

Bereavement round up: supporting people bereaved by dementia and women bereaved by stillbirth

Laura Rooney Ferris

Information & Library Manager
Irish Hospice Foundation
Laura.rooneyferris@hospicefoundation.ie

Laura Rooney Ferris presents a round up of recent research literature and other publications relating to bereavement.

Dementia caregivers' coping with pre-death grief: effects of a CBT-based intervention

Meichsner F, Wilz, G (in press October 28 2016). *Aging and Mental Health*, <http://dx.doi.org/10.1080/13607863.2016.1247428>

A dementia diagnosis, and the subsequent grief of loss of personhood, impacts not only the patient but has far reaching effects on family and caregivers. Meichsner and Wilz indicate that with the increasing global incidence of dementia the number of those coping with caring for a loved one with the disease has reached significant proportions.

While acknowledgement and examination of the unique anticipatory grief experience of dementia sufferers and their families is not new, efforts to outline and evaluate the effectiveness of specific interventions are still under examination. The application of Cognitive-Behavioral Therapy (CBT) as the authors indicate has been shown to be successful. This study seeks to evaluate whether CBT can increase the coping skills of dementia caregivers in the pre-death period and if it can be sustained in a six month follow up. Drawing on observations from the literature and from their own previous work (2015) the authors added the variables of: care situation, gender, and relationship to the patient to their method.

The analysis was conducted using a Randomised Controlled Trial (RCT) approach. A nationwide recruitment of participants was undertaken calling for people who were primary carers of a person with dementia who had no

prior history of mental illness or psychotherapy. A total of 273 were recruited and randomised with 139 receiving a telephone based CBT intervention and the remaining 134 acting as a control group.

For those in the intervention group, twelve 50 minute telephone-based sessions were delivered by CBT trained psychologists. They also received information on dementia and caregiving. This group were also given a payment of 40 Euros for their participation. ■

Developing a dementia loss module

In addition to the telephone-based support, a manual of 10 modules was developed covering aspects of caring and coping with loss. The module focusing on coping with loss was informed by the authors' previous experience in supporting dementia caregivers. It emphasised grief as a natural response to the experience of caring for a loved one with dementia. Participants were facilitated to develop coping skills for the emotional experience of anticipatory grief.

Participant assessment was conducted three times: before randomisation; on completion of the six month intervention; and again at six month follow up. The caregiver grief scale developed by Meichsner, Schinköthe and Wilz (2015) was used to assess anticipatory grief. The assessments were completed by participants who placed relatives in nursing homes in the course of the trial. However those who were bereaved in the process did not complete assessments post-bereavement.

The study findings were supportive of other research on dementia carers in their participant profile with over 80% being female, over 60% caring for a spouse and the mean age being 64 years. Of the range of persons with dementia being cared for by participants, the majority (45.1%) had

been diagnosed with Alzheimer's. Of the 273 recruited participants, only 36 left the study between baseline and final six-month assessment. The reasons for leaving included changes in situation brought on by admission of the patient to a care home or bereavement (n=22).

The key overall study findings indicated that for participants who remained with the study and remained in the role of carer, the six month post-intervention assessment showed a reduction in pre-death grief. As anticipated, the relationship to the care recipient had a significant influence on extent of pre-death grief, with spouses and women having the highest level of grief. ■

Applying an RCT design approach

The study is significant in being the first application of a RCT design using CBT as an intervention for the anticipatory grief. The authors themselves indicate that therapists' open interpretation of the bereavement support manual for the study might have limited treatment fidelity.

That participants who were bereaved in the course of the study were exited with no follow-up assessment limits the potential findings for this study. Follow-up with the bereaved participants alongside those continuing in the caring role may have offered some valuable insight into the contrasts and differences between pre and post death grieving in dementia carers. ■

Meichsner F, Schinköthe D, Wilz G (2015). Managing loss and change: grief interventions for dementia caregivers in a CBT-Based Trial. *American Journal of Alzheimer's Disease & Other Dementias*, Vol 31(3) 231–240.

The process of change in complicated grief group therapy for bereaved dementia caregivers: an evaluation using the *Meaning of Loss Codebook*

Supiano K, Burns L, Pond V (2017). *Journal of Gerontological Social Work*, doi/10.1080/01634372.2016.1274930.

The impact of dementia caring is also the focus of Supiano *et al's* article which explores interventions for complicated grief in dementia carers. This article addresses another of the specific aspects of the grief experience for dementia carers and again emphasises the unique experience of the grieving process for dementia carers.

The stress of dementia caring and extent to which the mental health strains of caring carry over into bereavement have been well documented. As the authors note, however, there are still conflicting theoretical frameworks on dementia grief. Although those grieving following dementia caring may take different paths in their adaptation to bereavement most will ultimately integrate their grief. The authors note though that for 9-25% of bereaved dementia carers their

grief trajectory will be extended and prolonged, developing into complicated grief. This study sought to evaluate the progress of grief and the incidence of complicated grief of carers using complicated grief therapy. ■

Meaning making and dementia grief

A Complicated Grief Group Therapy was developed which incorporated techniques from established complicated grief therapy developed by Shear *et al* (2005). Among these techniques were discussions, sharing and storytelling activities. Participants worked towards integrating their memories, the story of the death and their ongoing sense of the loss into an approach to their lives post-bereavement. In this focus on encouraging participants to connect with and make sense of their loss, the therapy was heavily informed by the theory of meaning reconstruction. Building on meaning making, the authors incorporated the *Meaning Loss Codebook* developed by Gillies, Neimeyer & Milman (2015) to categorise and define concepts of meaning.

The study was part of a randomised, controlled, wait list trial evaluating the impact of complicated grief therapy on dementia caregivers. Randomly selected participants were assigned to either a complicated grief therapy group or to a wait list group. Wait list participants received a weekly 30 minute phone call where they could report their grief status using the same questions as those in the treatment group.

The study's central question was to determine whether caregivers participating in complicated grief therapy change their construct of the meaning of the death and whether this meaning allowed participants to more easily integrate the memory of the lost loved one. ■

Adapting the *Meaning Loss Codebook* and assessing grief change

For the purposes of the study and to be able to apply the *Meaning Loss Codebook* (Gillies, Neimeyer & Milman, 2015), the researchers first reviewed video from another complicated grief therapy study to determine how to assign coding to participants' discussions. The researchers observe that meaning reconstruction displays in a number of ways: the retelling of the death, imaginary conversations with the dead loved one and integrating memories. In their observation of participants, they found the *Meaning Loss Codebook* worked well as a means of deciphering participants' discussions. Themes emerging in discussion were: regard and affection for the deceased, sense of unpreparedness for the death despite length of illness, family bonds and memories. They also noted that most participants expressed positive feelings in their discussions, with regrets generally being framed in relation to care decisions and anger directed at dementia. The negative expressions they noted emerged more in the later weeks of treatment. Participants' mentions

of 'moving on' or being released from the caregiver burden were also noted as emerging in the latter sessions. ■

Integrating grief and finding meaning

The gradual, steady process toward moving on and being able to integrate memories in the grieving process was seen as a positive outcome. Participants' pre and post group scores on the Complicated Grief Inventory showed reductions, with the follow-up score showing a reduction from 32.33 in the pre-test to 17.23 in the follow up. They also felt the *Meaning Loss Codebook* (Gillies, Neimeyer & Milman, 2015) to be a useful tool for deciphering and evaluating individuals' grief processing.

The study showed the value of facilitated groupwork in creating a space for participants to guide each other through meaning construction. These guided discussions gave participants an opportunity to gain support from each other. The researchers also note that the group work enabled them to determine which elements of the treatment worked or did not via observing and noting participants' responses.

Although the authors did note the self-selecting nature of participants and the small sample size as potential limitations, the study brings to light previously unexamined aspects of grief processing. The study offers a way forward for the prevention and support of complicated grief following long term caregiving. The observations and outcomes of the study are further indication of the need for dementia family caregivers to be educated about what to expect of the disease, the caregiving experience and the experience of grieving. The group discussions also gave the researchers a unique insight into grief processing after dementia caregiving and the idiosyncratic nature of finding meaning in loss. ■

Gillies J, Neimeyer R, Milman E (2015). The Grief and Meaning Reconstruction Inventory (GMRI): initial validation of a new measure. *Death Studies*, 39(1–5) 61–74.

Shear K, Frank E, Houck P, Reynolds C (2005). Treatment of complicated grief: a randomised controlled trial. *JAMA*, 293(21) 2601–2608.

Are participants in face-to-face and internet support groups the same? Comparison of demographics and depression levels among women bereaved by stillbirth

Gold K, Normandin M, Boggs M (2016). *Archives of Women's Mental Health*, 19 1073 – 1078.

As numerous studies have illustrated, peer support can be a valuable lifeline for the bereaved. Perinatal loss can be a particularly isolating grief experience and support offered

in the initial weeks and months after the loss can dissipate quickly. For various reasons, attendance at face-to-face bereavement support is not always possible. However, with the growing use of internet bereavement support groups, there is indication that these may offer similar success rates.

In their research Gold, Normandin and Boggs set out to examine the outcomes of internet bereavement support for women who have experienced stillbirth. They intended to address whether any variation in positive outcome is seen when comparing face-to-face with internet support for participants. ■

Surveying online and face-to-face support groups

The authors posted an online, anonymous survey on a pregnancy loss message board for an 8 month period. Questions focused on experiences of loss and level of support received through the online group. The Edinburgh Postnatal Depression Scale was included to identify depression levels. They followed this with a paper version of the internet survey conducted with participants from pregnancy and infant loss groups. Groups were sourced through internet searches of organisations and agencies providing perinatal bereavement support. The study was run from 2011 to 2015 with the time extended to gain sufficient participants.

Bringing together the online survey response and those from the face-to-face groups, the researchers then excluded all but participants who were within 5 years of their loss. This resulted in a total of 416 from the internet groups and 60 from in-person groups included in the analysis. ■

No significant difference in internet and face-to-face support

Results showed no real contrast in outcomes between the internet and face-to-face groups, with depression screening results for both groups being close. In the face-to-face group 64% of participants had a score of 10 or higher on the Edinburgh Scale, this was 62% in the internet group.

The authors noted that, comparable to other similar studies, their participant groups were largely white and well educated. The lack of participants from a broader ethnic and socioeconomic spectrum is indicated as a limitation and cause for concern by the authors. The relative homogeneity of participants limits the range of insight and extent of cross population application. Further similar studies may benefit from identification of targeted routes for recruitment of more diverse participants.

It was also notable that in the face-to-face group, most participants indicated that they had tried internet support groups in the past. Further examination of the crossover from internet groups to face-to-face support and the motivations in choosing one over another would add depth to the findings. ■