



Published literature related to Palliative Care Family Carer Research

Note:

This list of palliative care family carer research related publications 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 Jan 2019 – 22 Apr 2020**. The search yielded a total number of **23** 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. Benson JJ, Parker Oliver D, Demiris G, Washington K. Accounts of Family Conflict in Home Hospice Care: The Central Role of Autonomy for Informal Caregiver Resilience. *J Fam Nurs*. 2019 May;25(2):190-218. doi: 10.1177/1074840719828091. Epub 2019 Feb 17. PMID: 30773970.
2. Bijnsdorp FM, Pasman HRW, Francke AL, Evans N, Peeters CFW, Broese van Groenou MI. Who provides care in the last year of life? A description of care networks of community-dwelling older adults in the Netherlands. *BMC Palliat Care*. 2019 May 15;18(1):41. doi: 10.1186/s12904-019-0425-6. PMID: 31092227.
3. Caswell G, Hardy B, Ewing G, Kennedy S, Seymour J. Supporting family carers in home-based end-of-life care: using participatory action research to develop a training programme for support workers and volunteers. *BMJ Support Palliat Care*. 2019 Mar;9(1):e4. doi: 10.1136/bmjspcare-2017-001317. Epub 2017 Aug 2. PMID: 28768679.
4. Das K, Khanna T, Arora A, Agrawal N. Parents' acceptance and regret about end of life care for children who died due to malignancy. *Support Care Cancer*. 2020 Jan;28(1):303-308. doi: 10.1007/s00520-019-04806-0. Epub 2019 May 1. PMID: 31044306.
5. Dionne-Odom JN, Ornstein KA, Kent EE. What do family caregivers know about palliative care? Results from a national survey. *Palliat Support Care*. 2019 Dec;17(6):643-649. doi: 10.1017/S1478951519000154. PMID: 30957733.
6. Gerber K, Hayes B, Bryant C. 'It all depends!': A qualitative study of preferences for place of care and place of death in terminally ill patients and their family caregivers. *Palliat Med*. 2019 Jul;33(7):802-811. doi: 10.1177/0269216319845794. Epub 2019 May 3. PMID: 31046580.



7. Grant PC, Depner RM, Levy K, LaFever SM, Tenzek KE, Wright ST, Kerr CW. Family Caregiver Perspectives on End-of-Life Dreams and Visions during Bereavement: A Mixed Methods Approach. *J Palliat Med.* 2020 Jan;23(1):48-53. doi: 10.1089/jpm.2019.0093. Epub 2019 Jul 9. PMID: 31287370.
8. 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. PMID: 30767962.
9. Hudson P, Morrison RS, Schulz R, Brody AA, Dahlin C, Kelly K, Meier DE. Improving Support for Family Caregivers of People with a Serious Illness in the United States: Strategic Agenda and Call to Action. *Palliative Medicine Reports.* 2020 Apr;1(1):6-17. doi:10.1089/pmr.2020.0004.
10. 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. PMID: 30736788.
11. Judd R, Guy H, Howard RA. Caring for a Dying Partner: The Male Experience. *J Palliat Care.* 2019 Jan;34(1):5-11. doi: 10.1177/0825859718774679. Epub 2018 May 14. PMID: 29756532.
12. Lo Monaco M, Mallaci Bocchio R, Natoli G, Scibetta S, Bongiorno T, Argano C, Corrao S. Human relationships in patients' end-of-life: a qualitative study in a hospice ward. *Intern Emerg Med.* 2019 Dec 17. doi: 10.1007/s11739-019-02254-6. [Epub ahead of print]. PMID: 31848995.
13. McKibben L, Brazil K, Hudson P, McLaughlin D. Informational needs of family caregivers of people with intellectual disability who require palliative care: a two-phase integrative review of the literature. *Int J Palliat Nurs.* 2019 Jan 2;25(1):4-18. doi: 10.12968/ijpn.2019.25.1.4. PMID: 30676158.
14. Namisango E, Bristowe K, Murtagh FE, Downing J, Powell RA, Abas M, Lohfeld L, Ali Z, Atieno M, Haufiku D, Guma S, Luyirika EB, Mwangi-Powell FN, Higginson IJ, Harding R. Towards person-centred quality care for children with life-limiting and life-threatening illness: Self-reported symptoms, concerns and priority outcomes from a multi-country qualitative study. *Palliat Med.* 2020 Mar;34(3):319-335. doi: 10.1177/0269216319900137. Epub 2020 Feb 21. PMID: 32081084.
15. Nicholas D, Beaune L, Belletrutti M, Blumberg J, Ing S, Rapoport A, Barrera M. Engaging Fathers in Pediatric Palliative Care Research. *J Soc Work End Life Palliat Care.* 2020 Jan-Mar;16(1):42-56. doi: 10.1080/15524256.2019.1703877. Epub 2020 Jan 17. PMID: 31951504.
16. Oechsle K. Current Advances in Palliative & Hospice Care: Problems and Needs of Relatives and Family Caregivers During Palliative and Hospice Care-An Overview of Current Literature.



- Med Sci (Basel). 2019 Mar 12;7(3). pii: E43. doi: 10.3390/medsci7030043. Review. PMID: 30871105.
17. Petursdottir AB, Haraldsdottir E, Svavarsdottir EK. The impact of implementing an educational intervention to enhance a family-oriented approach in specialised palliative home care: A quasi-experimental study. *Scand J Caring Sci*. 2019 Jun;33(2):342-350. doi: 10.1111/scs.12628. Epub 2018 Nov 29. PMID: 30488975.
 18. 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 Jun;16(3):263-272. doi: 10.1177/1740774519829695. Epub 2019 Feb 19. PMID: 30782014.
 19. Reblin M, Baucom BRW, Clayton MF, Utz R, Caserta M, Lund D, Mooney K, Ellington L. Communication of emotion in home hospice cancer care: Implications for spouse caregiver depression into bereavement. *Psychooncology*. 2019 May;28(5):1102-1109. doi: 10.1002/pon.5064. Epub 2019 Apr 5. PMID: 30883985.
 20. Schoppee TM, Dyal BW, Scarton L, Ezenwa MO, Singh P, Yao Y, Suarez ML, Wang ZJ, Molokie RE, Wilkie DJ. Patients and Caregivers Rate the PAINReportIt Wireless Internet-Enabled Tablet as a Method for Reporting Pain During End-of-Life Cancer Care. *Cancer Nurs*. 2019 Sep 27. doi: 10.1097/NCC.0000000000000743. [Epub ahead of print]. PMID: 31517649.
 21. Spatuzzi R, Giuliotti MV, Ricciuti M, Merico F, Fabbietti P, Raucci L, Bilancia D, Cormio C, Vespa A. Exploring the associations between spiritual well-being, burden, and quality of life in family caregivers of cancer patients. *Palliat Support Care*. 2019 Jun;17(3):294-299. doi: 10.1017/S1478951518000160. Epub 2018 May 11. PMID: 29749317.
 22. Thienprayoon R, Grosseohme D, Humphrey L, Pestian T, Frimpong-Manso M, Malcolm H, Kitamura E, Jenkins R, Friebert S. "There's Just No Way to Help, and They Did." Parents Name Compassionate Care as a New Domain of Quality in Pediatric Home-Based Hospice and Palliative Care. *J Palliat Med*. 2019 Dec 27. doi: 10.1089/jpm.2019.0418. [Epub ahead of print]. PMID: 31880492.
 23. Tjia J, DeSanto-Madeya S, Mazor KM, Han P, Nguyen B, Curran T, Gallagher J, Clayton MF. Nurses' Perspectives on Family Caregiver Medication Management Support and Deprescribing. *J Hosp Palliat Nurs*. 2019 Aug; 21(4):312-318. doi: 10.1097/NJH.0000000000000574. PMID: 31033645.