

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' and 'palliative'; and spanning the period of **1 Sept 2013 – 13 Feb 2015**. The search yielded a total number of **66** 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: Aoun S, Deas K, Toye C, Ewing G, Grande G, Stajduhar K. **Supporting family caregivers to identify their own needs in end-of-life care: Qualitative findings from a stepped wedge cluster trial.** Palliat Med. 2015 Feb 2. pii: 0269216314566061. [Epub ahead of print] PubMed PMID: 25645667.

2: Totman J, Pistrang N, Smith S, Hennessey S, Martin J. 'You only have one chance to get it right': A qualitative study of relatives' experiences of caring at home for a family member with terminal cancer. Palliat Med. 2015 Jan 29. pii: 0269216314566840. [Epub ahead of print] PubMed PMID: 25634637.

3: Remedios C, Willenberg L, Zordan R, Murphy A, Hessel G, Philip J. **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. 2015 Jan 29. pii: 0269216314560008. [Epub ahead of print] PubMed PMID: 25634634.

4: Oshiro T, Oshiro H, Tanimizu M. [Effective methods of organizing complex information in advanced cancer patients]. Gan To Kagaku Ryoho. 2014 Dec;41 Suppl 1:26-9. Japanese. PubMed PMID: 25595074.

5: Oshiro H, Oshiro T, Tanimizu M. [Support for cancer caregivers during the palliative, hospice, and bereavement phases: the role of family physicians]. Gan To Kagaku Ryoho. 2014 Dec;41 Suppl 1:15-7. Japanese. PubMed PMID: 25595070.

6: Pompili A, Telera S, Villani V, Pace A. Home palliative care and end of life issues in glioblastoma multiforme: results and comments from a homogeneous cohort of patients. Neurosurg Focus. 2014 Dec;37(6):E5. doi: 10.3171/2014.9.FOCUS14493. PubMed PMID: 25434390.

7: D'Ambrosio G, Filippi A, Battaglia A, De Maria R, Cricelli C. [Patients with heart failure in the last year of their life: the primary care perspective]. *G Ital Cardiol (Rome)*. 2014 Oct;15(10):569-76. doi: 10.1714/1672.18310. Italian. PubMed PMID: 25424021.

8: Janze A, Henriksson A. Preparing for palliative caregiving as a transition in the awareness of death: family carer experiences. *Int J Palliat Nurs*. 2014 Oct;20(10):494-501. doi: 10.12968/ijpn.2014.20.10.494. PubMed PMID: 25350215.

9: McNulty JP, Muller G. Compounded drugs of value in outpatient hospice and palliative care practice. *Int J Pharm Compd*. 2014 May-Jun;18(3):190-200. Review. PubMed PMID: 25306765.

10: Lysaght Hurley S, Barg FK, Strumpf N, Ersek M. Same Agency, Different Teams: Perspectives From Home and Inpatient Hospice Care. *Qual Health Res*. 2014 Oct 7. pii: 1049732314554091. [Epub ahead of print] PubMed PMID: 25294344.

11: Ohnsorge K, Gudat H, Rehmann-Sutter C. What a wish to die can mean: reasons, meanings and functions of wishes to die, reported from 30 qualitative case studies of terminally ill cancer patients in palliative care. *BMC Palliat Care*. 2014 Jul 31;13:38. doi: 10.1186/1472-684X-13-38. eCollection 2014. PubMed PMID:25161387; PubMed Central PMCID: PMC4144684.

12: Lai C, Luciani M, Galli F, Morelli E, Cappelluti R, Penco I, Aceto P, Lombardo L. Attachment Style Dimensions Can Affect Prolonged Grief Risk in Caregivers of Terminally Ill Patients With Cancer. *Am J Hosp Palliat Care*. 2014 Aug 25. pii: 1049909114547945. [Epub ahead of print] PubMed PMID: 25155029.

13: Azuero CB, Harris GM, Allen RS, Williams BR, Kvale E, Ritchie CS. Team-based volunteerism with the seriously ill: a qualitative analysis from 10 volunteers' perspectives. *J Soc Work End Life Palliat Care*. 2014;10(3):282-95. doi:10.1080/15524256.2014.938893. PubMed PMID: 25148454.

14: Russell BJ, Rowett D, Currow DC. Pro re nata prescribing in a population receiving palliative care: a prospective consecutive case note review. *J Am Geriatr Soc*. 2014 Sep;62(9):1736-40. doi: 10.1111/jgs.12981. Epub 2014 Aug 14. PubMed PMID: 25124943.

15: Dean S, Libby K, McAuley WJ, Van Nostrand J. Access to bereavement services in hospice. *Omega (Westport)*. 2014;69(1):79-92. doi: 10.2190/OM.69.1.e. PubMed PMID: 25084710.

16: Lewis LF. **Caregivers' experiences seeking hospice care for loved ones with dementia**. *Qual Health Res*. 2014 Sep;24(9):1221-31. doi: 10.1177/1049732314545888. Epub 2014 Jul 30. PubMed PMID: 25079503.

17: West E, Romoli V, Di Leo S, Higginson IJ, Miccinesi G, Costantini M. Feasibility of assessing quality of care at the end of life in two cluster trials using an after-death approach with multiple assessments. *BMC Palliat Care*. 2014 Jul 15;13:36. doi: 10.1186/1472-684X-13-36. eCollection 2014. PubMed PMID: 25071416; PubMed Central PMCID: PMC4113121.

18: Cagle JG, Munn JC, Hong S, Clifford M, Zimmerman S. Validation of the quality of dying-hospice scale. *J Pain Symptom Manage*. 2015 Feb;49(2):265-76. doi: 10.1016/j.jpainsymman.2014.06.009. Epub 2014 Jul 22. PubMed PMID: 25057986; PubMed Central PMCID: PMC4303538.

19: Nageshwaran S, Davies LM, Rafi I, Radunović A. Motor neurone disease. *BMJ*. 2014 Jul 9;349:g4052. doi: 10.1136/bmj.g4052. PubMed PMID: 25008100.

20: Claxton-Oldfield S. Hospice palliative care volunteers: The benefits for patients, family caregivers, and the volunteers. *Palliat Support Care*. 2014 Jun 5:1-5. [Epub ahead of print] PubMed PMID: 24901841.

21: Cagle JG, Zimmerman S, Cohen LW, Porter LS, Hanson LC, Reed D. EMPOWER: An Intervention to Address Barriers to Pain Management in Hospice. *J Pain Symptom Manage*. 2015 Jan;49(1):1-12. doi: 10.1016/j.jpainsymman.2014.05.007. Epub 2014 May 28. PubMed PMID: 24880000.

22: Angelo J, Egan R. Family caregivers voice their needs: A Photovoice study. *Palliat Support Care*. 2014 May 20:1-12. [Epub ahead of print] PubMed PMID: 24845619.

23: Vedel I, Ghadi V, Lapointe L, Routelous C, Aegerter P, Guirimand F. Patients', family caregivers', and professionals' perspectives on quality of palliative care: a qualitative study. *Palliat Med*. 2014 Oct;28(9):1128-38. doi: 10.1177/0269216314532154. Epub 2014 May 12. PubMed PMID: 24821709.

24: Wittenberg-Lyles E, Parker Oliver D, Demiris G, Swarz J, Rendo M. **YouTube as a tool for pain management with informal caregivers of cancer patients: a systematic review.** *J Pain Symptom Manage.* 2014 Dec;48(6):1200-10. doi: 10.1016/j.jpainsymman.2014.02.015. Epub 2014 Apr 30. PubMed PMID: 24793505; PubMed Central PMCID: PMC4214907.

25: An AR, Lee JK, Yun YH, Heo DS. Terminal cancer patients' and their primary caregivers' attitudes toward hospice/palliative care and their effects on actual utilization: A prospective cohort study. *Palliat Med.* 2014 Apr 29;28(7):976-985. [Epub ahead of print] PubMed PMID: 24781817.

26: Clayton MF, Reblin M, Carlisle M, Ellington L. Communication behaviors and patient and caregiver emotional concerns: a description of home hospice communication. *Oncol Nurs Forum.* 2014 May;41(3):311-21. doi:10.1188/14.ONF.311-321. PubMed PMID: 24769595.

27: Cowan MM. The lived experiences of the Sikh population of South East England when caring for a dying relative at home. *Int J Palliat Nurs.* 2014 Apr;20(4):179-86. PubMed PMID: 24763326.

28: Repar PA, Reid S. Creatively caring: effects of arts-based encounters on hospice caregivers in South Africa. *J Pain Symptom Manage.* 2014 May;47(5):946-54. doi: 10.1016/j.jpainsymman.2013.10.023. Epub 2014 Apr 18. PubMed PMID: 24751119.

29: Kerr CW, Tangeman JC, Rudra CB, Grant PC, Luczkiewicz DL, Mylotte KM, Riemer WD, Marien MJ, Serehali AM. Clinical impact of a home-based palliative care program: a hospice-private payer partnership. *J Pain Symptom Manage.* 2014 Nov;48(5):883-92.e1. doi: 10.1016/j.jpainsymman.2014.02.003. Epub 2014 Apr 18. PubMed PMID: 24747224.

30: Harrop E, Byrne A, Nelson A. "It's alright to ask for help": findings from a qualitative study exploring the information and support needs of family carers at the end of life. *BMC Palliat Care.* 2014 Apr 17;13:22. doi: 10.1186/1472-684X-13-22. eCollection 2014. PubMed PMID: 24742046; PubMed Central PMCID: PMC3997794.

31: Noble B, King N, Woolmore A, Hughes P, Winslow M, Melvin J, Brooks J, Bravington A, Ingleton C, Bath PA. Can comprehensive specialised end-of-life care be provided at home? Lessons from a study of an innovative consultant-led community service in the UK. *Eur J Cancer Care (Engl).* 2014 Apr 15. doi: 10.1111/ecc.12195. [Epub ahead of print] PubMed PMID: 24735122.

32: Yap R, Akhileswaran R, Heng CP, Tan A, Hui D. Comfort care kit: use of nonoral and nonparenteral rescue medications at home for terminally ill patients with swallowing difficulty. *J Palliat Med.* 2014 May;17(5):575-8. doi: 10.1089/jpm.2013.0364. Epub 2014 Apr 7. PubMed PMID: 24708221.

33: Ohnsorge K, Gudat H, Rehmann-Sutter C. Intentions in wishes to die: analysis and a typology--a report of 30 qualitative case studies of terminally ill cancer patients in palliative care. *Psychooncology.* 2014 Sep;23(9):1021-6. doi: 10.1002/pon.3524. Epub 2014 Apr 4. PubMed PMID: 24706488; PubMed Central PMCID: PMC4312918.

34: Ng R, Chan S, Ng TW, Chiam AL, Lim S. An exploratory study of the knowledge, attitudes and perceptions of advance care planning in family caregivers of patients with advanced illness in Singapore. *BMJ Support Palliat Care.* 2013 Sep;3(3):343-8. doi: 10.1136/bmjspcare-2012-000243. Epub 2012 Sep 5. PubMed PMID: 24644754.

35: Girgis A, Abernethy AP, Currow DC. Caring at the end of life: do cancer caregivers differ from other caregivers? *BMJ Support Palliat Care.* 2014 Jan 22. doi: 10.1136/bmjspcare-2013-000495. [Epub ahead of print] PubMed PMID: 24644201.

36: Hudson P, Aranda S. The Melbourne Family Support Program: evidence-based strategies that prepare family caregivers for supporting palliative care patients. *BMJ Support Palliat Care.* 2014 Sep;4(3):231-7. doi: 10.1136/bmjspcare-2013-000500. Epub 2013 Jun 4. PubMed PMID: 24644195; PubMed Central PMCID: PMC4145448.

37: Davies N, Maio L, Rait G, Iliffe S. Quality end-of-life care for dementia: What have family carers told us so far? A narrative synthesis. *Palliat Med.* 2014 Mar 13;28(7):919-930. [Epub ahead of print] Review. PubMed PMID: 24625567; PubMed Central PMCID: PMC4232347.

38: Holland JM, Currier JM, Kirkendall A, Keene JR, Luna N. Sadness, anxiety, and experiences with emotional support among veteran and nonveteran patients and their families at the end of life. *J Palliat Med.* 2014 Jun;17(6):708-11. doi:10.1089/jpm.2013.0485. Epub 2014 Mar 7. PubMed PMID: 24605892.

39: Angelo J, Wilson L. Exploring occupation roles of hospice family caregivers from Māori, Chinese and Tongan ethnic backgrounds living in New Zealand. *Occup Ther Int.* 2014 Jun;21(2):81-90. doi: 10.1002/oti.1367. Epub 2014 Feb 28. PubMed PMID: 24578104.

40: Hopp FP, Trzcinski E, Roth R, Deremo D, Fonger E, Chiv S, Paletta M. Cost Analysis of a Novel Interdisciplinary Model for Advanced Illness Management. *Am J Hosp Palliat Care*. 2014 Feb 21. [Epub ahead of print] PubMed PMID: 24563027.

41: de la Cruz M, Noguera A, San Miguel-Arregui MT, Williams J, Chisholm G, Bruera E. Delirium, agitation, and symptom distress within the final seven days of life among cancer patients receiving hospice care. *Palliat Support Care*. 2014 Feb 20:1-6. [Epub ahead of print] PubMed PMID: 24556057.

42: van der Steen JT, van Soest-Poortvliet MC, Hallie-Heierman M, Onwuteaka-Philipsen BD, Deliens L, de Boer ME, Van den Block L, van Uden N, Hertogh CM, de Vet HC. Factors associated with initiation of advance care planning in dementia: a systematic review. *J Alzheimers Dis*. 2014;40(3):743-57. doi: 10.3233/JAD-131967. Review. PubMed PMID: 24531163.

43: Sheehy-Skeffington B, McLean S, Bramwell M, O'Leary N, O'Gorman A. Caregivers experiences of managing medications for palliative care patients at the end of life: a qualitative study. *Am J Hosp Palliat Care*. 2014 Mar;31(2):148-54. doi: 10.1177/1049909113482514. PubMed PMID: 24526788.

44: Rhondali W, Chirac A, Laurent A, Terra JL, Filbet M. Family caregivers' perceptions of depression in patients with advanced cancer: A qualitative study. *Palliat Support Care*. 2014 Feb 13:1-8. [Epub ahead of print] PubMed PMID: 24524805.

45: Fernando J, Percy J, Davidson L, Allan S. The challenge of providing palliative care to a rural population with cardiovascular disease. *Curr Opin Support Palliat Care*. 2014 Mar;8(1):9-14. doi: 10.1097/SPC.000000000000023. Review. PubMed PMID: 24496229.

46: Leclerc BS, Lessard S, Bechennec C, Le Gal E, Benoit S, Bellerose L. Attitudes toward death, dying, end-of-life palliative care, and interdisciplinary practice in long term care workers. *J Am Med Dir Assoc*. 2014 Mar;15(3):207-13. doi: 10.1016/j.jamda.2013.11.017. Epub 2014 Jan 23. Erratum in: *J Am Med Dir Assoc*. 2014 Jun;15(6):446. PubMed PMID: 24461725.

47: Nanni MG, Biancosino B, Grassi L. **Pre-loss symptoms related to risk of complicated grief in caregivers of terminally ill cancer patients.** *J Affect Disord*. 2014 May;160:87-91. doi: 10.1016/j.jad.2013.12.023. Epub 2013 Dec 30. PubMed PMID: 24445130.

48: Yoon SJ, Kim JS, Jung JG, Kim SS, Kim S. **Modifiable factors associated with caregiver burden among family caregivers of terminally ill Korean cancer patients.** Support Care Cancer. 2014 May;22(5):1243-50. doi: 10.1007/s00520-013-2077-z. Epub 2014 Jan 16. PubMed PMID: 24424483.

49: McKay EA, Taylor AE, Armstrong C. "What she told us made the world of difference": carers' perspectives on a hospice at home service. J Palliat Care. 2013 Autumn;29(3):170-7. PubMed PMID: 24380216.

50: Buck HG. Help family caregivers in the "sandwich generation". Nursing. 2013 Nov;43(11):19-20. doi: 10.1097/01.NURSE.0000435206.88399.c8. PubMed PMID: 24141579.

51: Selman L, Simms V, Penfold S, Powell RA, Mwangi-Powell F, Downing J, Gikaara N, Munene G, Higginson IJ, Harding R. 'My dreams are shuttered down and it hurts lots'-a qualitative study of palliative care needs and their management by HIV outpatient services in Kenya and Uganda. BMC Palliat Care. 2013 Oct 7;12(1):35. doi: 10.1186/1472-684X-12-35. PubMed PMID: 24098941; PubMed Central PMCID: PMC3851824.

52: Marcus DA. The role of volunteer services at cancer centers. Curr Pain Headache Rep. 2013 Nov;17(11):376. doi: 10.1007/s11916-013-0376-1. Review. PubMed PMID: 24096385.

53: Irwin SA, Mausbach BT, Koo D, Fairman N, Roepke-Buehler SK, Chattillion EA, Dimsdale JE, Patterson TL, Ancoli-Israel S, Mills PJ, von Känel R, Ziegler MG, Grant I. Association between hospice care and psychological outcomes in Alzheimer's spousal caregivers. J Palliat Med. 2013 Nov;16(11):1450-4. doi: 10.1089/jpm.2013.0130. Epub 2013 Oct 5. PubMed PMID: 24093721; PubMed Central PMCID: PMC3822398.

54: Beland P. Implications for carers of terminally ill patients dying at home. Nurs Stand. 2013 Sep 18-24;28(3):40-5. doi: 10.7748/ns2013.09.28.3.40.e7651. PubMed PMID: 24044859.

55: Meeker MA, Waldrop DP, Schneider J, Case AA. Contending with advanced illness: patient and caregiver perspectives. J Pain Symptom Manage. 2014 May;47(5):887-95. doi: 10.1016/j.jpainsymman.2013.06.009. Epub 2013 Sep 12. PubMed PMID: 24035069.

56: Daaleman TP, Reed D, Cohen LW, Zimmerman S. Development and preliminary testing of the quality of spiritual care scale. *J Pain Symptom Manage*. 2014 Apr;47(4):793-800. doi: 10.1016/j.jpainsymman.2013.06.004. Epub 2013 Aug 30. PubMed PMID: 23998778.

57: Morita T, Sato K, Miyashita M, Akiyama M, Kato M, Kawagoe S, Kinoshita H, Shirahige Y, Yamakawa S, Yamada M, Eguchi K. Exploring the perceived changes and the reasons why expected outcomes were not obtained in individual levels in a successful regional palliative care intervention trial: an analysis for interpretations. *Support Care Cancer*. 2013 Dec;21(12):3393-402. doi: 10.1007/s00520-013-1910-8. Epub 2013 Aug 10. PubMed PMID: 23934223.

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59: Partinico M, Corà A, Ghisi M, Ouimet AJ, Visentin M; QPM Group. A new Italian questionnaire to assess caregivers of cancer patients' satisfaction with palliative care: multicenter validation of the post mortem questionnaire-short form. *J Pain Symptom Manage*. 2014 Feb;47(2):298-306. doi: 10.1016/j.jpainsymman.2013.03.018. Epub 2013 Jul 12. PubMed PMID: 23856096.

60: Heese O, Vogeler E, Martens T, Schnell O, Tonn JC, Simon M, Schramm J, Krex D, Schackert G, Reithmeier T, Nikkha G, Sabel M, Steiger HJ, Schlegel U, Löffler M, Weller M, Westphal M; German Glioma Network. End-of-life caregivers' perception of medical and psychological support during the final weeks of glioma patients: a questionnaire-based survey. *Neuro Oncol*. 2013 Sep;15(9):1251-6. doi: 10.1093/neuonc/not089. Epub 2013 Jun 28. PubMed PMID: 23814266; PubMed Central PMCID: PMC3748923.

61: Bascioni R, Giorgi F, Esperide B, Brugni M, Basirat F, Rastelli F, De Signoribus G, Giustini L. Medical oncologist's commitment in end-of-life care of cancer patients. *Palliat Support Care*. 2014 Oct;12(5):351-4. doi:10.1017/S1478951513000291. Epub 2013 Jun 17. PubMed PMID: 23768912.

62: Lai C, Luciani M, Morelli E, Galli F, Cappelluti R, Penco I, Aceto P, Lombardo L. Predictive role of different dimensions of burden for risk of complicated grief in caregivers of terminally ill patients. *Am J Hosp Palliat Care*. 2014 Mar;31(2):189-93. doi: 10.1177/1049909113490227. Epub 2013 May 20. PubMed PMID: 23689368.

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64: Jang J, Lazenby M. Current state of palliative and end-of-life care in home versus inpatient facilities and urban versus rural settings in Africa. *Palliat Support Care*. 2013 Oct;11(5):425-42. doi: 10.1017/S1478951512000612. Epub 2013 Jan 23. PubMed PMID: 23340322.

65: Ewing G, Brundle C, Payne S, Grande G; National Association for Hospice at Home. The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: a validation study. *J Pain Symptom Manage*. 2013 Sep;46(3):395-405. doi: 10.1016/j.jpainsymman.2012.09.008. Epub 2012 Dec 12. PubMed PMID: 23245452.

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