



International Palliative Care Family-carer Research Collaboration  
(EAPC Family Carer Reference Group)

# Newsletter

October 2021

## Recent Event

The IPCFRC EAPC Family Carer Reference Group held a symposium on: ***“Strategies to improve psychosocial wellbeing of family carers: How international collaborations make a difference”*** at the recent 17<sup>th</sup> World Congress of the European Association for Palliative Care (EAPC 2021). A/Prof Nick Dionne-Odom (University of Alabama at Birmingham, USA) & Professor Gunn Grande (The University of Manchester, UK) chaired the session, which included the following presentations:

*“Evidence synthesis of factors affecting family carers’ psychological wellbeing”*

by Dr Tracey Shield and Professor Gunn Grande, The University of Manchester, UK.

*“Supporting family carer decision-making in palliative dementia care”*

by Professor Kevin Brazil, Queen's University Belfast, UK.

*“Key considerations when selecting family carer outcome measures”*

by A/Prof Nick Dionne-Odom, University of Alabama at Birmingham, USA.

## EAPC Task Force on Costs of Family Caregiving in Palliative Care

The IPCFRC EAPC Family Carer Reference Group is linked with the EAPC Task Force on Costs of Family Caregiving in Palliative Care. The taskforce aims to establish an international network of researchers, clinicians, policymakers with an interest in research on the costs of caring in palliative care, and form the basis of an international, multidisciplinary research collaboration with the aim of furthering the research agenda on the costs of family caring in palliative care. Find out more about the taskforce [\[here\]](#).

## Published literature related to family carer research

One of the initiatives of the IPCFRC EAPC Family Carer Reference Group is to compile a listing of publications related to family caregiver research in palliative care. This list is updated annually, and serves as a key resource to aid those who are looking for peer-reviewed publications related to family caregivers. The 2021 version is available as a downloadable resource on the [\[IPCFRC website\]](#).

IPCFRC is a Reference Group of the European Association for Palliative Care (EAPC) and is administered in partnership with the Centre for Palliative Care, St. Vincent's Hospital and a Collaborative Centre of the University of Melbourne, Australia.

Email: [centre.palliativecare@svha.org.au](mailto:centre.palliativecare@svha.org.au) or Telephone: +61 3 9416 0000

## Conferences relevant to IPCFRC EAPC Family Carer Reference Group members

**Please note:** due to COVID-19, please check the relevant conference websites for the most recent updates/information on conference status and dates.

1<sup>st</sup> Annual Meeting of the International Neuropalliative Care Society (INPCS)

Dates: November 4-6, 2021

Location: Virtual

Website: [\[INPCS 2021\]](#)

14<sup>th</sup> Asia Pacific Hospice Conference

Dates: November 13-14, 2021

Location: Virtual

Website: [\[APHC 2021\]](#)

48<sup>th</sup> Clinical Oncology Society of Australia (COSA) Annual Scientific Meeting

Dates: November 16-18, 2021

Location: Melbourne VIC, Australia

Website: [\[COSA 2021\]](#)

29<sup>th</sup> Annual International Conference of the Indian Association of Palliative Care (IAPCON 2022)

Dates: February 11-13, 2022

Location: Virtual

Website: [\[IAPCON 2022\]](#)

2022 Palliative Care Nurses Australia (PCNA) Conference

Dates: May 1-4, 2022

Location: Virtual

Website: [\[PCNA 2022\]](#)

3<sup>rd</sup> and 4<sup>th</sup> Sapporo Conference for Palliative and Supportive Care in Cancer

Dates: July 21-23, 2022

Location: Sapporo, Japan

Website: [\[SCPSC 2022\]](#)

7<sup>th</sup> Public Health Palliative Care International (PHPCI) Conference

Dates: September 20-23, 2022

Location: Bruges, Belgium

Website: [\[PHPCI 2022\]](#)

23<sup>rd</sup> International Congress on Palliative Care

Dates: October 18-21, 2022

Location: Montréal, Canada

Website: [\[ICPC 2022\]](#)

## Recent articles relevant to IPCFRC EAPC Family Carer Reference Group members

In each edition we will feature some recently published articles relevant to IPCFRC EAPC Family Carer Reference Group members. If you have published in a peer-reviewed journal recently and the subject matter is relevant to the IPCFRC EAPC Family Carer Reference Group community, please email [centre.palliativecare@svha.org.au](mailto:centre.palliativecare@svha.org.au) with the subject 'IPCFRC Newsletter' and we will feature your publication in an upcoming edition.

Aker N, West E, Davies N, Moore KJ, Sampson EL, Nair P, Kupeli N. Challenges faced during the COVID-19 pandemic by family carers of people living with dementia towards the end of life. *BMC Health Serv Res.* 2021 Sep 21;21(1):996. doi: 10.1186/s12913-021-07019-6. PMID: 34548067.

Bijnsdorp FM, Onwuteaka-Philipsen BD, Boot CRL, van der Beek AJ, Klop HT, Pasman HRW. Combining paid work and family care for a patient at the end of life at home: insights from a qualitative study among caregivers in the Netherlands. *BMC Palliat Care.* 2021 Jun 24;20(1):93. doi: 10.1186/s12904-021-00780-9. PMID: 34167518.

*Continued...*



StChristopher's



## Recent articles relevant to IPCFRC EAPC Family Carer Reference Group members

*Continued...*

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 Oct;38(10):1230-1237. doi: 10.1177/1049909121991524. Epub 2021 Feb 8. PMID: 33550835.

Davies N, Sampson EL, West E, DeSouza T, Manthorpe J, Moore K, Walters K, Denning KH, Ward J, Rait G. A decision aid to support family carers of people living with dementia towards the end-of-life: Coproduction process, outcome and reflections. *Health Expect*. 2021 Oct;24(5):1677-1691. doi: 10.1111/hex.13307. Epub 2021 Jul 19. PMID: 34288291.

Durepos P, Akhtar-Danesh N, Sussman T, Ploeg J, Boerner K, Kaasalainen S. Evaluation of the Caring Ahead: Preparing for End-of-Life With Dementia Questionnaire. *J Am Med Dir Assoc*. 2021 Oct;22(10):2108-2114.e4. doi: 10.1016/j.jamda.2021.06.032. Epub 2021 Jul 22. PMID: 34302752.

Guo P, Pinto C, Edwards B, Pask S, Firth A, O'Brien S, Murtagh FE. Experiences of transitioning between settings of care from the perspectives of patients with advanced illness receiving specialist palliative care and their family caregivers: A qualitative interview study. *Palliat Med*. 2021 Sep 3:2692163211043371. doi: 10.1177/02692163211043371. Epub ahead of print. PMID: 34477022.

Ikander T, Dieperink KB, Hansen O, Raunkiær M. Patient, Family Caregiver, and Nurse Involvement in End-of-Life Discussions During Palliative Chemotherapy: A Phenomenological Hermeneutic Study. *J Fam Nurs*. 2021 Sep 22:10748407211046308. doi: 10.1177/10748407211046308. Epub ahead of print. PMID: 34551643.

Thompson T, Ketcher D, Gray TF, Kent EE. The Dyadic Cancer Outcomes Framework: A general framework of the effects of cancer on patients and informal caregivers. *Soc Sci Med*. 2021 Oct;287:114357. doi: 10.1016/j.socscimed.2021.114357. Epub 2021 Aug 30. PMID: 34500320.

van Oosterhout SPC, Ermers DJM, Ploos van Amstel FK, van Herpen CML, Schoon Y, Perry M, van Geel M, Kuip EJM, Engels Y. Experiences of bereaved family caregivers with shared decision making in palliative cancer treatment: a qualitative interview study. *BMC Palliat Care*. 2021 Sep 7;20(1):137. doi: 10.1186/s12904-021-00833-z. PMID: 34493262.

## Membership

The IPCFRC EAPC Family Carer Reference Group has 325 registered members from many countries of the world, including: Australia, Brazil, Canada, Denmark, France, Germany, India, Iran, Ireland, New Zealand, Nigeria, Norway, Spain, Sweden, South Africa, Thailand, UK and USA. Institutional collaborators of the IPCFRC EAPC Family Carer Reference Group include: [Centre for Palliative Care](#) (a department of [St Vincent's Hospital Melbourne](#) and a Collaborative Centre of [The University of Melbourne](#)), Melbourne, Australia; [International Observatory on End of Life Care \(IOELC\)](#), Lancaster University, UK; [St Christopher's Hospice](#), UK; and [The Palliative Care Research Cooperative Group \(PCRC\) - Caregiver Core](#), Denver, USA.

Individuals from all continents with a genuine interest in palliative care research related to family carers may become individual members of the IPCFRC EAPC Family Carer Reference Group. **Membership is FREE.** To formalise your membership please complete the [\[online form\]](#) on the IPCFRC EAPC Family Carer Reference Group website.



## Would you like to be profiled in the IPCFRC EAPC Family Carer Reference Group e-News?

One of the key objectives of the IPCFRC EAPC Family Carer Reference Group is to encourage researchers interested in family caregiver research to make connections and collaborate. To help enable this we would like to offer members the opportunity to be profiled in the IPCFRC EAPC Family Carer Reference Group e-News. One researcher will be profiled within each edition.

If you are interested in being considered, please provide the details below to [centre.palliativecare@svha.org.au](mailto:centre.palliativecare@svha.org.au) with the subject 'IPCFRC member profile'.

Please provide the following details: Your Name, Professional Role/Title, Discipline, Institution, City/Country, Specific area of interest in family caregiver research and your Email address (so that other members can contact you directly).

## Forward our E-News to your networks!

Please forward this newsletter to friends or colleagues interested in family carer research. They can also sign up for [\[free membership\]](#)!

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