



Literature Reviews on Palliative Care Family Carer Research

Note:

This list of literature reviews on 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 **18 Jan 2018 – 25 Feb 2019**. The search yielded a total number of **41** 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. Ankuda CK, Kersting K, Guetterman TC, Haefner J, Fonger E, Paletta M, Hopp F. What Matters Most? A Mixed Methods Study of Critical Aspects of a Home-Based Palliative Program. *Am J Hosp Palliat Care*. 2018 Feb;35(2):236-243. doi: 10.1177/1049909117691929. Epub 2017 Feb 6. PubMed PMID: 28166640.
2. Armstrong MJ, Alliance S, Corsentino P, DeKosky ST, Taylor A. Cause of Death and End-of-Life Experiences in Individuals with Dementia with Lewy Bodies. *J Am Geriatr Soc*. 2019 Jan;67(1):67-73. doi: 10.1111/jgs.15608. Epub 2018 Oct 6. PubMed PMID: 30291740.
3. Ateş G, Ebenau AF, Busa C, Csikos Á, Hasselaar J, Jaspers B, Menten J, Payne S, Van Beek K, Varey S, Groot M, Radbruch L. "Never at ease" - family carers within integrated palliative care: a multinational, mixed method study. *BMC Palliat Care*. 2018 Mar 1;17(1):39. doi: 10.1186/s12904-018-0291-7. PubMed PMID: 29490657; PubMed Central PMCID: PMC5831577.
4. Chi NC, Han S, Barani E, Parker Oliver D, Washington KT, Lewis FM, Walker A, Demiris G. Development and Preliminary Evaluation of a Pain Management Manual for Hospice Providers to Support and Educate Family Caregivers. *Am J Hosp Palliat Care*. 2018 Oct 10:1049909118804984. doi: 10.1177/1049909118804984. [Epub ahead of print] PubMed PMID: 30304938.
5. Choi JY, Kong KA, Chang YJ, Jho HJ, Ahn EM, Choi SK, Park S, Lee MK. Effect of the duration of hospice and palliative care on the quality of dying and death in patients with terminal cancer: A nationwide multicentre study. *Eur J Cancer Care (Engl)*. 2018 Mar;27(2):e12771. doi: 10.1111/ecc.12771. Epub 2017 Sep 15. PubMed PMID: 28913848.
6. Cloyes KG, Hull W, Davis A. Palliative and End-of-Life Care for Lesbian, Gay, Bisexual, and Transgender (LGBT) Cancer Patients and Their Caregivers. *Semin Oncol Nurs*. 2018 Feb;34(1):60-71. doi: 10.1016/j.soncn.2017.12.003. Epub 2018 Jan 3. Review. PubMed PMID: 29306523; PubMed Central PMCID: PMC5863535.



7. Diffin J, Ewing G, Harvey G, Grande G. The Influence of Context and Practitioner Attitudes on Implementation of Person-Centered Assessment and Support for Family Carers Within Palliative Care. *Worldviews Evid Based Nurs.* 2018 Oct;15(5):377-385. doi: 10.1111/wvn.12323. Epub 2018 Aug 27. PubMed PMID: 30152150.
8. Ellington L, Cloyes KG, Xu J, Bellury L, Berry PH, Reblin M, Clayton MF. Supporting home hospice family caregivers: Insights from different perspectives. *Palliat Support Care.* 2018 Apr;16(2):209-219. doi: 10.1017/S1478951517000219. Epub 2017 May 3. PubMed PMID: 28464961; PubMed Central PMCID: PMC5670030.
9. Ferrell BR, Twaddle ML, Melnick A, Meier DE. National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines, 4th Edition. *J Palliat Med.* 2018 Sep 4. doi: 10.1089/jpm.2018.0431. [Epub ahead of print] PubMed PMID: 30179523.
10. Freytag A, Krause M, Bauer A, Ditscheid B, Jansky M, Krauss S, Lehmann T, Marschall U, Nauck F, Schneider W, Stichling K, Vollmar HC, Wedding U, Meißner W; SAVOIR Study group. Study protocol for a multi-methods study: SAVOIR – evaluation of specialized outpatient palliative care (SAPV) in Germany: outcomes, interactions, regional differences. *BMC Palliat Care.* 2019 Jan 26;18(1):12. doi: 10.1186/s12904-019-0398-5. PubMed PMID: 30684958; PubMed Central PMCID: PMC6348077.
11. Gonthier C, Pelletier S, Gagnon P, Marin A, Chiquette J, Gagnon B, Roy L, Cléophat JE, Joly Y, Dorval M. Issues related to family history of cancer at the end of life: a palliative care providers' survey. *Fam Cancer.* 2018 Apr;17(2):303-307. doi: 10.1007/s10689-017-0021-y. PubMed PMID: 28674754.
12. Graham-Wisener L, Watts G, Kirkwood J, Harrison C, McEwan J, Porter S, Reid J, McConnell TH. Music therapy in UK palliative and end-of-life care: a service evaluation. *BMJ Support Palliat Care.* 2018 Sep;8(3):282-284. doi: 10.1136/bmjspcare-2018-001510. Epub 2018 Feb 22. PubMed PMID: 29475896.
13. Guo P, Dzingina M, Firth AM, Davies JM, Douiri A, O'Brien SM, Pinto C, Pask S, Higginson IJ, Eagar K, Murtagh FEM. Development and validation of a casemix classification to predict costs of specialist palliative care provision across inpatient hospice, hospital and community settings in the UK: a study protocol. *BMJ Open.* 2018 Mar 17;8(3):e020071. doi: 10.1136/bmjopen-2017-020071. PubMed PMID: 29550781; PubMed Central PMCID: PMC5879599.
14. Hack TF, McClement SE, Chochinov HM, Dufault B, Johnston W, Enns MW, Thompson GN, Harlos M, Damant RW, Ramsey CD, Davison SN, Zacharias J, Strang D, Campbell-Enns HJ. Assessing Symptoms, Concerns, and Quality of Life in Noncancer Patients at End of Life: How Concordant Are Patients and Family Proxy Members? *J Pain Symptom Manage.* 2018



- Nov;56(5):760-766. doi: 10.1016/j.jpainsymman.2018.07.019. Epub 2018 Aug 2. PubMed PMID: 30076964.
15. Harrop E, Nelson A, Rees H, Harris D, Noble S. The challenge pathway: A mixed methods evaluation of an innovative care model for the palliative and end-of-life care of people with dementia (Innovative practice). *Dementia (London)*. 2018 Feb;17(2):252-257. doi: 10.1177/1471301217729532. Epub 2017 Sep 14. PubMed PMID: 28905647; PubMed Central PMCID: PMC5802546.
 16. Hatano Y, Morita T, Otani H, Igarashi N, Shima Y, Miyashita M. Physician Behavior toward Death Pronouncement in Palliative Care Units. *J Palliat Med*. 2018 Mar;21(3):368-372. doi: 10.1089/jpm.2017.0239. Epub 2017 Sep 25. PubMed PMID: 28945507.
 17. Havyer RD, Pomerantz DH, Jayes RL, Harris PF, Harman SM, Ansari AA. Update in Hospital Palliative Care: Symptom Management, Communication, Caregiver Outcomes, and Moral Distress. *J Hosp Med*. 2018 Jun 1;13(6):419-423. doi: 10.12788/jhm.2895. Epub 2017 Dec 20. PubMed PMID: 29261818.
 18. Huang LT, McMillan SC. Mutual Effects of Depression on Quality of Life in Patients and Family Caregivers. *Oncol Nurs Forum*. 2019 Mar 1;46(2):208-216. doi: 10.1188/19.ONF.208-216. PubMed PMID: 30767962.
 19. Hughes NM, Noyes J, Eckley L, Pritchard T. What do patients and family-caregivers value from hospice care? A systematic mixed studies review. *BMC Palliat Care*. 2019 Feb 8;18(1):18. doi: 10.1186/s12904-019-0401-1. PubMed PMID: 30736788; PubMed Central PMCID: PMC6368799.
 20. Hwang IC, Kim YS, Lee YJ, Choi YS, Hwang SW, Kim HM, Koh SJ. Factors Associated With Caregivers' Resilience in a Terminal Cancer Care Setting. *Am J Hosp Palliat Care*. 2018 Apr;35(4):677-683. doi: 10.1177/1049909117741110. Epub 2017 Nov 15. PubMed PMID: 29141459.
 21. Johnson MJ, Allgar V, Chen H, Dunn L, Macleod U, Currow DC. The complex relationship between household income of family caregivers, access to palliative care services and place of death: A national household population survey. *Palliat Med*. 2018 Feb;32(2):357-365. doi: 10.1177/0269216317711825. Epub 2017 Jun 7. PubMed PMID: 28590165.
 22. Leng A, Jing J, Nicholas S, Wang J. Geographical disparities in treatment and health care costs for end-of-life cancer patients in China: a retrospective study. *BMC Cancer*. 2019 Jan 8;19(1):39. doi: 10.1186/s12885-018-5237-1. PubMed PMID: 30621633; PubMed Central PMCID: PMC6325809.



23. Mather H, Guo P, Firth A, Davies JM, Sykes N, Landon A, Murtagh FEM. Phase of Illness in palliative care: Cross-sectional analysis of clinical data from community, hospital and hospice patients. *Palliat Med*. 2018 Feb;32(2):404-412. doi: 10.1177/0269216317727157. Epub 2017 Aug 16. PubMed PMID: 28812945; PubMed Central PMCID: PMC5788082.
24. McIlpatrick S, Muldrew DHL, Hasson F, Payne S. Examining palliative and end of life care research in Ireland within a global context: a systematic mapping review of the evidence. *BMC Palliat Care*. 2018 Sep 27;17(1):109. doi: 10.1186/s12904-018-0364-7. Review. PubMed PMID: 30261860; PubMed Central PMCID: PMC6161399.
25. Miyashita M, Aoyama M, Yoshida S, Yamada Y, Abe M, Yanagihara K, Shirado A, Shutoh M, Okamoto Y, Hamano J, Miyamoto A, Nakahata M. The distress and benefit to bereaved family members of participating in a post-bereavement survey. *Jpn J Clin Oncol*. 2018 Feb 1;48(2):135-143. doi: 10.1093/jjco/hyx177. PubMed PMID: 29244140.
26. Naoki Y, Matsuda Y, Maeda I, Kamino H, Kozaki Y, Tokoro A, Maki N, Takada M. Association between family satisfaction and caregiver burden in cancer patients receiving outreach palliative care at home. *Palliat Support Care*. 2018 Jun;16(3):260-268. doi: 10.1017/S1478951517000232. Epub 2017 May 2. PubMed PMID: 28462749.
27. Osman H, Shrestha S, Temin S, Ali ZV, Corvera RA, Ddungu HD, De Lima L, Del Pilar Estevez-Diz M, Ferris FD, Gafer N, Gupta HK, Horton S, Jacob G, Jia R, Lu FL, Mosoiu D, Puchalski C, Seigel C, Soyannwo O, Cleary JF. Palliative Care in the Global Setting: ASCO Resource-Stratified Practice Guideline. *J Glob Oncol*. 2018 Jul;(4):1-24. doi: 10.1200/JGO.18.00026. PubMed PMID: 30085844; PubMed Central PMCID: PMC6223509.
28. Pinto C, Bristowe K, Witt J, Davies JM, de Wolf-Linder S, Dawkins M, Guo P, Higginson IJ, Daveson B, Murtagh FEM. Perspectives of patients, family caregivers and health professionals on the use of outcome measures in palliative care and lessons for implementation: a multi-method qualitative study. *Ann Palliat Med*. 2018 Oct;7(Suppl 3):S137-S150. doi: 10.21037/apm.2018.09.02. PubMed PMID: 30339764.
29. Porter LS, Samsa G, Steel JL, Hanson LC, LeBlanc TW, Bull J, Fischer S, Keefe FJ. Caregiver-guided pain coping skills training for patients with advanced cancer: Background, design, and challenges for the CaringPals study. *Clin Trials*. 2019 Feb 19:1740774519829695. doi: 10.1177/1740774519829695. [Epub ahead of print] PubMed PMID: 30782014.
30. Poulos RG, Harkin D, Poulos CJ, Cole A, MacLeod R. Can specially trained community care workers effectively support patients and their families in the home setting at the end of life? *Health Soc Care Community*. 2018 Mar;26(2):e270-e279. doi: 10.1111/hsc.12515. Epub 2017 Nov 21. PubMed PMID: 29164739.



31. Siler S, Mamier I, Winslow B. The Perceived Facilitators and Challenges of Translating a Lung Cancer Palliative Care Intervention Into Community-Based Settings. *J Hosp Palliat Nurs*. 2018 Aug;20(4):407-415. doi: 10.1097/NJH.0000000000000470. PubMed PMID: 30063635; PubMed Central PMCID: PMC6070356.
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36. Vaughan CL, Kluger BM. Palliative Care for Movement Disorders. *Curr Treat Options Neurol*. 2018 Feb 21;20(1):2. doi: 10.1007/s11940-018-0487-4. Review. PubMed PMID: 29464435.
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