



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 **23 Apr 2020 – 30 Mar 2021**. The search yielded a total number of **48** 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: Porter LS, Steel JL, Fairclough DL, LeBlanc TW, Bull J, Hanson LC, Fischer S, Keefe FJ. Caregiver-guided pain coping skills training for patients with advanced cancer: Results from a randomized clinical trial. *Palliat Med*. 2021 Mar 29;2692163211004216. doi: 10.1177/02692163211004216. Epub ahead of print. PMID: 33775175.

2: Spatuzzi R, Giulietti MV, Romito F, Reggiardo G, Genovese C, Passarella M, Raucci L, Ricciuti M, Merico F, Rosati G, Attademo L, Vespa A. Becoming an older caregiver: A study of gender differences in family caregiving at the end of life. *Palliat Support Care*. 2021 Mar 19;1-7. doi: 10.1017/S1478951521000274. Epub ahead of print. PMID: 33736742.

3: Husain A, Cohen E, Dubrowski R, Jamieson T, Kurahashi AM, Lokuge B, Rapoport A, Saunders S, Stasiulis E, Stinson J, Subramaniam S, Wegier P, Barwick M. A. Clinical Communication Tool (Loop) for Team-Based Care in Pediatric and Adult Care Settings: Hybrid Mixed Methods Implementation Study. *J Med Internet Res*. 2021 Mar 3;23(3):e25505. doi: 10.2196/25505. PMID: 33656445.

4: Zou Z, Bai J, Gu Y, Zou Q, Xiao C, Yang J, Zhang Q, Lazenby M. Cultural adaptation and psychometric evaluation of the Chinese version of the nurse-specific end-of-life professional caregiver survey: a cross-sectional study. *BMC Palliat Care*. 2021 Feb 16;20(1):32. doi: 10.1186/s12904-021-00725-2. PMID: 33593352; PMCID: PMC7885229.

5: Lei L, Gerlach LB, Powell VD, Maust DT. Caregiver support and place of death among older adults. *J Am Geriatr Soc*. 2021 Feb 15. doi: 10.1111/jgs.17055. Epub ahead of print. PMID: 33590479.

6: Walshe C, Barnes H, Turner M, Hughes S. Constructing a new role for family carers and volunteers providing care towards the end of life: an action research approach exploring a new model of hospice care. *Health Soc Care Community*. 2021 Feb 13. doi: 10.1111/hsc.13315. Epub ahead of print. PMID: 33580991.

7: Mack JW, Currie ER, Martello V, Gittzus J, Isack A, Fisher L, Lindley LC, Gilbertson-White S, Roeland E, Bakitas M. Barriers to Optimal End-of-Life Care for Adolescents and Young Adults With Cancer:



Bereaved Caregiver Perspectives. *J Natl Compr Canc Netw*. 2021 Feb 11:1-6. doi: 10.6004/jnccn.2020.7645. Epub ahead of print. PMID: 33571955.

8: Cruz-Oliver DM, Abshire M, Budhathoki C, Hladek MD, Volandes A, Jorgensen L, Oliver DP. Comparison of Traditional Videos With Telenovelas for Hospice Family Caregivers Education. *Am J Hosp Palliat Care*. 2021 Feb 8:1049909121991524. doi: 10.1177/1049909121991524. Epub ahead of print. PMID: 33550835.

9: Lung EYL, Wan A, Ankita A, Baxter S, Benedet L, Li Z, Mirhosseini M, Mirza RM, Thorpe K, Vadeboncoeur C, Klinger CA. Informal Caregiving for People With Life-Limiting Illness: Exploring the Knowledge Gaps. *J Palliat Care*. 2021 Jan 20:825859720984564. doi: 10.1177/0825859720984564. Epub ahead of print. PMID: 33467993.

10: Boyden JY, Feudtner C, Deatrck JA, Widger K, LaRagione G, Lord B, Ersek M. Developing a family-reported measure of experiences with home-based pediatric palliative and hospice care: a multi-method, multi-stakeholder approach. *BMC Palliat Care*. 2021 Jan 14;20(1):17. doi: 10.1186/s12904-020-00703-0. PMID: 33446192; PMCID: PMC7809872.

11: Tate CE, Venechuk G, Pierce K, Khazanie P, Ingle MP, Morris MA, Allen LA, Matlock DD. Development of a Decision Aid for Patients and Families Considering Hospice. *J Palliat Med*. 2021 Jan 13;24(4):505–13. doi: 10.1089/jpm.2020.0250. Epub ahead of print. PMID: 33439075; PMCID: PMC7987356.

12: Hasson F, Jordan J, McKibben L, Graham-Wisener L, Finucane A, Armour K, Zafar S, Hewison A, Brazil K, Kernohan WG. Challenges for palliative care day services: a focus group study. *BMC Palliat Care*. 2021 Jan 12;20(1):11. doi: 10.1186/s12904-020-00699-7. PMID: 33435954; PMCID: PMC7802306.

13: Holland DE, Vanderboom CE, Dose AM, Moore D, Robinson KV, Wild E, Stiles C, Ingram C, Mandrekar J, Borah B, Taylor E, Griffin JM. Death and Grieving for Family Caregivers of Loved Ones With Life-Limiting Illnesses in the Era of COVID-19: Considerations for Case Managers. *Prof Case Manag*. 2021 Mar-Apr 01;26(2):53-61. doi: 10.1097/NCM.0000000000000485. PMID: 33181608.

14: Sacchi S, Capone R, Ferrari F, Sforacchi F, Di Leo S, Ghirotto L. "Achieve the best while rushing against time": A grounded theory study on caring for low-income immigrant cancer patients at end of life. *Palliat Med*. 2021 Feb;35(2):426-436. doi: 10.1177/0269216320974275. Epub 2020 Dec 25. PMID: 33356971.

15: Levy K, Grant PC, Clem K, Eadie DS, Rossi JL. Holding onto Hurt: The Prevalence of Interpersonal Hurt and Need for Forgiveness-Focused Solutions for Hospice Family Caregivers. *J Palliat Med*. 2020 Dec 10. doi: 10.1089/jpm.2020.0521. Epub ahead of print. PMID: 33305995.



16: Limonero JT, Maté-Méndez J, Gómez-Romero MJ, Mateo-Ortega D, González-Barboteo J, Bernaus M, López-Postigo M, Sirgo A, Viel S, Sánchez-Julve C, Bayés R, Gómez-Batiste X, Tomás-Sábado J. Family caregiver emotional distress in advanced cancer: the DME-C scale psychometric properties. *BMJ Support Palliat Care*. 2020 Dec 4:bmjspcare-2020-002608. doi: 10.1136/bmjspcare-2020-002608. Epub ahead of print. PMID: 33277319.

17: Kang KA, Kim SJ. Comparison of Perceptions of Spiritual Care Among Patients With Life-Threatening Cancer, Primary Family Caregivers, and Hospice/Palliative Care Nurses in South Korea. *J Hosp Palliat Nurs*. 2020 Dec;22(6):532-551. doi: 10.1097/NJH.0000000000000697. PMID: 33044420.

18: Stochitoiu IA, Vadeboncoeur C. Adaptation and Feasibility of the interRAI Family Carer Needs Assessment in a Pediatric Setting. *Health Serv Insights*. 2020 Nov 23;13:1178632920972655. doi: 10.1177/1178632920972655. PMID: 33281455; PMCID: PMC7686600.

19: Oliver DP, Benson JJ, Ulrich C, Washington KT, Rolbiecki AJ, White P, Smith JB, Lero C, Landon OJ, Demiris G. Perceived Benefits and Burdens of Participation for Caregivers of Cancer Patients in Hospice Clinical Trials: A Pilot Study. *J Pain Symptom Manage*. 2020 Nov 6:S0885-3924(20)30853-8. doi: 10.1016/j.jpainsymman.2020.10.024. Epub ahead of print. PMID: 33166583.

20: Lund L, Ross L, Petersen MA, Blach A, Rosted E, Bollig G, Juhl GI, Farholt HB, Winther H, Laursen L, Hasse M, Weensgaard S, Guldin MB, Ewing G, Grande G, Groenvold M. Effect of the Carer Support Needs Assessment Tool intervention (CSNAT-I) in the Danish specialised palliative care setting: a stepped-wedge cluster randomised controlled trial. *BMJ Support Palliat Care*. 2020 Oct 28:bmjspcare-2020-002467. doi: 10.1136/bmjspcare-2020-002467. Epub ahead of print. PMID: 33115831.

21: Cassidy L, Hill L, Fitzsimons D, McGaughey J. The impact of psychoeducational interventions on the outcomes of caregivers of patients with heart failure: A systematic review and meta-analysis. *Int J Nurs Stud*. 2021 Feb;114:103806. doi: 10.1016/j.ijnurstu.2020.103806. Epub 2020 Oct 22. PMID: 33248290.

22: Pesut B, Duggleby W, Warner G, Bruce P, Ghosh S, Holroyd-Leduc J, Nikolaichuk C, Parmar J. A mixed-method evaluation of a volunteer navigation intervention for older persons living with chronic illness (Nav-CARE): findings from a knowledge translation study. *BMC Palliat Care*. 2020 Oct 15;19(1):159. doi: 10.1186/s12904-020-00666-2. PMID: 33059655; PMCID: PMC7565322.

23: Nicholas DB, Belletrutti M, Dimitropoulos G, Katz SL, Rapoport A, Urschel S, West L, Zwaigenbaum L. Perceived Impacts of the COVID-19 Pandemic on Pediatric Care in Canada: A Roundtable Discussion. *Glob Pediatr Health*. 2020 Sep 30;7:2333794X20957652. doi: 10.1177/2333794X20957652. PMID: 33088851; PMCID: PMC7545748.

24: Bajwah S, Oluyase AO, Yi D, Gao W, Evans CJ, Grande G, Todd C, Costantini M, Murtagh FE, Higginson IJ. The effectiveness and cost-effectiveness of hospital-based specialist palliative care for



adults with advanced illness and their caregivers. *Cochrane Database Syst Rev.* 2020 Sep 30;9:CD012780. doi: 10.1002/14651858.CD012780.pub2. PMID: 32996586.

25: Krakowiak P. Gaps in end-of-life care and lack of support for family carers in Poland and Central Eastern Europe. *Palliat Care Soc Pract.* 2020 Sep 29;14:2632352420958001. doi: 10.1177/2632352420958001. PMID: 33063014; PMCID: PMC7536374.

26: Carmel S, Singer Y, Yosef-Sela N, Bachner YG. Open communication between caregivers' and terminally ill cancer patients about illness and death: The role of gender - A correlational study. *Eur J Oncol Nurs.* 2020 Dec;49:101828. doi: 10.1016/j.ejon.2020.101828. Epub 2020 Sep 9. PMID: 33070046.

27: Chua GP, Pang GSY, Yee ACP, Neo PSH, Zhou S, Lim C, Wong YY, Qu DL, Pan FT, Yang GM. Supporting the patients with advanced cancer and their family caregivers: what are their palliative care needs? *BMC Cancer.* 2020 Aug 15;20(1):768. doi: 10.1186/s12885-020-07239-9. PMID: 32799834; PMCID: PMC7429720.

28: Cruz-Oliver DM, Abshire M, Budhathoki C, Oliver DP, Volandes A, Smith TJ. Reflections of Hospice Staff Members About Educating Hospice Family Caregivers Through Telenovela. *Am J Hosp Palliat Care.* 2021 Feb;38(2):161-168. doi: 10.1177/1049909120936169. Epub 2020 Jul 8. PMID: 32638608; PMCID: PMC7752841.

29: Phongtankuel V, Reid MC, Czaja SJ, Teresi J, Eimicke JP, Kong JX, Prigerson H, Shalev A, Dignam R, Baughn R, Adelman RD. Caregiver-Reported Quality Measures and Their Correlates in Home Hospice Care. *Palliat Med Rep.* 2020 Jul 7;1(1):111-118. doi: 10.1089/pmr.2020.0055. PMID: 32856023; PMCID: PMC7446245.

30: Ko E, Fuentes D, Singh-Carlson S, Nedjat-Haiem F. Challenges and facilitators of hospice decision-making: a retrospective review of family caregivers of home hospice patients in a rural US-Mexico border region-a qualitative study. *BMJ Open.* 2020 Jul 1;10(7):e035634. doi: 10.1136/bmjopen-2019-035634. PMID: 32611740; PMCID: PMC7332198.

31: Kumar V, Ankuda CK, Aldridge MD, Husain M, Ornstein KA. Family Caregiving at the End of Life and Hospice Use: A National Study of Medicare Beneficiaries. *J Am Geriatr Soc.* 2020 Oct;68(10):2288-2296. doi: 10.1111/jgs.16648. Epub 2020 Jun 30. PMID: 32602571; PMCID: PMC7718293.

32: Hasegawa T, Sekine R, Akechi T, Osaga S, Tsuji T, Okuyama T, Sakurai H, Masukawa K, Aoyama M, Morita T, Kizawa Y, Tsuneto S, Shima Y, Miyashita M. Rehabilitation for Cancer Patients in Inpatient Hospices/Palliative Care Units and Achievement of a Good Death: Analyses of Combined Data From Nationwide Surveys Among Bereaved Family Members. *J Pain Symptom Manage.* 2020 Dec;60(6):1163-1169. doi: 10.1016/j.jpainsymman.2020.06.031. Epub 2020 Jun 29. PMID: 32615299.



- 33: Wittenberg E, Kerr AM, Goldsmith J. Exploring Family Caregiver Communication Difficulties and Caregiver Quality of Life and Anxiety. *Am J Hosp Palliat Care*. 2021 Feb;38(2):147-153. doi: 10.1177/1049909120935371. Epub 2020 Jun 26. PMID: 32588639.
- 34: Aoyama M, Sakaguchi Y, Fujisawa D, Morita T, Ogawa A, Kizawa Y, Tsuneto S, Shima Y, Miyashita M. Insomnia and changes in alcohol consumption: Relation between possible complicated grief and depression among bereaved family caregivers. *J Affect Disord*. 2020 Oct 1;275:1-6. doi: 10.1016/j.jad.2020.06.023. Epub 2020 Jun 24. PMID: 32658810.
- 35: Capodanno I, Rocchi M, Prandi R, Pedroni C, Tamagnini E, Alfieri P, Merli F, Ghirotto L. Caregivers of Patients with Hematological Malignancies within Home Care: A Phenomenological Study. *Int J Environ Res Public Health*. 2020 Jun 5;17(11):4036. doi: 10.3390/ijerph17114036. PMID: 32517057; PMCID: PMC7312962.
- 36: McPherson L, Milligan S, Stevens E. Participating in the personal care of a person living with a life-limiting illness in a hospice inpatient setting: the informal caregiver's perspective. *Int J Palliat Nurs*. 2020 Jun 2;26(5):246-257. doi: 10.12968/ijpn.2020.26.5.246. PMID: 32584693.
- 37: Trandel ET, Kavalieratos D, Basile M, Hobler MR, Georgiopoulos AM, Chen E, Goggin JL, Goss CH, Hempstead SE, Faro A, Dellon EP. Palliative care skills in CF: Perspectives of adults with CF, caregivers, and CF care team members. *Pediatr Pulmonol*. 2020 Aug;55(8):2017-2024. doi: 10.1002/ppul.24806. Epub 2020 May 8. PMID: 32384215.
- 38: Wolff JL, Freedman VA, Ornstein KA, Mulcahy JF, Kasper JD. Evaluation of Hospice Enrollment and Family and Unpaid Caregivers' Experiences With Health Care Workers in the Care of Older Adults During the Last Month of Life. *JAMA Netw Open*. 2020 Apr 1;3(4):e203599. doi: 10.1001/jamanetworkopen.2020.3599. PMID: 32347947; PMCID: PMC7191321.
- 39: Cruz-Oliver DM, Pacheco Rueda A, Viera-Ortiz L, Washington KT, Oliver DP. The evidence supporting educational videos for patients and caregivers receiving hospice and palliative care: A systematic review. *Patient Educ Couns*. 2020 Sep;103(9):1677-1691. doi: 10.1016/j.pec.2020.03.014. Epub 2020 Mar 19. PMID: 32241583; PMCID: PMC7495206.
- 40: Armstrong MJ, Alliance S, Corsentino P, Maixner SM, Paulson HL, Taylor A. Caregiver-Reported Barriers to Quality End-of-Life Care in Dementia With Lewy Bodies: A Qualitative Analysis. *Am J Hosp Palliat Care*. 2020 Sep;37(9):728-737. doi: 10.1177/1049909119897241. Epub 2020 Jan 6. PMID: 31902223; PMCID: PMC7335680.
- 41: Hasson F, Muldrew D, Carduff E, Finucane A, Graham-Wisener L, Larkin P, Mccorry N, Slater P, McIlpatrick S. 'Take more laxatives was their answer to everything': A qualitative exploration of the patient, carer and healthcare professional experience of constipation in specialist palliative care. *Palliat Med*. 2020 Sep;34(8):1057-1066. doi: 10.1177/0269216319891584. Epub 2019 Dec 23. PMID: 31868574; PMCID: PMC7388148.



42: 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*. 2020 Sep;15(6):975-980. doi: 10.1007/s11739-019-02254-6. Epub 2019 Dec 17. PMID: 31848995.

43: Tay RY, Hum AYM, Ali NB, Leong IYO, Wu HY, Chin JJ, Lee AOK, Koh MYH. Comfort and Satisfaction With Care of Home-Dwelling Dementia Patients at the End of Life. *J Pain Symptom Manage*. 2020 May;59(5):1019-1032.e1. doi: 10.1016/j.jpainsymman.2019.12.004. Epub 2019 Dec 16. PMID: 31837451.

44: Weaver MS, Robinson JE, Shostrom VK, Hinds PS. Telehealth Acceptability for Children, Family, and Adult Hospice Nurses When Integrating the Pediatric Palliative Inpatient Provider during Sequential Rural Home Hospice Visits. *J Palliat Med*. 2020 May;23(5):641-649. doi: 10.1089/jpm.2019.0450. Epub 2019 Dec 5. PMID: 31808722.

45: Liu CJ, Kung PT, Chu CC, Chou WY, Shih CM, Tsai WC. Effect of the Integrated Prospective Payment Program on Family Members' Knowledge and Acceptance of Hospice Care of Patients on Prolonged Mechanical Ventilation. *Respir Care*. 2020 Apr;65(4):464-474. doi: 10.4187/respcare.06934. Epub 2019 Nov 12. PMID: 31719192.

46: Herbst FA, Gawinski L, Schneider N, Stiel S. Adult Child-Parent Dyadic Interactions at the End of Life: A Scoping Review. *BMJ Support Palliat Care*. 2020 Jun;10(2):175-185. doi: 10.1136/bmjspcare-2019-001894. Epub 2019 Aug 7. PMID: 31395611.

47: Vermorgen M, De Vleminck A, Leemans K, Van den Block L, Van Audenhove C, Deliens L, Cohen J. Family carer support in home and hospital: a cross-sectional survey of specialised palliative care. *BMJ Support Palliat Care*. 2020 Dec;10(4):e33. doi: 10.1136/bmjspcare-2019-001795. Epub 2019 Jun 26. PMID: 31243021.

48: Hum A, Tay RY, Wong YKY, Ali NB, Leong IYO, Wu HY, Chin JJ, Lee AOK, Koh MYH. Advanced dementia: an integrated homecare programme. *BMJ Support Palliat Care*. 2020 Dec;10(4):e40. doi: 10.1136/bmjspcare-2019-001798. Epub 2019 Jun 25. PMID: 31239257.