Grief and Palliative Care: Mutuality

Paul J. Moon
Alacare Home Health & Hospice, Birmingham, Alabama, USA. Corresponding author email: paul.moon@alacare.com

Abstract: Grief and palliative care are interrelated and perhaps mutually inclusive. Conceptually and practically, grief intimately relates to palliative care, as both domains regard the phenomena of loss, suffering, and a desire for abatement of pain burden. Moreover, the notions of palliative care and grief may be construed as being mutually inclusive in terms of one cueing the other. As such, the discussions in this article will center on the conceptualizations of the mutuality between grief and palliative care related to end-of-life circumstances. Specifically, the complementarity of grief and palliative care, as well as a controvertible view thereof, will be considered.

Keywords: grief, palliative care, hospice, bereavement, suffering, complementary

Palliative Care: Research and Treatment 2013:7 19–24

doi: 10.4137/PCRT.S10890

This article is available from http://www.la-press.com.

© the author(s), publisher and licensee Libertas Academica Ltd.

This is an open access article published under the Creative Commons CC-BY-NC 3.0 license.
Grief and Palliative Care: Mutuality

“Strange that a harp of thousand strings should keep in tune so long. It is not, to my mind, so wonderful that men should die so soon, as it is that they should live so long.”

—JC Ryle (1816–1900), Sickness

It is now a commonplace idea that palliative care (and hospice care) is about ‘living until you die’ or some such variation, where life remains the focus. But there can be no substantive contention to the fact palliative care exists because intractable disease and death are as real as life. As such, “it’s all about life—not death!”1 is not a representative pronouncement concerning palliative care, as the very need for such care must be credited to the undeniable certainty of human mortality—that the clinical, existential, personal, and actual outcome of all human life is demise and death. Thus it may be more valid to assert that palliative care is about improving the quality of both life and the process of death.2 As much as palliative care occurs amid a sufferer’s remaining life, it is yet warranted due to irrefutable suffering and terminality, which reap grief that blankets and saturates the circumstances. Grief and palliative care are inseparable.

Grief and palliative care are interrelated and perhaps mutually inclusive. Conceptually and practically, grief intimately relates to palliative care, as both domains regard the phenomena of loss, suffering, and a desire for abatement of pain burden. Moreover, the notions of palliative care and grief may be construed as being mutually inclusive in terms of one cueing the other.3 Indeed it is not easy to imagine a palliative care scenario where no trace of tacit or explicit grief is evidenced. In the same, it is deemed difficult to postulate a grief-striking condition where some degree of palliation would not be sought.

In the space of this article, the breadth of nuances of grief and palliative care (i.e., grief of children and teens, full diversity of loss types, nonmalignant palliative care, etc.) cannot be duly covered. Instead, the nature of the proceeding discussions will center on the conceptualizations of the mutuality between grief and palliative care related to end-of-life circumstances. Specifically, the complementarity of grief and palliative care, as well as a controllable view thereof, will be considered.

Grief and Palliative Care

Complementarity exists between grief and palliative care, in that grief is embedded in palliative care and palliative care necessarily concerns matters of grief based on objective and subjective losses. This complementarity relationship depicts the entrenched nature of grief ‘in’ palliative care, as psychosocial grief support is key item in palliative care.4 However, some discourses can promote a bifurcation motif. For instance, it is published, “when bereavement support can be offered alongside palliative care, such early intervention can be thought of as preventive bereavement care.”5 A critique here is how bereavement care and palliative care are treated as separate (and separable) entities, which address 2 distinct life circumstances. Such a view disconnects (perhaps unintentionally) what is unitary. Moreover, deliberately working on grief dynamics prior to a death event would not be preventive bereavement care (from above quote) in that bereavement cannot be prevented (when death occurs), nor should bereavement be prevented, as grief is deemed to be natural.6 Thus, a clearer designation of actively addressing grief amid premortem palliative care might be preparatory bereavement care (for discussion on anticipatory mourning see Rando7; for literature review of anticipatory grief see Reynolds and Botha8). Hence, given the preparatory nuance, the hybridity of grief amid palliative care is further deepened as eventual death must be accounted for, which in turn sparks anxiety and uneasiness, characteristic of loss dynamics.9

One intentional aim of accentuating the complementarity of grief and palliative care is to lessen the cultural inhibition concerning the public (visible) display of grief (or more technically, mourning),10 as well as the private (internal) grief response, for all parties involved in relevant circumstances. Extant literature depicts the reality of healthcare professionals’ discomfort with mortality, which can lead to avoiding unequivocal conversations regarding grave or terminal prognosis that can contribute to delaying certain end-of-life care processes for persons.11 This was illustrated via a family caregiver’s remark: “…when my husband was going through his final months, his oncologist was so upbeat…it made it impossible to have a truthful conversation.”12 It is a wonder if a culture more permissive of unrestrained grief expressions would have encouraged the oncologist to take a more somber or serious stance, hence laying the groundwork...
Grief and palliative care

for necessary conversations and planning. Physicians’ presentation can initiate a useful tone in these circumstances, and there is even proffered evidence of connections between doctors’ lucid and truthful communication and family members’ perception of the sick person’s death as having been dignified.

But even in absence of healthcare professionals from the equation, there are signs of inhibiting ambience among family members. Whether it is a sick person’s refusal to admit terminality or family members’ disengagement from reality of dismal diagnosis/prognosis, family systems can successfully arrest open discussions regarding grief and palliative care. This dynamic can have a snowball effect of increasing the risk of social constraint whereby outward expressions of grief are stifled due to the nature of social feedback. Such closed social circumstances are unfortunate in light of long-term recognition of how manifest grief can elicit support from other persons. When emancipatory dialogues occur, there can be greater room for significant issues of legacy-leaving (akin to the psychosocial principle of generativity) and interpersonal business to be more fully addressed.

Introspection

In modern history, the coining of the moniker of palliative care is associated with Balfour Mount (physician) in 1973. In time, a veritable bevy of additional (modified) phrasings have been constructed and disseminated. Some argue this evolution of nomenclature to be an attempt to euphemize and create distance from the explicit depiction of terminal care, such as care facilities no longer being frankly called home for the dying. In a like manner, the lexicon related to grief and loss is vulnerable to being supplanted by less stark language, such as ‘celebration of life’ instead of funeral, or ‘visitation’ instead of wake, or ‘expired’ instead of died. These are yet further examples of the inhibitory forces that suppress the complementarity of grief and palliative care where visibly manifesting the plain link between the 2 realities is dampened.

Given the sociopolitical glossarial issues (i.e., euphemizing tendency), it is a wonder if the phraseology of palliative care is itself culpable in stymying a more lucid expressive communication. For instance, the term palliation (palliative care) is still rather esoteric and is a minority word in conventional diction, which may promote under- or misinformed persons to resort to social affectations (giving the appearance of knowledge in the actual absence of it) when such jargon is employed. But what if, instead of hospice or palliative care, it was strictly ‘end of life care’ or ‘dying care’? Might there be less ambiguity in concept understanding as well as more clarity in practical social engagement in such circumstances? Might there be an increased appropriation of manifest grief demonstration among the parties involved, hence potentially diminishing deceptive pathways of conversations on related issues? Although such rephrasing (relabeling) may seem awkward (perhaps attesting to engrained cultural radars), the complementarity of grief and palliative care may nevertheless rise more unfettered to the surface if conventional discourse was altered to be more candid and directly descriptive.

Yet, beyond the veritable word jungle, another complexity can color the complementarity. Some assert that the unruliness and unpredictability of human grief is subjugated via conceptual organization (i.e., theorizing grief). In other words, the attempts to codify grief (as normal, persistent and complex, etc.) and regulate grief processes (via models of stages, phases, tasks, orientations) may be an artificial undertaking to advance a managerial propaganda against a disruptive, inconvenient dynamic. Moreover, some construe the irrepressible reality of death as ‘policed’, in part, by authoritarian, premeditated, scripted procedural practices (for sociological perspective on medical professionals’ functioning as ‘death brokers’, see Timmermans). Such critique, applied to the current discussion, may relate to dispensing care to dying and grieving persons with mere clinical and antiseptic posture that only reinforces the skeptical stances held by some towards the medical (and medicalizing) industry. To combat the all too frequent routinization and systematization of the human process of caring for dying persons and sorrowing grievers, it may be yet worthwhile to bring to surface the embedded and necessary complementarity of grief and palliative care by conscientiously establishing a culture where open grief display is normative in palliative care and palliative care is executed frankly to consistently disclose the grievous nature of its reality.

Grief as Palliative Care

To date, a motley set of assertions have been posited concerning the nature of grief. Freud described grief as natural response to loss, even permitting
psychotic manifestation as part of the process without nosologically adjudicating it as deviant or pathological. Others have opined grief to be a normal and natural reaction to perceived loss. Some, however, postulate the existence of grief types that rise to the level of mental disorder. As a precursor, it seems, Engel roused the idea of grief as a disease, yet his view was arguably limited by a penchant towards scientism, thereby excluding alternative analogies, hence possibilities.

Towards a more broad understanding of human grief, there is evidence of an association between grief and existential growth as well as personal transformation. This (perhaps controvertible) branch of ideas concerns the construct of grief as a prompter towards personal improvement rather than degeneration in terms of perceiving reality and consequent living. In other words, grief can be salutary. In this way, then, grief can serve as ‘palliative care’.

Per insight from a bygone era, grief itself was averred to be medicine. The idea that grief is medicinal can be, like other medicines, received as helpful, rejected as unhelpful, or be resigned toward as a mere matter of course. Of these stances, grief received (perceived) as helpful can foster a palliative effect upon accompanying stresses. Alternatively, when grief is only seen as oppressive and cumbersome, then any chance for beneficial outcomes is forestalled. Moreover, when grief is beheld as a pain to only ‘put up with’ or ‘get over’, then it is easy to imagine how any gains can be precluded. Thus, grief as ‘palliative care’ may warrant a modicum of tolerance to the possibility that the process of human sorrowing may bear existential development and progress.

The growth being referred to here is akin to perspectival (worldview) maturity whereby certain ‘wisdom’ is learned that helps to jettison the illusions of life. Consequently, a reoriented set of outlooks is adopted that is more “...emotionally capable of change, and reflective so that they may generate beliefs and opinions that will prove more true or justified to guide action.” In other words, a person may be ‘sadder but wiser’, and sadness is not solely negative as it may more so depend on the way it is accessed (for deliberate cognitive processing see Calhoun and Tedeschi) and what a person volitionally chooses to do with the emotion (see Attig for operationalization of grieving).

Grief as palliation can perhaps be more clearly posed in terms of future time perspective. For instance, minimizing regret is a pointed goal in palliative care occasions, and this project can be processed by employing greater attention and immediacy to current opportunities rather than choosing procrastination, which is a bane to more constructive outcomes in existentially urgent times. More concretely, a griever who painstakingly self-reflects on the array of actions/inactions related to recent/present loss, who then gradually relearns an altered life-world towards self-committing to more selfless, prudent, authentic approaches of living, is, by virtue, investing in the palliative role of grief for future losses. Evidence of empirical accounts indicates this very phenomenon. Moon, for example, documented a bereaved mother’s sentiments:

...life’s more precious to me now...I’ve learned to live every day to the fullest because I may not have that opportunity again!

Every night before we go to bed [my husband] says our prayer. ... I don’t worry about things like [death] any more ... it’s just a different feeling. ...I don’t worry like I used to worry about my age and [my husband’s] age, about us dying and everything.

A logical extension is that this transformed life approach may serve to minimize regret. What further deepens the potential impact for such a griever is underpinned by another study’s finding of how prior meaning structure (personally espoused mental mechanisms to interpret life events) seems to shape adjustment to loss. Stated simply, some grief experiences can palliate future grief experiences; lessons learned from one loss can activate existential changes in a person that provoke life pattern reformations, which can subsequently impact that person’s grief reactions to loss in future. Thus, a tempering effect of intentionally and particularly processed grief can be an impetus to minimize regret related to future grief.

Concluding Remarks
This brief discussion emphasized the conceptualizations of the mutuality between grief and palliative care. The task remains, however, to make more manifest this complementarity in practice, as well as to better understand the controvertible notion of grief as palliation. As the known human condition insures...
the persistence of the relevance of grief and palliative care, it is hoped that further conceptual and empirical excavation concerning pertinent matters will evince richer life lessons.

Author Contributions
Wrote the first draft of the manuscript: PJM. Developed the structure and arguments for the paper: PJM. Made critical revisions and approved final version: PJM. The author reviewed and approved of the final manuscript.

Funding
Author discloses no funding sources.

Competing Interests
Author discloses no potential conflicts of interest.

Disclosures and Ethics
As a requirement of publication the author has provided signed confirmation of compliance with ethical and legal obligations including but not limited to compliance with ICMJE authorship and competing interests guidelines, that the article is neither under consideration for publication nor published elsewhere, of their compliance with legal and ethical guidelines concerning human and animal research participants (if applicable), and that permission has been obtained for reproduction of any copyrighted material. This article was subject to blind, independent, expert peer review. The reviewers reported no competing interests. Provenance: the authors were invited to submit this paper.

References
1. Cramer CF. To live until you die. Clin J Oncol Nurs. 2010;14(1):53–56.
2. Ferris FD, Gómez-Batiste X, Fürst CJ, Connor S. Implementing quality palliative care. J Pain Symptom Manage. 2007;33(5):533–541.
3. Lo B, Quill T, Tulsify J. Discussing palliative care with patients. Annals of Internal Medicine. 1999;130(9):744–749.
4. Morrison RS, Meier DE. Palliative care. New England Journal of Medicine. 2004;350:2528–2590.
5. Kissane D. Family focused grief therapy. Bereavement Care. 2003;22(1):6–8.
6. Corr CA, Corr DM. Death & Dying, Life & Living. 7th Ed. 2013; Belmont, CA: Wadsworth, Cengage Learning.
7. Rando TA. Clinical Dimensions of Anticipatory Mourning: Theory and Practice in Working with the Dying, Their Loved Ones, and Their Caregivers. 2000; Illinois: Research Press.
8. Reynolds L, Botha D. Anticipatory grief: its nature, impact, and reasons for contradictory findings. Counselling, Psychotherapy, and Health. 2006; 2(2):15–26.
9. Lynn J, Schuster JL, Harrold, J. Handbook for Mortals: Guidance for People Facing Serious Illness, 2nd Ed. 2011; New York: Oxford University Press.
10. Parkes CM. Complicated Grief in the DSM-5: Problems and Solutions. In: Doka KJ, Tucci AS, Eds. BeyondKubler-Ross: New Perspectives of Death, Dying and Grief. 2011; Washington: Hospice Foundation of America; 93–112.
11. McGorryt EK, Borstein BH. Barriers to physicians’ decisions to discuss hospice: insights gained from the United States hospice model. J Eval Clin Pract. 2003;9(3):363–372.
12. Rousseau P. Physicians and end-of-life care. American Journal of Hospice and Palliative Medicine. 2002;19(1):9–11.
13. Balaban RB. A physician’s guide to talking about end-of-life care. J Gen Intern Med. 2000;15(3):195–200.
14. van Gennip IE, Roelte H, Pasman W, et al. Death with dignity from the perspective of the surviving family: A survey study among family caregivers of deceased older adults. Palliat Med. 2013;27(7):616–624.
15. Groot MM, Vermeij-Dassen DJ, Cruul BJ, Grol RP. General practitioners (GPs) and palliative care: perceived tasks and barriers in daily practice. Palliat Med. 2005;19(2):111–118.
16. Cordova MJ, Cunningham LL, Carlson CR, Andrykowski MA. Social constraints, cognitive processing, and adjustment to breast cancer. J Consult Clin Psychol. 2001;69(4):706–711.
17. Averill JR. Grief: its nature and significance. Psychol Bull. 1968;70(6): 721–748.
18. Billings JA. What is palliative care? Journal of Palliative Medicine. 1998;1:73–81.
19. Pastrana T, Jünger S, Ostgathe C, Elnser F, Radbruch L. A matter of definition—key elements identified in a discourse analysis of definitions of palliative care. Palliat Med. 2008;22(3):222–232.
20. Humphreys C. *Waiting for the last summons*: the establishment of the first hospices in England 1878–1914. Mortality. 2001;6(2):146–166.
21. Offi D. Doctors and the ‘D’ word. New York Times; 2011. Available at http://well.blogs.nytimes.com/2011/05/26/doctors-and-the-d-word/ Accessed March 15 2013.
22. Manu E, Mack-Biggs TL, Vitale CA, Galecki A, Moore T, Montagnini M. Perceptions and attitudes about hospice and palliative care among community-dwelling older adults. Am J Hosp Palliat Care. 2013;30(2): 153–161.
23. Craib I. The Importance of Disappointment. 1994; New York: Routledge.
24. Timmermans S. Death brokering: constructing culturally appropriate deaths. Social Health Illn. 2005;27(7):993–1013.
25. Hall BA. An essay on an authentic meaning of medicalization: the patient’s perspective. ANS Adv Nurs Sci. 2003;26(1):53–62.
26. Freud S. Mourning and Melancholia. In: Strachey J, Freud A, Strachey A, Tyron A, eds. The Standard Edition of the Complete Psychological Works of Sigmund Freud, Volume 14. 1953; London: Hogarth Press; 239–258.
27. Walter CA, McCoyd JLM. Grief and Loss Across the Lifespan: A Biopsychosocial Perspective. 2009; New York: Springer.
28. Strada EA. Complicated Grief. In: Qualls SH, Kasl-Godley JE, eds. End-of-Life Issues, Grief, and Bereavement: What Clinicians Need to Know. 2011; Hoboken: John Wiley & Sons, Inc; 181–200.
29. Prigerson HG, Horowitz MJ, Jacobs SC, et al. Prolonged grief disorder: Psychometric validation of criteria proposed for DSM-V and ICD-11. PLoS Med. 2009;6(8):e1000121.
30. Engel GL. Is grief a disease? A challenge for medical research. Psychosom Med. 1960;23:18–22.
31. Tedeschi RG, Calhoun LG. Posttraumatic growth: conceptual foundations and empirical evidence. Psychological Inquiry. 2004;15:1–18.
32. Trippett KN, Tedeschi RG, Cann A, Calhoun LG, Reeve CL. Posttraumatic growth, meaning in life, and life satisfaction in response to trauma. Psychological Trauma: Theory, Research, Practice, and Policy. 2012;4:400–410.
33. Berzoff J. The transformative nature of grief and bereavement. Clinical Social Work Journal. 2011;39(3):262–269.
34. Cowper W. Charity. In: Bailey JG, ed. Poems of William Cowper. 2007; London: Methuen and Co. Available at: http://www.archive.org/stream/poemsofwilliamco00cowpi#page/Stream Accessed March 7, 2013.
35. McKee P, Barber C. On defining wisdom. Int J Aging Hum Dev. 1999; 249:149–164.
41. Tedeschi RG, Calhoun LG, Addington E. Positive Transformations in Response to the Struggle with Grief. In: Doka KJ, Tucci AS, Eds. Beyond Kubler-Ross: New Perspectives on Death, Dying and Grief. 2011; Washington, DC: Hospice Foundation of America; 61–75.

42. Moon PJ. Bereaved elders: transformative learning in late life. Adult Education Quarterly. 2011;61(1):22–39.

43. Braun ML, Berg DH. Meaning reconstruction in the experience of bereavement. Death Studies. 1994;18:105–129.