well as support them in their role. In contrast to the previous article, this one describes a very different way of providing supervision and support for staff working in end of life and facing loss as an inherent part of their job role. ■

## Early Parental Death and Remarriage of Widowed Parents as Risk Factors for Alzheimer's Disease.

Norton, M C, Smith, K R, østbye, T, and 8 others. (2011) *The Cache County Study. Am J Geriatr Psychiatry* 2011 September; 19(9): 814–824

This remarkable paper reports results of a sophisticated statistical study of 570 participants with Alzheimer's Disease and 3,538 without dementia in Utah, USA. Based on evidence from death registrations, a confirmed diagnosis of Alzheimer's Disease (but not other forms of dementia) was found to be associated with a previous history of death of father before the patient had been aged five and death of a mother when the patient was aged 11–17. In these age groups the loss of the parent was associated with a doubling of the risk of Alzheimer's Disease. These findings remained statistically significant only when the parent had not remarried. They were not affected by the gender of the patient.

They suggest that loss of parents can have effects on the child's brain that do not become apparent until old age. It seems likely that it was the effect of the father's death on the mother that impaired her care of the infant and laid the seeds of later brain disorder. Loss of the mother during the child's teen years seems more likely to have had a direct effect on the child's vulnerability. Remarriage may have reduced vulnerability because it was a sign of the bereaved parent's recovery from the stress

of bereavement and/or because of the care given by the new parent to the child and the spouse. ■

## Visiting the site of death: experiences of the bereaved after the 2004 Southeast Asian Tsunami

Kristensen P, Tonessen A, Weisæth L Heir T (2012). *Death Studies* 36(5) 461–476

This study examines a very specific group of people, those from Norway that have been bereaved as a result of the Tsunami in South East Asia in 2001. 84 people from Norway were killed in this natural disaster and the Norwegian government arranged commemoration journeys for those for those who had lost close relatives in 2005 and 2006.

The study aimed to find out how many Norwegians had travelled to the disaster area after 2004 and visited the actual site where the deaths occurred, what this meant to them and whether there were differences in mental health between those who have visited the site and those who had not. The Norwegian register held names of 200 bereaved individuals of this disaster. The authors clearly provide information on each of these 200 individuals and whether or not they participated. 130 eventually participated either completing a postal questionnaire or an interview or both. The clarity of this information is impressive.

Most of the participants in the study had been to the Thailand site at some time after the tsunami and had visited the site where their loved ones died. The majority of these said the visit had been very important to them. In particular they said it had increased their understanding of what had happened and they had a sense of closeness to the deceased. Participants had also been asked to complete three self-report questionnaires a) the Inventory of Complicated Grief (ICG), b) the Impact of Event Scale, c) a general health questionnaire. With regard to the Impact of Event Scale which measures symptoms of traumatic stress disorder, those who had not visited the site showed greater avoidance (ie avoiding trauma reminders) whether or not they had been present at the time of the disasters. All showed greater arousal (eg. sleep disturbance irritability, hypervigilance) if they had been exposed to the disaster, whether or not they visited the site. Only one of the 19 items on the ICG revealed a significant difference in scores. This was between those who had not been present at the time of the tsunami in Thailand and who had not subsequently visited the site. Those who visited the site had less difficulty accepting the loss.

The reasons as to why people did not visit the site included family conflict and ill-health so acceptance of the death may be tangled with issues not connected with visiting or not visiting the site. Nevertheless visiting the place of the disaster, confronting what had happened and having a greater understanding of what had happened was the judged the most helpful aspect of the visit. In particular, it helped those who had been present during the disaster to realise their powerlessness in being able to rescue anyone. ■