



Literature Reviews on Palliative Care Family Carer Research

Note:

This list of literature reviews in palliative care family carer research is compiled by the IPCFRC Administrator via [PubMed](#) search using the search terms: 'caregiver', 'carer', 'hospice', 'family', 'research' and 'palliative'; and spanning the period of **1 Feb 2015 – 12 Feb 2016**. The search yielded a total number of **94** publications which are listed below. This list will be reviewed and updated annually and serves as a basic resource to aid those who are looking for publications related to family carer research. Please note that this is not a comprehensive list of publications in the area of family carer research.

1. Allen, R. S., et al. (2015). "'It Was Very Rewarding for Me ...': Senior Volunteers' Experiences With Implementing a Reminiscence and Creative Activity Intervention." *Gerontologist*. Doi: 10.1093/geront/gnu167
2. Ammari, A. B., et al. (2015). "Recruitment and Reasons for Non-Participation in a Family-Coping-Orientated Palliative Home Care Trial (FamCope)." *J Psychosoc Oncol* 33(6): 655-674.
3. Aoun, S., et al. (2015). "Supporting family caregivers to identify their own needs in end-of-life care: Qualitative findings from a stepped wedge cluster trial." *Palliat Med* 29(6): 508-517.
4. Aoun, S., et al. (2015). "Enabling a family caregiver-led assessment of support needs in home-based palliative care: Potential translation into practice." *Palliat Med* 29(10): 929-938.
5. Azami-Aghdash, S., et al. (2015). "Perspective of patients, patients' families, and healthcare providers towards designing and delivering hospice care services in a middle income Country." *Indian J Palliat Care* 21(3): 341-348.
6. Baker, N., et al. (2015). "PA14 The legacy of cancer: why a health promoting approach is so important in palliative care." *BMJ Support Palliat Care* 5 Suppl 1: A23-24.
7. Beach, P. R. and B. E. White (2015). "Applying the evidence to help caregivers torn in two." *Nursing* 45(6): 30-37; quiz 37-38.
8. Benitez-Rosario, M. A., et al. (2015). "Spanish Validation of the Care Evaluation Scale for Measuring the Quality of Structure and Process of Palliative Care From the Family Perspective." *J Pain Symptom Manage*. Doi: 10.1016/j.jpainsymman.2015.11.002
9. Bentley, B. and M. O'Connor (2015). "Conducting research interviews with bereaved family carers: when do we ask?" *J Palliat Med* 18(3): 241-245.
10. Breen, L. J., et al. (2015). "The effect of caregiving on bereavement outcome: study protocol for a longitudinal, prospective study." *BMC Palliat Care* 14: 6.
11. Buzgova, R., et al. (2015). "Assessment of Quality of Life of Family Members of Inpatients with End-Stage Disease." *J Palliat Care* 31(4): 250-257.



12. Cagle, J. G., et al. (2015). "Correlates of a good death and the impact of hospice involvement: findings from the national survey of households affected by cancer." *Support Care Cancer* 23(3): 809-818.
13. Candy, B., et al. (2015). "Does involving volunteers in the provision of palliative care make a difference to patient and family wellbeing? A systematic review of quantitative and qualitative evidence." *Int J Nurs Stud* 52(3): 756-768.
14. Caswell, G., et al. (2015). "Communication between family carers and health professionals about end-of-life care for older people in the acute hospital setting: a qualitative study." *BMC Palliat Care* 14: 35.
15. Cohen, S. R., et al. (2015). "OA8 Caring for the family caregiver: working with volunteers to implement and improve a service to enable family caregivers to maintain their own wellbeing." *BMJ Support Palliat Care* 5 Suppl 1: A3.
16. Conte, T., et al. (2015). "Effect of pediatric palliative care programs on health care resource utilization and costs among children with life-threatening conditions: a systematic review of comparative studies." *CMAJ Open* 3(1): E68-75.
17. Dionne-Odom, J. N., et al. (2015). "Benefits of Early Versus Delayed Palliative Care to Informal Family Caregivers of Patients With Advanced Cancer: Outcomes From the ENABLE III Randomized Controlled Trial." *J Clin Oncol* 33(13): 1446-1452.
18. Eichorst, M. K., et al. (2015). "Health Care Communication and Agreement and Disagreement About Symptoms Within the Context of Multimorbidity." *J Soc Work End Life Palliat Care* 11(3-4): 346-366.
19. Ersek, M., et al. (2015). "Exploring End-of-Life Care in Veterans Affairs Community Living Centers." *J Am Geriatr Soc* 63(4): 644-650.
20. Ewing, G., et al. (2015). "The role of the Carer Support Needs Assessment Tool in palliative home care: A qualitative study of practitioners' perspectives of its impact and mechanisms of action." *Palliat Med*. Doi: 10.1177/0269216315596662
21. Fasse, L., et al. (2015). "Describing and understanding depression in spouses of cancer patients in palliative phase." *Psychooncology* 24(9): 1131-1137.
22. Fassier, T., et al. (2015). "Who Am I to Decide Whether This Person Is to Die Today? Physicians' Life-or-Death Decisions for Elderly Critically Ill Patients at the Emergency Department-ICU Interface: A Qualitative Study." *Ann Emerg Med*. Doi: 10.1016/j.annemergmed.2015.09.030
23. Funk, L. M., et al. (2015). "What family caregivers learn when providing care at the end of life: a qualitative secondary analysis of multiple datasets." *Palliat Support Care* 13(3): 425-433.



24. Gaab, E. and D. M. Steinhorn (2015). "Families' Views of Pediatric Palliative Aquatics: A Qualitative Study." *Pain Manag Nurs* 16(4): 526-533.
25. Gardiner, C., et al. (2015). "Approaches to capturing the financial cost of family care-giving within a palliative care context: a systematic review." *Health Soc Care Community*. Doi: 10.1111/hsc.12253
26. Germain, A., et al. (2015). "The potential therapeutic value for bereaved relatives participating in research: An exploratory study." *Palliat Support Care*: 1-9.
27. Giesbrecht, M., et al. (2015). "Identifying socio-environmental factors that facilitate resilience among Canadian palliative family caregivers: a qualitative case study." *Palliat Support Care* 13(3): 555-565.
28. Gott, M., et al. (2015). "'No matter what the cost': A qualitative study of the financial costs faced by family and whanau caregivers within a palliative care context." *Palliat Med* 29(6): 518-528.
29. Grande, G. E., et al. (2015). "Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: a stepped wedge cluster trial." *BMJ Support Palliat Care*. Doi:10.1136/bmjspcare-2014-000829
30. Henriksson, A., et al. (2015). "Factors associated with feelings of reward during ongoing family palliative caregiving." *Palliat Support Care* 13(3): 505-512.
31. Henriksson, A., et al. (2015). "Feelings of rewards among family caregivers during ongoing palliative care." *Palliat Support Care* 13(6): 1509-1517.
32. Henriksson, A., et al. (2015). "Use of the Preparedness for Caregiving Scale in Palliative Care: A Rasch Evaluation Study." *J Pain Symptom Manage* 50(4): 533-541.
33. Holm, M., et al. (2015). "Short-term and long-term effects of a psycho-educational group intervention for family caregivers in palliative home care - results from a randomized control trial." *Psychooncology*. Doi: 10.1002/pon.4004
34. Holm, M., et al. (2015). "Delivering and participating in a psycho-educational intervention for family caregivers during palliative home care: a qualitative study from the perspectives of health professionals and family caregivers." *BMC Palliat Care* 14: 16.
35. Holm, M., et al. (2015). "Preparing for family caregiving in specialized palliative home care: an ongoing process." *Palliat Support Care* 13(3): 767-775.
36. Hopkinson, J. B. and A. Richardson (2015). "A mixed-methods qualitative research study to develop a complex intervention for weight loss and anorexia in advanced cancer: the Family Approach to Weight and Eating." *Palliat Med* 29(2): 164-176.



37. Hudson, P., et al. (2015). "Reducing the psychological distress of family caregivers of home based palliative care patients: longer term effects from a randomised controlled trial." *Psychooncology* 24(1): 19-24.
38. Jack, B. A., et al. (2015). "Supporting family carers providing end-of-life home care: a qualitative study on the impact of a hospice at home service." *J Clin Nurs* 24(1-2): 131-140.
39. Jho, H. J., et al. (2015). "Perceived timeliness of referral to hospice palliative care among bereaved family members in Korea." *Support Care Cancer* 23(9): 2805-2811.
40. Johnson, A. (2015). "Analysing the role played by district and community nurses in bereavement support." *Br J Community Nurs* 20(6): 272-277.
41. Kars, M. C., et al. (2015). "The parents' ability to attend to the "voice of their child" with incurable cancer during the palliative phase." *Health Psychol* 34(4): 446-452.
42. Kearney, J. A. and M. W. Byrne (2015). "Understanding parental behavior in pediatric palliative care: Attachment theory as a paradigm." *Palliat Support Care* 13(6): 1559-1568.
43. Kearney, J. A., et al. (2015). "Standards of Psychosocial Care for Parents of Children With Cancer." *Pediatr Blood Cancer* 62 Suppl 5: S632-683.
44. Knighting, K., et al. (2015). "Development of the Carers' Alert Thermometer (CAT) to identify family carers struggling with caring for someone dying at home: a mixed method consensus study." *BMC Palliat Care* 14: 22.
45. Knighting, K., et al. (2016). "Gaining consensus on family carer needs when caring for someone dying at home to develop the Carers' Alert Thermometer (CAT): a modified Delphi study." *J Adv Nurs* 72(1): 227-239.
46. Knobf, M. T., et al. (2015). "The 2014-2018 Oncology Nursing Society Research Agenda." *Oncol Nurs Forum* 42(5): 450-465.
47. Kramer, B. J. and A. Z. Boelk (2015). "Correlates and Predictors of Conflict at the End of Life Among Families Enrolled in Hospice." *J Pain Symptom Manage* 50(2): 155-162.
48. Krug, K., et al. (2016). "Correlation between patient quality of life in palliative care and burden of their family caregivers: a prospective observational cohort study." *BMC Palliat Care* 15(1): 4.
49. Kuhlen, M., et al. (2015). "Critical Situations in Children, Adolescents and Young Adults with Terminal Cancer within the Home Setting." *Klin Padiatr* 227(3): 137-143.
50. Lee, G. L., et al. (2015). "Quality of life domains important and relevant to family caregivers of advanced cancer patients in an Asian population: a qualitative study." *Qual Life Res* 24(4): 817-828.



51. Leow, M., et al. (2015). "A pilot randomized, controlled trial of the effectiveness of a psychoeducational intervention on family caregivers of patients with advanced cancer." *Oncol Nurs Forum* 42(2): E63-72.
52. Leroy, T., et al. (2015). "Crossed views of burden and emotional distress of cancer patients and family caregivers during palliative care." *Psychooncology*. Doi: 10.1002/pon.4056
53. Ling, J., et al. (2016). "Parental decision-making on utilisation of out-of-home respite in children's palliative care: findings of qualitative case study research - a proposed new model." *Child Care Health Dev* 42(1): 51-59.
54. Ljungberg, A. K., et al. (2015). "Translation and cultural adaptation of research instruments - guidelines and challenges: an example in FAMCARE-2 for use in Sweden." *Inform Health Soc Care* 40(1): 67-78.
55. Lowther K, Selman L, Simms V, Gikaara N, Ahmed A, Ali Z, Kariuki H, Sherr L, Higginson IJ, Harding R. (2016). "Nurse-led palliative care for HIV-positive patients taking antiretroviral therapy in Kenya: a randomised controlled trial." *The Lancet HIV* 2(8): e328 - e334.
56. Luker, K., et al. (2015). "Development and evaluation of an intervention to support family caregivers of people with cancer to provide home-based care at the end of life: a feasibility study." *Eur J Oncol Nurs* 19(2): 154-161.
57. Lysaght Hurley, S., et al. (2015). "Same agency, different teams: perspectives from home and inpatient hospice care." *Qual Health Res* 25(7): 923-931.
58. Malhotra, C., et al. (2015). "Comparison of preferences for end-of-life care among patients with advanced cancer and their caregivers: A discrete choice experiment." *Palliat Med* 29(9): 842-850.
59. McKeown, K., et al. (2015). "Determinants of care outcomes for patients who die in hospital in Ireland: a retrospective study." *BMC Palliat Care* 14: 11.
60. McMillan, S. C., et al. (2015). "Issues Faced by Family Caregivers of Hospice Patients with Head and Neck Cancers." *ORL Head Neck Nurs* 33(2): 8, 10-13.
61. Meeker, M. A., et al. (2015). "Examining family meetings at end of life: The model of practice in a hospice inpatient unit." *Palliat Support Care* 13(5): 1283-1291.
62. Moir, C., et al. (2015). "Communicating with patients and their families about palliative and end-of-life care: comfort and educational needs of nurses." *Int J Palliat Nurs* 21(3): 109-112.
63. Morgan, T., et al. (2016). "Gender and family caregiving at the end-of-life in the context of old age: A systematic review." *Palliat Med*. PMID: 26814213

64. Murray, L., et al. (2016). "Advance care planning in motor neuron disease: A qualitative study of caregiver perspectives." *Palliat Med*. PMID: 26847526
65. Nkhoma, K., et al. (2015). "An Educational Intervention to Reduce Pain and Improve Pain Management for Malawian People Living With HIV/AIDS and Their Family Carers: A Randomized Controlled Trial." *J Pain Symptom Manage* 50(1): 80-90 e84.
66. Noble, H., et al. (2015). "An appraisal of end-of-life care in persons with chronic kidney disease dying in hospital wards." *J Ren Care* 41(1): 43-52.
67. Oosterveld-Vlug, M. G., et al. (2015). "Can personal dignity be assessed by others? A survey study comparing nursing home residents' with family members', nurses' and physicians' answers on the MIDAM-LTC." *Int J Nurs Stud* 52(2): 555-567.
68. O'Sullivan, D. and P. O'Mahoney (2015). "PA16 Carer proofing: empowering family carers to design an online tool to meet their information needs." *BMJ Support Palliat Care* 5 Suppl 1: A24.
69. Paiva, B. S., et al. (2015). "'Oh, yeah, I'm getting closer to god': spirituality and religiousness of family caregivers of cancer patients undergoing palliative care." *Support Care Cancer* 23(8): 2383-2389.
70. Paiva, B. S., et al. (2015). "Validation of the Holistic Comfort Questionnaire-caregiver in Portuguese-Brazil in a cohort of informal caregivers of palliative care cancer patients." *Support Care Cancer* 23(2): 343-351.
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72. Penders, Y. W., et al. (2015). "Awareness of dementia by family carers of nursing home residents dying with dementia: a post-death study." *Palliat Med* 29(1): 38-47.
73. Pesut, B., et al. (2015). "Feasibility of a rural palliative supportive service." *Rural Remote Health* 15(2): 3116.
74. Pleschberger, S. and P. Wosko (2015). "[Informal non-kin support for elderly people living alone and end of life care. Literature review]." *Z Gerontol Geriatr* 48(5): 457-464.
75. Remedios, C., et al. (2015). "A pre-test and post-test study of the physical and psychological effects of out-of-home respite care on caregivers of children with life-threatening conditions." *Palliat Med* 29(3): 223-230.
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78. Sealey, M., et al. (2015). "A scoping review of bereavement risk assessment measures: Implications for palliative care." *Palliat Med* 29(7): 577-589.
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81. Stamatakis, Z., et al. (2015). "Assessing the impact of diagnosis and the related supportive care needs in patients with cutaneous melanoma." *Support Care Cancer* 23(3): 779-789.
82. Steinhauser, K. E., et al. (2015). "What constitutes quality of family experience at the end of life? Perspectives from family members of patients who died in the hospital." *Palliat Support Care* 13(4): 945-952.
83. Sutherland, N., et al. (2015). "Gendered Processes in Hospice Palliative Home Care for Seniors With Cancer and Their Family Caregivers." *Qual Health Res*. Doi: 10.1177/1049732315609571
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87. Wallace, C. L. (2015). "Family communication and decision making at the end of life: a literature review." *Palliat Support Care* 13(3): 815-825.
88. Wegleitner, K., et al. (2015). "OA51 Caring community in living and dying - engaging communities through participatory research, an austrian case study." *BMJ Support Palliat Care* 5 Suppl 1: A16.
89. Weisser, F. B., et al. (2015). "Experiences of burden, needs, rewards and resilience in family caregivers of people living with Motor Neurone Disease/Amyotrophic Lateral Sclerosis: A secondary thematic analysis of qualitative interviews." *Palliat Med* 29(8): 737-745.



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92. Williams, L., et al. (2015). "OA1 There's plenty of talk about advance care planning but should women be listening?" *BMJ Support Palliat Care* 5 Suppl 1: A1.
93. Wright, D. K., et al. (2015). "Delirium as letting go: An ethnographic analysis of hospice care and family moral experience." *Palliat Med* 29(10): 959-966.
94. Wright, S. T., et al. (2015). "Meaning-centered dream work with hospice patients: A pilot study." *Palliat Support Care* 13(5): 1193-1211.