How do communities best support the bereaved?

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Compassionate initiatives to support the bereaved increasingly come from a diverse range of different resources within our local and national communities. There has been a growing recognition by researchers of the significance of the wide variety of community support available, identifying and describing some of the characteristics and benefits of these different resources. As we consider our local community, and how best we serve the needs of the bereaved, these studies can give us inspiration and guidance as we create networks of provision.

What do people really think about grief counselling?

Breen, L. J., Croucamp, C. J., & Rees, C. S. (2019). What do people really think about grief counseling? Examining community attitudes *Death Studies,* 43(10), 611– 618. DOI: 10.1080/07481187.2018.1506527

This study seeks to understand how individuals understand bereavement counselling, and why bereaved people who are highly distressed may significantly underutilise grief counselling and therapy. It assumes that how individuals appreciate and understand bereavement counselling and how it might help them is influenced by their personal attitudes. This study in Australia recruited 156 adult participants (81 men, 75 women) ranging in age from 19 to 79, and used a modified attitude questionnaire requiring participants to create up to seven of each beliefs (cognitive), emotions (affective), and experiences (behavioural) toward grief counselling and then to rate each of these responses. This method allows participants to express their own attitudes and then to rate them. The researchers used qualitative and thematic approaches to group the findings. Overall, the attitude was positive, with women reporting a

significantly more positive attitude than men, although there were no associations between attitude and age, country of birth, previous counselling, or bereavement experience.

This study gives valuable insight into the different attitudes to grief counselling as well as finding some of the variables that explain these attitudes. The researchers demonstrate how individuals base their attitudes towards seeking grief counselling both on their cognitive (beliefs), and affective (emotional) responses. For example, participants identified some of the following positive emotions, followed by the statement made by them in relation to this feeling:

Connectedness – I feel … less alone and not like a number.

Relief – I feel … relieved I'm not the only shoulder to cry on.

However, they also identified positive emotions, followed by the statement made by them in relation to this feeling:

Vulnerability – I feel … like I'm a weak person for not having better ways of coping.

Embarrassment – I feel … embarrassed about showing my emotions to someone who I do not know.

Stigma – I feel … I would worry about being ostracized by undergoing grief counselling.

Hurt – I feel … hurt because people around you don't understand what you are going though.

Fear – I feel … scared of judgement.

Some of the thoughts or beliefs attributed by participants were as follows:

It is not always effective – I believe … it causes more pain. What if it doesn't help and you're left with painful memories?

Experiences are unique to the individual – I believe … everyone experiences and expresses grief in their own way, often shaped by culture.

The efficacy of grief counselling depends on the counsellor – I believe … that a good counsellor is required for it to have benefit.

Grief counsellors require appropriate training – I believe … someone who provides such a service should have several credentials and not just be a funeral or church worker.

The findings are consistent with literature associations between negative attitudes toward psychological help-seeking, and increased shame and decreased emotional openness. This study identifies the significance of promoting mental health literacy about grief services, which may increase the appropriate uptake of these services. As the researchers state, 'Given that increased stigma is associated with negative attitudes toward psychological help seeking, the results suggest that health promotion and mental health literacy campaigns should target beliefs about grief counseling. Actively promoting accurate beliefs and targeting false beliefs about grief counseling will likely mean that bereaved individuals most in need of specialist grief counseling and therapy will be more likely to seek it.' (Breen, L. et al, 2019 43:10, p616).

Building community capacity around death, dying and bereavement, a public health approach to bereavement support?

With medical and mental health services coming under increasing pressure, the multi-dimensional needs of the bereaved may not be considered until severe suffering or symptoms develop. Can consideration of communal approaches to bereavement support lead to improved networks of care? A further study, also Australian and published last year, looked at the support offered from funeral directors.

Aoun, S. M., Lowe, J., Christian, K. M., & Rumbold, B. (2019). Is there a role for the funeral service provider in bereavement support within the context of compassionate communities? *Death Studies*, 43(10), 619-628. DOI:10.1080/07481187. 2018.1506835.

839 Australians participated in a postal survey, taken between 6–24 months into their bereavement. A survey of 82 questions explored the views of the bereaved, also collecting data about the bereaved individual demographics, including gender, age, marital status, cultural background, main employment, and relationship to the deceased. Questions explored the bereaved individual's experience with the funeral service provider, bereavement support provided and used, and grief symptomatology.

The research found that funeral providers were reported to be the third most prevalent form of bereavement support after friends and family. Six themes emerged that were related to perceived helpful or unhelpful support: instrumental support, professionalism, informational support, financial tension, communication, and emotional support. Bearing these findings in mind, local community bereavement services might usefully build links with funeral providers to support them to continue with proactive approaches, offering personalized and ongoing support to the bereaved.

The research enabled exploration of bereaved individuals' experiences with funeral service providers, understanding how and why those service interactions are perceived as helpful or unhelpful. It also identified the contribution funeral service providers make to the community-based assets described by the public health approach to bereavement support. The research proposes:

[A]…'proactive approach envisaged by some respondents is primarily a sharing of information concerning resources that can be readily accessed within the local community for additional and ongoing bereavement support. Examples described by respondents include access to information brochures, grief counselors, bereavement support services, and community-based support groups. This may be a welcome suggestion given that many funeral directors perceive their professional role to incorporate education that promotes social understanding of bereavement' (Schafer & Mcmanus, 2016).

Peer support groups

This systematic literature review assesses the evidence regarding benefits of peer support services for bereaved survivors of sudden or unexpected death.

Bartone, P. T., Bartone, J. V., Violanti, J. M., & Gileno, Z. M. (2019). Peer support services for bereaved survivors: A systematic review. *OMEGA – Journal of Death and Dying*, *80*(1), 137–166. DOI:10.1177/0030222817728204

32 studies met all the inclusion criteria, rated for quality and applicability using PRISMA (Higgins & Green, 2008) to aid the quality of the review.

A key aspect of a peer support approach is the significance of shared experiences and life circumstances, with the expressed view that peers are better able to establish connections of trust and support to those in similar need. The study found that a significant factor to the success of this support is the social aspect that is offered.

There was evidence that peer support was helpful to the bereaved with reducing grief symptoms and increasing wellbeing and personal growth. Self-help therapy offered by peers or 'paraprofessionals' was found in some cases to be as effective as therapy provided by professionals. Interesting to note is the growing number of Internet-based peer support programmes, particularly beneficial due to the ease of access. The discussion section of this paper offers many examples from the literature providing excellent examples of different aspects of the usefulness of peer support with eleven studies showing an association with lowered grief symptoms, such as depression, loneliness, and sense of isolation. Twenty-one of the studies found evidence that having experiences of similar losses to those of the bereaved is an important characteristic for peer supporters.

How can we best enable anticipatory grief?

Finally, a fourth study researches how preparedness for loss affects bereavement outcome.

Caserta, M., Utz, R., Lund, D., Supiano, K., & Donaldson, G. (2019). Cancer caregivers' preparedness for loss and bereavement outcomes: Do pre-loss caregiver attributes matter? *OMEGA – Journal of Death and Dying*, *80*(2), 224–244. DOI:10.1177/0030222817729610

This study discusses preparedness for death defined as 'a caregiver's perception of his/her readiness for the death' (Hebert, Prigerson, Schulz, & Arnold, 2006, pp. 1165–1166). Key variables measured by the study included both emotional and practical preparedness as well as the overall combination of these two. 226 spouses/partner cancer caregivers were sampled retrospectively, with half reporting they did not feel emotionally prepared and 35% feeling underprepared for the practical challenges associated with loss.

Bereavement outcome measures used included symptom distress items from the PG-13 Scale (Prigerson et al., 2009), taken 2–3 months after the death. Findings showed that preparedness was the strongest predictor of bereavement outcome. Results also showed that higher levels of anxiety and depression during caregiving were associated with more 'adverse consequences post loss'. The research measures and data collection evidence a wide range of variables. Despite the possible limitation of self-reports of preparedness taking place after the death, the discussion of the correlational findings and the regression results which are clearly described, provide useful insight into the different issues that might be considered when supporting carers up to and beyond their bereavement.

This study reminds us that compassionate community based care for the bereaved needs to begin before a death takes place and the authors recommend that preparedness is a valuable target for early intervention particularly with those caregivers who would be at greatest risk for adverse outcomes later in bereavement. ■

Hebert, R. S., Prigerson, H. G., Schulz, R., & Arnold, R. M. (2006). Preparing caregivers for the death of a loved one: A theoretical framework and suggestions for future research. *Journal of Palliative Medicine*, *9*(5), 1165–1171.

Higgins, J., & Green, S., & The Cochrane Collaboration. (2008). *Cochrane handbook for systematic reviews of interventions*. Chishestser: Wiley. Retrieved from http://handbook.cochrane.org [accessed 12 February 2020].

Prigerson, H. G., Horowitz, M. J., Jacobs, S. C., Parkes, C. M., Aslan, M., Goodkin, K.,…Maciejewski, P. K. (2009). Prolonged grief disorder: Psychometric validation of criteria proposed for DSM-V and ICD-11. *PLoS Med*, *6*(8), e1000121.

Schafer, C., & Mcmanus, R. (2016). Authenticity, informality and privacy in contemporary New Zealand post-mortem practices. In S. Dobscha (Ed.), *Death in a consumer culture*. New York: Routledge.