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“Caregrieving” in Palliative Care: Opportunities to improve Bereavement Services

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“Family” caregivers are often considered the unit of care in hospice and palliative medicine, making the grief of caregivers before and after the death – what we term “caregrieving” – a concern to palliative care providers. In comparison to professional caretakers and healthcare providers, family caregivers can experience more intense and protracted grief responses (see Maciejewski et al. *JAMA* 2007 for normal course of grief and Prigerson et al., 2009 for validated criteria for Prolonged Grief Disorder). Bereavement services for surviving family members have come to constitute an integral part of palliative care. Foulstone et al. (1993) and Roberts & McGilloway (2008) describe how bereavement services in palliative care have evolved from being more of an add-on to an integrated component of continuous care for the family after the patient has died. Some professionals report that offering bereavement support following the loss is positively associated with caregivers’ post-loss adjustment (Yi et al., 2006). By contrast, Grande et al. (2009) found that absence of emotional support is associated with significantly worse bereavement outcomes. To date, evidence for the helpfulness of bereavement services in palliative care remains equivocal.

Hospices have attempted to provide some types of bereavement follow-up or services, but the quality or standardization of the hospice bereavement follow-up has been lacking. Due to the ad hoc nature of many bereavement services, several studies argue that a more evidence-based and theoretical approach is needed to ensure the more uniform delivery of high quality bereavement care (Yi et al., 2006; Roberts & McGilloway, 2008; Donovan et al., 2015).

Most often, bereavement services delivered as part of hospice or palliative care are provided on an individual basis, such as by telephone or counseling, or in a group setting, such as in a memorial service, widow support groups, or family counseling (Yi et al., 2006; Wilkinson et al., 2007). With the development of new approaches to bereavement support, both psychotherapeutically (e.g., in the detection and intervention for those with intense and debilitating prolonged grief reactions) and technologically (e.g., with the availability of online resources for grievers) there will be a need for more rigorous evaluation of the effectiveness of these approaches.

Traditionally, bereavement follow-up is provided to the caregivers following the death of a patient. However, there has been recognition that preparing family caregivers in advance of an impending death of a loved one may ameliorate the post-loss distress and dislocation. It may also be a way to identify caregivers who are at risk for future maladjustment to the loss (McIlpatrick et al., 2017). Palliative care’s ability to provide continuity of care from pre-to-post loss may help to prepare the caregiver for their loved one’s approaching death and provide a sense that they have not been abandoned or forgotten by the service after the patient dies (see Persson et al., 2008; McIlpatrick et al., 2017, Prigerson, Jacobs, 2001).

The lack of an evidence-based, standardized protocol for screening caregivers at risk of a difficult bereavement adjustment has impeded progress in the delivery of bereavement care (Wilkinson et al., 2007; Donovan et al., 2015). There also is a concern that bereavement interventions not inadvertently inflict psychological harm on the bereaved survivor (Jordan & Neimeyer, 2003). Despite the exponential growth in technological applications in the realm of detection and intervention, hospitals and hospices have done remarkably little to capitalize on the potential usefulness of these technologies for improving bereavement diagnosis, support, resources, and care (see the review of Donovan et al., 2015).

There is a need for palliative care services to pay closer attention to the psychological needs of family caregivers, and to “caregrieving,” both while the patient is alive and after the patient has died. We believe attention to the detection of those at risk of significant psychological distress post-loss (e.g., of Prolonged Grief Disorder) and leveraging technology to provide greater support for the needs of bereaved survivors of palliative care patients, will reduce the pain and suffering of palliative “caregivers.” Efforts of palliative care to support the emotional needs of bereaved caregivers is needed, as is research to determine the effectiveness of these efforts.

References

1. Persson C, Östlund U, Wennman-Larsen A, Wengström Y, & Gustavsson P (2008). Health-related quality of life in significant others of patients dying from lung cancer. *Palliative medicine*, 22(3), 239–247. [PubMed: 18477718]
2. Donovan LA, Wakefield CE, Russell V, & Cohn RJ (2015). Hospital-based bereavement services following the death of a child: A mixed study review. *Palliative medicine*, 29(3), 193–210. [PubMed: 25395578]
3. Roberts A, & McGilloway S (2008). The nature and use of bereavement support services in a hospice setting. *Palliative Medicine*, 22(5), 612–625. [PubMed: 18612027]
4. Foulstone S, Harvey B, Wright J, Jay M, Owen F, & Cole R (1993). Bereavement support: evaluation of a palliative care memorial service. *Palliative medicine*, 7(4), 307–311. [PubMed: 8261197]
5. McIlpatrick S, Doherty LC, Murphy M, Dixon L, Donnelly P, McDonald K, & Fitzsimons D (2017). ‘The importance of planning for the future’: Burden and unmet needs of caregivers’ in advanced heart failure: A mixed methods study. *Palliative medicine*, 0269216317743958.
6. Wilkinson S, Croy P, King M, & Barnes J (2007). Are we getting it right? Parents’ perceptions of hospice child bereavement support services. *Palliative Medicine*, 21(5), 401–407. [PubMed: 17901099]
7. Yi P, Barreto P, Soler C, Fombuena M, Espinar V, Pascual L, ... & Suárez J (2006). Grief support provided to caregivers of palliative care patients in Spain. *Palliative medicine*, 20(5), 521–531. [PubMed: 16903406]

8. Grande GE, Ewing G, & National Forum for Hospice at Home. (2009). Informal carer bereavement outcome: relation to quality of end of life support and achievement of preferred place of death. *Palliative medicine*, 23(3), 248–256. [PubMed: 19251831]

Extra references

1. Maciejewski PK, Zhang B, Block SD, Prigerson HG. An empirical examination of the stage theory of grief. *JAMA*. 2007 2 21;297(7):716–23. [PubMed: 17312291]
2. Prigerson HG, Horowitz MJ, Jacobs SC, Parkes CM, Aslan M, Goodkin K, ... & Bonanno G (2009). Prolonged grief disorder: Psychometric validation of criteria proposed for DSM-V and ICD-11. *PLoS medicine*, 6(8), e1000121.
3. Prigerson HG, Jacobs SC. Perspectives on care at the close of life. Caring for bereaved patients: “all the doctors just suddenly go”. *JAMA*. 2001 9 19;286(11):1369–76. PubMed PMID: . [PubMed: 11560543]
4. Jordan JR, & Neimeyer RA (2003). Does grief counseling work?. *Death studies*, 27(9), 765–786. [PubMed: 14577426]