



Centre for  
Palliative Care  
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StChristopher's

International Palliative Care Family-carer Research Collaboration

# Newsletter

May 2019

## IPCFRC's new status as an EAPC Reference Group

We are pleased to announce that the IPCFRC has been awarded the status of an EAPC Reference Group. EAPC reference groups are representatives of a specific interest or sub-specialty focused on deliverable outcomes that fit with the overall strategic direction of the European Association for Palliative Care (EAPC) – these groups are an integral part of the structures of the EAPC and they are governed by the EAPC Board of Directors.

Professor Peter Hudson (Australia) and Professor Gunn Grande (UK) are co-chairs of the IPCFRC EAPC Reference Group. For a list of all the executive committee members please see the [EAPC Reference Group website](#).

The Aims & Objectives of the IPCFRC EAPC Reference Group are as follows:

### Aims:

1. Promote the development of high quality research and scholarship to improve the wellbeing of family carers supporting patients towards the end of life.
2. Provide a platform for international networking and collaboration.

### Objectives:

1. Undertake relevant steps to transition to an EAPC reference group (e.g. website, membership communiqué, administrative roles).
2. Contribute IPCFRC related content to EAPC e-newsletters (as pertinent).
3. Apply to host a family caregiver specific research forum at EAPC 2020.
4. Undertake a survey of EAPC members to get an understanding of the enablers and barriers to family carer research.
5. Develop a core set of evidence and consensus based family caregiver outcome measures that will result in a toolkit to aid clinicians and researchers and also be published in an international peer reviewed journal.

The Executive Committee will hold its inaugural reference group meeting at the upcoming 16<sup>th</sup> World Congress of the EAPC in Berlin.

## Review of literature related to family carer research

One of the initiatives of the IPCFRC 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 2019 version is available as a downloadable resource on the [\[IPCFRC website\]](#).

## Promoting collaboration amongst members

In order to promote collaboration amongst IPCFRC members, in the next edition of the IPCFRC e-newsletter we will be sending out a list detailing all of IPCFRC members' affiliations, email address, and areas of research interest. This list (which will be circulated to IPCFRC members only) will make it easier for members to contact other members directly about potential research collaborations.

**If you are an IPCFRC member and you would prefer that your details NOT be included for circulation, please inform us as soon as possible via email to: [centre.palliativecare@svha.org.au](mailto:centre.palliativecare@svha.org.au) . If we do not hear back from you by 31 May 2019, we will presume that you give consent for your details to be published and shared with other members.**

[\[Update your details now\]](#)

## Membership

The IPCFRC has 290 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.

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

## Recent IPCFRC Event

An open meeting for current and prospective IPCFRC members was held at the [\[22<sup>nd</sup> International Congress on Palliative Care in Montreal\]](#), in October 2018. The meeting was co-chaired by Professor Peter Hudson (Australia) and Professor Kelli Stajduhar (Canada). Some suggestions arising from the meeting will be considered by the IPCFRC Executive Committee.

Open meetings provide the opportunity for members and prospective members to hear about what is happening in the IPCFRC community and what IPCFRC has to offer, as well as meet the IPCFRC Executive Committee and their fellow IPCFRC members.

## Forward IPCFRC to a friend!

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

## Unsubscribe

If you are no longer interested in receiving correspondence from us, please unsubscribe by emailing: [centre.palliativecare@svha.org.au](mailto:centre.palliativecare@svha.org.au)

## Conferences relevant to IPCFRC members

16<sup>th</sup> World Congress of the European Association for Palliative Care (EAPC)  
Dates: May 23-25, 2019  
Location: Berlin, Germany  
Website: [EAPC 2019]

International Death, Grief and Bereavement Conference 2019  
Dates: June 3-5, 2019  
Location: Wisconsin, USA  
Website: [DGB 2019]

Multinational Association of Supportive Care in Cancer (MASCC)/ International Society of Oral Oncology (ISOO) Annual Meeting on Supportive Care in Cancer 2019  
Dates: June 21-23, 2019  
Location: San Francisco, USA  
Website: [MASCC/ISOO 2019]

Oceanic Palliative Care Conference (OPCC) 2019  
Dates: September 10-13, 2019  
Location: Perth, WA  
Website: [OPCC 2019]

21<sup>st</sup> International Psycho-oncology Society (IPOS) World Congress of Psycho-Oncology  
Dates: September 23-26, 2019  
Location: Banff, Canada  
Website: [IPOS 2019]

## Recent articles relevant to IPCFRC members

In each edition we will feature some recently published articles relevant to IPCFRC members. If you have published in a peer-reviewed journal recently and the subject matter is relevant to the IPCFRC 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.

Brazil K, Carter G, Cardwell C, Clarke M, Hudson P, Froggatt K, McLaughlin D, Passmore P, Kernohan WG. (2018). Effectiveness of advance care planning with family carers in dementia nursing homes: A paired cluster randomized controlled trial. *Palliative Medicine* 32(3): 603-612.

Carter G, McLaughlin D, Kernohan G, Hudson P, Clarke M, Froggatt K, Passmore P, Brazil K. (2018). The experiences and preparedness of family carers for best interest decision-making of a relative living with advanced dementia: A qualitative study. *Journal of Advanced Nursing* 74(7):1595-1604.

Cheung YB, Neo SHS, Teo I, Yang GM, Lee GL, et al. (2019). Development and evaluation of a quality of life measurement scale in English and Chinese for family caregivers of patients with advanced cancers. *Health and Quality Life Outcomes* 17(1):35.

Diffin J, Ewing G, Harvey G, Grande G. (2018). Facilitating successful implementation of a person-centred intervention to support family carers within palliative care: a qualitative study of the Carer Support Needs Assessment Tool (CSNAT) intervention. *BMC Palliative Care* 17:129.  
<https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-018-0382-5>

*Continued...*

## Recent articles relevant to IPCFRC members

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- Diffin J, Ewing G, Harvey G, Grande G. (2018). The influence of context and practitioner attitudes on implementation of person-centred assessment and support for family carers within palliative care. *Worldviews on Evidence Based Nursing* 15(5): 377-385. <https://sigmapubs.onlinelibrary.wiley.com/doi/full/10.1111/wvn.12323>
- Dionne-Odom J, Ornstein K, Kent E. (2019). What do family caregivers know about palliative care? Results from a national survey. *Palliative and Supportive Care*. doi:10.1017/S1478951519000154. [E-pub ahead of print].
- Huang LT, McMillan SC. (2019). Mutual Effects of Depression on Quality of Life in Patients and Family Caregivers. *Oncology Nursing Forum* 46(2):208-216.
- Hughes NM, Noyes J, Eckley L, Pritchard T. (2019). What do patients and family-caregivers value from hospice care? A systematic mixed studies review. *BMC Palliative Care* 18(1):18.
- Hudson P, Thomas K, Girgis A, Mitchell G, Philip J, Parker D, Currow D, Liew D, Le B, Moran J, Brand C. (2018). Benefits of Family Meetings for Hospitalized Palliative Care Patients and Their Family Caregivers. Published abstract from 22nd International Congress on Palliative Care, Montreal. *Journal of Pain and Symptom Management* 56(6):e56-e57.
- McKibben L, Brazil K, Hudson P, McLaughlin D. (2019). Informational needs of family caregivers of people with intellectual disability who require palliative care: a two-phase integrative review of the literature. *International Journal of Palliative Nursing* 25(1): 4-18.
- McVeigh C, Reid J, Larkin P, Porter S, Hudson P. (2018). The experience of palliative care service provision for people with non-malignant respiratory disease and their family carers: An all-Ireland qualitative study. *Journal of Advanced Nursing* 74(2):383-94.
- Metin S, Demirci H, Metin AT. (2019). Effect of health literacy of caregivers on survival rates of patients under palliative care. *Scandinavian Journal of Caring Sciences*. doi: 10.1111/scs.12662. [Epub ahead of print].
- Moore KJ, Lee CY, Sampson EL, Candy B. (2019). Do interventions that include education on dementia progression improve knowledge, mental health and burden of family carers? A systematic review. *Dementia (London)*. doi: 10.1177/1471301219831530. [Epub ahead of print].
- Oechsle K. (2019). Current Advances in Palliative & Hospice Care: Problems and Needs of Relatives and Family Caregivers During Palliative and Hospice Care-An Overview of Current Literature. *Medical Sciences* 7(3): 43.
- Ozdemir S, Jafar TH, Choong LHL, Finkelstein EA. (2019). Family dynamics in a multi-ethnic Asian society: comparison of elderly CKD patients and their family caregivers experience with medical decision making for managing end stage kidney disease. *BMC Nephrology* 20(1):73.
- Quiñoa-Salanova C, Porta-Sales J, Monforte-Royo C, Edo-Gual M. (2019). The experiences and needs of primary family caregivers of patients with multiple myeloma: A qualitative analysis. *Palliative Medicine*. doi: 10.1177/0269216319830017. [Epub ahead of print].
- Schmitt EM, Gallagher J, Albuquerque A, Tabloski P, Lee HJ, et al. (2019). Perspectives on the Delirium Experience and Its Burden: Common Themes Among Older Patients, Their Family Caregivers, and Nurses. *Gerontologist* 59(2):327-337.
- Wasilewski MB, Nonoyama M, Dale C, McKim DA, Road J, et al. (2019). Development of a Web-Based Peer Support Program for Family Caregivers of Ventilator-Assisted Individuals Living in the Community: Protocol for a Pilot Randomized Controlled Trial. *JMIR Research Protocol* 8(2):e11827.
- Zordan RD, Bell ML, Price M, Remedios C, Lobb E, Hall C, Hudson P. (2019). Long-term prevalence and predictors of prolonged grief disorder amongst bereaved cancer caregivers: A cohort study. *Palliative & Supportive Care*. doi: 10.1017/S1478951518001013. [Epub ahead of print].

## Featured Member



Roeline Pasman, MA, PhD  
IPCFRC Advocate Member

*Associate Professor of End of Life Research  
Department of Public and Occupational Health  
Amsterdam Universitair Medische Centra, VUmc  
Amsterdam, Netherlands*

**Roeline Pasman, MA, PhD**, is an Associate Professor of End-of-Life research at the Department of Public and Occupational Health at Amsterdam UMC, Amsterdam, the Netherlands. She is a certified nurse with a Master in Sociology and a PhD in Medical Social Sciences on the topic of *'Forgoing artificial nutrition and hydration in nursing home patients with dementia'*. She supervises PhD students in their research that focused on palliative care and medical decision-making at the end of life in all health care settings and in different patient groups, covering several topics such as advance care planning, participation in decision-making and family caregivers at the end of life. Roeline uses both qualitative and quantitative research designs. She has participated in several European funded (EU 7th FP) projects and is a member of the Expertise Center for Palliative Care Amsterdam. She also teaches Qualitative Research Methods for Health Sciences students at the Vrije Universiteit Amsterdam and delivers courses on palliative care for medical students at the VU University Medical Center.

### *What are you currently researching?*

*I am currently involved in two projects that are specifically focused on family carers. In one project, we developed caregiver profiles based on a q-methodological study and these profiles are used for training community nurses on how to support family caregivers. The CS NAT is also introduced to community nurses in that same training.*

*The other project focused on combining work and family caregiving. As a part of this study, we interview working family caregivers about their experiences and challenges of combining work and caregiving for someone needing palliative care. We follow them over time to study if things change when the situation of the family member worsens.*

***If you would like to know more about A/Prof Pasman and her work, you can contact her directly at [hrw.pasman@vumc.nl](mailto:hrw.pasman@vumc.nl)***

## Would you like to be profiled in the IPCFRC e-News?

One of the key objectives of the IPCFRC 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 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).